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## Malhotra, R., & Rowe, M. (2014). *Exploring Disability Identity and Disability Rights through Narratives.* London: Routledge. ISBN 978-0-415-53235.

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In their book, *Exploring Disability Identity and Disability Rights through Narratives*, Ravi Malhotra and Morgan Rowe show the importance of the in-depth narrative method in discerning the personal affects of oppression on the lives of disabled persons. Through the stories of the 12 disabled post-secondary students with physical impairments in their study, Malhotra and Rowe reveal the relationship between rights advocacy and personal identity. They recount how this relationship manifests in the students' lives when they face systemic barriers in educational, transportation, and employment settings. In doing so, Malhotra and Rowe build on the foundation provided by the important work of Engle and Munger (2003) in *Rights of Inclusion: Law and Identity in the Life stories of Americans with Disabilities*, and make an important contribution to our understanding of disability rights, law, and advocacy. The book traverses the fields of Canadian disability studies and socio-legal studies, and bolsters both as the authors document disabled people's life experiences and their relationship to law, and show the effectiveness of the use of narratives which are still not common in legal scholarship, with the view that "listening to the stories from the bottom is essential for social change" (1).

Malhotra and Rowe's analysis is informed by critical disability theory which encompasses their "operating paradigm" of the social model of disablement (1). As such the 12 narratives gathered were analysed through a social model lens. The first chapter of the book sets the stage for the reader by providing an impressive survey of the existing literature concerning the social model of disablement. This also traces the evolution of the use of narratives in feminist legal theory, critical race theory, and queer theory to show how narratives are an appropriate method for the authors' study and for the development of critical disability theory. In particular, narratives provide a rich and complex glimpse into the lives of marginalized people, and raise public awareness and knowledge of the issues they experience.

The second chapter outlines the grounded methodology inspired by the research of Engle and Munger, and the theoretical framework developed by Malhotra and Rowe which emphasizes the importance of an advocacy identity in tackling oppression. Engle and Munger originally identified a recursive relationship between personal identity and rights awareness after conducting narrative interviews over many years with 60 disabled Americans with physical and learning impairments. In their study, Malhotra and Rowe wanted to determine whether this recursive relationship would be impacted by the Canadian context with its very different disability rights system. In the United States disability rights are delineated primarily through a single dedicated federal law, the 1990 Americans with Disabilities Act (ADA), whereas disability rights are protected in Canada through general human rights legislation at the federal and provincial levels. In addition, Canada has constitutional protection provided under section 15 of the Canadian Charter of Rights and Freedoms, such that the rights of disabled people are protected alongside those of other marginalized groups. Ontario's 2005 Accessibility for Ontarians with Disabilities Act is currently the only legislation in Canada similar to the ADA that focuses solely on the rights of disabled people.

Malhotra and Rowe found from the students in their study that an advocacy identity was part of a cyclical recursive relationship between personal identity and rights awareness. Such a relationship meant that an awareness of rights (both a legal and informal awareness) enabled the disabled students to "define his or her own entitlements" (56); in turn, rights awareness and

personal identity were given voice through advocacy. The perceived necessity of advocacy in a particular situation was affected by personal identity and feelings about advocacy, which informed when rights and change were demanded.

These findings are illustrated in chapters three, four and five, which focus on the systemic barriers identified by the students interviewed in the areas of education, employment, and transportation respectively, and highlight the students' experiences and feelings. One student, for example, who was aware of his rights to access public transport, used his advocacy skills to demand change to the light rail ticket vending machines that were too high to reach from a wheelchair. When he was asked why he could not ask someone to get the ticket for him he said "Excuse me, sir, but I'm not going to get someone I don't know to go into my wallet to get money to put it in for the sake of a three dollar ticket. You get an accessible ticket machine, and I'll start using it, but until that point I am not going to pay, and I want you to know that" (138). In this case, advocacy was felt necessary to assert rights and personal identity.

Chapter six looks more closely at issues that emerged through the narratives related to gendered expectations, body image and identity, and caregiving roles. Malhotra and Rowe identified a "circular and self-informing" (159) interaction between body image and identity, meaning that the students' identities were impacted by the differences they perceived between their body and the ideal body as dictated by society. In relation to caregiving the authors argue for a focus on the interdependent nature of care and care work as some of the students had both the caregiver and cared-for role. This argument presents an important challenge to societal assumptions that disabled people only occupy the cared-for role.

The final chapter summarizes the findings and discusses how barriers may be reduced through law reform, such as elementary and high schools assigning Educational Assistants to a

student rather than a school. Ultimately though, social change and the creation of an accessible society, the authors argue, will come from grassroots organizing or "disability rights struggles from below" (194). In concluding, based on the information gleaned from the 12 students' narratives, Malhotra and Rowe call for the social model of disablement to be rethought to allow for the inclusion and analysis of impairment (an individual's medical condition) and its effects from a social theory perspective. They suggest that impairment needs to be theorized to account for the real impacts (such as exhaustion, pain, and emotion) it has on personal identity and hence rights awareness, advocacy, and experiences. With respect to body image, for example, the students in the study described the scrutiny to which they would often be subjected because of their impairment, and the toll self-image advocacy took on their emotions often leading to feelings of anger. Malhotra and Rowe argue that the current social model has been very effective politically in moving the focus away from the medical model, but that now it is time to study the effects of impairments and their policy implications.

There are a few areas where Malhotra and Rowe could have expanded the scope of their argument. With respect to their call for a theorization of impairment, the cultural model of disability could have been usefully explored to show other ways of examining impairment. The cultural model, contrary to the social model, understands impairment to be interwoven with disability in order to study how and why it is socially constructed through language, culture, and discourse. Snyder and Mitchell (2006), for example, following a cultural model approach stress the importance of personal narratives to "destabilize our dominant ways of knowing disability" (p. 4). They understand disability to be the result of how the construction of societal barriers *and* biological difference significantly impact the ways disabled people experience their lives. Similarly, Tremain's (2001) work on the government of disability de-naturalizes the concept of

impairment using a Foucauldian analysis of power. She discusses how the concept of impairment has been socially constructed as natural and innate by the medical establishment in order to conceal the power relations that govern and regulate the lives of disabled people.

Malhotra and Rowe could have also expanded the scope of their argument in relation to intersectionality. This is discussed in the findings with respect to gender but not with respect to any other dimension such as race or sexuality. This is the case despite the authors making reference in the first chapter to how feminist, critical race, and queer theories have raised public consciousness about experiences of oppression. A broader intersectional discussion would have strengthened the analysis of the students' disability and advocacy identities in relation to rights awareness.

Malhotra and Rowe's detailed account of the grounded theory methodology for analysing the narratives and deriving theory is appropriate and timely. There is an urgent need for more scholarly work that listens to the voices of marginalized people in the face of neo-liberal pressures and scientific advancements to promote "normalcy" and reduce deviancy from the "norm." Malhotra and Rowe's research expands the groundwork for future narrative-focused studies, in particular for such studies involving disabled people with intellectual impairments to explore their own advocacy identities. As the authors acknowledge, however, their study's conclusions are limited due to the small number of participants who were all students with physical impairments, compared to the 60 disabled people with physical and learning disabilities from a variety of backgrounds in the Engle and Munger study. Despite these limitations, Malhotra and Rowe's study does show the potential of narratives to influence social change and to lead to equality for people with disabilities and other marginalized peoples, such as Indigenous peoples and people living in poverty.

*Exploring Disability Identity and Disability Rights through Narratives* is also timely given that it looks at the Canadian disability rights context. While (unlike the United States) Canada does not as yet have a federal disability rights law, consultations are underway concerning the drafting of a federal *Canadians with Disabilities Act*. Malhotra and Rowe found that the students in their study had a less legalistic and more informal awareness of rights than the Americans in the Engle and Munger study. Should a Canadian federal statute be implemented, future research then can build on that of Malhotra and Rowe to see its impact on disabled Canadians' advocacy identity.

Overall, the excerpts from the students' narratives throughout the book paint a vivid and detailed picture of the advocacy mechanisms employed and emotions experienced to manage and challenge societal barriers, making this a very compelling and informative read. Their text makes a substantial contribution to understanding the relationship between disability identity, disability rights awareness, and an advocacy identity. As a result, I recommend the work to a broad audience: researchers within disability studies, socio-legal studies, sociology, and public administration; disability rights' advocates; policy makers; disability service providers; educators from elementary school to university; employers; and lawyers.

## References:

- Engle, D.M., & Munger, F.W. (2003). *Rights of Inclusion: Law and Identity in the Life Stories of Americans with Disabilities.* Chicago: University of Chicago Press.
- Snyder, S.L., & Mitchell, D.T. (2006). Cultural Locations of Disability. Chicago: University of Chicago Press.

Tremain, S. (2001). On the Government of Disability. Social Theory & Practice, 27(4), 617-636.