



Anne Waldschmidt, Hanjo Berressem, Moritz Ingwersen, eds.. *Culture-Theory-Disability: Encounters between Disability Studies and Cultural Studies*. Disability Studies: Body - Power - Difference Series. Bielefeld: Transcript Verlag, 2017. 280 pp. \$45.00, paper, ISBN 978-3-8376-2533-2.

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This is an important collection of essays that will be of interest to scholars from a range of disciplines. In a brief but compelling foreword, the editors explore both the etiology of their project and the evolution of disability studies more generally. A number of ambitious goals are set out and, to a large extent, are realized through the chapters that follow. The editors start with the aim of encouraging “the problematization of disability in connection with critical theories of literary and cultural representation, aesthetics, philosophies and sociologies of the body, the study of society and politics, science and technology” (p. 11). This is a demanding agenda, but the collection is made manageable by the way the book synthesizes impressive contributions from well-known figures in the field while also making space for what the editors term “innovative voices at its disciplinary fringes” (p. 12). The contributors are drawn from a number of countries and there is a clear commitment to internationalism and transnationalism. While the starting point for the book is the idea that cultural disability studies are comparatively new, certainly outside of the United States, the interdisciplinary nature of the work means that the project is underpinned by familiar methodologies and located within an already rich historiography. Indeed, European

scholars involved in the project readily acknowledge their debt to intellectual traditions that long predate an explicit twenty-first-century interest in critical disability studies—in, for example, the contribution from Hanjo Berressem.

Overall, there is no shortage of innovation in the collection, and each chapter constructively demonstrates the value of bringing alternative sources and new interpretations to existing debates while also posing genuinely new questions and suggesting avenues for further research. The contributors generally treat established methodological approaches with respect, even while strongly critiquing them, and this is helpful to the reader. The always fascinating text by Richard J. Evans *In Defence of History* (1997) describes with skill and subtle humor the tensions that can follow the emergence of new academic groupings, but the rise of a vibrant cultural history of disability, as set out in this collection, promises a sophisticated rather than shrill debate. If anything, the supporters of the new discipline veer toward over-caution by drawing attention to the, as yet, unrealized potential of their collective endeavors. Anne Waldschmidt, for example, contrasts the “coherence” of the established social model of disability with the “patchwork quilt” nature of the promising new “field of cultural disability stud-

ies” (p. 22). The idea that our understanding of the full implications of a critical and cultural model of disability is as yet only partial and preliminary is reinforced by the commentary offered within the book. Each of the eleven main chapters is followed by “responses” from two other scholars who address the studies that immediately precede them while offering a wider assessment of issues, sources, methodologies, and approaches. While there is broad agreement about what the key questions are, the commentaries surrounding the different case studies also point to significant areas of disagreement.

This explicit and wide-ranging dialogue between the scholars undoubtedly adds interest, but it also presents some difficulties for readers as well as contributors. Personally, I have only been involved in one publication where my work was reproduced alongside third-party commentary and I found it a rather uncomfortable experience that was quite different from the normal demands of peer review. I certainly commend the participants in this project for being open to such engagement and boldly setting out their findings and opinions. However, as a reader, I was also conscious of some unusual difficulties that seemed to follow from the chosen format. The complex nature of the themes under discussion, and the multiple perspectives offered, meant that I often wanted to refer back to earlier chapters to check points and compare the different approaches. This task was made unusually, and surely unnecessarily, difficult by a failure to straightforwardly number the chapters or provide an index. I think the editors could have offered the general reader more assistance, but in fairness it was helpful to have comprehensive references listed at the end of each chapter. Formatting issues do lead to consideration of who the book is really aimed at. On one level, the essays seem designed to showcase the value of an engagement between disability studies and contemporary cultural criticism and thus seek the widest possible audience. Yet, at the same time, there is a feeling that all the

participants share a sense of being “insiders” within the discipline. They frequently use, with only limited explanation, specialist terminology that will not be familiar to everyone working in relevant university departments let alone a wider public. As someone who has long supported accessible and inclusive social history of learning disability projects involving practitioners, service-users, and their families, this focus on the preoccupations of a rather narrow group of experts (including a certain number of disability activists) gave me pause for thought. This point is important because it is addressed in a particularly interesting way by one of the editors.

At the start of her chapter, Waldschmidt considers a particularly insightful commentary from Lennard J. Davis where he explains the difficulties presented by the way that disability, as a fairly common human experience, is erroneously treated as a readily understandable and non-complex subject.[1] Following this discussion, it becomes arguable that from such a starting point facile commentary and unhelpful policy “solutions” affecting the real rather than imagined lives of disabled people become all too comprehensible. Yet, even while reading this persuasive analysis, the reader is conscious that efforts to problematize and reconceptualize disability can also inadvertently encourage discrimination toward, and even within, the community of people living with various impairments who may, or may not, identify themselves as “disabled.” Paradoxically, it is surely the highly personal experiences of disability that make the issue so complex that bald stereotyping becomes the only way for laypeople (including many people living with disabilities) to make sense of the diversity. These unhelpful characterizations then become a barrier to developing collective identities and political action. In an entirely separate debate, in another publication, about homelessness, Jon Sparkes makes the important point that a failure to understand what homelessness, in all its different forms, actually is serves to prevent debates moving beyond a focus

on individual failings to social and economic causes.[2] For Sparkes, this has the negative effect of encouraging political disengagement and policies that aim to leave homelessness prevention and relief to private charity rather than the systematic state action that might challenge the prevailing view that a certain level of homelessness is inevitable.

Too often, disabled people are seen as worthy objects of charity but are denied access to the resources required to meet their needs even when these are apparently understood by leading academic thinkers and prominent politicians. In *Disability and the Welfare State in Britain: Changes in Perception and Policy 1948-79* (2016), Jameel Hampton captures the cruel irony that disabled people's calls for adequate cash benefits in the United Kingdom reached the heart of government just at the moment when the consensus of opinion that underpinned the classic welfare state was collapsing. As is so often the case, disabled people were promised much but received little in the way of enduring rights or immediate resources. In a very different context, the "cruel optimism of neoliberal transformations" is carefully unpacked by Kateřina Kolářová who reveals how disabled people in the new Czech Republic were first asked to defer their legitimate requests for equality, and then marginalized by initiatives that prioritized market forces and economic individualism that were themselves legitimated by recourse to narratives of disability that prized concepts of "recovery" and "cure" (pp. 231, 237).

Politics are usefully at the heart of most of the chapters in *Culture-Theory-Disability*, although some readers will perhaps share my concern that a focus on power is too often allowed to exclude any mention of social class. However, particularly interesting is analysis that looks at the rise of neoliberalism and its challenges for people living with disabilities. While toleration and inclusivity are oft-stated goals, the ideology relies on a rugged individualism that tends to mock depen-

dence rather than truly celebrate diversity. In such a scenario, tokenism is a real problem, with twenty-first-century governments in North America and Europe overtly celebrating the diversity of small elite groups of policymakers (or to take other examples from the book, publicizing the achievements of disabled actors/athletes) while simultaneously cutting the welfare entitlements and life chances of millions of disabled people. Disabled people in the United Kingdom have been targeted for welfare-to-work measures over the last twenty years, and while there are positive examples of individuals developing new competencies and simply enjoying the companionship and sense of self-worth that can follow from finding regular employment, it is also true that many vulnerable people have suffered from intrusive and/or flawed state-mandated assessments, delays in accessing support services, and poverty both in and out of work.

The United Nations is just one body asking the UK government to do more to protect the rights of disabled people in 2017.[3] Discrimination seems a perennial problem, and one that is now accompanied by a worrying rise in disability hate crime. In all kinds of distressing circumstances, vulnerable people who have identified themselves to public authorities as having special needs because of various disabilities have died recently. The Grenfell fire tragedy in London was compounded by the appalling knowledge that its least mobile residents had no obvious means of escape.[4] Acute housing shortages in many areas dictate the continued inappropriate use of inaccessible accommodation, but, before the fire, public debate on the subject was muted. There is perhaps a sense that people (both experts and the general public) are happier to ignore problems; and it took a strenuous campaign by the relatives of Connor Sparrowhawk not only to uncover the details of his death but also to encourage the appropriate investigation of other unexplained and premature deaths in the learning disability sector.[5] The murder of Bijan Ebrahimi, a victim of racism and

disability hate crime in Bristol, raises yet more disturbing questions.[6]

Alongside these concerns, the issues surrounding the representation of disabled people in novels and movies, problems of finding good roles for disabled television actors, and the difficulties created by the portrayal of participants in the Paralympic Games as “superhumans” can appear trivial, and it is a great credit to the authors and editors of *Culture-Theory-Disability* that these case studies seem laden with meaning and offer important insights into the wider struggles of disabled people. Each chapter is well worth a careful read, but there are also common themes that merit further attention. Work on the politics of identity/identity politics will engage the attention of scholars from many disciplines, although the thought-provoking discussion offered by the different commentators provides more questions than definitive answers. Likewise, the discussion surrounding the enabling and disabling effects of technology in a number of different current and near-future scenarios offers no simple solutions to a number of vexed questions about equality, fairness, the integrity of the body, and what it means to be human. These issues are mostly raised in connection with exploring the potential of prosthetic limbs, and it would be interesting to compare this analysis with ongoing work on the development and adoption of cochlear implants. This technology has certainly challenged the Deaf/deaf community in unexpected ways and may become an existential threat to its cultural development.

In a particularly disturbing chapter, Rosemarie Garland-Thomson makes the point that unless we can build a world (that is cultural as well as material) with disabled people in it, the disabled risk not just exclusion but also elimination. She ruthlessly unpacks the dangers of what seems an increasingly pervasive “eugenic logic,” and usefully explores a number of “counter-eugenic positions” (pp. 53, 54). Highlighting that disability

is “a conceptual category that represents something which goes beyond actual people with disabilities” seems important, but Garland’s focus on the “contradictions” of “the work disability does [in] the world” does not in itself offer any remedy for the pain and suffering that so many disabled people experience (pp. 59, 60). These themes of “contradictions” and “pain” are also explored in different contexts by Robert McRuer and Tobin Siebers. In a particularly interesting response to Siebers, Andreas Sturm not only explores how Siebers’s chapter implicitly challenges the social model of disability but also introduces a commentary on medical understandings of pain and disability that is oddly missing or glossed over in many of the other chapters.

While the social model explicitly rejects a medical model of disability and its focus on individual impairment, many disabled people remain very dependent on the medical profession and other health-care providers. Even where no ongoing treatment is sought or received, doctors nonetheless make crucial diagnoses and assessments that shape an individual’s access to a variety of services, payments, and entitlements. Many disabled people value the support of their personal physician, but the all-powerful medical profession has had a rather fraught relationship with disability rights, and, historically, there is much to be concerned about. A number of chapters explore the experiences of members of the LGBT community who also identify as “disabled” and, from this perspective, discuss the problematic nature of such concepts as “rehabilitation” and “cure.” Kateřina Kolářová makes the interesting point that while medical attempts to manage homosexuality are now rightly discredited, the disabled body remains an entirely legitimate target of the medical gaze.[7] This has costs as well as benefits for disabled people, although, to date, the most interesting discussions on this subject have tended to focus on end of life care and the potential

trade-off concerning quantity versus quality of life.[8]

There is clearly a need for theories of disability that are more critical and more culturally informed, but a crucial aim of *Culture-Theory-Disability* is to challenge, and even supersede, the social model of disability. This is a bold, but also highly controversial, undertaking. Personally, having worked on disability topics as a social historian, I was surprised to find myself in broad agreement with the critiques of the social model developed by Waldschmidt and Dan Goodley. The suggestion that the social model may have “become the victim of its own success” certainly intrigued me because it is the accessibility, universality, and utility of the social model that arguably gives it much of its power (p. 21). I am yet to be fully convinced that a workable alternative is now in place. Some leading proponents of the social model reject any attempt to modify it, let alone abandon the model in favor of new interpretations. This position is totally understandable, but I fear now unsustainable. Waldschmidt points out that the social model has indeed long been criticized for overlooking cultural (and other) factors and attacks the defense offered by such key thinkers as Michael Oliver. Oliver argues that since the social model arose from the lived experiences of disabled activists it must encompass consideration of these so-called neglected elements, but also concedes that in his opinion poverty and material deprivation are the real problems facing disabled people and they have to be addressed before a wider study of cultural issues can usefully begin. Here I strongly agree with Oliver that developing and protecting the social and economic rights of disabled people has to be the prime concern. The question is how best to advance this agenda.

Within the academic community, some humility seems helpful, with Waldschmidt renewing the call by Davis to start from a position of acknowledging our collective lack of knowledge about the

worlds of dis/ability. This seems entirely reasonable as all theories of disability have their limitations and even the dichotomy of dis/abled misses the point that all individuals are unique. Yet even while acknowledging that we cannot know everything, we also need to staunchly defend the value of rigorous evidence-based research in the post-truth era and thereby protect the hard-won rights of disabled people in an increasingly hostile economic and political climate. In their 2006 book, *Community Care in Perspective*, John Welshman and Jan Walmsley set out a very interesting timeline that associates major upheavals in learning disability care in different countries with responses to key publications that gained national or international recognition.[9] A new critical theory of disability, which engages scholars across many nations and many disciplines, may yet underpin a new transformation, although, personally, I think there is still a lot of work to be done.

#### Notes

[1]. Lennard J. Davis, introduction to *The Disability Studies Reader*, ed. Lennard J. Davis, 2nd ed. (New York: Routledge, 2006), xv-xviii.

[2]. Jon Sparkes, “Towards a New Narrative: Our Approach Needs to Change If We Want the Public to Believe Homelessness Can Be Ended,” *Inside Housing* (September 22, 2017): 23. Sparkes is the chief executive of Crisis, a UK charity concerned with homelessness.

[3]. A summary of the UN committee report and response from the UK government can be found in “Disability Assessors ‘Lack Right Skills,’” BBC News, August 31, 2017, [bbc.co.uk/news/av/uk-41117812/disability-assessors-lack-right-skills](http://bbc.co.uk/news/av/uk-41117812/disability-assessors-lack-right-skills).

[4]. On June 29, 2017, bereaved relative Nazanin Aghlani told the BBC that her disabled mother had no way of escaping from the eighteenth floor. See “London Fire: ‘We Can Accept Death But Not Being Burned Alive,’” BBC News, June 29, 2017, [bbc.co.uk/news/uk-40322596](http://bbc.co.uk/news/uk-40322596).

[5]. Michael Buchanan, “NHS Trust ‘Failed to Investigate Hundreds of Deaths,” BBC News, December 10, 2015, [bbc.co.uk/news/health-35051845](http://bbc.co.uk/news/health-35051845).

[6]. This case was explicitly identified as a disability hate crime. It was featured on “Bijan Ebrahimi: Bristol Murder Victim ‘Failed’ by Police,” BBC News, October 29, 2013, [bbc.co.uk/news/uk-england-bristol-24724534](http://bbc.co.uk/news/uk-england-bristol-24724534).

[7]. This point is worth exploring further in specialist studies, such as Tommy Dickinson, *“Curing Queers”: Mental Nurses and Their Patients, 1935-74* (Manchester: Manchester University Press, 2016).

[8]. Emily K. Abel, *Living in Death’s Shadow: Family Experiences of Terminal Care and Irreplaceable Loss* (Baltimore, MD: Johns Hopkins University Press, 2017).

[9]. John Welshman and Jan Walmsley, “Timeline: The UK in International Context,” in *Community Care in Perspective: Care, Control and Citizenship*, ed. John Welshman and Jan Walmsley (Basingstoke: Palgrave Macmillan, 2006), xiii-xxi.

If there is additional discussion of this review, you may access it through the network, at <https://networks.h-net.org/h-disability>

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