BOOK REVIEW

Healthcare Justice for Women with Disabilities: The Need for Integrative Primary Care Services and Education for Medical Providers

Eliminating Inequalities for Women with Disabilities: An Agenda for Health and Wellness. Edited by Shari E. Miles-Cohen and Caroline Signore, Washington, DC, American Psychological Association, 2016. 296 pp., $69.95 (APA Members, $49.95). ISBN: 978-1-4338-2253-7

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Women with disabilities are significantly more likely than are women without disabilities to have medical problems, limited access to healthcare and health insurance, and less positive relationships with their primary care providers. The authors note that women with disabilities compose about 19.8% of the population of all U.S. women. Among this group, ambulatory difficulties are most prevalent, followed by challenges with cognitive functioning, in independent living, and with hearing and vision. Moreover, mental health issues are prevalent across all different groups of physical and cognitive impairments, and especially prevalent among those who experience multiple oppressions (e.g., identify as LGBT or as a Person of Color) (May and Kennedy 2010; Comas-Diaz and Greene 2013).

The aforementioned research raises the following questions: Why do women with disabilities experience poorer healthcare outcomes than able-bodied women do? What intersecting factors should primary care providers consider when treating cisgender girls and women and transgender men and women with disabilities? And how can other healthcare specialists become involved in primary care to ensure the delivery of holistic, comprehensive, and culturally-informed medical treatment? In *Eliminating Inequalities for Women with Disabilities: An Agenda for Health and Wellness,* edited by Shari E. Miles-Cohen and Caroline Signore, each of the contributing authors seeks to answer these questions.

In this collection, the editors put forth well-researched and timely chapters that focus on the unique health disparities that women with disabilities from different backgrounds frequently encounter, draw attention to how the healthcare system at large contributes to the inequality of healthcare services, and offer up an accessible action plan rooted in structural changes to improve wellness and health among this underserved population. The book is divided into four major sections. The first, aptly titled "The Big Picture" contains three chapters that discuss health disparities among women with disabilities (authored by Margaret A. Nosek), equity within healthcare (authored by Marsha Saxton), and health promotion and disease prevention (authored by Susan Parish, Monika Mitra, and Lisa Iezzoni). In this section, readers are exposed to the social, personal, and systemic issues that affect healthcare for women with disabilities. These authors in this first section implicitly reject the medical model of disability (i.e., the belief that something is "wrong" with the person and that disability needs "fixing"), preferring instead to see disability as a social construction made harder for the individual when healthcare resources are not readily accessible. For instance, physical health issues tend to be more prevalent in working class rural areas than in major cities. This disparity is largely due to lack of accessible transportation (e.g., a vehicle equipped for a wheelchair user) and lack of medical facilities within walking distance. When physical health problems go unaddressed, it is not uncommon for the person to feel despair or distress, which, if untreated, may cause a mental health issue such as depression.

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Marsha Saxton (in "Access to Care") makes the argument that healthcare equity increases when patients are able to become active partners in their care and when providers extend their focus "beyond the presenting symptoms…to the woman's background and…disability-related needs" (p. 55). Vulnerable conversations about disability-related needs behind closed doors are most effective when providers have received some training in disability issues, when providers operate within integrated medical teams that include other healthcare specialists (such as a psychologist), and when the workplace regularly hires women with disabilities. Empowerment and safety occur when patients see themselves mirrored in their environment, and women with disabilities are no exception.

The second section of this groundbreaking book includes chapters on telehealth care, that is, the use of technology to assess, diagnose, and provide healthcare services (Anju Khubchandani & Denise Thew), reproductive and sexual health care (Caroline Signore), and oral health and dental care (H. Barry Waldman & Steven P. Perlman). As noted by Anju Khubchandani and Denise Thew in Chapter 4, given that 14% of women with disabilities live in rural areas, the integration of Telehealth in primary settings will increase access to healthcare services for this population, especially those who do not have the means to travel long distances. Moreover, and perhaps unsurprisingly, women with disabilities frequently lack adequate access to, and education about, sexual health and dental care, as if these two medical domains are somehow considered less important to individuals with disabilities. In Chapter 5, Caroline Signore cites research showing that many healthcare providers do not inquire about the sexual health of women with disabilities and may even perceive women with disabilities as being asexual, with the consequence being that these patients are not given access to important resources (such as safe sex education or referrals for STD testing). A similar phenomenon occurs within the oral healthcare field, where lack of education or implicit biases among dentists about disability-related needs result in less comprehensive care. Barry Waldman and Steven Perlman's suggestion that preventive dental care services be offered in settings that women with disabilities are more likely to frequent (such as community health centers or family practices) is one such example of how an integrative medical setting is most effective in terms of drawing attention to healthcare issues that frequently go unaddressed or are seen as less urgent.

The third, and most comprehensive, section of the book, "Specific Populations," offers well-researched chapters that highlight how intersecting marginalized identities may affect the health of women with disabilities, such as being young or elderly, being a Person of Color, being LGBT, or being a parent with a disability. Given that 70% of primary care visits are thought to stem from psychosocial issues (Robinson and Reiter 2016; Tuso 2014), an understanding of how minority stress impacts the experience of disability is most essential to providing effective comprehensive and culturally-sensitive medical care. The research presented in this section illustrates a host of difficulties that arise when primary care providers are not well educated about the effect of multiple oppressions on one's well-being or specific individual concerns within different marginalized subgroups (e.g., when transgender Patients of Color and Person of Color do not feel safe with their cisgender White male provider and thus may not disclose their full medical history). In my observations from working at a primary care setting, negative consequences seem to arise not just for the patients themselves, but also for the larger healthcare system: When the initial presenting concern is poorly addressed due to intersecting factors that are overlooked, the result is often that new health problems develop, creating an additive effect that further taxes the healthcare system and its providers.

In the final section, "Recommendations," editors Shari Miles-Cohen and Caroline Signore highlight once again the importance of a patient-centered, integrated care framework for treating women with disabilities. The editors recommend that medical providers become educated in disability issues as well as issues faced by those in marginalized subgroups. They also encourage patients to become involved in their own care and to give voice to their experiences by publishing and participating in research studies. Most importantly, they take the recommendations integrated throughout the text to put forth action-based agendas for increasing access to education, improving healthcare access and delivery, and promoting specific health policies. This chapter alone will be a valuable resource for healthcare administrators and researchers looking to improve the overall systemic structure of their respective institutions.

Reading this book, I found myself thinking of the term "universal design," coined by disability and queer activists in 1996. "Universal design" is based on the principle that environmental structures, educational materials, and healthcare should be accessible to all, regardless of disability. Rather than having specific individualized accommodations to meet specific individualized needs, such as ramp for a wheelchair user at a separate entrance to the hospital, all entrances would have wheelchair access (Myers and Crockett 2012). All local community-based centers would have access to Telehealth, not just major hospitals. All online educational materials would automatically include subtitles for the benefit of not just those with hearing impairments but also those who retain information better visually. A universal-design approach to primary care healthcare is one that would move "beyond private conversations about individualized accommodations to public conversations about needs for all" (Wagner and Lothian 2014), where the dialogue in these public conversations results in structural changes with regard to how healthcare services are accessed among those with disabilities. From a universal design framework, we can begin to

imagine a world where inequalities for women with disabilities becomes something of the past and comprehensive healthcare is available to all persons—disabled or not—across all cultural, religious, class, and racial/ethnic backgrounds.

As a psychology postdoctoral resident working at a primary care setting at a large Veteran's Affairs hospital, the chapters in this feminist-oriented book were especially relevant to my work with cis-gender, genderqueer, and transgender veterans. I became excited after reading just a few pages of the first chapter and looked forward to sharing the text with my own medical team. This book is also relevant to nurse practitioners, social workers, administrators, researchers, and medical providers across all disciplines because it explains how social, personal, and systemic issues affect healthcare for women with disabilities, Indeed, this book is timely and relevant for anyone interested in the unique challenges women with disabilities experience when trying to access healthcare services, especially those clients from historically oppressed backgrounds.

Through my own qualitative research in disability issues, I have learned from participants that the experience of disability is often seen as an identity rather than an impairment or even a social construction. Individuals who experience disability as a source of community and pride often reject the equation of disability with poor physical and mental health or as a risk factor. For example, many members of the Deaf community perceive their hearing loss as a cultural asset rather than as a medical deficit. The inclusion of more scholarship from contemporary disability studies would have offered another perspective when thinking about how women with "disabilities" qualitatively experience their otherness. Although most chapters in this volume included recommendations for improving healthcare for women with disabilities, a few chapters felt lacking. In "We Exist: The Health and Well-Being of Sexual Minority Women and Trans People with Disabilities," Lesley A. Tarasoff included well-researched and culturally-sensitive guidelines for how to ask about sexual health as well as how to integrate the American Psychological Association's best practice standards. Other chapters were less concrete in their recommendations, and I found myself wishing for specific steps or guidelines for implementation that I could bring to my own primary care team.

Placed alongside other similar texts, this momentously important collection is an excellent companion to Kim Q. Hall's (2011) "Feminist Disability Studies," Martha Banks and Ellyn Kaschak's (2003) "Women with Visible and Invisible Disabilities: Multiple Intersections, Multiple Issues, Multiple Therapies," and Peter Lindsay's (2011) "Care of the Adult with an Intellectual Disability in Primary Care." In fact, the chapters in Miles-Cohen and Signore's book go beyond these earlier texts in their recognition that women with disabilities often experience other forms of oppression that affect access to and delivery of healthcare. Although the relative lack of inclusion of scholarship from disability studies means that this text will be better suited to practitioners than to theorists, it will be invaluable to healthcare professionals across disciplines. *Eliminating Inequalities* succeeds fully in its aim to deliver a radical new approach to education, research, healthcare delivery, and healthcare policy for providers who treat women with disabilities.

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