

51 The intersection of sexuality and intellectual disabilities

Shattering the taboo

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The right to sexual expression is a fundamental human right (Rogers 2016; Whittle and Butler 2018). For many disabled people, however, the right to *intimate citizenship* is often elusive (Ignagni et al. 2016). *Intimate citizenship* refers to our “rights to choose what we do with our bodies, our feelings, our identities, our relationships, our genders, our eroticisms and our representations” (Plummer 1995: 17). People with intellectual disabilities have the same romantic and sexual desires as nondisabled people. However, the intersection of disability and sexuality remains taboo, constraining their intimate citizenship rights (Medina-Rico et al. 2018).

People with intellectual disabilities are commonly targeted by desexualizing and infantilizing stereotypes. They face what Collins (1990) calls *controlling images* – social constructions aimed at normalizing and justifying forms of inequality – that, in this case, desexualize and construct disabled people as “eternal children” and, on the other hand, portray especially men with intellectual disabilities as potentially “dangerous” (Santinele Martino 2020). Whether people with intellectual disabilities are perceived as “potential victims” or as displaying “unacceptable sexual behaviors,” their intimate rights are usually restricted (Noonan and Gomez 2011: 177; Gill 2015). Infantilizing attitudes by people in their lives limit their “acceptable” sexual expression (Santinele Martino 2020). The label “intellectual disability” often disqualifies disabled people from participating in collective sexual life because their sexuality is perceived as “requiring oversight” (Gill 2015). Not being understood to be adults (regardless of chronological age) can lead to various forms of sexual expression being off-limits to disabled people, as only adulthood is tied to rights and opportunities (Starke et al. 2016).

Many individuals with intellectual disabilities encounter barriers when preparing themselves for sexual expression and intimacy (Slater and Liddiard 2018). For example, children and youth with intellectual disabilities are commonly denied access to the formal sex education curriculum, and even the *hidden curriculum* composed of informal interactions outside the classroom (Gougeon 2009). Consequently, they may explore their sexuality with little social support and feel unprepared to navigate their sexual lives (Gill 2015).

Making space for disabled people to share their stories

The disability rights movement has long advocated for “nothing about us, without us” (Charlton 1998), asserting the importance of meaningfully including disabled people in research and practice. People with intellectual disabilities are rarely given the opportunity to speak on their own behalves and instead are represented by family members and support workers (Santinele Martino and Fudge Schormans 2018). Although people with

intellectual disabilities emphasize the importance of speaking about their own experiences (Fudge Schormans et al. 2011; McDonald et al. 2015), they are commonly seen as incapable of participating in research or as able to provide useful data (Lai et al. 2006). When I began this project, I was asked by an ethics committee member whether disabled people were “able to give [me] any good data,” and I was “highly encouraged to speak with the parents or support workers instead.” This illustrates how gatekeeping around disabled people is such that they have few opportunities to share their perspectives regarding their romantic and sexual lives (Santinele Martino and Fudge Schormans 2018). I believe it is crucial to make space for people with intellectual disabilities to share their experiences with love and intimacy, as this is often subjugated knowledge. To that end, I interviewed 46 adults with intellectual disabilities from Ontario, Canada. Instead of relying directly on medical or psychological truth claims that often construct intellectual disability through medical definitions, measurements, and diagnostic procedures, I recruited participants through agencies and self-advocacy groups who self-identified as having an intellectual disability. My aim was to challenge the invisibility of disabled voices and sexualities and contribute to new research that finally listens to disabled people (Rushbrooke et al. 2014). The following sections highlight some of the barriers that participants have faced in exploring their sexuality and forming intimate relationships.

Infantilization

Although it is the norm for adult “nondisabled” people to have privacy, romantic relationships, and to be sexual, the same expectations do not often apply to those with intellectual disabilities (Taylor Gomez 2012). Reaching the chronological age of adulthood does not necessarily lead to more opportunities for relationships, privacy, and intimacy. Disabled adults may live in a state of “suspended adolescence” (Azzopardi-Lane and Callus 2015: 33), which can result in fewer opportunities for sexual expression.

Disabled people’s sexualities are frequently shaped by caregivers and family members, who are well-intentioned, but may socialize disabled people in infantilizing ways due to their own sense of discomfort or lack of support. Caregivers engage in *boundary work* – meaning they engage in decisions and practices that distinguish between groups (Lamont et al. 2015) – in this case between the disabled/nondisabled. Caregivers determine whether and which sexual practices people with intellectual disabilities are supposedly “ready for.”

Randy, a 39-year-old man, has never had a romantic relationship (pseudonyms have been used for all participants in this chapter). He lives at home with his mother. Randy repeatedly noted that he was not “ready yet” for any kind of romantic relationship. When asked why, he stated, “My mother told I am not ready.” Asked to elaborate, he stated, “I have too much homework. Too much.” Being told that one has “too much homework” is typically said to children and adolescents. Shifting the focus onto “homework” communicates that his time should be spent on nonsexual activities and postpones his sexual expression.

Randy expects to eventually “be ready” for a romantic relationship, “when I get a bit older, like 50.” Waiting until one is 50 years old contrasts with nondisabled adults who tend to form romantic relationships and be sexually active at much earlier ages. He also is forbidden from watching pornographic films, which could provide him with opportunities for sexual pleasure. He shared, “Mom told me I need to be older to watch that.” Randy’s account speaks to the experience of being in a state of “prolonged adolescence” by being desexualized and blocked from adult sexual development. By dictating what

sexual practices he is or is not “ready” for, Randy’s mother is engaging in a form of boundary work, and he has not questioned such boundaries. His example demonstrates the insidious ways in which social processes create disability oppression, as he internalizes disabling messages regarding his own sexuality.

Thomas, who is 36 years old, also expressed the expectation that he should wait until a later age to consider getting married – in his case, until his late forties – something he had heard from both parents and support workers. Thomas seemed unsure about the age one is legally allowed to marry, asking during his interview: “So, you have to be 36 to get married?” When informed that individuals in Ontario are legally allowed to marry at 18, he was surprised and remarked, “Okay, so if you are 18, you can get married. Okay, because no one ever tell me about that.” Some studies have found that people with intellectual disabilities can be purposely misinformed to delay, discourage, and prevent sexual expression (Gil-Llario et al. 2018).

Participants living in group homes and residential facilities also may experience infantilization, lack of privacy, and lack of decision-making power (Santinele Martino 2021). Mike shared his experience of living in a group home,

I first have to tell my staff of everything in that, bringing my girlfriend. If they . . . my staff . . . said yes or no. Because if you bring your girlfriend, then I have to tell her staff. [. . .] Because I don’t want to get in trouble.

Many participants living in group homes tended to live with other disabled people that they did not choose and they have little privacy in small rooms with single beds and no door locks (Santinele Martino 2019). This curtails potential romantic and sexual expression.

Learning about sexuality

Receiving sex education eases youths’ transition to adulthood as they continue to develop their sexual selves and prepare to engage in sexual expression safely (McDaniels and Fleming 2016; Wilkinson et al. 2015). Access to sex education can be especially crucial for disabled people. They require support to develop their sexual identities and enjoy safe and fulfilling intimate lives (Frawley and Wilson 2016). People with intellectual disabilities, however, are less likely to participate in sex education than nondisabled people.

Almost half of the participants I interviewed had not received (or could not recollect receiving) any form of sex education – school-based or otherwise. This lack of sexual information is particularly problematic for people with intellectual disabilities, considering that they experience significantly higher rates of sexual abuse compared to nondisabled people (Schaafsma et al. 2013; Swango-Wilson 2009). Several studies suggest that lack of sex education and opportunities to make their own decisions contributes to their sexual vulnerability (Gil-Llario et al. 2018; Hollomotz 2011). Wendy, for example, mentioned the importance of having access to sexual information to feel better equipped to navigate (abusive) relationships:

Learning about ways they could be taken advantage of. . . . And to kind of be aware ‘cause I know like . . . yeah, I guess with myself, disability leads to a lot of lack of confidence and like blurry consent, I guess. [. . .] So maybe, yeah. Yeah, just really driving it in that you have a choice.

For participants who acquired some sex education, not all needed information was included. Mike suggests that there is a missing component in sex education regarding the social and interactional components of dating, which can be difficult for some people with intellectual disabilities. As he put it, whereas “they teach you the game” in sex education, “they expect you to pick up the social side of it [on your own].” For many, sex education omits information about how people can actually form relationships and negotiate interactions with potential intimate partners. However, learning about how to form and maintain fulfilling intimate relationships was exactly the type of sexual information that most participants reported as being important to have better intimate lives. Mike observed,

Relationships require knowledge that is not actually taught to you [. . .] they [school] try to teach you to play nice, and how to play, and what to do to play, but they don’t teach you how to play with each other.

Participants lacked knowledge about intimate relationships and their sexual rights, but they had a great knowledge of the illegal behaviors that could bring them trouble (Santinele Martino 2020). For example, Randy articulated that adults should not engage in sexual interactions with underage people, stating, “Momma taught me, you kiss a little girl, you get caught.” Similarly, Joshua stated, “A friend of mine told me to be careful because like 15 and 16 teenagers calling you, it is a dark deal. It’s very bad.” These men’s accounts show how the controlling images that impact the sexualities of disabled people are highly gendered, with men more likely to be seen as potentially dangerous. The denial of disabled people’s sexual rights is often justified based on such controlling images.

Like most sex education in Canada, sex education for people with intellectual disabilities solely focused on the “negative” aspects of sexuality, including risks, sexual abuse, and sexually transmitted infections (Connell 2006). This negative emphasis discouraged participants from engaging in sexual expression. For example, David talked about the sex education that he had received:

DAVID: Well, we talked about the parts, the different parts of the male and the female.

A: Mm-hmm.

DAVID: About what STDs, what STIs, what transmitted diseases are. I think we talked about everything. What sexuality is all about.

David has a limited knowledge of “what sexuality is all about,” from sex education solely focused on biology and STIs. The positive aspects of sexuality did not receive equal attention. This negative focus even scared some. Randy referred to dating as “scary.” When asked to elaborate, he immediately asserted, “Somebody wants to rape you like that.” Likewise, Christopher asserted about sex, “Sometimes they make it scary. [. . .] ‘This is inappropriate,’ or ‘this is wrong,’ or ‘this is illegal,’ or ‘this is dangerous.’ This isn’t fun anymore. I don’t want to do it [have sex]. It is not gonna be any good.” Christopher abstained from having sex, stating, “I never really had sex with anybody for a long time because I didn’t think it was appropriate and I never knew how to ask, and I didn’t want to upset them [potential partners].” He disagreed with this negative emphasis in sex education, observing, “I don’t think it’s the appropriate way to do it myself because they rely on you to think you can’t have relationships because they scared you too badly.” As Slater and Liddiard (2018: 324) articulate, “Biopolitical regimes work to secure the infantilization of

disabled young people whilst pacifying those who are considered ‘active’ through misinformation, scaremongering, and demonization.”

As a result of both formal and informal lessons about sexuality, some talked about having relationships devoid of physical touching. James spoke about how having a romantic relationship in the “right way” meant not sexually touching his girlfriend (whom he has dated for a few years), or being touched by her, noting, “No touch. I never touch her. [. . .] My girl would never, too. I ask her to stop.” Similarly, Allison, a woman in her late thirties, has been in a romantic relationship with a man with intellectual disabilities for ten years. For her, intimate relationships done in the “right way” do not involve kissing or hugging. Instead, they involve keeping some physical distance from her boyfriend. She spoke about the importance of being “always distanced from each other,” adding, “I am okay if he’s beside me, but not that close.” She had learned this from her family and support workers. This negative emphasis in sex education can serve as a mechanism of social control, a means to restrict the sexualities of people with intellectual disabilities, leading them to choose to remain celibate or be extra cautious when pursuing intimate relationships.

Where do I start? Lacking self-confidence

Those with intellectual disabilities face unique challenges navigating the private sphere of intimacy, with little to no social support. They also may face explicit barriers for seeking romantic relationships. In contrast, they receive high levels of social support regarding issues in the public sphere concerning disability rights to seek work and education. However, less attention has been paid to sexuality and sexual expression, which are generally considered part of the private sphere (Alexander and Gomez 2017).

Participants expressed frustration and posed questions during their interviews about how to find partners, how to develop sexual self-confidence, as well as about their sexual rights. Linking back to infantilization, Tony’s mother told him, “You don’t need a girlfriend.” He thus faced the conundrum of wishing to have a girlfriend but not knowing how to find one; as he noted, “I don’t even know how to start looking.” The only advice about finding a girlfriend Tony received came from his support worker who told him to “just go out, no cigar, no smoke.” Participants such as Tony repeatedly spoke about challenges in figuring out where to find a partner, how to take the initiative in flirtation that would not land them into “trouble,” and how to form an intimate relationship. Iago shared his frustration,

I don’t know how to engage in conversations. I don’t know how to start a conversation and how to find a girlfriend. Like, where do I start? So, that is the toughest one that I have – where to start and how do I make a conversation?

Andrew also stated, “I don’t even know how to start looking. I’ve looked [for a girlfriend] almost all over. Nobody.” Like Iago, he faces this challenge alone, despite his desire for greater help with this aspect of his life. Andrew noted, “People don’t help me. [. . .] I’d have loved if someone could help me find a girlfriend.” This demonstrates their desire for greater support regarding information about sexuality and relationships. As Peter expressed when asking me for support, “Can you write that? Put, ‘I want to get a girlfriend.’ So, where can I go? How can I make it happen? Can you tell me? Can you help me? How can I make this happen?” There is a clear sense of urgency in Peter’s stream of questions and request for information. He describes being single and struggling to figure out how to find an intimate partner as both “hard” and “sad.” He shared, “Being

single, it's hard to be single. It's hard to be single. It's not fair I'm single. That's not fair, you know?" He went on, "You know how I feel? Sad. I'm being single. Sad. I want to fix that. I want to fix that, okay? Fix it. I want to fix that for me." Yet, facing limited social support to help him "fix" that part of his life, he has not figured out ways to participate in sexual fields, much less to find a girlfriend.

Relatedly, participants often pointed out that pursuing intimate relationships requires some level of confidence. Iago, who had never had a girlfriend, asserted, "Gotta be, you know, confident to meet new people." Likewise, Mike's lack of sexual self-confidence was made plain when he spoke about putting up a "protective barrier" to avoid rejection,

I don't feel good enough in my own mind. I just don't feel good enough and a lot of the time, again, I push people away because I think that I'm going to be pushed away, so it's . . . it's kind of a wall that I put up.

Some interviewees, demonstrating their lack of support, inquired about what to do. Iago, for instance, asked me, "So, what do I do? How do I get confidence, meet people? What do I do?"

Participants who reported low levels of self-confidence considered whether to participate in collective sexual life at all. Feeling that they lacked the "right tools" to build confidence, some opted out of intimate relationships. Such beliefs resulted in deliberate decisions to remain "inactive" players in *sexual fields*, a term that describes an arena of social life where individuals seek intimate partners and compete for sexual status (see Green, Chapter 59 in this volume). Randy, for example, spoke about his decision to passively "just let it happen," remarking,

Dating is really, really, really hard. It's not easy to date someone. You don't have a chance, so why bother? So just let it happen. Since you can't really control it. If you try to control it, you'll do more – you'll do more damage than good.

He believes that any potential misstep in attempting to form an intimate relationship could land him into trouble. When talking about his decision to remain celibate, he noted, "I mean, I'll be frustrated, but at least I won't get in trouble." Thus, Randy has taken a back seat as a sexual actor.

Some thought they did not "have a chance" as sexual actors, that they were not "worthy" as prospective intimate partners. There was a sense amongst a few participants that there is "always someone better" than themselves, either actual sexual actors around them or a *generalized other* (Mead 1934). Some compared themselves to an imagined generalized other – someone who occupied a more favored position within hierarchies of desirability. This is illustrated in Randy's refusal to pursue relationships, as he asserted, "Aaaaand [sigh] um . . . and they always seem to find anyone better anyways it seems. And then you just feel awful and you don't even feel like it's worthwhile. It's like why do you bother trying?" Others compared themselves to specific social actors in their lives. Tony compared himself with his neighbor and with his support worker. He said, "My other neighbor found a girlfriend just like that [snaps his fingers]. My other neighbor found a girlfriend. He goes out and comes back with one." He offered yet another example – that of his support worker: "He found a girlfriend like that [snaps his fingers] in college. He found a girlfriend in school." Tony has not had an opportunity to attend college, a sexual field that grants many nondisabled young people opportunities for sexual exploration and intimate partnerships.

Similarly, Aaron is a man in his early fifties who experienced a car accident that resulted in a visible impairment. Bodies with visible differences tend to be perceived as undesirable and unattractive (Erickson 2015; Shah 2017), which can also lead to a decision to be sexually inactive or passive. He comments,

I'm not as good-looking as I used to be because of the accident. I don't go out of my way to strut my stuff, I guess, so I don't really feel sexy. If I'm attracted to somebody, they'll know it, but aside from that, I'm pretty much like a life raft. I just . . . I'm on the water.

Not feeling “as good looking” or “sexy” impacts Aaron’s self-confidence to pursue intimate relationships. His metaphor of being a “raft on the water” is compelling as a statement of his perceived lack of *sexual capital*, which refers to a person’s attributes, resources, and competencies that generate a sexual response in others and provide status to certain sexual actors within sexual fields (Green 2014). His perceived lack of sexual capital has led to passivity as a sexual actor as he chooses to wait and take whatever does or does not happen. Disabled people continue to be “systematically devalued and excluded by modern western societies,” and they are “often not in the right place to begin that task of self-love and self-worth” (Shakespeare 2000: 161).

Conclusion

There has been some progress in questioning stereotypes about disability and sexuality (Retznik et al. 2021). This is seen, for example, in the growing activism, especially in online spaces, of disabled people who are asserting themselves as sexual beings (Santinele Martino and Campbell 2019). At the same time, we still live in a culture that commonly engenders fear and silence when it comes to sexuality, especially when it is about the sexualities of disabled people. Family members and other caretakers may not allow them to exercise sexual agency, as they struggle with balancing letting people with intellectual disabilities make their own decisions regarding their sexual lives with their own worries and desire to protect disabled people (Löfgren-Mårtenson 2004).

People with intellectual disabilities are actively kept out of sexual life through a series of disabling social processes. These processes include infantilization, the failure to provide them with sufficient and accurate information regarding sexuality, and the decision to emphasize the negative aspects of sex in what little sex education that is provided. This results in low sexual self-confidence and a lack of a “feel for the game.” Sexuality shaped by these various processes led some people with intellectual disabilities to internalize oppressive and restrictive understandings of themselves as people with intellectual disabilities and to come to perceive themselves as unable, not ready, and unworthy of intimate relationships. These processes have led to an understanding of sexuality that is limited to negative aspects like risk and danger. To some, this view of sexuality becomes their idea of “what sexuality is all about.” In such a manner, disabled sexualities are “seldom opened up to the possibility of pleasure” (Slater and Liddiard 2018: 326).

Chapter review questions

1. According to the chapter, what are some of the messages about sexuality that people with intellectual disabilities receive from other social actors in their lives?

2. How is the intimate citizenship of disabled people constrained? What are specific examples from the chapter that illustrate constraints?
3. What are controlling images of intellectually disabled people? What are ways that they internalize such images?

Author biography

Alan Santinele Martino is an instructor in community rehabilitation and disability studies in the Community Health Sciences Department at the University of Calgary, Canada. His main research interests are in critical disability studies, gender, and sexualities; feminist and critical disability studies theories; and qualitative and community-based research, particularly using participatory and inclusive research methodologies. His doctoral research examined the romantic and sexual lives of adults with intellectual disabilities in Ontario, Canada, by putting into conversation theories from the sociology of sexualities and critical disability studies.

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