H-Net Reviews in the Humanities & Social Sciences

Michelle Jarman, Leila Monaghan, Alison Quaggin Harkin, eds.. Barriers and Belonging: Personal Narratives of Disability. Philadelphia: Temple University Press, 2017. 286 pp. \$94.50, cloth, ISBN 978-1-4399-1387-1.

Reviewed by Henry C. Alphin Jr

Published on H-Disability (March, 2018)

Commissioned by Iain C. Hutchison (University of Glasgow)

Michelle Jarman, Leila Monaghan, and Alison Quaggin Harkin provide a wondrous outlet for thirty-seven autoethnographic narratives on living with disability and on internalizing imperfections in an ableist society developed largely for perfect bodies. The editors are university instructors of differing levels, from associate professor to temporary assistant lecturer. Their common theme of interest is disability studies, and this book provides insight in understanding various levels of ability and the inner conflict, stigmas, and myriad other challenges associated with disability.

The compilation includes thirty-seven chapters in six parts: Laying the Groundwork; Families, Adaptive Living, and Reorienting Expectations; Disability and Communication; Mapping Complex Relations; Identity, Resistance, and Community; and Theories and Lives. Some common themes in the narratives include wrestling with self-disclosure, visible/invisible disabilities, stigma, ableism, privilege, activism, the social versus the medical model of disability, and accessibility.

Part 1 quickly transports the reader into the authors' lived experiences. The reader gets a front row seat in witnessing how disability frames perception and perception reframes disability. In this group of chapters, perception is altered by a vari-

ety of author actions and explorations, including a transfer to a more welcoming college campus, country relocation, sociocultural perspectives, sport, dance, and multiple individual outlook readjustments. The authors in part 1 inform the observer that each of us has an excellent opportunity to turn stigma into empowerment and open our minds to possibility.

In chapter 1.6, Zachary A. Richter discusses how the academic work of Fiona Kumari Campbell led him to articulate his experiences with multiple disabilities, including autism, and set a path for his involvement in radical disability theory and activism. This chapter is a poignant example of how perception and a framework reset can assist in overcoming societal limitations. In this section, we observe individuals moving beyond acceptance toward understanding and rewriting of narratives. For these authors, their methods of success are different, but they each display strength and resilience in redefining who they are and what they plan to accomplish in this lifetime. Part 1 lays the groundwork because of its ability to mesh society's prescribed visions of ableism and misrepresentations of disability with individual reflection, overcoming, and empowerment.

Part 2 brings the reader closer to family issues, from understanding to caregiving, accep-

tance to appreciation. The topics in this section are quite moving. There is a particular strength in those individuals who are caring for, or reconnecting with, others in similar family struggles. In chapter 2.6, Douglas Kidd discusses the evolution of his role as a disability activist and more involved sibling. Douglas has a brother, Richard, who is a traumatic brain injury (TBI) survivor of an incident in the late 1980s. Incredibly, Douglas also received a TBI in 2005. The outcome of this event is twofold: Douglas's survival experience blossomed into a sense of disability understanding and appreciation which, in turn, cultivated a closer bond with Richard. These chapters are family-centric, portraying realistically the family's reception of disability both positively and negatively. But the moving part of this group of chapters is the transition from acceptance to appreciation, as the authors discuss the onset of disability and how they were able to internalize the concept and turn their new reality into empowerment.

In part 3, the reader better understands disability through authors' interactions with others and their coming to terms with the social model of disability. In chapter 3.1, Joshua St. Pierre discusses stuttering, disability pride, communication, and discrimination. His chapter leads the reader along the path from being ashamed of stuttering to understanding it as another form of communication. He notes that individuals communicate "in many different ways ... we all have a right to be heard" (p. 103). And that perspective presents the unconquerable mind-set of the authors in part 3. Each of these authors has been forced to confront how the external world perceives disability and societal expectations of those individuals with visible and invisible disabilities. Internalization and acceptance again become modes of empowerment.

Part 4 discusses the complexities involved with disability as a distinguishing element of character. Disability suggests both positive and negative components of identity. The reader discovers that the tragic view of disability is one in need of change; various forms of ability—even sudden onset of disability—can have positive effects on the lives of the individuals afflicted. Invisible disabilities, in particular, pose greater complexity when defining character. Michael T. Salter, in chapter 4.5, discusses his reintegration into his family and community as a returning veteran with PTSD. Salter's confusion while attempting to assimilate back into civilian life from the combat world substantiates the stark difference between the two identities. In the latter, Salter perceived his life as significantly impactful, "making a difference," while the former makes him feel "misunderstood and no longer [able to make] a difference" (p. 165). Fortunately, Salter continues to progress favorably through counseling. Disability, particularly late-onset occurrences, can create substantial intricacies. In these chapters, those intricacies require a labyrinthine network of treatment, reflection, and focus on self-value.

Part 5 explores the convoluted interrelations of disability within social groups, particularly communities of disability. The authors of this section discuss the persuasive endeavor of conformity as well as issues of self-disclosure. Within the higher education disability process, self-disclosure is the prefatory move toward obtaining assistance. Some college students with various levels of ability wish to remain outside of the stigmatized group's boundaries. These chapters grapple with similar processes. In chapter 5.5, Suzanne Walker discusses the dichotomy of an escapist personality unwilling to self-disclose in her courses versus an active participant seeking better understanding of disability through online identity creation and in-class discussions. The chapters in this section provide diverse opinions on discovering identity both personally and through communities of disability, yet each also demonstrates that disability is not the definitive identity of an individual.

Part 6 dives deeper into the social theory of, and medical approaches toward, disability. In chapter 6.5, Rebekah Moras writes about a duty to bring madness deeper into disabilities studies discussions. It is easy to see how disability is personal yet can play a constituent role in social interaction. Community groups bring together like-minded individuals, whether they were born on a point along the spectrum of ability or acutely thrust into that identity. Accordingly, we inherently desire a sense of belonging in human social connections.

The main criticism I have of the contents within this book is the same criticism I have with the direction of disability studies: the inner conflict and hierarchy within disability studies creates angst and unnecessary division. While communities of common scope, such as D/deaf culture and blind communities, can be divisive internally according to individual level of assimilation or sociopolitical objectives, disability studies has the potential to bridge these gaps and bring differing factions of particular communities together. However, in an effort to be inclusive, disabilities studies has, unfortunately, morphed into further segmentation and gradation under the privilege moniker. As an example, take a student with a learning disability. Rather than using the momentum of community development to confront ableism, the student is encouraged to address and rank gender, sexual orientation, race, ethnicity, and myriad other factors, akin to checking off boxes before a hierarchy is determined. Instead of coming together to form a powerful base, there is division within the foundation. While these authors pour their hearts out for this book, many take time to encourage gradation and division or discuss their role within a prescribed hierarchy. Such an effort forces affected individuals further down the identity scale to accept being labeled or to remain silent so as to not offend others perceived as being higher in the hierarchy.

This book would serve as an excellent supplemental text in the disciplines of psychology, anthropology, sociology, and disability or rehabilitation studies. The challenge for students will be to find common ground in order to form powerful allegiances in the disability studies community rather than create further subdivisions.

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

Citation: Henry C. Alphin Jr. Review of Jarman, Michelle; Monaghan, Leila; Harkin, Alison Quaggin, eds. *Barriers and Belonging: Personal Narratives of Disability.* H-Disability, H-Net Reviews. March, 2018.

URL: https://www.h-net.org/reviews/showrev.php?id=49559

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