Intellectual and Developmental Disabilities

“She like, sugarcoats things”: Maternal influence on sexual (in)agency of young college women with disabilities

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“SHE LIKE, SUGARCOATS THINGS”: MATERNAL INFLUENCE ON SEXUAL (in)AGENCY OF YOUNG COLLEGE WOMEN WITH DISABILITIES

Abstract

By amplifying the voices of young college women with intellectual and developmental disabilities, this study explores the intersections of disability, gender, sexuality, and higher education. It highlights how maternal socialization shapes their sexual knowledge prior to college, revealing that mothers often leave their daughters misinformed, disempowered, and dependent, even into adulthood. The study also addresses how persistent taboos and embodied avoidance strategies, such as euphemisms and gestures, limit these women's agency and reflect constrained communication patterns from their upbringing. The findings underscore the crucial role of mothers in their daughters' sexual self-determination and advocate for tailored resources to support both mothers and their daughters, aiming to enhance sexual autonomy and education for women with disabilities.

Introduction

Historically, scholarship in the area of sexuality for young women with intellectual and developmental disabilities has often been rooted in dominant approaches that dismiss, marginalize, and/or subjugate women and create barriers to leading joyful, autonomous lives. Due to these misconceptions and assumptions, young women with intellectual and developmental disabilities often lack access to sexual and reproductive education and healthcare (Dotson, et al., 2008; Payne et al., 2016). Moreover, women with intellectual disabilities, are frequently denied recognition as women, potential partners, mothers, and sexual beings (Fitzgerald & Withers, 2013).

Harmful histories persist today, as disabled women continue to experience disproportionately high rates of sexual abuse and harm (Schaafsma et al., 2015; Winges-Yanez, 2013) while also facing infantilizing ideologies that portray them as “eternal children” incapable of sexual desire and dependent on others (Gil, 2015; Waxman, 2004). Women are often presumed not to date and face negative attitudes about their sexuality from individuals with traditional gender beliefs that deny women the opportunity for sexual identity development (Pebdani & Tashjian, 2022; Parsons et al., 2017; MacKeigan, 2021). As a result, some may internalize these stereotypes and question whether they should engage in relationships, particularly given the perceived risks associated with reproduction as someone with a disability (Hops et al., 2017). These barriers are exacerbated by some restrictive caregiving practices that prioritize safety and control over empowerment, often depriving women with intellectual disabilities of opportunities to explore and express their sexuality (Black & Kammes, 2019). Additionally, societal stigma surrounding intellectual disability perpetuates the false narrative that these women are either asexual or hypersexual, further limiting their access to sexuality education and meaningful relationships (Black & Kammes, 2021). As a result, their voices are often excluded from discussions about their own sexual and reproductive rights, reinforcing systemic inequities that deny their autonomy and agency.

However, since the 1990s, the disability justice movement has sought to reimagine disability –inclusive of intellectual and developmental disabilities—and sexuality through strengths-based, intersectional approaches — rejecting ideologies of infantilization and inability, and instead championing self-determination, understood as an individual exercising control over areas of life considered important to them (Abery & Stancliffe, 2003). In fact, literature at the intersections of gender, disability, and sexuality highlights the nuances of social stigma that dismisses the possibility of disabled women having sexual lives or desires. In the context of sexuality, self-determination relates to sexual design-making processes and sexual self-knowledge (Skuban-Eiseler, 2022). However, self-determination processes do not occur in isolation; surrounding environments and continuous interactions with others —particularly family — play a central role. Given the widespread lack of inclusive sex education in schools and the oversized responsibilities parents have in the development of their children with disabilities at-large, families often take on the role of educators or advisors of romantic and sexual experiences, as well as overall sexual development throughout adolescence and into adulthood (Kammes et al., 2020; Linton & Williams, 2019; Shtarkshall et al. 2007; Scholma & Gorman, 2021).

Many parents and caregivers recognize the importance of sex education for their children (Eyres et al., 2022; Gibbon et al., 2021), and yet, navigating the complex landscape of these topics while balancing the tension between advocating for self-determination and providing necessary support is challenging. (Pownall et al., 2011; Swango-Wilson, 2008). While parents and caregivers may have opportunities to shape their child's sexual identity development through personalized guidance and access to resources, several challenges arise making it difficult to know when to intervene: some may feel discouraged or fearful of providing misinformation (Frank & Sandman, 2019) or believe they are unqualified or unprepared (Scholma & Gorman, 2021; Dupras & Dionne 2014; Evans et al., 2009). Others may harbor fears linked to the high prevalence of sexual abuse and potential health complications for their children with intellectual and developmental disabilities (Parchomiuk, 2012).

Researchers have found that females, usually mothers, often serve as the primary caregivers of young adults with disabilities, also taking on the responsibility of supporting their children's sexual development and education (Pryde & Jahoda, 2018). As a result of their relationship, they are more likely to engage in conversations about sex-related topics with their children. For some mothers of daughters with disabilities, discussing subjects like menstruation or puberty felt more comfortable due to shared experiences as women (Dilorio et al., 2003). However, other mothers may approach these conversations with caution, avoiding topics they consider inappropriate due to age or cultural beliefs (Pownall et al., 2012).) These differences illustrate the influence of maternal attitudes on their child's sexuality and sexual experiences, as well as the complexities of mother-daughter relationships. Varying levels of closeness, depth and connection, and open communication may play significant roles as mothers strive to protect and care for their daughters without stifling their self-determination and development. Researchers have found that it is important to cultivate intimate connections, nurture romantic relationships, and ensure equitable access to sexual health education, all while actively working to dispel common misconceptions about sex and intellectual disability (Black & Kammes, 2019, 2021). Nevertheless, maternal hesitancy or reluctance can have implications during the transition from adolescence to adulthood in college, as daughters prepare to navigate increased independence and social interactions.

Theoretical Framing: Feminist Critical Disability Studies and Sex as Taboo

A Transdisciplinary Approach

Building upon the minimal focus on student perspectives from inclusive postsecondary education programs (Bacon & Baglieri, 2021) and the limited research centering young women with I/DD (Kammes et al., 2020; Dotson et al., 2008), this work is positioned as a feminist project. Throughout my analysis, I apply a transdisciplinary lens, drawing from women's and gender studies, disability studies, sexuality studies, and linguistics, to understand the experiences of young college women with disabilities in an inclusive postsecondary education (IPSE) program. Using a feminist critical disability studies approach with an intersectional analysis, I interrogate the social construction of disability, gender, health, and sexuality, while also validating the experiences of oppression these women face (Crenshaw, 1989, 1991; Garland-Thomson, 2005, 2011; Samuels, 2002). Additionally, I use sociocultural linguistic concepts to analyze the discursive strategies these women employ to communicate meaning and construct their own identities (Bucholtz & Hall, 2005). Discursive moves such as word choice, laughter, gesture, and pauses are seen as agentive interactional practices that provide a deeper understanding of their experiences (Calhoun, 2021). Rejecting the discrimination and "social subjection of women with disabilities" (MacKeigan's, 2021, p.672) as potential romantic or sexual beings, this work center stories first-person accounts from college women with intellectual disabilities. It explores how discourse shapes their narratives and subjectivities, positioning women with disabilities as knowledge creators at the intersections of disability and gender, advocating for sexual self-determination and agency over their romantic and sexual desires as self-knowers.

Sex and Sexuality as Taboo

Taboo refers to social, cultural, or political norms that deem certain behaviors, practices, or language as off-limits, inappropriate, or harmful (Allan & Burridge, 2006). These taboos are shaped by societal and cultural standards, gendered and racialized expectations, and institutions of power like religion, education, and media. While some taboo language or subjects may be accepted in everyday conversation, others remain highly offensive or unspeakable. Commonly flagged taboo topics include sex, marriage, abortion, and slang terms for genitalia. Romantic and sexual behaviors, such as kissing or masturbation, are also often taboo. Additionally, politically sensitive subjects like abortion, LGBTQ+ healthcare, reproductive rights, or pornography may be taboo due to moral or faith-based objections. Given the negative connotations associated with taboo, euphemisms are frequently used to soften or avoid sensitive discussion (Gao, 2013).

Sex, along with related behaviors and language often carry varying levels of approval and social acceptance (Askew, 2007; Kulick & Wilson, 2005). For people with disabilities, however, these taboos are even more pronounced. Their sexualities are often viewed as uniform and inherently taboo, resulting in heightened stigmatization as society tends to desexualize or infantilize them, denying individuals with disabilities the same sexual autonomy and rights afforded to others (Santinele Martino, 2022). As a result, discussions around sex, sexuality, sexual health, or even romantic relationships can evoke profound discomfort for both individuals with disabilities and those participating in the conversation, further complicating access to resources and support in these areas. This reinforces cycles of exclusion where their potential romantic or sexual identities are rendered invisible or treated as inappropriate.

Methodology

Today I finished interviewing all seven of the young college women and as I think about each of their stories and experiences with sexual education prior to college, I'm realizing how much I have learned about their relationships with their mothers. When I started this work, I was thinking more about information or content young women were introduced to in school, or specific conversations around topics they shared with their families. These women shared such complexities of their relationships with their moms: some so deeply devoted to their well-being and yet controlling in ways that some daughters wished they were not. I wasn't thinking intentionally enough about the complexities of parenthood and disability, particularly between mothers and daughters with disabilities until now

[Fieldnote Journal Entry July 2023]

The data in this article draws on ethnographic fieldwork I began in 2021 in Success & Wellness for Inspiring Pathways (SWIP, pseudonym) – an inclusive postsecondary education program named at a public research university in the southwestern US, focusing on sex education for college students with I/DD. SWIP is a four-year integrated certificate program designed to help young adults with I/DD transition to independent living and employment through mentoring, academic support, and skill development opportunities. I began participant observation by attending SWIP classes and events, building relationships with students and staff. Key contributors to data collection were Anne, a social worker, and Elizabeth, a doctoral student and former special education teacher, who both mentored and taught SWIP students. In 2022, I introduced the research project to SWIP students, explaining that it aimed to advance sexual and reproductive health education for individuals with disabilities. I invited all interested students in SWIP to participate, as enrollment in the program was the inclusion criteria. Of the 16 enrolled students, 15 (8 men, 7 women) consented to interviews. This work focuses on the experiences of SWIP women enrolled during the 2022-2023 academic year; while the male student's ethnographic interviews are not included, they remain integral to the broader ethnographic goals.

Participants and the Interview Experience

All seven SWIP women, aged 18 to 23, chose pseudonyms to protect their confidentiality and to further safeguard their identities, specific disability labels were not used. Instead, they are collectively described as having multiple intellectual and developmental disabilities, including Down syndrome, autism, visual impairment, and other learning disabilities. They were in various stages of their college education, from freshman to junior standing (Table 1) offering a diverse range of experiences. The interview process prioritized participants' preferences, aiming for inclusivity and sensitivity to potential challenges or discomfort (Diaz et al., 2023; Sigstad & Garrels, 2018). Some participants chose individual interviews, while others opted to be interviewed in the company of friends, reflecting the strong relationships they had built in the program. They were also given the option to be interviewed by me alone or with Anne and Elizabeth (SWIP staff), ensuring flexibility and comfort.

Interviews began with a reminder of the broader ethnography's aims and guiding research question: what experiences and influences shaped the sex education and knowledge of young college students with intellectual and developmental disabilities prior to college? I explained that the discussions would explore what they had learned, where they learned, and how or if it had influenced their lives. Open-ended questions, such as "Tell me about the first place you learned about sex?" and "What information or messaging have you learned about relationships or dating?" guided the conversation. Although prepared questions were created to open exploratory avenues of adults' earlier adolescent experiences, the interviews were kept as conversational and informal as possible. Each interview lasted between 45 and 60 minutes. At the end, women received a $20 Amazon gift card as compensation. Audio recordings were anonymized using pseudonyms before being transcribed and uploaded to NVivo, a qualitative data analysis software.

Positionalities of the Research Team

My positionality significantly impacts the research process, shaped by personal experiences as an educational researcher and faculty member. As a white cisgender femme, queer, and able-bodied, I am acutely aware of my privileges and limitations. Although deeply committed to advancing sexual and reproductive health education, my understanding of individuals with I/DD is shaped by my lack of experience in this area; having never navigated special education settings or lived with a disability, my perspective and analyses are inherently biased. The scope and design of my research are informed by my professional training and commitment in sexual and reproductive health education, including young adults with disabilities. Nevertheless, as Muwwakkil (2023) asserts, “No one has lived a day outside of their own body...who we are necessarily shapes what we see and how we see it” (134). This awareness underscores the ethical considerations of power and positioning in my role as a researcher and interviewer, highlighting the need for critical reflexivity throughout the entire research process.

Anne identifies as a queer white female and has worked as a social worker for four years, with much of her experience focused on supporting students with intellectual and developmental disabilities as a full-time staff member in the SWIP program. Her passion for this work stems from the glaring lack of inclusive and comprehensive sexual health education for individuals with disabilities, which drives her scholar-practitioner commitment to advancing equity in this area. Anne approaches this research with an awareness of how her own identities and experiences inform her perspective, particularly her commitment to advocating for agency, autonomy, and inclusion. Through her everyday work and this research, she seeks to foster environments where SWIP students can access the resources and support needed to navigate healthy and joyful lives, particularly in the realm of sexual and reproductive health, while centering the voices and experiences of those most impacted.

Elizabeth is a white female with an acquired disability who has worked with individuals with disabilities for over 10 years, both as a special education teacher and now as a doctoral student researcher and employee in the SWIP program. Her interest in sexuality and healthy relationship education for people with I/DD is grounded in a commitment to self-determination, inclusion, and equity. Recognizing that individuals with I/DD are often excluded from essential conversations due to systemic barriers and lack of accessible resources, she seeks to address these opportunities for promoting autonomy and reducing vulnerability. Through her work in transition and self-determination education, she has witnessed the profound impact of empowering individuals to make informed decisions in all areas of life, including relationships. She is dedicated to challenging ableism and fostering strengths-based practices that ensure individuals with I/DD have access to the knowledge and tools necessary to build meaningful and healthy lives on their own terms.

As a research team of women, we are collectively committed to conducting this work within a feminist framework that centers the lived experiences and agency of the seven women in the SWIP program with intellectual and developmental disabilities. We align with the principles of disability justice, advocating for and believing that individuals with I/DD deserve affirming sexual health education that supports their right to explore their sexuality and experiences with support, confidence, and dignity. Together, we challenged ourselves and each other, recognizing that this work is rooted in collaboration and community, with a focus on amplifying the voices of women.

Data Analysis

I used participant-observant methods, collecting ethnographic fieldnotes, informal conversations with students and SWIP staff, and interviews with the seven young college women, to explore how their adolescent and pre-college sex education experiences shaped their understanding of sex education and related topics (e.g., sex, romantic relationships, and bodily processes of puberty and reproduction). Employing a discourse analytical framework, I examined how language functions as a critical resource for analyzing both structural and interactional dimensions of the data (Bucholtz & Hall, 2005; DuBois, 2015). Audio-recorded interactions were transcribed to reveal discursive features of the interviewees’ spoken and unspoken linguistic choices. Interview excerpts were organized by single intonation units–discrete pieces of discourse marked by slight pauses, changes in tone, stress, or pitch (Table 2).

By focusing on how interviewees use language to position themselves relative to others and ideas, or “stancetaking” (Jaffe, 2009; Du Bois 2007) or how they use double-voiced discourse to create “constructed dialogue” (Tannen, 1986) by voicing those not present (designated as </VOX/), my analysis provides a comprehensive understanding of women’s experiences. Using discourse analysis allows me to glean not only these young women’s understanding of sex and sexuality, but also their disposition to the topic and how that disposition was informed. In the interview, I asked women to describe the first time they learned about sex or received sex education, including what they had learned, where they had learned it, and from whom. Their responses highlighted experiences from both school and home environments. Elizabeth, Anne, and I reviewed audio recordings and transcripts multiple times, collaboratively interpreting and reflecting on the data. We employed strategies such as triangulation and member checking (as a team and with participants) to ensure accurate representation of women’s shared stories and experiences (Brantlinger et al., 2005; Trainor & Graue, 2014).

Findings: Maternal Control and the Infantilization of Sexual Knowledge

By integrating our positionalities and diverse experiences with SWIP students with the multidisciplinary epistemological traditions validated through ethnographic methods, analysis revealed recurring themes, notably the role of parents, especially mothers, in shaping sex education. Drawing on the original guiding research question – what experiences and influences shaped the sex education and knowledge of young college students with intellectual and developmental disabilities prior to college – and after iterations of analysis, themes surfaced in the data as the young women detailed instanced of earlier sex education experiences. Many participants described family-based sex education experiences that led to discomfort and limited open dialogue. As college students, and as adults, this resulted in a significant theme of infantilization, where some women felt their autonomy was undermined and discussions around sex were either avoided or controlled. Participants employed discursive strategies such as using euphemisms, relying on gestures, and displaying embodied affective responses, which reinforced the taboo nature of sex and its persistence into college. These strategies suggested that earlier socialization during adolescence, especially through the influences of their mothers, led to daughters often being perceived as unprepared for meaningful discussions about sex, reflecting a broader hesitation to address these topics openly with them.

Navigating Taboos Through Euphemism

During interviews, the seven young adult women were asked about their pre-college sex education, and all referenced their mothers while recounting experiences and messages from adolescence. For example, Crystal, a 21-year-old sophomore, shared that although she found her mother "too overprotective" about romantic relationships, they once talked about future plans like marriage and having children. Crystal said her mother was the only person she trusted to discuss sex education, relying on her mother's experiences as an adult. She explained, "sometimes I just wanna know what's not good, or what's really bad." When asked about specific topics they discussed, Crystal mentioned condoms:

Crystal: Um so we did talk about like,
if he–
it's kind of like a,
p word like uh:
that stuff and-
Jenny: You said p word.
Is penis?

You mean?

Crystal: Hm ((MOVES HER HEAD IN AGREEMENT THEN LOOKS AWAY)).

Jenny: So if you,

if you:

I can say the word?

Does it help if I say the words?

Crystal: ((MOVES HER HEAD TO LOOK DOWN WHILE GIGGLING))Yeah.

Um yeah just we don’t talk about it so,

this ((EXTENDS ONE INDEX FINGER)) is his.

Jenny: Okay.

Crystal: And this ((EXTENDS OTHER INDEX FINGER)) is me right there.

Jenny: Uh [huh].

Crystal: [And] then just connect it ((MOVES FINGERS TO TOUCH)).

Jenny: Mhm.

Crystal: And that means like you got do the ess-ee-ex stuff ((DRAWING EACH LETTER IN THE AIR AS THEY ARE SPELLED OUT)).

Like Crystal, Michelle, a 23-year-old junior, avoided directly talking about sex when asked to share her earlier experiences with sex education. Instead, she used euphemisms, recalling past conversations with her mother. When asked to share any experiences or sex education around dating or relationships, Michelle recalled that at age nine she “asked Jesus into my heart.” She explained that after her baptism and throughout high school, her parents’ sex education advice focused on finding a “person who is a Christian…and that way you can get married to him.” Through multiple classroom observations and informal conversations with Michelle since the start of the ethnographic project, it became evident how influential Christianity was to her and her family. When asked what she learned about sex before college, she hesitated to answer, but after further prompting, shared her thoughts on having children:

Jenny: Do you know where like,
kids come from?
Michelle: Mhmm ((EXTENDS HER INDEX FINGER AND POINTS UP TO THE SKY)).
Jenny: From god?
Michelle: Yeah.
Jenny: Okay and,
do you know,
like the process of how,
like babies are made?
Do you think it comes from god?
I–((NOTICES MICHELLE REST HER HANDS ON HER STOMACH))
You're touching your stomach?
Michelle: Yeah.
When woman gets pregnant.
Jenny: Yeah.
Michelle: Like when you’re telling your husband that like,
when you’re telling your husband,
I’m pregnant!

In addition to her limited understanding of the human reproductive biology, Michelle also recounted messages from her mother about potential sexual experiences with Christian boys she might meet in college:

Michelle: And they say,
Like,
<VOX> Hey Shelly,
I want you to keep those inappropriate ways,
so I want you to keep it to yourself.
Don't say anything about to your friends or nothing. </VOX>
Jenny: What inappropriate ways are you talking about?
Michelle: Well,
Jenny: What are you keeping to yourself?
Michelle: Like with my mom say,
<VOX> Shelly you you can't touch right here, ((TOUCHES HER OWN WAISTBAND))
You can't:
touch below the waist down.
Jenny: Mhm.
Michelle: Just just touch upper,
up your body.
Okay?
Jenny: Of yourself or of your boyfriend?
Or both?

Michelle: ((EXHALING LOUDLY)) If you have a boyfriend you can hug him.

Jenny: Yeah mhm.

Michelle: You can kiss him and then so don't touch below his waist down. </VOX>

Jenny: Ok.

Michelle: And I'll say:

<VOX((OF FORMER SELF))> Okay. </VOX>

<VOX((OF MOTHER))> But also the the the:

Good thing you're going to do:

You you can hold his hand. </VOX>

Navigating Taboos Through Embodied Affective Responses

Squirmish movements, avoidant eye contact, and uncomfortable laughter while discussing body parts or describing sexual practices were common signs of internalized discomfort among all the women interviewed. Zach, an 18-year-old freshman, spoke at length about the complexities of having divorced parents and an "overprotective mother" who made her uncomfortable discussing these topics. When asked about her past sex education experience, she shared:

Jenny: You're kind of making a squinty face?

What is that?

What does that mean?

This one. ((JENNY CRUNCHES HER NOSE UPWARDS WHILE SQUINTING HER EYES, ROUGHLY MOVING HER LIPS TO A HALF SMILE))

[Like]:

Zach: [I'm just] grossed out by it.

With expressive facial movements, Zach was visibly uneasy and confirmed this affective disposition, explaining that she's "just grossed out by it" – referring to sex. Similarly, Crystal (previously mentioned) had an embodied physical reaction when discussing body parts, particularly genitalia. When asked to explain what sex education meant to her and to share her experiences, I noticed her body shiver multiple times as she used her bangs to hide her eyes:

Crystal: I'm I'm when you,
when I hear tha–
it's just maybe I guess:
too:
gross?

In addition to the visible discomfort expressed by many of the women, one participant shared feelings of frustration about her experience discussing sex-related topics with her mother as a person with a disability. Alexis, a 21-year-old sophomore, described the challenges of growing up as the middle child between an older sister who frequently dated and a younger brother who frequently teased her during puberty. She struggled to balance these dynamics and the limited information she received from her family with what she sought from friends at school. Upon learning that her older sister and mother had openly discussed dating and sex – conversations she never had– Alexis realized how her parents avoided certain topics and withheld detailed information, despite her interest:

Alexis: Sometimes it's a little awkward cause like,
I don't know why,
but like I guess cause I never got it at school,
and like most of like my I guess knowledge:

is like from other kids at school,
or like my sister's friends:
they're like–
my sister has a bunch of friends that have babies and like,
getting it from them and like I know my parents like did talk about it,
but I feel like they like,
I guess:
sugarcoated it a little bit.

Alexis continued, explaining that her mother didn't start talking openly about sex until Alexis unexpectedly got her period at school–a terrible experience, one in which she thought her body was dying due to a lack of information around menstruation. Speaking about her mother, she said:

Alexis**:** But she doesn't like:
she likes sugarcoat things a little bit.
And I don't know if it's 'cause like I have a disability?
Or like what.
But sometimes she does sugarcoats things.

Discussion

Throughout adolescence and before college, the young women emphasized their mothers' significant influence in their lives, particularly regarding sex education. Their shared stories revealed how their mothers' socialization practices deeply shaped their knowledge, perceptions, and behaviors around topics like sex, dating, and having children. It was evident that mothers framed sex and sexual agency as taboo—too sensitive for open discussion—possibly due to stereotypes and stigma. These taboos, perceived as exceeding acceptable boundaries within their family and cultural context, ultimately shaped the daughters' experiences and interactions. In the following sections, I explore how this maternal influence restricted the women's romantic and sexual agency and autonomy as adults.

Daughter's Avoidance Through Euphemisms

Crystal exemplifies the lasting impact of her infantilization during adolescence and her mothers' avoidance of common taboo sex-related terms, shown through her use of "p-word," highlighted the lasting impact of her socialization during adolescence. When asked about sex education, Crystal echoed her mother's teachings and embodied sex as taboo through gesture. Crystal's request for me to say the word, illustrated her continued self-censorship not only in an interview space intended for open discussion, but in college. When she states, "...just we don't talk about it" the ambiguity of her pronouns (Stapleton, 2017) blurs whether she's referencing herself and her mother, or us in the present moment. This ambiguity extends to her use of present tense, suggesting that this avoidance is ongoing, indicating a continuity of socialization that persists from the past into the present.

In addition to her avoidance of spoken terms, Crystal's gestures highlighted the impact of socialization of sex as taboo. She used her index fingers to simulate a sexual connection, saying "and then just connect it," with the physical touching of her fingertips reinforcing her avoidance strategy. Her gesture, paired with the phrase "connect it," and her use of "it" as referent, emphasized her reluctance to discuss sex directly. Crystal further distanced herself by fingerspelling out the world "sex" in the air and referring to it as "doing the sex stuff." This use of gesture as a strategy to avoid direct mention was a deliberate choice to protect her emotion. Initially, Crystal positioned herself within her description, represented through one of her index fingers, saying, “this is me right here,” reflecting a glimpse of her sexual self-advocacy. However, by spelling out “sex,” she distanced herself from the direct reality and potential feelings it might evoke, illustrating her effort to “create a metaphorical spatiality” (Duncan, 2019 p. 3). Crystal’s approach demonstrates the complex interplay between agency, emotional protection, and ingrained socialization regarding sex.

Michelle, like Crystal, used gestures to explain her understanding of procreation and conception. First, she pointed to the sky, indicating “from god” which both avoided directly discussing sex and overtly invoked her Christian belief that a newborn is a gift from god. When asked for further clarification, Michelle moved her hands to her stomach and said, “yeah, when woman gets pregnant,” suggesting that sex, in her view, is solely for procreation as per religious doctrine. Although she did not explicitly mention sex, the associations she made with “babies,” “god,” “woman,” and “pregnant” revealed how religious socialization framed sex strictly within a procreative context. This perspective reflects abstinence-only ideologies, which view premarital sex and sexual desire as shameful and deviant, traditionally aligned with Christian values of purity and virginity.

Michelle’s values resurfaced when discussing her mother’s advice about dating and intimacy with a potential Christian boyfriend. Using the discursive strategy of “voxing” (DuBois, 2015) to alternate between her mother’s and her own voice, Michelle explained that her mother deemed some dating-related actions as “inappropriate” for Michelle. While hugging or kissing was allowed, discussing sexual experiences with friends was discouraged, and any “touch[ing] below the waist” was prohibited. Socialized by her mother in a family with strict religious beliefs, Michelle’s limited exposure to intimate discussion with friends impacts her bodily and sexual autonomy.

Both Michelle and Crystal demonstrated similar tendencies, resorting to gesture when discussing their experiences. Their discursive strategy of using euphemisms reflects the ongoing influence of maternal socialization around taboo topics and the effects of infantilizing censorship (Azzopardi-Lane & Callus, 2025; Gill, 2015; Santinele Martino, 2022) even in the absence of their mothers. Crystal's aversion to eye contact and her preference for spelling out words serve a dual purpose: as an avoidant strategy to avoid saying the word sex aloud, and as a way to mirror the adult who taught these ideas. These decisions illustrate the lasting impact of her socialization around sex even while away at college, geographically distanced from the mother. For Michelle, religious views limit her understanding of sex as a source of pleasure and connection. These tendencies underscore the potential disadvantages of relying on euphemistic language in sex education, such as misunderstandings and the normalization of sex as taboo. While gestures may seem like less confrontational ways to discuss sensitive topics, they often serve as coping mechanisms for navigating discomfort with sex.

Embodied Lasting Impressions

As a result of their socialization, young women often internalized the belief that discussing sex was taboo, a perception that persisted into adulthood. For some, this belief was so ingrained it evoked a sense of embodied revulsion or disgust. Additionally, the infantilizing stereotype that discussing sex and sexuality is taboo for people with disabilities further hindered their sexual self-determination and socialization. Zach's scrunched face and Crystal's tendency to hide her gaze while avoiding saying the word sex, revealed the acute discomfort experienced by the women. Both Zach and Crystal described feeling "gross" while talking about sex, reflecting the deep impact of their mothers' socialization on their aversion to discussing sex. This aversion discouraged open discourse and perpetuated stigma, especially for women with disabilities. Beyond explicit emotional responses, mothers' socialization strategies led some daughters to internalize infantilizing misconceptions that altered their sense of self. Alexis, for example, frequently used the term "sugarcoating" to describe her mother's controlling narratives around sex, which she felt were specific to her disability. This "sugarcoating" not only implied fragility through infantilization, but also reinforced the notion of potentially overprotective parental control, denying adult women their rights to self-determination while in college. This work highlights the significant influence mothers have on the sexual socialization of their daughters with disabilities. This dynamic is complicated by the many varied roles and added sense of responsibility mother navigate: wanting to protect and care for their children, while at the same time striving to provide them with the guidance and autonomy needed to take control of their own lives (Curryer et al., 2020). As a result of infantilizing attitudes and limited access to accurate information, some women are socialized into (in)agentivity through "disabling social processes" (Santinele Martino 2022, p. 467) that hinder informed decision-making. This aligns with research emphasizing the importance of providing family caregivers with comprehensive information to support their children while also allowing them the space to exercise sexual agency on their own terms. (Powell et al., 2024; Löfgren-Måtenson, 2005).

Limitations

This study acknowledges the complexities inherent in exploring sexuality development and support for women, and all people, with intellectual and developmental disabilities. While the focus was not on the broader, cultural, historical, sociopolitical, or religious influences on sexuality, these factors undoubtedly shape societal attitudes and individual experiences of the women. For example, dominant perspectives on gender and sexuality—rooted in heteronormativity and patriarchal socialization practices—can significantly impact the formation of sexual selfhood. Similarly, the role of religion in shaping beliefs about sexuality and disability warrants further exploration, particular in its intersections with race and gender, as these may interest with or amplify stigmas and stereotypes. By not fully addressing these dimensions, this study provides only a partial view of the barriers to sexual self-determination for women with I/DD. Although a more nuanced understanding of how these factors influence access to sexuality education and support is outside the scope of this manuscript, they remain critical for fostering inclusive practices in the field.

Future Directions

The socialization experiences of these college women highlight the critical need for tailored and readily available resources for mothers, helping them navigate the new challenges their children face in college, which differ significantly from those in prek-12 schooling (Graff et al., 2019). Just as advocacy efforts for comprehensive sex education in secondary schools are crucial for students and families, IPSE programs must also provide specialized curricula for students and families – particularly for young adults with disabilities.

As more IPSE programs are established, there is an increasing need for culturally responsive, inclusive, and liberatory resources that support sexual self-advocacy for individuals with I/DD (VanHorn Stinnett et al., 2021; Sinclair et al., 2015; Kammes et al., 2020). One recommendation is for IPSE programs to include curricula that encourage exploration and provide support for students' sexual identity development, including safe romantic or sexual experimentation. This new curriculum should be accompanied by resources created for, and by mothers – and other caregivers– that address the pressures and tensions they may experience as they continue to support their child’s self-determination journey.

In all, young women with I/DD face unique sexual and reproductive health challenges that impact their daily lives, leading healthcare providers to call for "multi-disciplinary efforts" (Verlenden et al., 2019 p. 552) to address their needs. IPSE professionals support these calls by advocating for team-based approaches that emphasize interdisciplinary and individualized support, holistic care, and collaboration among students' families, program staff, and college campus community resources (Graff et al., 2019; Thorpe & Oakes, 2019; Stein et al., 2018). By addressing these needs as a committed collective, we move closer to "shattering the taboo" (Santinele Martino, 2022) at the intersections of disability, gender, and sexuality, ultimately centering the sexual health, autonomy, and desires of women with disabilities in college and beyond.

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Table 1

Transcription Conventions for Interview Adapted from Dubois (2015)

Convention	Meaning
.	end of intonation unit
,	continuing intonation
?	rising/question intonation
--	break in the intonation unit; self-interruption
:	lengthening
<VOX</>	Voice of another; imitating another person's speech

Table 2

Participant Information

Name (Pseudonym)	Year in College	Age
DJ	*Freshman*	*20*
TN	*Freshman*	*18*
Taco	*Freshman*	*19*
Zak	*Freshman*	*20*
Alexis	*Sophomore*	*21*
Crystal	*Sophomore*	*21*
Michelle	*Junior*	*21*