1

Disability and Sexual Citizenship

For decades, people with disabilities have been physically segregated from others in separate classrooms, schools, and, in some cases, institutional living facilities. However, a topic given less attention is their sexual segregation and lack of *sexual citizenship*, which is defined as a "belonging" and "acceptance in wider society" (Weeks, 1998). Although progress has been made over the years to address public and educational accommodations, intimate relationships and the sexual rights of people with disabilities remain taboo (Americans with Disabilities Act, 1990 [42 U.S.C. 12101 et seq.]; Individuals with Disabilities Education Act [IDEA], 2004 [P.L. 101-476]). People with disabilities are commonly perceived as "asexual," and if they exhibit sexual behavior, it is often viewed as less acceptable, unsafe, or inappropriate (Murphy, Elias, & Council on Children with Disabilities, 2006; Shandra & Chowdhury, 2012). Research demonstrates that people with various disabilities have just as much, if not more, experience and desire for sex and intimate relationships than others (Donenberg, Emerson, Brown, Houck & Mackesy-Amiti, 2012; Löfgren-Mårtenson, 2011; Mandell et al., 2008). However, their rights to obtain sex education and receive support to have safe sex and intimate relationships

are limited by both informal and formal practices and policies (Swango-Wilson, 2011; Tissot, 2009).

This book explores the intimate and sexual health needs of people with disabilities through the perspectives of the social workers who work with them. Using the life course and ecological systems perspectives, we interviewed social workers serving people with a range of disability types and levels of severity. In sharing the experiences and perspectives of social workers, we give voice to advocates of those with disabilities. We talked to social workers serving children, adolescents, adults, and older adults across a variety of practice contexts, including child welfare, adoption, school social work (including those working at specialized schools for specific disabilities), medical social work, private practice, family support agencies, forensic social work, and nursing homes—in essence, those who understand firsthand the gaps, stigma, and disenfranchisement this population faces in their everyday lives. Our findings reflect those of the National Association of Social Workers (NASW), which found that between 75 percent and 88 percent of social workers support people with chronic medical, neurological, physical, and developmental disabilities (NASW, 2006). Despite this finding, very little specialized education is provided for social workers even though it is required by the Council on Social Work Education (CSWE) 2008 educational policy and accreditation standards (Bean & Krcek, 2012; Laws, Parish, Scheyett, & Egan, 2010; Quinn, 1995). Thus, social workers are left to make decisions at their discretion using the guidance of their generalist social work practice education and the NASW (2015a) code of ethics. Because of limiting organizational and governmental practices and policies, such as abstinence-only policies in schools or rules that prohibit cohabitation in supportive housing for people with disabilities, social workers often face ethical dilemmas while supporting people with disabilities to meet their intimate relationship and sexual health needs.

As social work scholars and practitioners, we are dedicated to ensuring that social workers are equipped to empower people with various disabilities to safely experience sexual behaviors and intimate relationships. Similar to CSWE's (2008) accreditation standards, we believe that disability is an element of diversity rather than a pathology. This lens challenges

the medical model of disability and does not see disability as an inferiority. Rather, we hope to equip social workers to view disability through a strengths perspective that simultaneously views disability as similar to other elements of diversity (for example, race, ethnicity, gender, age) and recognizes unique challenges faced by people with disabilities that require special consideration and service delivery.

We originally conducted a phenomenological study of 13 school social workers' perspectives of the intimate and sexual health needs of adolescents with disabilities. A phenomenological design meant that we prioritized social workers' voices in communicating their experiences and the meaning they gave to those experiences (Padgett, 2008). We were inspired by these social workers' depth of exploration on the topic, dedication to their clients, and determined call for additional resources to address the needs of people with disabilities. Thus, we expanded our scope to include a total of 42 social workers who supported people with disabilities throughout the lifespan in various roles in three southwestern, southern, and West Coast states. The social workers we interviewed described the intimate relationship and sexual health needs of people with disabilities in various stages of life, the roles they held, and their recommendations for practices and policies to address their needs. They also spoke extensively about their own needs across systemic levels in supporting people with disabilities toward greater sexual and relationship health. Interviewing social workers serving children ($n = 13$), adolescents ($n = 13$), adults ($n = 11$), and older adults ($n = 5$) enhanced the rigor of our findings by assessing the extent to which themes were transferable across settings and served as a form of methodological triangulation by offering different types of information on the same topic (Padgett, 2008). Social workers also represented different self-reported genders (female = 31; male = 11), races and ethnicities (white = 26; Hispanic = 6; more than one race or ethnicity = 5; black = 2; Italian = 2; and Asian American = 1), and education levels (PhD = 1; MSW = 36; BSW = 5).

In addition, using phenomenological design, we interviewed eight young adults between the ages of 22 and 29 years with various mental health, physical, intellectual or developmental, and learning disabilities and asked them to reflect on their experiences with intimacy and sexual

health. We share passages from these interviews along with those of the social workers to give voice to people with disabilities themselves. They also represented different genders (female = 5; male = 3) and races and ethnicities (white = 5; Mexican American = 2; Ghanaian American = 1).

One of the authors, Kristen Faye Linton, has over a decade of experience supporting people with various disabilities across the lifespan. Heidi Adams Rueda and Lela Rankin Williams bring specific expertise in romantic and sexuality research, especially pertaining to vulnerable and ethnic minority youth populations. Thus, this book was developed from a combination of clinical practice and research. The reader will take from it a better understanding of the issues encountered in social work practice among people with disabilities. As consumers of research, they may also develop their own sense of inquiry around this subject matter as many questions are left unanswered in the academic literature. Finally, as advocates, they may feel a tug within their own professional lives to advocate across multisystemic levels for change that is required to meet the sexual and intimate relationship needs of people with disabilities.

The structure of this book is inspired by the social workers' acknowledgment that the intimate relationships and sexual development of people with disabilities are influenced by their immediate settings (microsystem), the interactions between those settings (mesosystem), settings in which the person is not always present (exosystems), and cultural patterns in society (macrosystem), which is indicative of Bronfenbrenner's ecological systems theory (1977, 1979). Social workers often serve in micro- and mesosystemic roles, although we also include attention to exo- and macrosystemic influences. We include many examples throughout, providing direct quotations from social workers as often as possible to reflect the meanings they conveyed.

Disability is widely defined because it is not uncommon for social workers to work with people with various and often co-occurring disabilities. The Americans with Disabilities Act (1990) broadly defines *disability* as a physical or mental impairment that limits one or more major life activities. References to specific disabilities were consistent with diagnoses defined by recent editions of the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000, 2013) and IDEA

(2004). Brief definitions of disabilities will be provided, yet social workers are encouraged to learn more about these disabilities in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and IDEA. Because interviews were conducted before and during the transition to the use of the DSM-5, social workers sometimes referred to diagnoses that have since changed (American Psychiatric Association, 2000, 2013). The following types of disabilities are discussed by social workers in this book: psychiatric, intellectual, developmental, learning, neurological, and physical. Psychiatric disabilities included emotional, behavioral, or mental health challenges. Clients with psychiatric disabilities were often referred to as those with "ED," or emotional disabilities. Intellectual disability was previously known as mental retardation. Social workers who supported children with these disabilities often referred to them as people with "cognitive impairments" or the "sped kids," the latter denoting those who received special education services. Developmental disabilities included developmental delays, Down syndrome, and autism spectrum disorders. Learning disabilities included specific learning disorder and dyslexia. Neurological disabilities included brain injuries and dementia. Physical disabilities included any ambulatory impairments. The most common disabilities discussed by social workers were intellectual and developmental.

Choosing language to communicate about disability that is respectful and accepted universally is difficult. The U.S. disability rights movement argues for use of person-first language (that is, a person with a disability) over disability-first language (that is, a disabled person) to acknowledge that a disability is only one aspect of a person's identity (Tobin, 2011). The American Psychiatric Association has supported the disability rights movements' use of person-first language (Peers, Spencer-Cavaliere, & Eales, 2014). However, more recently, perspectives have shifted to advocating for the use of disability-first language. The social model of disability, which resulted from the U.K. disability movement, posits that people do not have disability, "but rather, societies have actively disabled people" (Peers et al., 2014, p. 273). To clarify, the societal structures have disabled (used as a verb) people. The social model of disability suggests that social structures, policies, and attitudes create disability. This model focuses on

macrosystemic influences, such as societal perspectives, structures, and policies, rather than individual diagnoses. In doing so, it recognizes challenges faced by individuals as a result of living within societies that do not provide accommodations to meet their needs.

Social workers often perform their work within a medical model framework and use the DSM-5 for billing and professional communication purposes. For example, clients often need to receive a formal diagnosis to receive services; thus, reference to diagnoses becomes important in the social work profession. The social model of disability is also consistent with social work professionals who ethically strive and are bound to conduct social and political advocacy on their clients' behalf (NASW, 2015a). Social workers must balance use of the medical and social models of disability. As with any language used in social work practice, it is important to communicate with clients about their desired preference in use of disability- or person-first language. Social workers' quotes are used verbatim in line with our phenomenological perspective taken, with the exception that we removed identifying references to ensure confidentiality and made person-first language changes when it appeared disrespectful. For example, some social workers would refer to "the mentally retarded" client rather than "the client with intellectual disability." While we were writing this book, an End-the-R-Word campaign in the United States advocated for ending the use of the word "retardation." In addition, because this word was removed from the DSM-5, it seemed appropriate to make changes to represent the accurate diagnosis and use more acceptable language.

Our hope is that this book will serve as a source of information about the intimate relationships and sexual health of people with disabilities across the lifespan, including the social welfare policies and practices aimed at improving their development. We also hope that the interviewed social workers' acknowledgment of systemic challenges and ideas for radical solutions will inspire you not only to provide direct support for people with disabilities, but to advocate for changes in societal structures that have further disabled people.