Disability Goes Cultural

The Cultural Model of Disability as an Analytical Tool

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Even today, with the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) adopted in December 2006 and disability-related discourses, structures, and practices gradually changing throughout the world according to the new human rights approach, there are many people who still take disability as a simple natural fact. Not only myself, but probably other critical disability studies scholars also feel that Lennard J. Davis expresses a common experience:

"When it comes to disability, 'normal' people are quite willing to volunteer solutions, present anecdotes, recall from a vast array of films instances they take for fact. No one would dare to make such a leap into Heideggerian philosophy for example or the art of the Renaissance. But disability seems so obvious – a missing limb, blindness, deafness. What could be simpler to understand? One simply has to imagine the loss of the limb, the absent sense, and one is half-way there." (xvi)

However, it is not only 'normal people' who tend to underestimate the complexity of disability. Academia itself often chooses to apply somewhat undifferentiated approaches to this phenomenon. When it comes to disability, rehabilitation sciences, medicine, psychology, education, and social policy research dominate the field. To avoid misunderstandings: Social protection and rehabilitative assistance are important; persons with disabilities do rely on societies committed to the principles of solidarity and equality instead of leaving them to a destiny of negligence and ignorance. Still, this is only one side of the coin. Traditional approaches ignore that impairment is a common experience in human life and that we all are differently able-bodied. At the same time, it is important to acknowledge that while most people are likely to be impaired at some point during their lifetime being disabled is, as Tom Shakespeare puts it, "a specific social identity of a minority" (295). Why then are certain differences subsumed under the label 'disabled' and others

considered as 'normal' manifestations of diversity? Why do modern societies see the need to categorize people as 'normals' and 'deviants'? Why and how is disability negatively valued? In which ways is 'otherness' – and disability is a form of alterity – (re-)produced in history, society and culture?

To answer these questions, we ought to take notice of discourses other than just those of traditional rehabilitation sciences. We need encounters between disability studies and those disciplines that at first sight seem to have nothing to do with disability, such as philosophy and anthropology, history and sociology, ethnology and archaeology, literary studies and linguistics, media studies and religious studies, etc. At the same time, we have to bear in mind that doubts are also raised about such an interdisciplinary approach: What can disability studies gain by incorporating culture as an analytical tool more fully into its work? Is it truly important that disability studies meet cultural studies?

With sociology as my academic background, this discussion is familiar to me. In its founding phase at the beginning of the 20th century, sociology was originally considered one of the humanities. However, in the 1950s and 1960s as a side effect of the then dominant empirical approach that was interested primarily in quantifiable data, the issue of culture was pushed into the background in mainstream sociology. It needed the cultural change of the 1970s and the birth of cultural studies to make possible a renewed attention to culture as an analytical category essential for a comprehensive understanding of society. In short, I am arguing for an interdisciplinary approach which I believe useful and relevant for shedding new light on our contemporary societies, cultures and histories. This approach assumes that impairments and disabilities are structuring culture(s) and at the same time are structured and lived through culture. And it is not only myself who is of this opinion. For example Rosemarie Garland-Thomson was already calling for "New Disability Studies" in 2001 (see Joshua and Schillmeier 4). However, many works are still being published that apply traditional ways of thinking and more established approaches, such as the social model of disability, still remain at the centre of most scholars' attention.

APPRECIATING AND CRITIQUING THE SOCIAL MODEL OF DISABILITY

Since its introduction in the late 1970s, the social model of disability has changed international disability discourses. This model, as academics and activists with a disability studies background well know, emphasizes that disability is a social construction. Basically, it implies three assumptions. First, disability is a form of social inequality and disabled persons are a minority

group[1] that is discriminated against and excluded from mainstream society. Second, impairment and disability need to be distinguished and do not have a causal relation; it is not impairments *per se* which disable, but societal practices of 'disablement' which result in disability. Third, it is a society's responsibility to remove the obstacles that persons with disabilities are facing.

When this model of disability was introduced by disability rights organisations and developed further by activists and academics in parallel processes in both the United Kingdom and the United States, it offered a fundamental critique of capitalist society and a new way of thinking. However, in the course of the last 40 years this approach has somewhat become the victim of its own success. It has proven an 'all-rounder,' a useful tool for both academic discourse, disability rights activism and, last but not least, for laypersons and their identity politics. Moreover, the incorporation of its basic ideas into transnational policies, such as the UN CRPD and the two disability classifications of the World Health Organisation of 1980 and 2001, has resulted in pragmatist policies and the opinion that disability as a social problem can be 'solved' through accessibility and participation, mainstreaming and human rights policies. Especially in recent years, many interpretations have tended to ignore the revolutionary impetus of the social model and have watered it down to reformist aspirations of social inclusion and participation. Against this background, the social model seems 'a little dusty' today and it may be time to rethink or amend the concept.

In the following, I refrain from discussing merits and weaknesses of the social model at length. Instead, I will focus on the aspect of culture, which is itself a multifaceted phenomenon in need of specification. Before providing a definition, it is worth mentioning that the social model has frequently been criticised, as Katie Ellis contends, for "neglecting cultural imagery, certain personal experiences and the impacts of impairment" (3). Michael Oliver, one of the British originators of the social model, has reacted to this critique by pointing out that the model emerged directly out of the personal experiences of disabled activists and does indeed allow for the study of impairment effects. Regarding the argument that cultural representation has been neglected, however, he confirms the view of his critics as he does not consider "cultural values" to be crucial, at least as long as so many persons with disabilities are

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1 | As the British version of the social model of disability is implicitly based on the minority group theory, I cannot see a big difference compared with the US-American minority model and will for this reason not follow Goodley (Disability 11-18) in this point. There are other disability models, often established in competition to the social model, but they are also disputable. Be it the minority model or the relational model, the social policy model or the civil rights model and the human rights model, they all are more or less variants of a social science (sic!) perspective on disability.

still suffering from poverty and material deprivation (49). This assessment, although understandable in terms of practical politics, is astonishing from a sociological point of view: It clearly underestimates the role and the relevance of cultural practices in and for society and their influence on our understanding of disability. My feeling is that this lack of regard may be traced back to some shortcomings of the cultural studies approach. But before I elaborate this point, let me trace the contours of a cultural model of disability.

DRAFTING A CULTURAL MODEL OF DISABILITY

Until today, efforts to develop a cultural model of disability have been rare. However, in parallel with the development of the social model and its critical discussion and partly independent of them, the past decades have witnessed an increase in cultural studies oriented works with regard to disability and we can already identify cultural disability studies as an innovative and prolific research field carried out in the humanities. Yet, it is striking that in contrast to the social model of disability, which is characterised by strong coherence and therefore often accused of dogmatism, the field of cultural disability studies still looks more like a patchwork quilt. It has not yet found its unique contours, despite an ongoing discussion on the implications of culture for disability constructions.

As early as 1994, Tom Shakespeare called for a greater attention to cultural representations of disabled people. Inspired by feminist debates he discussed different theoretical approaches and suggested "that disabled people are 'objectified' by cultural representations" (287), under which he subsumed theatre, literature, paintings, films, and the media. In the following years, prominent scholars in the Anglo-Saxon world such as Lennard J. Davis, Rosemarie Garland-Thomson, Robert McRuer, David T. Mitchell and Sharon L. Snyder, Margrit Shildrick, Tobin Siebers, Shelley Tremain, and others (for an overview, see Goodley, *Disability* 14-15) published a wide variety of cultural and literary analyses showing the value and productivity of treating "disability as a cultural trope" (Garland-Thomson 2). In 2006, Snyder and Mitchell explicitly introduced a "cultural model of disability" but they defined it narrowly as an approach that was primarily associated with US-American disability studies. In terms of content, they remained rather vague:

"We believe the cultural model provides a fuller concept than the social model, in which 'disability' signifies only discriminatory encounters. The formulation of a cultural model allows us to theorize a political act of renaming that designates disability as a site of resistance and a source of cultural agency previously suppressed [...]." (10)

In introducing the phrase "cultural locations of disability," referring to "sites of violence, restriction, confinement, and absence of liberty for people with disabilities" (x), Snyder and Mitchell offered a tool for interdisciplinary work on disability within and beyond cultural studies. Additionally, some scholars have argued for the usefulness of a cultural model of disability to study intersections between migration, ethnicity, 'race,' and disability. In 2005, Patrick J. Devlieger, who teaches cultural anthropology in Leuven (Belgium), pleaded for a dialectical cultural model focussing on communication and cultural diversity, following Michel Foucault, Jacques Derrida and Karl Marx. Recent works in postcolonial studies ask the question "how disability is figured in the global, postcolonial history of the modern" and aim "to highlight specific located examples of disability in cultural contexts" (Barker and Murray 65). Meanwhile, the cultural model of disability has also been acknowledged in religious studies as a 'key term.' In this context, Nyasha Junior and Jeremy Schipper define it as an approach which analyses "how a culture's representations and discussions of disability (and nondisability or able-bodiedness) help to articulate a range of values, ideals, or expectations that are important to that culture's organization and identity" (35).

We can state that there is an ongoing reflection on the strengths of a cultural approach to disability. The Liverpool-based *Journal of Literary & Cultural Disability Studies*, which celebrated its tenth anniversary in 2016, is a witness to this lively debate. At the same time however, the respective 'model' still seems to have rather blurred features. Further, the debate tends to reproduce the dominance of English-speaking disability studies (see for example Goodley *Disability*) and overlooks contributions from other countries, such as the longstanding works of French philosopher Henri-Jacques Stiker. With regard to Germany, both the interdisciplinary book series "Disability Studies" published since 2007 by *transcript* and the Edinburgh German Yearbook's fourth volume on disability in German literature, film, and theatre from 2010 attest to a great wealth of works drawing on a cultural studies approach. The editors of the yearbook, Eleoma Joshua and Michael Schillmeier, define the cultural model as "the analysis of the representations of disabled people in the cultural spaces of art, media, and literature" (5) and even speak of a "cultural turn" in disability studies (4).

It is beyond the scope of this essay to discuss these different proposals extensively. Instead I will, in what follows, explain my own approach. Based on contributions published in 2005 and 2012, the latter together with Werner Schneider, I develop a cultural model of disability for the purpose of providing a joint framework for the already numerous contributions which analyse disability with the help of methodologies and approaches originating from cultural studies. My intention is not to suggest that a cultural model should replace the social model of disability. Rather, critical disability studies should

acknowledge that disability is *both* socially and culturally constructed (on this point, see also Ellis 2).

THE CULTURAL MODEL OF DISABILITY AS AN ANALYTICAL TOOL

What is the core of a cultural model of disability? My starting point is that such a model needs to reflect first of all its own understanding of culture. As both a social practice and an analytical category, culture not only implies cultural activities in the narrow sense, be it so-called high culture or popular culture. Instead, for innovative research it is much more productive to apply a broad conception of culture that denotes the totality of 'things' created and employed by a particular people or a society, be they material or immaterial: objects and instruments, institutions and organisations, ideas and knowledge, symbols and values, meanings and interpretations, narratives and histories, traditions, rituals and customs, social behaviour, attitudes and identities (see Moebius 7-9; Schneider and Waldschmidt 146).

In my opinion, if we were to use such a general understanding of culture, a cultural model of disability would not be dismissed as focalising only symbols and meanings, but could broaden our analytical perspective to investigate the relations between symbolic (knowledge) systems, categorization and institutionalisation processes, material artefacts, practices and 'ways of doing things,' and their consequences for persons with *and* without disabilities, their social positions, relations and ways of subjectivation. Such a cultural disability model thus differs from other approaches in important aspects: It considers disability neither as only an individual fate, as in the individualistic-reductionist model of disability, nor as merely an effect of discrimination and exclusion, as in the social model. Rather, this model questions the other side of the coin, the commonly unchallenged 'normality,' and investigates how practices of (de-)normalization result in the social category we have come to call 'disability.' As a consequence of this shift in focus, four programmatic ideas arise.

First, a cultural model of disability should regard neither disability nor impairment as clear-cut categories of pathological classification that auto-matically, in the form of a causal link, result in social discrimination. Rather, this model considers impairment, disability *and* normality as effects generated by academic knowledge, mass media, and everyday discourses. These terms are 'empty signifiers' or blurred concepts referring to a mixture of different physical, psychological and cognitive features that have nothing in common other than negative or, as in the case of ability and normality, positive attributions from society. In any culture at any given moment these classifications are dependent on power structures and the historical situation; they are contingent upon and determined by hegemonic discourses. In short, the cultural model considers

disability not as a given entity or fact, but describes it as a discourse or as a process, experience, situation, or event.

Second, from this premise arises the notion that disability does not denote an individual's feature, but an always embodied category of differentiation. Disability is taken as 'true' because it is not a natural fact but a naturalized difference. It is ascribed to the evidence of physical or embodied expression (even in the case of not directly observable alterities), and it is interpreted within a dichotomous framework of bodily differences: healthy, complete, and normal versus diseased, deficient, and deviating. It exists only when and insofar as certain (bodily and embodied) differences can be distinguished and thought of as 'relevant for health' within a given cultural and historical order of knowledge.

Third, both disability and ability relate to prevailing symbolic orders and institutional practices of producing normality and deviance, the self and the other, familiarity and alterity. By assuming a constructivist and discursive character of disability, the historical contingency and cultural relativity of inclusion and exclusion, stigmatization and recognition can come into consideration, as well as socio-cultural patterns of experience and identity, meaning-making and practice, power and resistance. Furthermore, from this perspective disability is connected to specific social imperatives addressing all relevant parties, on the one hand the experts for support and the rehabilitation business, and on the other hand the laypersons, whether able-bodied or disabled, with their desire or their defiance to adapt and comply to socio-cultural normative expectations. Thus, a cultural model of disability shows that the individual and collective subjectivities of 'disabled' and 'nondisabled' persons are interdependent.

Fourth, when one employs such a 'de-centring' approach, surprising new insights become possible, insights into our late modern societies, their trajectories and processes of change. Instead of continuing to only 'stare' at persons with disabilities, asking what kind of problems they are confronted with and how society should support them, the focus can widen to a look at society and culture in general, aiming to understand the dominant ways of problematizing issues of health, normality, and functioning; how knowledge of the body is produced, transformed and mediated; which and how normalities and deviations are constructed; how exclusionary and including practices in everyday life are designed by different institutions; how identities and new forms of subjectivity are created and shaped.

In sum, the cultural model of disability implies a fundamental change of epistemological perspective since it does not deal with the margin but rather with the 'centre' of society and culture. As a consequence, it changes disability studies into 'dis/ability studies' (for this approach see also Goodley *Dis/ability*). The introduction of the slash indicates that one should no longer problematize

just the category of disability, but rather the interplay between 'normality' and 'disability.' In short, the transversal and intersectional should become the actual object of research. Dis/ability understood as a contingent, always 'embodied' type of difference relating to the realms of health, functioning, achievement and beauty (and their negative poles), offers essential knowledge about the legacies, trajectories, turning points, and transformations of contemporary society and culture.

Conclusion

This essay has discussed the relevance of culture as an analytical category for the study of disability. It has attempted to show that a cultural model of disability has emerged over the last two decades, cross-cutting different academic disciplines and transnational with regard to languages and contexts. Of course, bringing disability and culture together does not progress smoothly; it involves "contact zones," i.e., "social spaces where cultures meet, clash and grapple with each other, often in contexts of highly asymmetrical relations of power [...]" (Pratt 34). This volume offers these conflictual yet productive spaces through which new ways of seeing and thinking can emerge. Let me finish my contribution citing Davis again: "[W]hile most 'normals' [and academics] think they understand the issue of disability" and can "speak with knowledge on the subject," we need to commence from the assumption that "in fact [we] do not" (Davis xvi). The belief that one is lacking knowledge seems a good point of departure for new journeys into the worlds of dis/ability.

References

Barker, Clare and Stuart Murray. "Disabling Postcolonialism: Global Disability Cultures and Democratic Criticism." *The Disability Studies Reader*. Ed. Lennard J. Davis. New York, Milton Park: Routledge, 2013 (4th ed.). 61-73. Print.

Davis, Lennard J. "Introduction." *The Disability Studies Reader*. Ed. Lennard J. Davis. New York, Milton Park: Routledge, 2006 (2nd ed.). xv-xviii. Print.

Devlieger, Patrick J. "Generating a Cultural Model of Disability." Paper presented at the *19th Congress of the European Federation of Associations of Teachers of the Deaf (FEAPDA)*, October 14-16, 2005. Web. 02 June 2011. <http://feapda.org/Geneva%20Files/culturalmodelofdisability.pdf>.

Ellis, Katie. *Disability and Popular Culture: Focusing Passion, Creating Community and Expressing Defiance*. Farnham: Ashgate, 2015. Print.

Garland-Thomson, Rosemarie. "Integrating Disability, Transforming Feminist Theory." *Feminist Disability Studies*. NWSA Journal 14.3 (2002). 1-32. Web. 25 Feb. 2013. <http://www.jstor.org/stable/4316922>.

Goodley, Dan. *Dis/ability Studies. Theorising Disablism and Ableism*. London, New York: Routledge, 2014. Print.

Goodley, Dan. *Disability Studies: An Interdisciplinary Introduction*. Los Angeles, New York: Sage, 2011. Print.

Joshua, Eleoma and Michael Schillmeier. "Introduction." *Disability in German Literature, Film, and Theater. Edinburgh German Yearbook. Volume 4.* Rochester, New York: Camden House, 2010. 1-13. Print.

Junior, Nyasha and Jeremy Schipper. "Disability Studies and the Bible." *New Meanings for Ancient Texts: Recent Approaches to Biblical Criticisms and Their Applications*. Eds. Steven L. McKenzie and John Kaltner. Westminster: John Knox Press, 2013. 21-37. Print.

Moebius, Stephan. "Kulturforschungen der Gegenwart – die Studies." *Kultur. Von den Cultural Studies bis zu den Visual Studies: Eine Einführung*. Ed. Stephan Moebius. Bielefeld: transcript, 2012. 7-12. Print.

Oliver, Michael. *Understanding Disability. From Theory to Practice*. Basingstoke, London: Palgrave, 2009 (2nd ed.). Print.

Pratt, Mary Louise. "Arts of the Contact Zone." *Profession 91*. New York: MLA, 1991. 33–40. Print.

Schneider, Werner and Anne Waldschmidt. "Disability Studies: (Nicht-) Behinderung anders denken." *Kultur. Von den Cultural Studies bis zu den Visual Studies: Eine Einführung*. Ed. Stephan Moebius. Bielefeld: transcript, 2012. 128-150. Print.

Shakespeare, Tom. "Cultural Representation of Disabled People: Dustbins for Disavowal?" *Disability & Society* 9.3 (1994). 283-299. Print.

Snyder, Sharon L. and David T. Mitchell. *Cultural Locations of Disability*. Chicago: University of Chicago Press, 2006. Print.

Waldschmidt, Anne. "Disability Studies: Individuelles, soziales und/oder kulturelles Modell von Behinderung?" *Psychologie & Gesellschaftskritik* 29.1 (2005). 9-31. Print.