

A VISION OF JUSTICE

Seeing the Sex-ABILITY of People with Intellectual Disabilities

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Many would argue that society is saturated by sex. We have access to more sexual images, research, news, music, political discussion than at any other time in history. Yet, “there is no area of human life cloaked in more secrecy, hypocrisy, inconsistency, ambiguous legality, ignorance and emotionalism, than sexuality” (Gochros, 1986, p. 9). The social work discourse is not immune to this observation. Some might claim that this is evidenced in the profession’s scholarly whispers on sexuality. Nowhere is this silence more discernible than in the poverty of sexuality research, education, and practice with marginalized communities such as people with disabilities, specifically those with intellectual disabilities (I.D.). These “many silences” (Foucault, as cited in Blyth and Carson, 2007, p. 37) contribute to an internal ableism, among youth with intellectual disabilities, whereby they embrace an able-normative world and reinforce that experience as “natural” and “normal” in their language, beliefs, and actions.

Our cultural narrative is based on a skewed sexuality framework that depicts adults with I.D. in two extremes: Pure and innocent children that need protection or oversexed animals, incapable of real love. I have discussed in previous work (Turner, 2012) that these “stereotypes sabotage society’s opportunity to develop a realistic representation of the developmental disability community and their view of their own social-sexuality” (p. 1). In my experience as a sex educator and disability professional, if there is a sexuality conversation, it is clouded in fear. This fear dominates the discourse regarding adults with I.D. This has led to program development and scholarship focused on fear of pregnancy or sexual abuse. Rarely in this space is there a chance to expand the dialogue to a more holistic and comprehensive understanding of a person’s sexuality to include emotional intimacy. This total disregard of the importance of relational bonds and a hyper focus on deficits is ripe for social workers training in the strengths perspective (Turner, 2020).

Social work must correct the distorted discourses and deafening silence around the sexual ability (sexability) of intellectually disabled people. Social work has been complicit in contributing to a cultural illiteracy on this topic. Social workers wary of tackling sexuality might consider framing this topic as a *sexual justice* (Turner, Vernachio, Satterly, 2018) issue and part of their training in social justice. Sexual ignorance and sexual shame, it may be argued, lead to sexual vulnerability and poorer quality of life for people with I.D. It also robs the larger society of realistic representation of this community and their capacity for love, desire, romance, and sex.

In the absence of this universal human experience, sex, we create a space of otherness. Here, distortions as undeserving, asexual, incapable *others* can perpetuate stereotypes and may contribute to a professional social work culture where clinicians do not get trained, educators never discuss the sexuality strengths of this group and researchers are derelict in adding to the scholarship. This culture of sex and disability negativity disproportionately impacts people with I.D.

This chapter provides a pedagogical tool for social work educators to introduce the topic of sexuality and disabilities, specifically for adults with I.D., by using case studies to illuminate this often-othered group. This chapter is designed to expand social workers' understanding of sexuality, and more importantly pose the question of who gets to be sexual. Challenging stereotypes of adults with I.D. as it relates to sexual/romantic relationships posits that sexual justice is social work. Social work educators should prepare students for the important work of advocating for sexual inclusion of others relegated to the sidelines of sexuality. By sharing the first-hand lived experiences of a marginalized group and the challenges faced in their quest to live an authentic and sexual life, this chapter aims to expose social workers to real people who have a right to be sexual. The chapter challenges social workers to grapple with how disability and sexuality fits into their role as advocates, clinicians, researchers, and educators. First, *sexability*, an affirmative social work practice is discussed before an examination of the current scholarship on the topic. Next, the concept of a *sexual voice* is introduced. The term *sexual voice* (Turner, 2012) was coined to describe the traits needed for a person to live authentically as their social-sexual self. I then position myself within this conversation by sharing how my experiences and history have influenced my relationship to this work. Subsequently, four case studies elucidate the sexability of intellectually disabled adults. These glimpses provide a face and voice to the sexuality challenges, experiences, and dreams of a population often forgotten in social work sexuality discourses. By grounding the reader's understanding in the lived experiences of the social-sexual lives of people with disabilities, the chapter aims to demonstrate opportunities for support by sexually literate social workers. Case studies provide up-close illustration through a case formulation. Finally, a discussion critically examines the case, exploring lessons learned and suggestions for the field of social work.

Disability Language

Language is powerful and sometimes contentious, evoking strong emotions both within and outside a community. How language is used is often evolving and that is no different for the disability community. Specifically, it is relevant to note two sometimes opposing philosophies within disability discourse: People-first language and identity-first language.

Introduced in the late 1980s, *People-First* language is the generally accepted practice in the United States for professionals (Simonsen and Mruzec, 2019). Aligned with the social model of disability, it attempts to shift the focus from the impairment to the social barriers that prevent full community participation. Tenets encourage seeing the person before the disability and reflecting that in language usage by emphasizing abilities. For example, it is better to say, "an adult with a disability" rather than "a handicapped adult" and "developmental delay" rather than "slow".

In contrast, *Identity-First* language is based on the minority model of disability, which asserts that disability is a diverse cultural experience and an essential identifier (Altman, Albrecht, Seelman, and Bury, 2001). Its position is that it is empowering to acknowledge the disability which is fundamentally a part of who the person is in the world. For example, "I am a disabled person" or "John, an autistic person". Concerns are raised that ignoring the disability seems shameful. While some communities, such as the Autistic and Deaf community and geographi-

cal locations such as in the United Kingdom (Johnson, 2019), strongly prefer identity-first language, those with I.D. usually prefer people-first language. This may be in part due to self-advocacy groups mainly run by and for people with intellectual disabilities around the globe called People-First dating to the 1970s.

It may be claimed that both are attempting to show respect and minimize discrimination and negative stereotypes. Allowing a person to define themselves is the recommended approach. Similar to the use of “black” vs. “African-American” and “Latino/a/x vs. Hispanic” or “queer” vs. “gay” or “L.G.B.T.Q.I.”, social workers should ask the group or person how they would like to be referred to. Supporting people to self-identify aligns with social work values. For the purpose of this chapter, I have used both people-first and identity-first language interchangeably.

Sex-ABILITY-Affirming Practice

In order to disrupt the dominant discourse where people with I.D. are typically not viewed as sexual, I have coined the term, *sexability*, from sexuality ability to highlight a needed fundamental shift in this discourse; people with I.D. are as innately sexual as all humans are, they have right to be seen as sexually capable (Turner and Crane, 2016a; Turner and Crane, 2016b). The default sexuality conversation, if discussed at all, is often from a deficit lens. While sex-negativity clouds most conversations, there is a privileging for non-disabled people that our sexuality is innate and that we have a right to discuss it, pursue it, express it, and advocate for it; whereas for adults with I.D., there is typically a pause in our discussion as if we must purposefully wrap our heads around the idea that this group of humans is sexual.

I propose *sexability* celebrates the social-sexuality abilities of people with disabilities, centering their capacity for desire (Turner and Crane, 2016a; Turner and Crane, 2016b). Desire is an acknowledgment that you want and need romance, love, and sexual contact. It is self-affirming. It is a revolutionary act of claiming self-worth. It is a bold statement that you belong to a universal human experience. Further, a sexability lens is an affirming social work practice that supports a view that disabled people are inherently capable of sexual desire. It is an approach that starts with sexually literate and disability-aware practitioners. These practitioners are sex-positive. (For a more detailed discussion on sex-positivity see Turner, 2020 and Dodd, 2020.) These social workers address best practices on the continuum of micro to macro level, advocating for comprehensive, accessible, medically accurate, shame-free, inclusive and pleasure-affirming, sex-positive, informed client services. This is an alignment with other social work values such as self-determination, dignity of risk, client rights, choice, natural consequences, and person-centered services.

Sex and Disability in the Literature

Turner and Crane (2016a) outlined a sexual voice illuminating that “here in the shadows, their sexuality can be shamed, segregated, and silenced” (p. 5). This study framed the discussion as a social justice issue calling on social workers to increase their advocacy efforts on this topic. Further, the authors asserted that this imposed estrangement from their sexuality perpetuates adults with I.D. as *others*. It is with the exercising of a sexual voice that adults with I.D. move from a “passive position where sexuality happens to them [to a position where they] own their story. It provides them the tool to exercise that right, to tell their own story” (p.2). Similarly, *sexual self-advocacy*, an element of this sexual voice research, was examined by Friedman, Arnold, Owen, and Sandman (2014); and Owen, Arnold, Friedman, and Sandman (2016).

The second article (Turner and Crane, 2016b) explored the erotic potential of adults with I.D., highlighting that social workers aiming to increase the quality of life for people with I.D. should address sexual pleasure in pursuit of this goal. The research notes that “pleasure would be a natural fit within [social work discourse], epitomizing core pillars of social work: Self-determination and the strengths perspective” (p. 3). Further it posits that romantic and sexual partners, such as friends, impact a disabled person’s continued social development.

Despite the fact that codes of ethics in the U.S. (National Association of Social Workers [N.A.S.W.] Code of Ethics, 2008) and internationally (International Federation of Social Workers, 2016) recognize the importance of human relationships as a core value, relatively speaking, there is a poverty of scholarship in social work journals on sexuality and the first-hand, lived experiences of adults with I.D. In 2017, N.A.S.W. Press released a book, *Disability, Intimacy, and Sexual Health: A Social Work Perspective* (Linton, Rueda, and Rankin Williams), which included 42 interviews of social workers who supported people with disabilities throughout the lifespan and 8 disabled people. The book reports on the authors’ own qualitative research in the United States and the interviewees mostly discussed intellectual and developmental disabilities. The book offers social workers practice considerations and ethical concerns when supporting the sexual health of disabled people. Additionally, social work was the focus in 2014 of a special issue of *Sexuality and Disability: The Emerging Intersection of Sexuality and Disability in the Profession of Social Work*. Of seven articles, two addressed people with I.D.

A call for more social work education on disability content is not new (Dana, 1965). Cramer (1977) noted that substantial services for adults with I.D. was needed and urged social work education to prepare practitioners for this specialization. While social work scholars have examined the integration of disabilities into social work curricula (Bean and Krcek, 2012), how MSW programs can play a role in encouraging student interest in working with people with development disabilities (D.D.) (Russo-Gleicher, 2008), and challenging ableism (Shier, Sinclair, Gault, 2011), the scholarship specifically looking at sexuality is limited. Ballan (2008) did provide sexuality lecture points and classroom activities to expand the social work curriculum.

Though the social work scholarship is limited, a body of literature on sexuality and disabilities and social work has been established in journals dedicated either to sexuality or disability. Rueda, Bolin, Linton, Williams, and Pesta (2017) looked to identify social workers’ roles in supporting the developing sexuality of children with disabilities. They noted that, while social workers supported issues such as puberty, maturation, hygiene support, and social skills support, they more frequently were asked to address problematic behaviors such as masturbating in the hallway. Lam, Yau, Franklin, and Leggat (2019) examined 16 qualitative articles across the literature looking at sexuality and disabilities. These scholars concluded, “People with intellectual disabilities (PID) share the same needs for affectionate and intimate relationships as other people” (p. 203).

Sexual Voice

According to Turner and Crane (2016a) a sexual voice describes “how a person reveals their social-sexual self through communication” (p. 2). They further note the following elements are present in an adult with I.D. who has a developed sexual voice: a) Sexual self-determination; b) sexual self-advocacy skills; c) sexual knowledge; d) sexual communication skills; e) self-identification as a sexual person; and f) a sexual script. A sexual voice is a tool of power enabling the owner to navigate an integrated life within their community. A sexual voice (Turner and Crane, 2016a) counters being “defined by others, and treated as voiceless objects” (p. 2). Disabled people with a sexual voice regain the narrative of who they are as sexual beings. A sexual voice

allows a disabled person to curate their sexual story, as all people do. It places them as the rightful owner of that story and how to tell it. A sexual voice is based on the feminist focus of moving from silence to speech (hooks, 1989). Without a sexual voice, there is silence.

Social workers wanting to implement a sexual voice lens to their work will find the transition fits nicely within social work values such as strengths perspective, self-determination, rights, and social justice. Social work practice that supports a sexual voice helps a disabled person assert their right to find a loving partner(s) as well as addressing systemic barriers that only look at “love” as a legitimate pathway for a disabled adult to experience their carnal needs. A social worker committed to supporting a sexual voice advocates for a disabled person’s right to express themselves erotically, such as having their sexual desires acknowledged by friends, co-workers, support staff, and health-care providers. Social workers practicing from a sexual voice model see it as a tool for disabled people to challenge societal discourses that create narratives that diminish or misrepresent them as less than a full sexual person. A sexual voice amplifies a marginalized population’s right to and access to sexual health knowledge, services, and opportunities as much as those traditionally privileged in our society to be viewed as sexually valued. The concept of a sexual voice provides a framework of sex-positivity and disability self-determination that might guide research, planning, programs, treatment, and policies designed to address health disparities and inequities. Social workers would benefit from knowing how to integrate the sexual voice model to enhance best practices for people with I.D. The sexual voice model provides a clinical lens for social workers striving to practice with cultural humility and champion sexual well-being. The sexual voice model aligns with the disability rights movement which has long pushed for “nothing about us, without us” (Masutha and Rowland, as cited by Charlton, 2000, p. 3).

Positioning Myself: The Shaggy Love Van

As a disability advocate and researcher, my position (Creswell and Poth, 2018) – my history – uniquely situates me in relationship to my work. These experiences influence and bias my view of the topic. As Patton (2015, p. 14) described, “the researcher is the instrument”. Thus, to be transparent and mindful of my position, I offer a recollection of how I began this journey. With my undergraduate degree newly obtained, I entered the field as a direct support professional working with adults with intellectual disabilities. My initiation into the field began by picking up clients at a sheltered workshop and transporting them home to their apartments, group homes, or parents’ home in the community. A sheltered workshop is a segregated work site for people with disabilities that typically consists of assembly work such as packing orders to be shipped. My experience of sheltered workshops is that client-employees often are under strict supervision and must comply with paternalistic rules that often restrict adult behaviors such as flirting and touching.

Needless to say, after a day of Big Brother scrutiny, the ride home with a newbie staff was often a bit of an experiment in adulting. Clients navigated the drama of being a best friend one minute and out the next. They explored the dance of flirtatious banter, lustful stares, and titillating handholding. In daring moves they exchanged sexual information as if they were bartering on the black-market, looking for a deal, answers to sexual questions from the sage peers in the group. These men and women were more interested in finding a date for bowling that weekend than any of the formally scheduled learning activities awaiting them at home that night.

These clients opened my eyes. Was there really any doubt what activities were more in demand: Housecleaning vs. hooking up? Their desires for social and relational interactions were no different than mine. They too wanted to be seen as a fully sexual citizen. They wanted access to sexual health information. They deserved support to fulfill their maximum potential as a

sexual person. They had a right to be sexual! I am reminded of a quote by Dave Hingsburger, a disability advocate from Canada who often shares in his workshops, “Teach a person with a disability to make his bed, they will have a neat room. Teach them to make a friend and they’ll have a neat life” (Hingsburger, D. personal communication).

This freedom was a natural developmental milestone in finding a sexual voice that most of us transverse. It is, however, often delayed for adults with I.D. due to a variety of factors including constant supervision. In comparison to the watchful eyes at work during the day and the staff or parent supervision at home in the evening, this 1.5-hour drive was a peer-to-peer-led teaching of romance where clients tested a new version of themselves as sexual adults. They seemed more authentic and less on guard performing the “good” child/client role. I have since dubbed this relaxed, and somewhat sexually free environment, the “Shaggy Love Van”, based on the 1969–1970 Scooby-Doo cartoon which was based on a youth, Shaggy, his dog, and their friends. These characters traveled around solving mysteries in their psychedelically painted van. The sexual revolution was a key historical event during this time with “free-love” a common mantra of youth. It seemed a fitting image for me. Partly because, like in the anti-establishment era of the 1960s/1970s where youth rebelled against, among other things, conservative sexuality, my clients seemed to be finding their own way despite a lack of support from others in positions of power. In many ways it was my clients who educated me about the sexual oppression they were facing.

And while I received, as part of my new staff orientation, comprehensive training on medications, first-aid, and agency policies and procedures, there was no discussion on supporting client relationships or sexuality. The impact of the glaring absence of a critical human experience, our sexual expression, cannot be underestimated. In a workplace where staff were often intimately involved in client care such as bathing or toileting, there was no mention of client sexuality. The only discussion that might take place was in a cloud of paternalism and protection or when client behaviors were deemed problematic. This systemic approach to client sexuality fundamentally framed my early understanding of client support. Granted, many agencies today provide excellent client sexuality training as part of their orientation. However, I note this absence in my training because I worked, at the time, at one of the premier non-profits in the area supporting people with disabilities. Not only is it important to acknowledge that this was the environment that introduced me to the profession of social services, I now know this lack of training in client sexuality was endemic then and I believe still problematic for the field today.

A Case Study: Teachers from My Past

I invite the reader to close your eyes and picture a person with I.D. What image do you see? What is their life like? Many social workers do not have first-hand experience with this population and do not have much professional training to augment this lack of experiential knowledge. In light of this vacuum, social workers must be self-aware and reflective. A self-check of attitudes and beliefs is warranted to ensure best practices. How do you see a typical 20-something-year-old spending their Friday night? What if we swap that person out with an adult with I.D.? Specifically, social workers need to note any bias or stereotypes regarding the sexuality of adults with I.D. What cultural, religious, or family messages have you received about adults with I.D.? This process is important for social workers to see where there may be bias, oppression, sexual injustice.

I began working in the field of disabilities as a young adult in my 20s. Many of the people I supported were my contemporaries. One of the many stark differences I noted was that I and many of my friends spent a considerable amount of time preparing for the weekend when we

could gather at our favorite dance club, drink alcoholic beverages, and socialize in support of a larger mission to find a sexual partner. And while there may be some in the larger society that did not approve of this routine or even some peers who did not engage in this activity, it was viewed as typical 20-year-old social behavior. Further, I didn't need to run this weekly agenda by anyone for approval.

My experience was that, while normalization was the mantra where it was the goal to integrate adults with I.D. into typical community life, the clients I supported were not permitted or encouraged to join the mainstream activities of hooking up also known as searching for a sexual partner. In contrast, my clients were segregated to weekends of group outings with others from the program, not necessarily just their friends, to activities such as bowling and monthly dance parties in a high school gymnasium. It was the Friday routine for my clients to run home, grab their weekly budgeted money, and hustle back to the 15-person van for a group dining experience at Dairy Queen, the local fast-food restaurant. Once a month, this activity was expanded to include the option to, again as a group, attend a city-wide religious youth Bible-study group. Part social event, part religious teaching, this event targeted a middle-high school (11–18-year-old) crowd. So, you might ask, why were my clients who were in their 20s, 30s, and 40s attending? That's easy! Agency staff saw my clients as children and this option as a safe and moral social activity. My solution, which ironically did require approval from the administration, was to offer the agency's clients an option. While my co-workers would continue with the standard routine, I began coordinating alternative weekend plans such as going to a restaurant where clients had to not only learn to tip wait staff but budget for that. We would also attend "happy hour" at a nearby hotel bar that had a DJ and dance floor. I share this simple observation to highlight how an agency and staff became complicit in sexually silencing clients. It happened very naturally with staff who oversaw organizing client outings operating from their own experience. Staff at the time were considerably older than most of the clients, married with families, and religiously conservative. Thus, client activities mirrored staff views and values. How will you as a social worker honor the diversity of the clients you support?

I now present this selection of curated case studies – voices from my past in an effort to bring to light the lived experiences of my clients, adults with I.D. The perpetrators who shamed, segregated, and silenced the sexual voices of these clients didn't necessarily intend to harm them. While it may be easier if I had an example of maleficence to chain to the offenders: Agency leadership, professional staff, parents, and, yes, even myself, I think harm was often introduced innocuously, naively, and foolishly. Ideally these cases will enrich the social work training and practice landscape on disability social work, bringing to life the complicated, real world of social work practice. Rather than an attempt to provide the right answer or a cookbook social work recipe, I enter a space of vulnerability and self-reflection to critically examine not only system failings but my own practice shortcomings. This is an opportunity for you the reader to consider best practices from the luxury of time, distance, and perspective.

These vignettes represent clients from when I was a direct support professional working in a supportive living program. While dated, I believe these cases can speak to a contemporary social work practice. And, unfortunately, variations of these stories continue to unfold even today within client services everywhere. Pseudonyms are used and details have been altered to provide anonymity to my former clients. I also would like to acknowledge that these are my recollections of these people and situations. As a direct care support worker, I did not have access to potentially critical information held by parents or administrative personnel. These are a range of clients that I worked with either directly or indirectly, representing diverse genders, sexual orientations, relationship statuses, and sexual voices.

These four case studies explore issues such as homophobia, slut-shaming, religious oppression, relationship bias, and more. This collection of case studies is a postage-stamp-sized view in time, but hopefully breathes life into a topic that many social workers are poorly informed on: People with I.D. and their sexuality. In presenting this snapshot, marginalized voices are given an audience. By sharing these stories, I celebrate my clients; I briefly give homage to these silenced voices. I hope their collective voice is able to utter a message of resilience, hope, and sexability. I hope the reader asks follow-up questions that I as a young and naïve professional failed to do.

Each case is organized into a case formulation, which is meant to provide a brief and focused view of a client and their sexuality. The intent is to ground this discussion in the experiences of adults with I.D. navigating their sexuality. The following is an attempt to amplify the voices of adults with I.D.

Manny: “Pearls and Purses”

Case formulation. Manny grew up in state institutions in the South. I supported him early in my career in a supportive living program where he shared an apartment with other clients. He was a Latino male, approximately 40 years old. Part of my job responsibilities were teaching daily living skills such as grocery shopping, meal preparation, and budgeting. Manny was liked by staff and clients. He was soft spoken and passive. He had a great smile and enjoyed a popular Mexican restaurant chain, Dos Amigo’s. He attended church every Sunday and was especially fond of the social time after the Sunday service where cookies and coffee were served.

On my first day of orientation working with Manny, he was described as having a proclivity for collecting black purses and pearls. In fact, he had squirreled away his loot out of site in his closet according to my supervisor. My only official guidance on the topic was that I should monitor this activity and keep him from adding to his closet treasure. Unofficially, I was left with the sense that the behavior was seen as problematic and needed constant oversight, since it was described that Manny would “manipulate” new staff, otherwise unknowing co-conspirators, in helping him procure more from the nearby Kmart. He never wore the purses or pearls in public and he never opted to share more about his collection with me. I was never given the backstory of why Manny collected these items; there were no official notes in his casebook describing this hobby or interest, and sadly I never asked him.

Randy: “Pray the Pervert Away”

Case formulation. Randy was a white man who was approximately 30 years old. He was articulate and somewhat of a smooth talker, meaning he knew the social skill of providing compliments and showing interests in a person. He gravitated to female staff and would be overly complimentary to gain physical proximity. Randy was a tall, lanky man, and due to health issues he had sunken eyes. He masturbated to the point of bleeding and frequently called sex phone lines, running up bills he could not afford. He also had invited sex workers to his home that he shared with roommates. The masturbation and engagement with the sex worker industry was frowned upon by his mother who was religiously conservative. Randy’s mom was actively involved in his life living nearby, but she was an older woman with her own health issues. In addition to me, Randy had other support staff who worked with him, another staff person and my supervisor, both of whom followed a fundamentalist religious teaching. They would often pray with his mother and Randy to address his sexual interests. They frequently quoted the Bible to address behaviors they deemed inappropriate. And, I recall one particular incident where I

was invited to pray with the group where I awkwardly declined. I believe my actions may have tarnished my working relationship with my co-workers and Randy's mother.

Brenda: "Garbage Slut"

Case formulation. Brenda was an independent, capable young woman in her 20s receiving services from an agency. For years, I provided peripheral support filling in during her primary staff's absence as needed. Brenda needed very little outside aid, having mastered many of the tasks necessary to be independent. She lived in an apartment with a roommate and, like many 20-year-old women, was interested in finding love. She dated regularly. Securing a boyfriend consumed her. And, it eventually was her downfall.

Brenda began dating someone that both her family and the agency deemed inappropriate. For months, her staff, the agency, and her family tried to guide her away from this boyfriend. She continued to exert her independence and chose to "break the rules" by "sneaking around" until she was discovered having sexual intercourse with her boyfriend in a large commercial garbage dumpster nearby her house. The system (i.e., the agency and legal professionals) decided Brenda needed more supervision. She was officially labeled as unable to make good choices and her guardianship was stripped, which means the court system authorized her parents to be her legal guardians. This allowed the parents to force her to move from her own apartment into a 24-hour oversight group home, isolated more than 20 miles away with adults who needed considerably more staff support. Unofficially, I heard the whispers of "slut" fueling this sexual segregation.

Sam and Molly: "Someday Love"

Case formulation. Sam and Molly were in their 20s, dating, and living a hallmark greeting card on love. Both had jobs in the community and needed limited outside assistance. While they lived in their own apartments, they spent all their free time together. They were in a monogamous relationship and planned on getting married. Sam's party line was, "Molly and I are hoping to get married in five years". Sam dutifully completed weekly prescribed tasks on proper dating skills, which included staff checking off boxes such as "budgeted money for dinner", and "called Molly to ask out on a date".

Jackie: "Lesbian in Plain Sight"

Case formulation. Jackie, a young woman with Down syndrome, was an avid athlete, loved wearing her hair short, and lived in a group home. While I did not directly work with her, I routinely saw her at agency functions and knew about her through staff conversations. Most in the agency assumed Jackie was a lesbian and this was supported by the fact that she often referred to female staff as her girlfriend. However, since her mother was the board president, no one would publicly broach the subject. When Jackie showered her affection on female staff, it was politely minimized and sometimes quietly mocked. Her sexual voice was segregated to the shadows, given neither the respect nor attention deserved.

Discussion

Disability support services must come to a place where they privilege a sexual voice as critical to the principles of normalization. Community integration strategies cannot be fully achieved without *sexability*-affirming social services. Adults with I.D. want and need skills to enhance

their navigation of a social life of meaningful, safe, pleasurable, and consensual relationships. Social work can advance *sexability*-affirming practice by providing better education to our students on both sexuality and disability. Moreover, we should advance the idea of disability practice as a field of practice within social work field education. Disability support services offer students an entry point into agency work and social work. Here, sexually literate social work is desperately needed both at the micro and macro level. By expanding the conversation around human sexuality to include marginalized communities such as people with disabilities, and specifically around pleasure, needs, feelings, and relationships, adults with I.D. are given a personal voice as it relates to their social-sexuality.

People with disabilities, and more specifically those with intellectual disabilities, are often left out of both social work and sexuality scholarship. Advancing disability sexual health is the radical idea that people with disability are sexual and have the right to reach their full potential as a sexual citizen. In an effort to champion sexual health equity, a more explicit sexuality discourse is encouraged in mainstream social work practice, education, and research. Social workers must challenge a distorted narrative of adults with I.D. and their sexuality that is typically marred with misrepresentation, myths, and fear. Using case studies that illuminate the lived experiences of adults with I.D. and their sexuality is a practical solution to augmenting social work education. The purpose of the discussed case studies is to augment social work students' understanding of adults with I.D. By providing a focused lens into the sexuality of this group and dissecting the illuminated lessons learned, students can take a self-inventory of their attitudes, skills, and knowledge (Knowles, 1984), and reflect on their own abilities to work effectively with the group.

The identified lessons learned are relevant to the field of social work because they may help facilitate *sexability*-affirming social work practice. The cases illuminate lessons learned, both at a micro and macro level, which are now discussed along with suggestions. Rather than an inert or academic discussion, I will critically examine my own and systemic shortcomings in the hope that the reader considers their own potential lack of or deficit in their clinical skills and how they might address those. Additionally, readers should ask what macro issues needed to be addressed then or need to be addressed now to ensure sex-positive, medically accurate, shame-free, age-appropriate, holistic, and affirming social work practice with adults with I.D. Finally, I want to offer some brief suggestions on how a sexually literate social work response might look. The reader might consider questions such as: How might you have engaged the client differently? Where would your advocacy efforts have focused? What ways would you convey to the client a safe environment? Here, the reader should ponder or grapple with the question, "how would I have done things better?"

Manny

Lessons learned. I learned to recognize that my own professional immaturity at the time of working with Manny limited my sexual advocacy abilities. I was not a social worker yet. I began my pursuit of an M.S.W. after I had been in the field of disability for several years. Also, I needed to learn how to navigate the often-tumultuous landscape of gender expression within sex education and sexuality advocacy. This takes skill that is often learned over years. It requires a nuanced clinical approach and advanced interpersonal skills that I did not possess at the time. Systemic shortcomings started with hiring front-line staff without a social work degree. It is an unfortunate yet common deficiency within disability services that front-line staff are not paid well nor required to have much experience or bring much advanced training to the job. Further, many social service organizations can have a religious affiliation or history; thus, may

have conservative views regarding sexuality. Clearly there was sex-negativity conveyed during my orientation with Manny. My supervisor may have also been operating from a trans/homophobic view in providing their directive to manage the pearls and purse situation. In this toxic environment, I have no doubt that it was also kink-phobic. According to Nichols and Fedor (2017), this may be associated with having negative societal attitudes such as horror, shame, or repulsion associated with “kink”, which is described as

a slang term meaning sex that is non-standard and may include any of the following: role play (e.g., teacher/student, army sergeant/army private), performances of power dynamics (e.g., dominant/submissive roles), and unusual forms of stimulation (e.g., flogging or spanking, bondage), as well as use of specific objects or materials (e.g., leather) or a focus on specific non-genital body parts (e.g., feet) to achieve sexual satisfaction.

(p. 420)

Perhaps even more endemic was the culture of sexual silence where all things sex-related were pushed underground and not open for debate or discussion. Thus, while the agency would have proudly answered that they operated from a client-centered philosophy, their policy and practice would have demonstrated differently in relation to client sexuality.

Suggestions. Social workers need to be curiously interested in the stories of their clients. We need to recognize the difficulty this can create if the client story is outside our experience. How do we see something that we are unfamiliar with? Working within an often-broken, paternalistic, sex-negative system to best support a client is a social work skill set. After working at the agency for some time, I began to question some of the directives I had been given. And, while my direct supervisor was most likely homophobic and the agency unofficially privileged a conservative religious viewpoint, I was able to work the system to Manny’s benefit by introducing Mardi Gras beads. While not pearls, the brightly colored bead necklaces were a more culturally approved attire for men. And, most importantly, Manny loved them. He routinely wore them out in public and seemingly beamed with pride. I wish I had asked Manny more questions about the pearls and purses. As social workers, we must be willing to advocate for the whole client to be welcomed by service providers. A client’s sexual voice, along with their pearls and purses, should never be closeted.

Randy

Lessons learned. One of the lessons learned is that disabilities services need professionalization so that staff are not mixing their personal values and views with that of the clients. Further religious oppression, especially around sexuality, is a common theme that needs to be addressed. Social workers need not only to be prepared for how to honor a clients’ religious practices and views but also maintain a level of professional and ethical practice when dealing with conflicting client/staff/agency views, practices, and policies. Also, I needed more training around a common social work challenge, answering to the agendas of multiple constituents (client, parents, co-worker, and employer), and how to recognize your primary client and your role as their advocate. An additional lesson learned is that disability services are often left with nowhere to turn for sex education, or sex therapy. With a lack of availability or knowledge of these community resources, people will often turn to their place of worship for mental health services. And, in the absence of that option it is not uncommon for people to turn toward prayer, especially if they view the issue as a moral issue. Social workers need to use this as way to meet the client where

they are to offer support in the form of sex education and counseling. For more information, see my discussion of the P.L.I.S.S.I.T. model in the Sex Therapy chapter of this *Handbook* (Turner, 2021 – Chapter 26).

Suggestions. There is a dearth of social workers choosing the field of developmental disabilities services. Social workers should advocate at state level policy and funding discussions to encourage the hiring of B.S.W./M.S.W.-trained, front-line staff. Additionally, our field education offices could partner with disability organizations to build a stronger representation with placement field sites for students. This introduction of social work students to this population may seed the field with more professional social workers. Additionally, sexuality groups such as the American Association of Sexuality Educators, Counselors and Therapists (A.A.S.E.C.T.) should reach out to these organizations, educating them on the certified professionals within their communities. This simple marketing would provide an invaluable resource of qualified sex-positive professionals for agency staff to utilize with clients struggling to find a healthy sexual life. In the absence of professional social work staff, social work educators might consider student-led course projects that help identify, develop, and deliver agencies training around professional boundaries. This could be delivered in a face-to-face presentation or by allowing students to write a blog or website piece for agencies to share with their staff.

Brenda

Lessons learned. I learned that slut-shaming is a universal theme for women, regardless if disabled or non-disabled. Disabled women may not have the personal skill set present in a well-honed sexual voice that typical women possess to weather this misogynistic tactic. Even more insidious is that disabled women are subject to a cloaked gendered control where women are treated as children and viewed as needing an adult, usually a man, to make better judgments on their behalf. The legal system is still susceptible to this paternalistic oversight regarding women with I.D. Additionally, we cannot underestimate that sexual pleasure, especially the sexual pleasure of women, is often seen as needing to be controlled. Our system privileges safety over pleasure more so for marginalized communities.

Further, I learned that the system is self-protecting and prone to victim-blaming. No representative of the system scrutinized their own part in why Brenda was opting for sex in a public, dangerous location instead of at her apartment. I believe that line of questioning was avoided partially because the system would have had to find itself culpable in Brenda's actions. Her home was not private; she was not allowed to voice her desires; no support for comprehensive sex education was provided. The system had silenced her and put her in danger.

An important lesson was realizing that social injustice is not necessarily carried out by a mysterious enemy, a shadowy bad character, but rather may be given life by our own inactions. Moments of advocacy may only present themselves in a blink. People with good intentions silenced Brenda's sexual voice. I remained on the sidelines; I too was complicit. Social justice work is not always popular with the establishment and practical skills need to be taught within social work classrooms to know when and how to question authority.

Suggestions. Comprehensive policy outlining a person-centered, sexuality-focused service provision should be state mandated for all agencies. Accreditation bodies such as the Commission on Accreditation of Rehabilitation Facilities (C.A.R.F.) should explicitly define sexuality services as part of best practices. In addition to staff training on the topic, agencies should consider offering parent and sibling training to client family members who are often in primary support roles, as well as to various allied supporters such as guardians, judges, and psychiatrists.

Sam and Molly

Lessons learned. I learned that adults with I.D. have a deep capacity for love. They hope for many of the same life goals that we all do, including to live a life within a meaningful, community-recognized, and respected relationship. Sam and Molly were resilient. Despite that, during my eight years agency tenure, the marriage carrot always moved just out of reach year after year. I am guessing because parents and staff deemed it safer for them to remain single. The couple held onto the standard script that marriage was within their sight. I learned that adults with I.D., as is common practice for many marginalized communities, are held to a higher standard. The system can demand relationship perfection for those we place into a space of other. Yet, ironically, many of my own friends had been in and out of multiple sexual relationships, let alone some who had married, divorced, and re-married during this same time frame.

Suggestions. I recommend that agencies are mindful of cultural norms regarding dating and relationships and mirror the values and beliefs of the client. While dating skills are important, they shouldn't be based on gendered stereotypes. It is important to recognize that, like with much of life, it is in the living it that we learn, grow, and master the skills needed to be successful. Adults with I.D. want the same opportunities for love as the majority, including the chance to fail. Trained social worker staff might be a voice for client self-determination.

Jackie

Lessons learned. I learned that homophobia was integrated throughout the agency on multiple levels. I also saw that the measure of social injustice is subjective and judged by time. Marginalized people learn to accept their place. It can be challenging to see a life that you have never known. I recall thinking how progressive the agency seemed. As a gay man, I felt supported and welcomed. And it is only on reflection, against a new standard that is hosted in a time of marriage equality, Ellen DeGeneres, and PrEP, that I view that level of acceptance as unacceptable. I learned that, despite a lesbian living her best and most authentic life, the system can be manipulated against you. I learned that paternalistic overreach happens for marginalized communities and even a progressive, well-funded, privileged agency may not step up to the plate to protect the people it is serving. Especially if the violation has not registered as an injustice due to the cultural zeitgeist.

Suggestions. Board of director training on not only sexuality in general but the Lesbian, Gay, Bisexual, Transgender, Intersex, Asexual, Queer, Two-Spirit community (L.G.B.T.I.A.Q.2+.) specifically is warranted. Additionally, sexual lifestyle awareness training such as kink and poly relationships should be included to expose board members to diverse communities that may seek to utilize their services. Social work educators could offer an assignment that pairs students with a non-profit organization to conduct a policy audit with the goal of helping agencies become more sexually inclusive. Additionally, a system of anonymous suggestions could be put into place, asking staff for areas of improvement specifically around potential conflict, rights violations, social injustice, nepotism. Again, this could be coordinated by an outside source such as a social work class each year that would analyze the data and make recommendations.

Conclusion

Sexuality is the last frontier in the field of developmental disabilities. These uncharted service areas in disability services would benefit from the skills of professional social workers with their advanced clinical skills in interpersonal relationships and a strong history of social justice. To secure a more substantial professional role within social services for adults with I.D., the social

work academy first must establish a more rigorous discourse in our profession on sexuality. Our current efforts are scattered and, in comparison to other disciplines, virtually silent. As noted by Dodd and Tolman (2017),

in this academic silence, social work is missing a significant opportunity to contribute to the larger conversation around healthy sexuality in a way that illuminates a more holistic perspective and that acknowledges desire and sexual satisfaction across the spectrum, including among marginalized and oppressed groups.

(p. 227)

Social workers must be an instrument to amplify the sexual voices of adults with I.D. It is not enough to survive in this world, but to thrive means to have access to our sexuality.

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