

INTRODUCTION

SHARI E. MILES-COHEN AND CAROLINE SIGNORE

Another young lady with a disability was [at the gynecologist's office] when I was there and the doctor raced around the place saying, "Oh my god, she's pregnant; I can't believe it, she can't be!" She was so loud everyone in the waiting room heard it. I was disgusted. When I went in for my appointment they did a pregnancy test on me even though I didn't request it. When it came back negative, they said "Oh, well thank god you're not pregnant!" I cannot even begin to tell you how upset I was, not only for myself, but for the other woman—she was a grown woman with a job—and they carried on so horribly.

—Kim Yancy, Member, Independence Care System
(Independence Care System & New York
Lawyers for the Public Interest, 2012, p. 8)

<http://dx.doi.org/10.1037/14943-001>

Eliminating Inequities for Women With Disabilities: An Agenda for Health and Wellness, S. E. Miles-Cohen and C. Signore (Editors)

Copyright © 2016 by the American Psychological Association. All rights reserved.

One public hospital mammography supervisor even told me, “People like you cannot come here.” When I asked where I should go, the supervisor responded “where people like you go.”

—Marilyn E. Saviola, Vice President of Advocacy and the Women’s Health Access Program, Independence Care System (Independence Care System & New York Lawyers for the Public Interest, 2012, p. 5)

My first time in program, everything was in one room so I didn’t have to undress and come in through the back door. I usually have a real hard time with spasticity, but the chair lift worked and I was able to get on the chair pretty much by myself. That the table actually came down to me—that made a huge difference. She did the examination the way it should be done. I’m 49 years old and that was the first time I had a totally accessible experience.

—M. Lyons, Member, Independence Care System
(Independence Care System & New York Lawyers
for the Public Interest, 2012, pp. 17–18)

In the 2013 American Community Survey, 20.2 million American women and girls (approximately 12.7% of all noninstitutionalized U.S. women and girls) reported having a disability (U.S. Census Bureau, 2013). According to 2011 data, approximately 10% of women 21 to 64 years of age (about 9.5 million women) and approximately 38% of women ages 65 and older (about 8.5 million women) are estimated to have a disability (Erickson, Lee, & von Schrader, 2013). These numbers are expected to increase, in part because of the aging of the population of the United States (Vincent & Velkoff, 2010), increased survival from traumatic injuries (Halfon, Houtrow, Larson, & Newacheck, 2012), and increasing prevalence of disability in childhood (DeVivo, 2012). In the general population, women have a higher rate of disability than do men. In addition, women have higher disability rates than do men in all of the major ethnic and racial groups except among Native Americans (Brault, 2012). These differences are partly due to women’s higher average longevity. However, disparities in health care among women with disabilities have also been amply documented as contributing to these differences (National Council on Disability, 2009).

According to the Center for Research on Women With Disabilities (2004), women with disabilities are significantly more likely than women without disabilities to have limited access to health care, increased prevalence of secondary complications, and diminished quality of life. In addition, women with disabilities are less likely to receive screenings for conditions common to all women.

Structural, environmental, and social barriers operate to prevent women with disabilities from accessing effective, culturally competent care and services. The current U.S. health care delivery system is inadequately responsive to the

needs of women with disabilities, in part because of a lack of relevant education and training of physical health and mental health professionals. Clinicians frequently lack knowledge and skills needed to provide optimal care to women with disabilities (Bellil et al., 2013; Strike, Skovholt, & Hummel, 2004). In 2004, the U.S. Department of Health and Human Services (USDHHS) sponsored a summit meeting titled “Breaking Down the Barriers to Health Care for Women With Disabilities.” Education was declared to be a critical next step toward improving care for this diverse, underserved population (USDHHS, Office of the Secretary, Office on Disability, 2004).

Informed by the emergent field of disability studies (Syracuse University, 2010) and an integrated biopsychosocial life course approach to health (World Health Organization, 2000, 2002), the American Psychological Association (APA), with funding from the USDHHS Office on Women’s Health, hosted an interdisciplinary conference to promote improvement in the health and wellness of women with disabilities (APA, 2011). Although the idea for this edited volume was born at the 2011 “Inequity to Equity: Improving the Health and Wellness of Women with Disabilities” conference, this volume significantly broadens the scope by presenting interdisciplinary work in the areas of research, education, practice, and policy on promoting the health and wellness of women with disabilities—in all of their diversity—using an integrated care framework (Heath, Wise Romero, & Reynolds, 2013) as its foundation.

APA (n.d.) defined *integrated care* as “an approach characterized by a high degree of collaboration and communication among health professionals” (physicians, psychologists, nurses and other health care providers) who work together to treat the whole patient from a biopsychosocial framework. Furthermore, evidence suggests that integrating psychological care with primary care and other services can enhance patients’ access to services, improve the quality of their care, and lower overall health care costs (APA, n.d.).

Doherty, McDaniel, and Baird (1996) proposed a five-level integrated care model that describes qualitative distinct levels of collaboration in the context of a continuum of care ranging from minimal collaboration to close collaboration in a fully integrated system (see Table 1).

The contributors to this volume represent a range of disciplines, disabilities, and other demographic characteristics and address their individual topics broadly so as to appropriately represent the diversity of women with disabilities, especially the intersections of identities and experiences across disability (physical, sensory, intellectual, mental health and emotional, developmental, and invisible). This book aims to use the chapters herein as a foundational body of knowledge to create a framework, with a clear and specific agenda for education, research, health care delivery, and policy, that can be pursued by future researchers as well as health care professionals, administrators, educators,

TABLE 1
Five Levels of Collaboration Between Primary Care and Behavioral Health

Level of collaboration	Description
Level 1 Minimal collaboration	Health care professionals work at different locations, do not integrate their services, and have little communication.
Level 2 Basic collaboration from a distance	Health care professionals practice in different locations and do not integrate their services, but they do communicate more frequently. They see each other as resources, but they do not share power or responsibility, and they do not understand each other's organizational culture.
Level 3 Basic collaboration onsite	Health care professionals colocate services, but they do not integrate their services. Providers communicate frequently. Although they see themselves as part of a larger system and they value the role other professionals play, they still do not appreciate each other's organizational culture.
Level 4 Close collaboration in a partly integrated system	Health care professionals colocate services and integrate some of their systems, including coordinated treatment plans. They also participate in more frequent communication and face-to-face consultation.
Level 5 Close collaboration in a fully integrated system	Health care providers colocate, have integrated systems, and provide seamless services. Health care providers meet routinely and have a deep appreciation of each other's organizational culture. Power and decision making are shared among all team members.

Note. Data from Doherty, McDaniel, and Baird (1996).

advocates, and women with disabilities themselves to lead to improved health and wellness for women with disabilities.

In addition to the Foreword, this Introduction, and an Afterword, this book contains four main parts: Part I, The Big Picture, with three chapters; Part II, Delivery of Care, with three chapters; Part III, Specific Populations, with six chapters; and finally, Part IV, Recommendations, with one chapter.

Part I, The Big Picture, begins with a chapter that describes the problems of health disparities experienced by women with disabilities. In Chapter 1, Nosek presents a strategic approach to addressing health disparities faced by women with disabilities. In Chapter 2, Saxton discusses social, personal, and systemic issues that impact health care for women with disabilities and also addresses clinical issues for health care providers. Parish, Mitra, and Iezzoni next review the existing research on health promotion and disease prevention, address the *International Classification of Functioning, Disability and Health*

(World Health Organization, 2002), and discuss barriers to the participation of women with disabilities in health promotion activities.

Part II, *Delivery of Care*, includes chapters on telehealth, reproductive and sexual health, and dental care. In Chapter 4, Khubchandani and Thew suggest that the remote use of technology to deliver health care services and information should be employed as a means to reduce barriers to care and as a central component to the future of integrated care. Also included in this section are chapters on reproductive and sexual health care and dental care, two arenas in which women with disabilities report the most challenging barriers to care (Stiefel, 2002). Chapter 5, contributed by volume coeditor Caroline Signore, describes reproductive health and health care delivery issues for women with disabilities and suggests opportunities for improved care delivered by an integrated health care team. Waldman and Perlman review the development of special needs dentistry and describe several model programs that are enhancing the training of dental professionals and increasing the provision of culturally competent dental care to women with disabilities.

Recognizing the rich diversity of identities and experiences that characterizes the lives of women with disabilities, Part III, *Specific Populations*, includes chapters that explore variability of experiences and intersecting identities within particular groups of women with disabilities. These chapters focus on adolescents and older women; mothers with disabilities; women of color; lesbian, bisexual, and transgender women; women veterans; and women with disabilities who are victims and survivors of violence. Simms-Cendan and Golden, in Chapter 7, describe the health care challenges and opportunities that distinguish girls from adult women with disabilities and that distinguish older women with disabilities from their younger counterparts. Correa-de-Araujo tackles the diverse variability of status and experiences, both within and between women of color and also explores opportunities to improve care afforded to them in Chapter 8. Next, Tarasoff reviews work on the health and wellness of sexual minority women and trans people with disabilities, including a cogitation of the reasons sexual minority women and trans people have been ignored and a call to researchers for greater inclusion. In Chapter 10, Andrews and Ayers describe the physical and attitudinal barriers that women with disabilities face in mothering. In Chapter 11, Cordes, Mona, and Saxon explore the intersections of gender, disability, and military culture for women with disabilities. Williams and Colvin provide the final chapter in this part, which presents data on the incidence and prevalence of abuse against women and girls and the unique risk factors that may make women and girls with disabilities vulnerable to abuse. Each of the chapters in Parts I through III concludes with a discussion of the ways in which interprofessional collaboration can improve the health and wellness of women with disabilities.

In the final chapter of the book, Miles-Cohen and Signore use insights gleaned from earlier chapters to present a research and action agenda for improving the health and wellness of women with disabilities.

This book is a worthy successor to *Health Care for Women: Psychological, Social, and Behavioral Influences*, which sought “to present information on research in women’s health that facilitates an understanding of the interplay of psychosocial, behavioral, and physiological functioning, and to synthesize from current knowledge practical applications for health care providers” (Gallant, Keita, & Royak-Schaler, 1997, p. xiii). Although considered cutting edge at the time for its full-fledged commitment to an integrated approach to research on women’s health, the volume did not include a chapter on women with disabilities, nor can one find the word *disability* in the volume’s index. The present volume aims to fill in this gap in focus and knowledge. Moreover, though it has been 18 years since *Health Care for Women*’s second printing, there is still much work to do (Institute of Medicine Committee on Disability in America, 2007) and current reforms to the U.S. health care system point to the tremendous promise that models of integrated behavioral and physical health care hold for health promotion, disease prevention, and wellness.

REFERENCES

- American Psychological Association. (n.d.). *Integrated health care*. Retrieved from <http://www.apa.org/health/integrated-health-care.aspx>
- American Psychological Association. (2011, August). Inequity to equity: Promoting health and wellness of women with disabilities. *Women’s Psych-E Newsletter*. Retrieved from <http://www.apa.org/pi/women/resources/newsletter/2011/06-08/women-disabilities.aspx>
- Bellil, L., Robey, K., Woodard, L., Graham, C. L., Smelter, S., Minihan, P., & Symons, A. (2013, April). Educating health professions students using a cultural competence framework. In W. Jones (moderator), *Health provider knowledge, attitudes, and competence*. Paper presented at Health Disparities Research at the Intersection of Race, Ethnicity and Disability: A National Conference, Washington, DC. Retrieved from http://www.ohsu.edu/xd/research/centers-institutes/institute-on-development-and-disability/public-health-programs/project-intersect/upload/Conference_Program-FINAL.pdf
- Brault, M. W. (2012). *American with disability: 2010. Household employment survey*, Current Population Reports (No. P70-131). Retrieved from U.S. Census Bureau website: <http://www.census.gov/prod/2012pubs/p70-131.pdf>
- Center for Research on Women with Disabilities. (2004). *Improving the health and wellness of women with disabilities: A symposium to establish a research agenda* (Executive Summary). Baylor, TX: CROWD.

- DeVivo, M. J. (2012). Epidemiology of traumatic spinal cord injury: Trends and future implications. *Spinal Cord*, 50, 365–372. <http://dx.doi.org/10.1038/sc.2011.178>
- Doherty, W. J., McDaniel, S. H., & Baird, M. A. (1996). Five levels of primary care/behavioral healthcare collaboration. *Behavioral Healthcare Tomorrow*, 5, 25–27.
- Erickson, W., Lee, C., & von Schrader, S. (2013). *Disability statistics from the 2011 American Community Survey (ACS)*. Ithaca, NY: Cornell University Employment and Disability Institute. Retrieved from <http://www.disabilitystatistics.org>
- Gallant, S. J., Keita, G. P., & Royak-Schaler, R. (Eds.). (1997). *Health care for women: Psychological, social, and behavioral influences*. Washington, DC: American Psychological Association. <http://dx.doi.org/10.1037/10235-000>
- Halfon, N., Houtrow, A., Larson, K., & Newacheck, P. W. (2012). The changing landscape of disability in childhood. *The Future of Children*, 22, 13–42. <http://dx.doi.org/10.1353/foc.2012.0004>
- Heath, B., Wise Romero, P., & Reynolds, K. (2013, March). *A review and proposed standard framework for levels of integrated healthcare*. Washington, DC: SAMHSA-HRSA Center for Integrated Health Solutions.
- Independence Care System & New York Lawyers for the Public Interest. (2012). *Breaking down barriers, breaking the silence: Making health care accessible for women with disabilities*. New York, NY: Authors.
- Institute of Medicine Committee on Disability in America. (2007). *The future of disability in America* (M. J. Field & A. M. Jette, Eds.). Washington, DC: The National Academies Press.
- National Council on Disability. (2009). *The current state of health care for people with disabilities*. Washington, DC: National Council on Disability.
- Stiefel, D. J. (2002). Dental care considerations for disabled adults. *Special Care in Dentistry*, 22(Suppl.), 26S–39S.
- Strike, D., Skovholt, T. M., & Hummel, T. J. (2004). Mental health professionals' disability competence: Measuring self-awareness, perceived knowledge, and perceived skills. *Rehabilitation Psychology*, 49, 321–327. <http://dx.doi.org/10.1037/0090-5550.49.4.321>
- Syracuse University. (2010). *A disability studies perspective*. Syracuse, NY: Author. Retrieved from <http://disabilitystudies.syr.edu/about/perspective>
- U.S. Census Bureau. (2013). *Disability characteristics: 2013 American Community Survey 1-year estimates*. Retrieved from http://factfinder2.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_13_1YR_S1810&prodType=table
- U.S. Department of Health and Human Services, Office of the Secretary, Office on Disability. (2004). *Breaking down the barriers to health care for women with disabilities: A white paper from a national summit*. Washington, DC: Author.
- Vincent, G. K., & Velkoff, V. A. (2010). The next four decades, the older population in the United States: 2010 to 2050. *Current Population Reports* (No. P25-1138). Washington, DC: U.S. Census Bureau.

- World Health Organization. (2000). *The implications for training of embracing a life course approach to health*. Geneva, Switzerland: World Health Organization. Retrieved from http://www.who.int/ageing/publications/lifecourse/alc_life-course_training_en.pdf
- World Health Organization. (2002). *Towards a common language for functioning, disability and health: ICF*. Geneva, Switzerland: Author. Retrieved from <http://www.who.int/classifications/icf/icfbeginnersguide.pdf?ua=1>