Missing Intersections: Contemporary Examinations of Sexuality and Disability

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10.1 Introduction

When we were asked to write this chapter we were excited to explore the intersection of sexuality and disability in greater depth than either of us had previously. What we discovered is that while the fields of sexuality and disability studies have existed independently for some time, they have only recently begun to merge together. Moreover, the existing literature represents an unbelievably broad range of definitions, methods, and perspectives, making a synthesized overview of the literature very difficult to accomplish. Other researchers have noted this lack of consistency (see Connell et al. 2014), but the breadth and depth of the diversity in regards to definitions, populations, methods, and findings surprised us.

One of the biggest issues we faced in compiling our review was the broad range of definitions that researchers relied upon. As we discuss in more detail in the following section, disability is a complicated and multidimensional concept that is difficult to define (Altman 2001). First, definitions of disability span the social, medical, political, and legal fields, all of which might be at odds with one another depending on the subject of inquiry and the perspectives of the researchers. Moreover, many researchers were not clear about how they operationalized disability (or sexuality, for that matter), leaving the reader unable to compare one study to another. Second, how these definitions are applied—and who is included in a given definition—can vary greatly. We found ourselves faced with the same challenge that many scholars of sexuality and disability have dealt with, and an issue that is the subject of longstanding debate within disability studies: inclusion.

Finally, our review was complicated by the fact that the methods employed in many studies were underdeveloped or lacked rigor. A great number of articles explored the concepts of disability and sexuality in an enlightening way, but the parameters used to define the population—when it was clearly explained at all—would often reduce the sample to a very niche group, excluding a broad range of people and types of disability. In addition, minority groups, and sexual minorities in particular, were often neglected in the existing literature (Caldwell 2010; Noonan and Taylor Gomez 2011), leaving those populations—and the issue of intersectionality—woefully understudied. Furthermore—perhaps because of the reliance on convenience samples drawn from medical and clinical populations—core definitions and basic elements of the studies' methods were often not clearly explained;

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we were often left wondering how the population was selected, how disability was defined, where and how participants were recruited, or whether the instruments used had a history of validity and reliability. The reliance on extremely small sample sizes as well as on autoethnographic research is another major issue we discovered while reviewing the existing literature. These studies, while invaluable in the depth and nuance they add to discussions of sexuality and disability, are by their very nature related to the most micro-level observations about sexuality and disability. The dearth of macro-level, large-scale, and representative sample research leaves a significant gap in our understanding about the relationship between disability and sexuality. While we realize that the field of sexuality and disability studies is in its infancy compared to other fields within the social sciences, these weaknesses only served to underscore our belief that more rigorous, well-developed research is needed at the intersection of disability and sexuality if the field is to continue to grow.

Given these challenges, and our desire to present a cohesive overview of the existing literature, what follows is a broad review of the available literature about sexuality and disability, organized primarily by subject area. First, we review commonly used definitions of disability and sexuality, as well as the controversies about the use of various terms. Next, we discuss popular theoretical perspectives used by contemporary researchers. Then, we present a broad literature review of existing research, including topics related to sexual rights of people with disabilities, attitudes toward and perceptions of the sexuality of adults and adolescents with disabilities, sex education, and finally sexual facilitation and satisfaction.

10.2 Key Terms

Gordon and Rosenblum (2001) argue that unlike other parts of the Western world, American researchers have, historically, taken a "peculiarly un-sociological" approach to studying disability, where most of the research "continues to frame disability along 'traditional' or 'individual' lines, that is by focusing on limitations, medicalization, diagnoses, individual adjustment, etc." (p. 16). In response to this perceived oversight, Gordon and Rosenblum (2001) applied a social constructionist approach to understanding disability, and argued that just as the categories of race, sex, sexual orientation, and gender are socially constructed, so too are our conceptualizations of disability. Social processes that create minority groups—whether that distinction is on the basis of gender, sex, race, sexual orientation, or disability—involve naming and aggregating into two or more groups, as well as segregating, stigmatizing, and devaluing those in the "non-normative" group and excluding them from full and total access to the larger society. Gordon and Rosenblum (2001) argue that the application of this theory, which has been applied to other social groups, should and can be applied to disability studies as well.

One of the challenges of researching sexuality and disability is reconciling the wide variety of definitions and terms that are used in the literature. Grönvik (2007) categorized five different definitions of disability, all of which were generated for different purposes. First, "functional definitions" focus on the individual's functional limitations (e.g., their use of a wheelchair). Second, a "relative" or "environmental definition" of disability focuses not on the individual, but on inaccessible or limited environments that they encounter; similarly, the "social model" of disability constructs disability as occurring entirely in the environment, which prevents individuals from participating in society. The fourth category, "administrative definitions," result from interactions with the government where one is defined as disabled, perhaps because of the use of some sort of mobility device. Finally, "subjective definitions" result from how the individual with the impairment would define themselves. Given the diverse origins and uses of these definitions, it should not be a surprise that they sometimes conflict with one another, creating multiple layers of definitions that may or may not be accepted by the disabled individual, the larger community, or the government/legal system. In our review of the literature, we found that when offering explicit definitions or operationalization of disability, researchers relied upon some or all of these categories.

It is also important to keep in mind that the population under study is very diverse. Disability studies encompass people with acquired and congenital disabilities; intellectual, cognitive, and physical disabilities; disabilities that are the result of trauma or illness; individuals with mild disabilities as well as those with very serious disabilities; those who need very little medical intervention or caretaking, and those who need significant medical management; those who maintain their own residences and those who reside in long-term care facilities. This diversity also includes individuals from a variety of racial/ethnic backgrounds, genders, sexual orientations, socioeconomic statuses, political perspectives, and national origins. Moreover, these differences are also reflected in (and combined with) the diversity of non-disabled individuals often included in disabled sexuality research, such as spouses, family members, caregivers, medical professionals, and members of the general public.

The variety of definitions, Grönvik (2007) argues, can lead to widely disparate (and sometimes contradictory) outcomes for researchers, as well as making it difficult for the reader to assess, evaluate, and apply findings. Researchers often do not discuss specifics of the population under study (instead referring to a sample of “people with cognitive disabilities” or “individuals with acquired physical disabilities”), perhaps because of the broad range of diversity that may be included in the sample. This diversity, though, is one of the factors that necessitates the use of carefully drawn definitions; it becomes almost impossible to compare, recreate, or build upon existing literature in a systematic way if one cannot assess these factors. And, as Gordon and Rosenblum (2001) point out, the language one chooses to use (e.g., “disabled person” versus “person with a disability”) reflects different ideological positions held by activists, researchers, and community members alike. Grönvik (2007) encourages researchers to think about the definitions they employ, as well as the consequences of their choices. Similarly, it is important for researchers and activists to understand the varied theoretical perspectives that can be employed, as one’s theoretical perspective often guides key methodological choices, including how disability is operationalized.

10.3 Theoretical Perspectives

Historically, most sexuality and disability research has been grounded in the medical model of disability. This research, which was conducted primarily by clinicians, doctors, and other medical professionals, often regarded an individual’s impairment as the cause of any and all disadvantages that were experienced; the solution, then, was treatment and cure of the underlying condition or impairment (Crow 1996). The result of this model, according to its critics, is that it tended to view and treat disabled individuals as

> not only broken or damaged, but also incompetent, impotent, undesirable, or asexual. Their inability to perform gender and sexuality in a way that meets dominant societal expectations is seen as an intrinsic limitation, an ‘unfortunate’ but unavoidable consequence of inhabiting a disabled body. (Rembis 2010, p. 51)

The social model of disability, which grew out of opposition to the medical model, shifts the focus away from the impairment and toward the disadvantages experienced by individuals. Under this model, the disability is not in the body, but instead is located in the reduced opportunities and discrimination that individuals with impairments face. As Shakespeare (2006) notes, as early as 1975 the Union of the Physically Impaired Against Segregation (UPIAS), a British activist organization, stated “it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (p. 198).

Shakespeare (2006) argued that the shift away from the medical model and to the social model has been effective in three broad areas. First, it has been effective politically, in large part because it is easily understood and offers terminology and language that can be used to easily separate allies from those who are not supportive of disability rights and/or activism (e.g., use of the term "disabled people," which indicates acceptance of the social model versus "people with disabilities," which does not) (Shakespeare 2006). Second, the social model has been effectively used to identify and critique discriminatory practices, encouraging legislative social change. Finally, the social model has played an important role in the improved psychological well-being of disabled individuals:

> In traditional accounts of disability, people with impairments feel that they are at fault. Language such as "invalid" reinforce a sense of personal deficit and failure. The focus is on the individual, and on her limitations of body and brain… The social model has the power to change the perception of disabled people. The problem of disability is relocated from the individual, to the barriers and attitudes which disable her. It is not the disabled person who is to blame, but society. She does not have to change, society does. Rather than feeling self-pity, she can feel anger and pride. (Shakespeare 2006, pp. 199–200)

Despite the usefulness and successes of the social model, it is not without its detractors. First, some critics have pointed out that the core group of activists responsible for the creation of the social model was primarily comprised of White, heterosexual men with physical impairments, which may have produced a limited view of disability (and possibly, in a limited range of interventions and mechanisms for social change). Second, some activists have argued that the social model minimizes the real, and often negative, impact that impairment has on individuals' lives (Shakespeare 2006; Crow 1996). In addition, the social model's definition of disability creates a tautological argument; under this model, disability and oppression are one and the same, so it is technically impossible to conduct research on individuals who are disabled but not oppressed (Shakespeare 2006). Furthermore, the social model has been critiqued for creating and reifying distinctions between impairment and disability that may not be so clear-cut in the lived experiences of disabled individuals. Finally, the social model hypothesizes the possibility of "barrier-free utopia," which is laudable in its intent but would be impossible to actualize, especially given the wide variety of accommodations that would be required (Shakespeare 2006).

Even under the social model, which was regarded a vast improvement over the medical model of disability, there are major issues regarding the incorporation of sexuality and gender issues in disability research. As Shakespeare (2000) points out, until recently, the public lives of disabled people were analyzed and discussed, while the private lives—including issues of sexuality, identity, and sexual relationships—were hidden. As such, issues related to sexuality went largely unexamined. Additionally, some have argued there is bias present in the existing research. Much of the research, they state, focuses on male-centric, heteronormative perceptions of gender and sexuality, with the result that "straight women and lesbians, especially those with congenital—as opposed to acquired—disabilities, gay men, bisexuals, and racial/ethnic minorities continue to experience the most hostility and/or neglect" (Rembis 2010, p. 54).

Some scholars (see Rembis 2010; O'Toole 2000) have argued that researchers need to take a more intersectional perspective, examining the multiple communities of which one is a member. In their interdisciplinary review of five years of articles published in peer-reviewed journals in sexuality, disability, and rehabilitation, Greenwell and Hough (2008) found that a variety of cultural factors were regularly addressed by researchers (e.g., gender, race), but that only about one-quarter of the studies included information about respondents' sexual orientation. In addition, they point out that although researchers often report demographic information about their sample, those variables are rarely used in analyses, "[raising] the question of whether potential investigative opportunities are being missed" (Greenwell and Hough 2008, p. 194). There has been increased attention regarding the intersection of sexual identities among people with disabilities. As discussions of sexual rights, sexual education and sexual satisfaction have increased, some scholars have noted the absence of voices from lesbian, gay, bisexual, and transgender people with disabilities (Caldwell 2010; Noonan and Taylor Gomez 2011; Tremain 2000). Additionally, as Tilley (1996) and O'Toole and Doe (2002) highlight, for individuals with multiple identities, it can be difficult to find support across groups, resulting in "forced and disempowering compromises and consequences" (Tilley 1996, p. 139).

10.4 Literature Review

In the following sections, we discuss topics that are commonly examined in sexuality/disability social research. We first address the topic of the sexual rights of individuals with disabilities, as it lays the foundation for understanding common barriers and legal issues that hinder the free expression of sexuality for people with disabilities. Attitudes toward, and perceptions of, the sexuality of adults and adolescents with disabilities are frequently addressed in the existing literature. This research focuses in large part on the opinions of those who might have social control over the sexuality of people with disabilities (e.g., parents, caregivers, or medical professionals). Sex education is similarly common as a research topic; researchers often focus on the lack of education available, as well as the types of information that individuals with disabilities themselves believe is still needed. Finally, we address issues of sexual facilitation (and conversely, the social control) of the sexuality of people with disabilities, as well as reviewing studies that explicitly address the topic of sexual satisfaction.

10.4.1 Sexual Rights

As proponents of the social model have pointed out, the private lives of disabled individuals have only recently become a subject of political and social action (Shakespeare 2000). One major development occurred in 2002, when the World Health Organization (WHO) convened a meeting of international experts on sexuality and sexual health to establish the importance of sexual health and sexual rights as part of the WHO agenda (WHO 2006). Part of the culmination of this conference was a working definition of sexual health and sexual rights, which has been frequently applied to discussions concerning the sexual rights and sexual health of individuals with disabilities. The adopted definition, which has been used by researchers and scholars alike, stated:

> …the application of existing human rights to sexuality and sexual health constitute sexual rights. Sexual rights protect all people's rights to fulfill and express their sexuality and enjoy sexual health, with due regard for the rights of others and within a framework of protection against discrimination. The fulfillment of sexual health is tied to the extent to which human rights are respected, protected, and fulfilled…. (WHO 2006)

In addition, the definition outlines how human rights are tied to sexual rights:

> Rights critical to the realization of sexual health include: the rights to equality and non-discrimination; the right to be free from torture or to cruel, inhumane, or degrading treatment or punishment; the right to privacy; the rights to the highest attainable standard of health (including sexual health) and social security; the right to marry and to found a family and enter into marriage with the free and full consent of the intending spouses, and to equality in and at the dissolution of marriage; the right to decide the number and spacing of one's children; the rights to information, as well as education; the rights to freedom of opinion and expression; and the right to an effective remedy for violations of fundamental rights. The responsible exercise of human rights requires that all persons respect the rights of others. (WHO 2006)

Despite the establishment of these criteria, there are many barriers still in existence regarding fully-realized sexual health for individuals with a disability (Shakespeare 2000). Sex education is still lacking for many disabled people, and social, civic, and public places are often inaccessible for people with disabilities, reducing the number of venues through which people meet sexual and intimate partners (Shakespeare 2000). Inaccessible spaces can also make it difficult for individuals and couples to engage in common dating and relationship activities (Bender 2012); public accommodations for individuals with disabilities, while a positive step, often do not allow for individuals to fully express themselves as sexual beings. For example, a respondent in Bahner's

(2012) study of Swedish people with disabilities stated that she and her boyfriend (who was also disabled) were often not able to use public transportation to go out, because only one wheelchair was allowed at a time on the bus. The special disability transportation system—which was unreliable and was more expensive—prohibited passengers who were not disabled from riding unless they were personal assistants or caregivers, which meant the system was "definitely not an option if you wanted to go home with somebody you had picked up from, for example, a bar" (Bahner 2012, p. 344). Barriers such as these are often invisible to the larger, ableist culture, and repeated experiences of exclusion, discrimination, and ableism can impact one's self-esteem and belief in one's self as a sexual being (Bender 2012). As Shakespeare (2000) points out, "being sexual demands self-esteem…yet disabled people, systematically devalued and excluded by modern Western societies, are often not in the right place to begin that task of self-love and self-worth" (p. 161).

Some research has been conducted in Western European countries that offer an interesting international perspective into sexual rights of disabled individuals. Western European nations often acknowledge a broader range of rights for disabled individuals, as well as offering more social supports and accommodations for individuals with disabilities (Bahner 2012). Broader recognition of sexual rights does not eliminate controversy, though. For example, Bahner (2012) discusses conflict around Swedish legislation regarding a disabled individual's right to live autonomously (often with the support of a personal assistant), and that assistant's right to refuse to engage in activities that may violate their personal values and beliefs (e.g., by assisting a disabled individual to prepare for or engage in solo or partnered sexual activities). Denmark, conversely has stated that it is the "personnel's duty to facilitate service users' sexuality, whether it concerns assistance in order to have sex with a partner, to masturbate, or to contact a prostitute" (Bahner 2012, p. 339). These macro-level social and legal supports of the sexual rights of individuals with disabilities share a reciprocal and mutually influential relationship with the more micro-level individual opinions and attitudes regarding the sexuality of disabled individuals.

10.4.2 Attitudes and Perceptions About Disabled Sexuality

A considerable amount of research discusses perceptions of sexuality and disability, assessing the attitudes and opinions of medical professionals and the general public, as well as of disabled individuals themselves. This research is quite diverse, and the studies often cannot be directly compared because they address different populations (nurses, doctors, or parents, for example), focus on different types of disabilities (e.g., intellectual versus physical), or use different scales, forms of measurement, or methods. And as previously mentioned, opinions and attitudes about disabled sexuality often differ based on the type and severity of the disability, as well as the personal characteristics of the disabled person (e.g., age, gender, etc.) This section will provide a brief and general overview of this literature, though it is important to keep the aforementioned limitations in mind.

Some of the existing attitudinal research examines the myths about disabled sexuality that are still commonly endorsed, including the myth that individuals with a disability are asexual. The existence of this myth stems, at least in part, from the belief that "with any level of sexual dysfunction, there would be a resultant decrease in sexual fulfillment and therefore a decrease in sexual needs" (Esmail et al. 2010, p. 1151). Heteronormative attitudes about sex prevail in the general public, among caregivers and medical personnel, as well as in resources for individuals with disabilities. These attitudes are often phallocentric, focusing on genital contact and performance, and assume that individuals with disabilities are heterosexual (Tilley 1996).These assumptions tend to make it difficult for individuals (i.e., non-disabled individuals, individuals with a disability, their partners, or caregivers) to modify their definitions of sex to include the sexual practices of disabled individuals, rendering those practices—and people—invisible (Esmail et al. 2010; Tilley 1996). For example, rehabilitation resources for individuals with physical disabilities may discuss sexuality, but they may focus on heterosexual intercourse as "the only means of sexual expression, and, of course, the woman was in the passive missionary position" (Tilley 1996, p. 141). As previously mentioned, sexual minorities are underrepresented in disability research, perhaps in part because of the assumption of heterosexuality. This lack of recognition of sexual minorities in disability research reinforces the larger issue of heteronormativity and isolation, as well as making complex intersectional research very uncommon (O'Toole 2000; Tilley 1996). In addition, these heteronormative beliefs can combine with cultural norms about attractiveness and beauty to negatively impact disabled individuals' (and their potential partners') views of themselves as sexual beings, as well as color the attitudes of members of the general public toward the acceptability (or existence) of disabled sexuality (Esmail et al. 2010; Tilley 1996).

In addition to the myth of asexuality, common gendered misperceptions exist about individuals with intellectual or cognitive disabilities. Cuskelly and Gilmore (2007) assessed attitudes of the general public about the sexuality of men and women with intellectual disabilities, hypothesizing that men with intellectual disabilities would be seen as sexually deviant (perhaps even dangerous) while women with similar disabilities would be viewed as "sexual innocents" or as vulnerable. Noonan and Taylor Gomez (2011) discussed similar attitudes, and concluded that individuals with intellectual disabilities often have their sexual rights curtailed because of the common perception that they are "potential victims of sexual abuse or [are expressing]…unacceptable sexual behavior. Either way, they become the focus of protection" (p. 177).

Attitudes of the general public regarding sexuality and disability have also been assessed. As with general attitudes about sexuality, older individuals tended to have more conservative attitudes and opinions about disabled sexuality than younger people, and people with higher levels of education tended to be more liberal than those with lower levels of education, at least with regards to the sexuality of individuals with intellectual disabilities (Gilmore and Chambers 2010; Cuskelly and Bryde 2004). Men and women had very similar attitudes toward disabled sexuality, though there were often different levels of acceptance of sexual expression based on the gender of the disabled individual, the type of disability they had, and the degree of impairment (Gilmore and Chambers 2010).

Attitudes and perceptions of parents and other caregivers (typically, medical professionals/support staff) are also commonly addressed in the literature. In general, parents of individuals with intellectual disabilities tend to be more conservative with regards to disabled sexuality than support staff, though this may be due to age or generational differences between the two groups rather than their relationship to the disabled individual (Gilmore and Chambers 2010; Cuskelly and Bryde 2004). In addition, the type of sexual expression being discussed often garnered different levels of acceptance from different populations; for example, Cuskelly and Bryde (2004) found that parents and medical staff members were less supportive of individuals with intellectual disabilities having children compared to other forms of sexual expression (e.g., masturbation, sexual intercourse, and marriage) than were members of the general public. As Cuskelly and Bryde (2004) point out, the attitudes and beliefs of caregivers can have significant impact on the lives of individuals with intellectual disabilities, and conflicting opinions and attitudes from caregivers could cause confusion for the individual with the disability about appropriate sexual behavior. As sexuality and aging scholars have noted elsewhere (Taylor and Gosney 2011), though attitudes of staff are important to assess, it is equally important to assess the policies and regulation of care facilities and group homes, as those policies inform the daily lives of the residents. As Siebers (2014) notes, structural factors in group homes and long-term care facilities may contribute significant barriers to the sexual expression of individuals with disabilities:

> Group homes and long-term care facilities pur-

> posefully destroy opportunities for disabled people to find sexual partners or to express their sexuality. Even though inhabitants in group homes pay rent for their rooms, the money buys no functional privacy or right to use personal space. The staff usually does not allow renters to be alone in the room with anyone of sexual interest… in many care facilities, staff will not allow two people to sit together alone in the same room. Some facilities segregate men and women. Add to these restrictions the fact that many people with disabilities are involuntarily confined in institutions, with no hope of escape, and the enormity of their oppression becomes palatable. (p. 379)

Existing institutional and structural barriers are often not discussed in attitude and opinion research, perhaps because the barriers themselves vary from institution to institution. Further research is warranted on the interaction on how micro-level perspectives on disabled sexuality can inform macro-level policies (and vice versa). One area of interaction between these two perspectives that has been studied frequently pertains to the sex education that is available for individuals with disabilities.

10.4.3 Sex Education

While sex education is neglected in general in most American schools, it is especially absent for individuals with disabilities (Tepper 2000). As McCabe (1999) and Gomez (2012) point out, sexuality education is not only key to fulfilling sexual experiences, but is also an essential part of preventing and reporting instances of sexual abuse; this is especially true for individuals with disabilities, who might be at increased risk for physical and sexual abuse victimization and perpetration (Lindsay et al. 2012; Plummer and Findley 2012). In fact, access to education and information about sex is an integral part of the WHO's (2006) definition of sexual rights, and increasing attention has been paid to issues of sexual education for individuals with disability.

Existing research on sex education for disabled individuals tends to focus on the sexual experiences, attitudes, or sexual knowledge of individuals with both physical and cognitive disabilities (both congenital and acquired, and at various types and levels of impairment), though few studies have attempted to compare individuals with physical and cognitive disabilities to members of the general public in terms of the quality and type of sex education received (McCabe 1999). In one exception, McCabe (1999) assessed individuals with physical or cognitive disabilities on measures of sexual knowledge and their frequency of a variety of sexual experiences, and found that individuals in the general public reported the highest rates of sexuality education, followed by individuals with physical disability, then followed by those with a cognitive or intellectual disability. In addition, disabled individuals were less likely than members of the general public to receive their sex education from parents or friends but more likely to receive information from the media, which may signal that disabled individuals may be receiving less accurate or relevant information, and may have fewer outlets to discuss their thoughts, feelings, and experiences (McCabe 1999). Similar research comparing individuals with intellectual disabilities to those without intellectual disabilities found that those with disabilities were significantly less knowledgeable about pregnancy, STIs, contraceptives, and masturbation (Murphy and O'Callaghan 2004). Whether this gap in knowledge was due to low retention of knowledge is unclear, but some literature (Lawrence and Swain 1993; McCabe 1999) has indicated that it may be due to limited exposure to sexuality curriculum and age-inappropriate communication style, rather than retention issues due to the disability. Indeed, less than 50% of McCabe's (1999) respondents with disabilities had received any sex education at all, compared to over 90% of the non-disabled participants, reinforcing the notion that lack of access to education may be the underlying issue. In another study among 74 young adults with cerebral palsy (aged 20–24), very few (10%) had discussions about sexuality during rehabilitation and many reported wanting more information about reproduction, interventions, and problems with partners (Wiegerink et al. 2011). Furthermore, as Tepper (2000) points out, sexual education may be particularly important for individuals with acquired disabilities:

> After injury things were "not the same." There were concerns about being sexual in the "normal" way. Feelings of "not the same" were rooted in who, what, where, and how participants learned about sexuality in the larger sexual culture. These changes experienced in comparisons to memories of what was normal for them before injury resulted in intrusive and uncontrollable thoughts during sexual activity. The absence of quality sexuality education combined with learning about sex primarily from having genital intercourse led to sexuality embodied in the genitals and cognitively focused on perfect performance with the goal of orgasm … resulted in consequences like low sexual self-esteem and lost hope. (p. 288)

The kinds of sexual education and counseling available following an acquired disability can also have varying impacts based on race, class, gender, and age at the time of injury (Bender 2012). The emphasis on heteronormative performance during rehabilitation for men following spinal cord injury can negatively impact some men's sense of a sexual self if, for example, they are unable to use medications to achieve an erection because of contraindications with other medications or the cost associated with purchasing such medications or devices.

10.4.4 Sexual Facilitation

One of the unique areas where sexuality and disability research intersects is in the area of sexual facilitation. Like many issues surrounding the study of disability and sexuality, the definitions of sexual facilitation used by researchers (if it is defined at all), can be quite varied, ranging from a caregiver having a sex positive attitude, assisting an individual so they can attend social events like parties or go to a bar, facilitating sexual activities with a partner (or partners), or to arranging for or assisting an individual in hiring a sex worker (Bahner 2013; Earle 2001). Given these broad and wide-ranging definitions, disabled individuals and caregivers alike have different perspectives on the appropriateness and usefulness of sexual facilitation. Many studies have demonstrated that a key to establishing comfort with sexual issues with caregivers and personal attendants was good communication with the caregiver, establishing boundaries, and the caregiver having received at least some education about the sexual lives of disabled individuals (Bahner 2012; Browne and Russell 2005; Earle 2001).

Caregivers and disabled individuals often had different perspectives and expectations about disabled sexuality in general, as Earle's (2001) findings demonstrate. Earle (2001) interviewed disabled individuals as well as caregivers, and found that caregivers often position sexuality as a "want" or a "desire," rather than a "need," which shaped the way they responded to their clients' requests (real or hypothetical) for sexual facilitation. In addition, Earle's (2001) caregiver respondents often endorsed (or had endorsed in the past) the belief that their disabled clients were asexual, because they believed their clients' physical impairments prevented them from pursing sexual satisfaction; as one caregiver put it, "if you've never been able to do it for yourself, you won't know what you're missing" (p. 317). In addition to establishing comfort with caregivers, determining boundaries, and overcoming ableist attitudes; social norms and sexual scripts could often act as barriers to sexual expression for some individuals. Bahner's (2012) Swedish participants discussed that there are norms surrounding sex—cultural scripts that most of us abide by; for example, not having sex loudly when other people are within earshot—and non-disabled individuals are often able to disregard these norms when in the privacy of their own home. Disabled individuals with attendants, though, often felt as though they had to abide by these norms even when in their own homes, hampering their rights to sexual expression.

10.4.5 Sexual Satisfaction

Sexual satisfaction is regarded as an integral part of a healthy and fulfilling sexual life, yet historically little attention has been paid to the levels of sexual satisfaction among individuals with disabilities (Tepper 2000). According to Tepper (2000) lack of sexual pleasure and low levels of sexual satisfaction among individuals with disabilities has "not been seen as problematic:"

> Neglect of the pleasurable aspect in the discourse of sexuality and disability is perpetuated by the assumptions that people with disabilities are child-like and asexual, a focus on procreative sex to the detriment of pleasure, and the assumption that people with disabilities are not physiologically capable of pleasure or orgasm. (p. 287)

Indeed, much of the existing research indicates that individuals who have an acquired disability reported receiving very little information about how their injury would impact their sexuality (Connell et al. 2014). A number of studies have been conducted to better understand the sexual satisfaction of disabled individuals, though these studies are difficult to compare due to differences in methods, populations, and study tools. Two studies examine the social-psychological impacts of injury/trauma, rather than purely physiological consequences on which much of the existing literature focuses. Tepper et al.'s (2001) phenomenological study of women with spinal cord injuries, proposed a system of understanding post-injury responses, including "cognitive-genital dissociation," "sexual disenfranchisement," and "sexual rediscovery." In their review of existing literature on the "lived experiences of sexuality changes in adult trauma survivors," Connell et al. (2014) expanded this system to include physiological effects on sexuality after injury, including issues related to pain, sexual function, medication side effects, and decreased libido.

Cognitive-genital dissociation refers to "shutting down" sexuality after injury, based on the false assumption that sexual pleasure or sexual functioning is no long possible (Tepper et al. 2001). As Connell et al. (2014) point out in their review of sexual satisfaction and disability literature, this process is linked with the lack of accurate information received in the rehabilitation setting, and this process contributed to sexual difficulties, as well as poor self-esteem and body image. This dissociation and lowered self-esteem and body image could result in sexual disenfranchisement, or avoidance of sex based on the belief that sex would be less satisfying after injury. Interestingly, Connell et al.'s (2014) review of the literature indicates that there were no correlations between the type or severity of injury and decreases in self-esteem, sexual satisfaction, or frequency of sex, indicating that any injury can significantly impact an individual's sexual life, regardless of the type or severity. Finally, sexual rediscovery, or increased confidence and sexual self-esteem, was correlated with both partners' willingness to expand and explore their sexual repertoire (Connell et al. 2014), demonstrating the importance of education not only for the disabled individual, but for their partner(s). Given the interconnectedness between sexual education, sexual satisfaction, and quality of life, it is critical to understand how increased education or rehabilitation with regards to sex and sexuality could increase the quality of life of individuals with disabilities.

10.5 Conclusion

The spheres of sexuality and disability research are both full of rich and well-developed descriptions of the sexual lives of people and of individuals with disabilities; however the overlap of these two fields is sparse. In this review, we have highlighted the areas with the greatest overlap including sexual rights, education, satisfaction, and sexual facilitation. Within each of these main areas we were cognizant of the variation in definitions and theoretical conceptualizations of disability in the literature, and we acknowledge that in our attempt to be broad and inclusive, we excluded some topics and populations from this review; like researchers, we were faced with the challenge of how to be inclusive when faced with such a diverse, yet understudied, topic.

For us, this review drew attention to a large gap in the recognition of people with disabilities as sexual beings with multiple identities. Few studies examined intersecting identities and hardly any examined sexuality across different types of disabilities (e.g., physical and intellectual). More research, especially representative research, is needed in a great number of areas, as well as more transparency in terms of researchers' definitions and methods. Additional financial support for sexuality and disability research would help to accomplish this goal, as well as more training for sexuality and/or disability researchers who wish to venture into the intersections of their fields, especially in relation to definitional and methodological issues. There is a great potential and urgent need for disability and sexuality scholars to bring their fields together to more fully understand the sexual lives and needs of people with disabilities, especially given the ability to create positive changes in the lived experiences of disabled individuals.

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