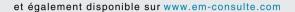


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Research paper

Disability-Culture-Society: Strengths and weaknesses of a cultural model of dis/ability



Handicap – Culture – Société : forces et faiblesse d'un modèle culturel des dis/abilities

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ABSTRACT

Drawing on the approach of disability studies this article claims the relevance of culture as an analytical category for the study of disability. It starts with differentiating several fields of research that focus on disability; then it explores the notion of culture. Next, it appreciates the social model of disability, sketches its history and resulting debates. It also provides an overview on earlier attempts of conceptualizing a cultural studies approach to disability. Further, it offers an analytical perspective that uses the concept of "dis/ability", analyses impairment, disability and normality as "empty signifiers", views dis/ability as naturalized and embodied difference, and understands this category as effected by symbolic orders, bodily practices and social institutions. Additionally, referring to the debate on independent living as an example, this article highlights the heuristic value of the cultural model of dis/ability for both research and practice by describing guiding questions resulting from individual, social and cultural models of disability. It concludes by discussing possible pitfalls of a cultural studies approach to dis/ability.

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RÉSUMÉ

Mots clés : Handicap Incapacités Culture société Méthodologie Modèle Vie autonome S'inspirant de l'approche des disability studies, cet article défend l'importance de la culture en tant que catégorie analytique pour l'étude du handicap. Tout d'abord, l'auteure différencie plusieurs domaines de recherche s'intéressant au handicap; puis, l'article explore la notion de culture. Ensuite, il évalue le modèle social du handicap et passe en revue son histoire et les débats qui en résultent. Cet article donne ensuite un aperçu des tentatives antérieures de conceptualisation d'une approche culturelle du handicap. En outre, il esquisse une perspective analytique qui utilise le concept de dis/ability, analyse la déficience, le handicap et la normalité comme des « signifiants vides », considère le handicap comme une différence naturalisée et incarnée, comprend cette catégorie comme construite par des ordres symboliques, des pratiques corporelles, des institutions sociales. Finalement, prenant comme exemple le débat sur la vie autonome, cet article met en évidence la valeur heuristique du modèle culturel des dis/abilities à la fois pour la recherche et pour le terrain en décrivant les questions centrales posées par les modèles individuels, sociaux et culturels du handicap. Il conclut en discutant des pièges possibles d'une approche culturelle des dis/abilities.

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1. Introduction

Since the 1980s, interdisciplinary disability studies has contributed to the discovery of unknown worlds of knowledge; it has changed our understandings of disability as well as made a difference in the everyday practice of persons with and without disabilities. However, these studies continue to be a marginalised discourse, when considering academia as a whole. As Grue (2017) observed: "Against the background of the proliferation of disability as a topic" there is still "the precariousness of disability as a scholarly field".

Whether one is inclined to subscribe to this argument or not might depend on the discourse one has access to. While scholars from the Anglo-Saxon world would perhaps tend to disagree, since English-speaking academia has been at the forefront of developing and establishing disability studies as a prolific field of research, other linguistic areas are lagging behind. In Germany, which is my country of origin, as well as in Austria and Switzerland, for example, disability studies only started at the turn of this century, i.e. roughly fifteen years ago, and is still faced with the lack of scientific infrastructure and a low prestige. A similar situation can be witnessed in other European countries such as the Czech Republic or Italy, to name only a few, or in other parts of the world, such as China or Latin America. Overall, disability studies seems to be in a comparable situation as sociology at the turn of the 20th century, when Weber (1982), a founding father of the latter discipline, described it as still "adolescent". In such a developmental stage a field of study is ususally struggling for profile and needs to establish its own epistemological framework.

Against this background, this article argues for the necessity of a cultural model of dis/ability. My belief is that, first, cultural approaches can enrich disability studies and, second, that doing research along the fault line "dis/ability" instead of investigating only disability will deepen our understanding and further problematize this phenomenon.

This article starts with differentiating several fields, such as disability research, disability studies, critical disability studies and cultural disability studies, which all centre on the seemingly same issue, but diverge in basic ideas or focal points of analysis. Next, I deal with the notion of culture and review some basic concepts in cultural anthropology and sociology. The remainder of this article is dedicated

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