
Reviewed by Alice Brumby (York St John University)

Published on H-Disability (August, 2022)

Commissioned by Iain C. Hutchison (University of Glasgow)

Ally Day's *The Political Economy of Stigma* is an ambitious and innovative piece of interdisciplinary scholarship. The study incorporates theories and methods from a range of disciplines, including feminist disability studies, HIV memoir, crip studies, queer theory, and sociological and literary methods. The work draws upon approaches from the medical humanities, to which Day's work is simultaneously opposed and yet indebted. Day is particularly critical of “narrative medicine” and its place within the political economy of stigma. The monograph takes an intersectional approach, exploring the differences and similarities between experiences, while remaining alert to intersectional hierarchies linked to class, race, wealth, and privilege. At its heart, this is a book that aims to resist reductive medical narratives and find ways to address medical and social inequality.

In forming her argument for her research, Day conducted reading groups in two “rust-belt” cities—one formed of women living with HIV and one formed of AIDS service workers. Her research aims to explore how the two groups responded to HIV and disability memoir. In doing so, the work generates ideas about reading practices and how different groups use personalized experiences to understand the disabled body and the texts that they were presented with. The work aims to highlight different ways of reading disability and HIV memoir, using the concepts of “diagnostic” and “differential” reading. Day argues that the AIDS service workers were more likely to read the assigned texts “diagnostically”, that is, diagnosing the texts and, she claims, imposing neoliberal values on to the writing. She argues, “to read diagnostically is to understand authors writing about chronic illness as always in need of medical intervention” (p. 135). The women living with HIV, however, were more likely to claim solidarity with the memoirs, thereby practicing “differential” reading. Sometimes, the obvious needs pointing out, and Day’s work does just that, showing how ways in which readers consume life narratives about illness and disability can be “deeply dependent on their own relationships to intersec-
tional privilege and their relationships to illness and disability itself” (p. 49).

Interestingly, within the group of the women living with HIV, none of the women actively and openly identified themselves firmly with a disability identity. Instead, their identification with disability linked only to their struggles with medical and governmental services, linked predominantly to accessing disability-related resources and facilities. This is informative, showing how disability is a fluid identity, which can be used or disregarded in different circumstances. The women were self-consciously resistant to this label and were able to move in and out of their identification with disability depending on situation and context. While it is clear that we can learn a lot from both of Day's reading groups—there is a genuine attempt at collaboration here—the small group sizes do make generalizations difficult. The group of women living with HIV contained only three participants, which does limit some of Day's findings. Nevertheless, the work is significant for providing an innovative methodology that could be replicated by scholars with other groups in other areas.

One of the problems facing all scholars of participatory research, like the research that Day engages in, is the dichotomy between creating an academic, theoretical narrative and creating an accessible output for the participants. Day pondered the problem in her introduction, asking “would my research participants ever be able to access this writing?” (p. 15). However, this central dichotomy between academic scholarship and accessibility remains an unresolved tension with the work. On the one hand, it is clear that the research experience has led to impactful outcomes for many participants, which should be praised. Yet, if it should be the case that these participants were unable to access Day's findings, then this would seem to replicate some of the flaws and issues with narrative medicine that Day actively protests against—namely, excluding patients from their own stories, for scholarly gain. Day's criticism of narrative medical practitioners for “getting as much detail as possible from their clients and then ... craft[ing] their writing around that material,” could be argued to apply uncomfortably closely to her own methodologies (pp. 104-105). After all, this book uses reading groups as a way of facilitating narratives of lived experiences to garner material for a piece of scholarly writing.

Nevertheless, the voices and lived experiences of the participants of Day's research are the most valuable aspect of the work. Its most important contribution is in identifying and discussing these unique experiences of living with HIV, especially in the sections where Day discusses “the complex negotiation of medical power dynamics” through the words of the women in her second reading group (p. 145). In this respect, the final section of the book is the most powerful. This section puts increased focus upon the words, actions, and lived experiences of the reading group formed of women living with HIV, prioritizing their views and words, thereby giving them voice in the text. In the neoliberal system where individual patient histories have been lost in a system concerned only with fixing symptoms, there is evidently a significant value in listening to the words of those marginalized through illness or disability.

Through analyzing HIV memoir and lived experience, Day highlights some of the failures of institutional systems of care and education in the neoliberal environment. In analyzing the “medical practices based on a profit model,” Day offers an American-centric approach, which quite rightly centralizes the links between poverty and disability (p. 92). She lambastes the health inequalities endemic to the United States, where “slow medicine” and narrative medicine are realities only available to the affluent and wealthy. The participative methodology Day has pioneered shines a light on these issues and is one of the book's most striking achievements.

While the link between poverty and disability is of course hugely significant worldwide, it would
be interesting to see scholars replicating this methodology in countries with systems and traditions of social medicine such as the United Kingdom. Similar studies with different groups in different medical contexts would enable readers to see how elastic and transnational Day's findings are. Her overriding conclusion is a case in point here. Day concludes that medical education needs to move away from “individual empathy” and responsibility, and instead move toward a model of social justice. Her thesis states that by focusing on the individual, and more problematically individual responsibility, the political economy of stigma helps to obscure the structural problems endemic in healthcare. This is an interesting philosophy, but to what extent is the emphasis on individual responsibility a specifically American preoccupation? To scholars working in different traditions and cultures, advising against “individual empathy” may seem, at best, counterintuitive.

Nevertheless, Day highlights how this concept is rooted in ideas of deserving and underserving disability central to an American medical culture rooted, as Day demonstrates, in a hierarchy of ableism.

The importance of this work is to highlight how social justice can help us to reframe the conversation away from stigma of disability and individual responsibility, and toward the systemic structures that reinforce the injustices of discrimination, race, poverty, ableism, and the narratives of wellness. It is clear from her research that the reading groups were a particularly important conduit that led to intimacy, disclosure, and friendship between participants, and were a vehicle to achieve openness and trust in the participant/researcher relationship. In this respect, Day's approach certainly offers an interesting apparatus for other disability scholars to consider.

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


**URL:** https://www.h-net.org/reviews/showrev.php?id=57409

This work is licensed under a Creative Commons Attribution-Noncommercial-No Derivative Works 3.0 United States License.