

American Journal on Intellectual and Developmental Disabilities

Family caregivers' attitudes and perspectives about the sexual and reproductive health

--Manuscript Draft--

Manuscript Number:	AJIDD-D-22-00018R3
Article Type:	Research Report
Keywords:	intellectual or developmental disabilities; family caregivers; Reproductive Health; sexual health
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Manuscript Region of Origin:	UNITED STATES
Abstract:	<p>Background: Limited research exists on the role of family caregivers in assisting women with intellectual or developmental disabilities (IDD) in accessing sexual and reproductive health services and information. Understanding caregivers' attitudes and perspectives is crucial for improving access to such services for women with IDD.</p> <p>Methods: A cross-sectional online survey was conducted from June to October 2018, involving 132 family caregivers of women with IDD. Quantitative analysis was performed for closed-ended responses, while qualitative analysis was conducted for open-ended responses.</p> <p>Results: The majority of participants, who were mostly parents, reported actively facilitating their family member's access to sexual and reproductive health services and information. Although most participants expressed that sexual and reproductive health services and information are essential for women with IDD, qualitative analysis revealed both supportive and restrictive attitudes among participants. Supportive attitudes and perspectives included (1) "knowledge is power;" (2) supported decision-making; and (3) protection against sexual abuse. Restrictive attitudes and perspectives included (1) dependent on the individual; (2) lack of autonomy; and (3) placing responsibility on disability.</p> <p>Conclusions: Greater attention from policymakers and practitioners to systems-level changes, including universal and accessible sexual education for women with IDD, supported decision-making, and sexual abuse prevention measures, are urgently needed.</p>

Family caregivers' attitudes and perspectives about the sexual and reproductive health of women with intellectual or developmental disabilities: An online survey

Background: Although sexual and reproductive health is critically important for women with intellectual or developmental disabilities (IDD), there is limited research elucidating the role of family caregivers in assisting women with IDD access sexual and reproductive health services and information. Understanding the family caregivers' attitudes and perspectives is essential to improving access to sexual and reproductive health services and information for women with IDD.

Methods: A cross-sectional online survey of family caregivers of women with IDD was administered between June and October 2018. Quantitative analysis was conducted for closed-ended responses, and qualitative analysis was conducted for open-ended responses. The analytic sample included 132 family caregivers.

Results: Most participants were parents and reported being closely involved in their family member's access to sexual and reproductive health services and information. Although most participants expressed that sexual and reproductive health services and information are essential for women with IDD, qualitative analysis of participants' open-ended responses revealed supportive and restrictive attitudes and perspectives on sexual and reproductive health services and information for women with IDD. Supportive attitudes and perspectives included (1) "knowledge is power;" (2) supported decision-making; and (3) protection against sexual abuse. Restrictive attitudes and perspectives included (1) dependent on the individual; (2) lack of autonomy; and (3) placing responsibility on disability.

Conclusions: Greater attention from policymakers and practitioners to systems-level changes, including universal and accessible sexual education for women with IDD, supported decision-making, and sexual abuse prevention measures, are urgently needed.

Keywords: intellectual or developmental disabilities, family caregivers, reproductive health, sexual health

Introduction

According to the World Health Organization (2009), people with disabilities have the right to and require sexual and reproductive health services and information. Sexual health is defined as “A state of physical, emotional, mental and social well-being in relation to sexuality...” (World Health Organization 2006), while reproductive health is defined as “A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, in all matters relating to the reproductive system and to its functions and processes.” (United Nations, 1994, p. 40). However, women with intellectual or developmental disabilities (IDD) face ongoing restrictions in accessing these services and exercising their rights (Powell & Stein, 2016). Intellectual disability (ID) involves significant intellectual functioning and adaptive behavior limitations. In contrast, developmental disabilities (DD) refer to severe and chronic impairments resulting in limitations in major life activity areas (Schalock et al., 2021). DD includes conditions such as cerebral palsy, fetal alcohol disorder, and autism spectrum disorder (Havercamp et al., 2019). Both ID and DD arise before age 18.

Family members, professionals, and society perceive women with IDD as sexually unwilling or unable (Azzopardi-Lane, 2021; Azzopardi-Lane & Callus, 2015). Consequently, women with IDD face disparities in accessing sexual and reproductive health services and information (Greenwood & Wilkinson, 2013). They receive inadequate sexual education, have limited contraceptive knowledge, and have lower contraceptive use rates compared to nondisabled women (Greenwood & Wilkinson, 2013; Galea et al., 2004; Isler et al., 2009; Swango-Wilson, 2011; Horner-Johnson et al., 2019; Mosher et al., 2018; Wu et al., 2018). Sterilization without medical necessity is more common among women with IDD than among women without IDD (Li et al., 2018), and they face barriers to perinatal care, leading to pregnancy complications and adverse outcomes (Brown et al., 2017a, 2017b; Höglund et al., 2012a, 2012b; Mitra et al., 2015, 2018; Parish et al., 2015). Additionally, they are less likely to receive preventive treatments like Pap tests and reproductive cancer screenings

(Parish & Saville, 2006; Parish et al., 2012, 2013, 2020; Sullivan et al., 2003; Swaine et al., 2013; Xu et al., 2017).

Despite a burgeoning body of research about sexual and reproductive health services and information for women with IDD, areas requiring further inquiry remain. First, existing studies tend to have a narrow focus, such as pregnancy-related topics. Therefore, there is a need for broader studies that encompass various aspects of sexual and reproductive health (Ransohoff et al., 2022). Second, although there is increasing attention to the sexual and reproductive health needs of women with IDD, limited information exists on how this attention has influenced the attitudes and perspectives of family caregivers, who have traditionally held paternalistic views on these matters (Carter et al., 2021). Indeed, a recent scoping review highlights the necessity for research on the role of family caregivers in facilitating access to sexual and reproductive health services and information for women and girls with IDD (Powell et al., 2020). Specifically, further investigation is needed on how family caregivers support women with IDD in accessing perinatal and preventive sexual and reproductive health services, as well as sexual abuse prevention and education (Powell et al., 2020). Additionally, exploring family caregivers' perspectives on pregnancy among women with IDD is crucial. The lack of current knowledge on how family caregivers assist women with IDD in accessing sexual and reproductive health services and information is significant, given that many adults with IDD rely on family caregivers, who often act as the primary decision-makers for health matters (Braddock et al., 2013; Braddock et al., 2011).

Theoretical framework and research questions

This study is informed by the socio-ecological model (SEM), a comprehensive framework that elucidates the complex interplay of factors contributing to health inequities (McLeroy et al., 1988). The SEM encompasses five levels: intrapersonal factors (e.g., knowledge, attitudes, beliefs, and behaviors), interpersonal factors (e.g., family, friends, peers, and social networks), institutional factors (e.g., healthcare systems and community organizations), community factors (e.g., community

resources), and policy factors (laws and policies). More recent iterations of the SEM also incorporate societal factors (e.g., social and cultural norms and historical context) (World Health Organization, 2019). Previous studies have employed the SEM to investigate the accessibility of sexual and reproductive healthcare services for females diagnosed with cerebral palsy (Shah et al., 2022). Similarly, another study focused on perinatal care for people with IDD using the SEM (Khan et al., 2021).

Improving access to sexual and reproductive health services and information for women with IDD necessitates understanding family caregivers' attitudes and perspectives. Accordingly, guided by the SEM, this study investigated the diverse influences on how family caregivers support women with IDD in accessing sexual and reproductive health services and information. The study had two primary research questions: (1) What are family caregivers' perceptions of their roles in facilitating women with IDD's access to sexual and reproductive health services and information? and (2) What are family caregivers' attitudes toward sexual and reproductive health services and information for women with IDD?

Methods

Study setting and population

The data for this study was obtained through an online cross-sectional survey targeting family caregivers of women with IDD in the United States. The survey is part of a broader research project investigating reproductive healthcare for women with IDD. Data were collected between June and October 2018 using the Qualtrics survey platform. Anonymity was ensured to encourage participants to provide honest and open responses. The study protocol received approval from the Institutional Review Board at Brandeis University, with consent implied through the completion of the survey.

Convenience and snowball sampling was used to recruit participants (Creswell, 2013). Following established online research protocols (Dillman et al., 2009; Gosling & Mason, 2015),

recruitment emails were distributed to around 400 national, state, and local organizations dedicated to supporting people with IDD and their families. These organizations included chapters of The Arc, United Cerebral Palsy, National Down Syndrome Society, and Developmental Disabilities Councils. The emails contained comprehensive details about the study, including information on the funding source, names of the investigators, and a survey link. Organizations were requested to disseminate the study information to their members via listservs and social media platforms. Two subsequent email reminders were sent to encourage participation before the survey closed. Additionally, the researchers shared the survey link through their institutions' social media channels.

To participate in the survey, individuals had to be at least 18 years old and family caregivers of reproductive-aged women with IDD (i.e., between the ages of 18 and 45). For this study, family caregivers were defined as "people who provide care for or help in some way a family member with an intellectual or developmental disability." IDD was based on self-identification by family caregivers. Two hundred and thirty individuals initiated the survey. Ninety-eight individuals were deemed ineligible because they did not satisfy the study's inclusion criteria or did not answer all of the survey's screening questions. The final analytic sample included 132 participants.

Participant and family member characteristics

Table 1 presents the participants' characteristics. Most participants were parents (89%), White (85%), and female (89%), and most were married (64%). Nearly all participants had some college education or beyond (82%), and a majority were employed full- or part-time (59%). Participants reported a range of household incomes.

<<Insert Table 1 about here>>

Table 2 shows the characteristics of participants' family members with IDD, as reported by participants. On average, participants' family members were 27 years old, and most resided with their families (73%). Most participants' family members had completed high school or earned a GED (61%). Participants' family members had a range of intellectual or developmental disabilities,

including intellectual disabilities, Down syndrome, autism, cerebral palsy, fetal alcohol disorder, and microcephaly. Many had multiple co-existing intellectual or developmental disabilities. Nearly all of the participants' family members were covered by at least one health insurer: Medicaid (79%), Medicare (34%), and private health insurance (51%).

<<Insert Table 2 about here>>

Survey instrument and measures

The survey was based on the SEM, a comprehensive literature review of relevant studies, and the authors' previous research on sexual and reproductive health for women with IDD. The survey included 48 questions, consisting of 41 closed-ended (i.e., dichotomous and multiple-choice) and seven open-ended questions. Participants were asked about their family member who is a woman with an IDD and background information about their caregiving role. Participants were then queried on their role in assisting their family member access sexual and reproductive health services and information, the types of assistance they have provided related to helping their family member access sexual and reproductive health services and information, the barriers and facilitators they encountered when assisting their family member access sexual and reproductive health services and information, and information on any unmet needs they or their family member have related to accessing sexual and reproductive health services and information. Thereafter, participants were asked about their attitudes and perspectives about sexual and reproductive health services and information for women with IDD: the importance of sexual and reproductive health services and information for women with IDD, the necessity of sexual education for women with IDD, and pregnancy among women with IDD. The survey ended with questions gathering demographic information about participants.

Data analysis

Closed-ended responses were analyzed using descriptive statistics in Stata Version 16. For the analysis of open-ended responses, qualitative thematic analysis was conducted using Dedoose

Version 8.0.35 analytic software. The thematic analysis followed an iterative and inductive approach (Braun & Clarke, 2006; Castleberry & Nolen, 2018). Thematic analysis is a valuable method for qualitative researchers to explore and comprehend the intricacies of qualitative data. It provides a structured and rigorous process to identify patterns, meanings, and relationships, resulting in a deeper understanding of the research topic and generating new insights (Braun & Clarke, 2006). Thematic analysis is particularly suitable for analyzing survey data (Castleberry & Nolen, 2018).

Two authors initially reviewed the open-ended responses, identified preliminary codes, and met to resolve any discrepancies and develop an initial codebook. The first author then conducted a comprehensive line-by-line analysis of the data. The open-ended responses were repeatedly reviewed, and the coding scheme was updated as new themes and categories emerged (Charmaz, 2003). Regular research team meetings were held throughout the process to discuss and refine the codes, and disagreements were resolved through consensus (Harry et al., 2005; Saldaña, 2011). The research team approved the final codebook.

Results

Family caregiver roles

Most participants reported being closely involved with their family members' access to sexual and reproductive health services and information (**Table 3**). Seventy-five percent of participants reported ever helping their family members access sexual and reproductive health services and information, and 64% are currently doing so. Many participants reported assisting their family members with finding sexual and reproductive health healthcare providers (58%), scheduling appointments (61%), attending appointments (64%), and communicating with providers (61%). Forty-one percent of participants reported making sexual and reproductive health decisions on their family member's behalf. Contraception is the most common sexual and reproductive health service with which participants helped their family members (43%). Nearly half (45%) of participants reported that their family members currently or previously used contraception, and family caregivers

are the most common requesters of contraception. One-third (33%) of participants reported that their family member's contraceptive use is for menstruation management (33%). Finally, most participants (58%) are their family members' guardians.

<<Insert Table 3 about here>>

Attitudes and perspectives towards sexual and reproductive health for women with IDD

Analysis of closed-ended questions found that most (86%) participants expressed that sexual and reproductive health services and information are important for women with IDD and that women with IDD should receive sexual education (**Table 4**). Nevertheless, qualitative analysis of participants' open-ended responses suggested both supportive and restrictive attitudes and perspectives on sexual and reproductive health services and information for women with IDD (**Table 5**). Supportive attitudes and perspectives included (1) "knowledge is power;" (2) supported decision-making; and (3) protection against sexual abuse. Restrictive attitudes and perspectives included (1) dependent on the individual; (2) lack of autonomy; and (3) placing responsibility on disability. These findings are described below using case examples and participant quotes.

<<Insert Table 4 about here>>

<<Insert Table 5 about here>>

Supportive attitudes and perspectives

"Knowledge is power"

Some participants expressed support for women with IDD accessing sexual and reproductive health services and information because "knowledge is power." These participants supported universally available and accessible sexual and reproductive health services and information for women with IDD—especially sexual education—because it could empower them to understand their bodies and sexual needs. Several participants believed accessible sexual education for women with IDD could be empowering because "knowledge is power." For example, the parent of a 24-year-old woman with Down syndrome stated, "Knowledge is power. They will know how their body works,

how the opposite sex's body works." Likewise, a parent of a 24-year-old woman with autism and other IDD said, "Knowledge is power. The more women know about their bodies and how they work, the better they are positioned to protect themselves from harm and to make the most of the opportunities they are offered, whatever those may be."

Some participants stated that women with IDD have the right to understand their bodies and sexual needs and should have access to accessible sexual education. For example, one parent of a 25-year-old woman with Down syndrome, autism, and other IDD said, "It is her right to know everything she can about her body and to have it presented to her in a way she can understand." In addition, some participants offered suggestions for accessible materials to help prepare their family members for visits with sexual and reproductive healthcare providers. For example, the parent of a 24-year-old woman with Down syndrome suggested multimedia resources: "A video of what's going to happen, a book with pictures." Participants also reported a need for additional information on how to best support their family member's access to sexual and reproductive health services and information. For example, the parent of a 31-year-old woman with Down syndrome noted she would benefit from "Classes to know how to educate/advise [my] loved one with sexual and reproductive health care."

The participants indicated that sexual and reproductive health information is necessary for helping women with IDD understand their bodies and prepare to be sexually active if they so choose. For example, the parent of a 24-year-old woman with autism and other IDD stated, "some women with IDD marry and/or become voluntarily sexually active; sexual and reproductive health care is a must, in those cases." Similarly, the parent of a 26-year-old woman with ID and microcephaly responded that accessible sexual education is essential for women with IDD "because some of the normal urges they experience can be frightening and may not be obvious unless they are explained."

Supported decision-making

Several participants described the importance of supporting their family members with IDD in making decisions about their sexual and reproductive health. Often, participants reported working with their family members to support them in making choices. For example, the parent of a 38-year-old woman with ID, autism, and other IDD stated she has assisted her family member with accessing sexual and reproductive health services and information by “discuss[ing] options so she could make an informed decision.” Likewise, some participants noted that they decided with their family members to use contraception because of irregular menstrual cycles.

Some participants explained that they supported their family members’ access to sexual and reproductive health services and information because they felt it would help their family members make decisions autonomously. For instance, the parent of an 18-year-old woman with ID, autism, and Down syndrome said women with IDD need sexual and reproductive health services and information because “they should be able to make as many informed decisions and choices that [are] appropriate for each person and need to have access to the information to support that decision-making.” Similarly, the parent of a 28-year-old woman with Down syndrome felt women with IDD should receive sexual education “so [they] can make informed decisions.”

Additionally, participants reported supporting their family members in understanding the responsibilities associated with pregnancy and parenthood so they could make informed choices about engaging in sexual activity, including whether they wanted to become parents. For example, the parent of a 26-year-old woman with autism stated that access to sexual education would help her family member make informed decisions about sexual activity: “If they choose to be sexually active, [they] should have all information to make informed choices.” A parent of a 38-year-old woman with ID, autism, and other IDD explained that women with IDD need access to sexual and reproductive health services and information to help them decide whether they want to have children. According to this participant, sexual and reproductive health services and information provided “opportunities

for the person to make informed decisions. For example, whether or not to get pregnant and responsibilities and skills involved in carrying a baby, delivering and raising a child.”

Protection against sexual abuse

Many participants expressed the need for women with IDD to access sexual and reproductive health services and information to be able to protect themselves against sexual abuse. Indeed, many participants described how women with IDD are vulnerable to sexual abuse, which caused them significant concern. As a result, some participants believed women with IDD should have access to sexual education because it could help safeguard them from abusive situations. For example, the parent of a 41-year-old woman with Down syndrome and autism stated that although a woman’s need for sexual education “depends on how sexually active they will become,” women with IDD should receive sexual education to help “protect them from assault.” Likewise, the parent of a 19-year-old woman with Down syndrome said women with IDD need sexual education for “safety” because “girls with Down syndrome are more likely to be sexually abused.” Consequently, for some participants, securing access to reproductive health services and information empowered women with IDD to safeguard themselves against sexual abuse.

Restrictive attitudes and perspectives

Dependent on the individual

Some participants believed that access to sexual and reproductive health services and information for women with IDD should depend on individual women’s specific circumstances rather than be widely available for all. For example, some participants assumed that women with IDD would not understand sexual education and, therefore, should not receive it. The parent of a 27-year-old woman with ID and autism believed women with IDD should receive sexual education “if able to understand it – if [they] cannot, then they don’t need it.” A parent of a 28-year-old woman with ID said that while some women with IDD should receive sexual education, “persons with significant cognitive issues” may not need it. Likewise, the parent of a 29-year-old woman with ID

and cerebral palsy felt women with IDD should receive sexual education only “if the individual is able to comprehend.” A parent of a 28-year-old woman with ID felt sexual and reproductive health should not be universally available to women with IDD: “Each person is different/unique and should be addressed accordingly. Not as a generality across the board.”

Some participants said sexual and reproductive health services and information are unnecessary for their family members because they believed their family members would never have sexual relationships. For example, a parent of a 35-year-old woman with ID and autism reported that sexual and reproductive health services are unnecessary for some women with IDD, including women who would not become sexually active: “It depends on the individual, type of disability and extent, etc. Can they or will they ever be sexually active?” Likewise, a parent of a 34-year-old woman with Down syndrome said that her daughter did not need sexual and reproductive health services and information because “she will never be sexually active” and reported that her family member should not receive sex education because “she would not understand.”

Lack of autonomy

Some participants’ responses suggested the need to limit the autonomy of some women with IDD with respect to decision-making concerning sexual and reproductive health. These participants explained instances in which they restricted their family members’ sexual and reproductive autonomy by making sexual and reproductive health decisions on their behalf, without their family member’s involvement, and sometimes appearing to frame those decisions in terms of their own needs or desires. For example, the parent of a 22-year-old woman with ID explained that her daughter used contraception to facilitate caregiving her: “The birth control was really sought in an effort to manage her periods.” Thus, contraception was used to manage the parent’s caregiving responsibilities and not necessarily the woman’s preferences.

Lack of autonomy for women with IDD came up most frequently in the context of participants ensuring their family members would not become pregnant. For example, the parent of a

34-year-old woman with ID and cerebral palsy explained that women with IDD need sexual and reproductive health services and information specifically so they do not become pregnant: “Some women have the cognitive ability to have a romantic relationship and need birth control.” Likewise, a parent of a 19-year-old woman with ID and Down syndrome described deciding her daughter would not get pregnant, saying, “Because we want to make sure that their health and mental state is not compromised by having a baby they are not able to take care of.”

Relatedly, some participants discussed sterilization. For example, the parent of a 25-year-old woman with Down syndrome responded that a challenge in assisting her daughter access sexual and reproductive health services and information is her family member’s physician’s unwillingness to perform sterilization on her family member when the participant wanted: “Doctor would not sterilize upon request because they said in 10 years she may want a baby. We were upset because it’s been over 10 years, and we do not want her to ever get pregnant.” Likewise, in response to a question about supports that would allow participants to better assist their family members with accessing sexual and reproductive health services and information, a parent of a 24-year-old woman with ID and Down syndrome stated, “Sterilization needs to be presented as an option. It’s hush-hushed, and parents are aware... I thought about it nearly 10 years before we did it.” This participant expressed the decision to have her family member sterilized as a matter of her autonomy rather than her family member’s, stating, “Respect my choice.” Another parent of a 24-year-old woman with ID and Down syndrome expressed concerns about “Arrogant physicians who are still trapped in eugenics backlash and cop judgmental attitudes about conservator choices of sterilization.”

Placing responsibility on disability

Some participants pointed to challenges associated with disability instead of systemic barriers within the healthcare system. These participants said their family members are too afraid to receive sexual and reproductive health care, placing responsibility on their family members instead of inexperienced clinicians or inaccessible healthcare systems. For example, the parent of a 27-year-old

woman with ID and autism said of her daughter, “She is frightened about all these sexual concerns. Having a Pap test, going for a mammogram, etc.” Similarly, the parent of a 43-year-old woman with ID and cerebral palsy reported that her daughter has “Difficulty during gynecology exam [because] she [feels] very scare[d],” and that it is challenging to secure sexual and reproductive health services for her. Other participants stated their family members could not receive Pap tests due to sensory or other issues, such as the parent of a 28-year-old woman with Down syndrome who said, “We have tried a couple of times to get a pap smear. She has not been able to sit still for this.” Other participants noted their family members are sedated or placed under anesthesia to receive Pap tests, such as the parent of a 38-year-old woman with ID, autism, and other IDD: “When she has dental work done, while under anesthesia, that’s when she also had a pap smear.” Thus, some participants blamed women’s disabilities for healthcare access challenges instead of systemic barriers.

Discussion

The findings of this study contribute new insights into the attitudes and perspectives of family caregivers regarding sexual and reproductive health services and information for women with IDD. These findings align with previous research (Azzopardi- Lane, 2022; Powell et al., 2020) and reveal a range of attitudes and perspectives among participants. Some participants expressed support for the importance of accessible sexual and reproductive health services and information for women with IDD, emphasizing empowerment, autonomy, and protection. Conversely, some participants held more restrictive views, suggesting limitations on access based on individual factors, the decision-making role of family caregivers, and inherent limitations associated with IDD. These responses shed light on family caregivers’ significant influence in facilitating or impeding access to sexual and reproductive health services and information for women with IDD. Consequently, these findings have implications for policy development and the implementation of practices that promote equitable and comprehensive reproductive health services and information for this population.

The findings of this study elucidate the interplay of factors within the SEM that either promote or hinder access to sexual and reproductive health services and information for women with IDD. These factors are intricately connected to the role of family caregivers in facilitating the access of women with IDD to such services and information. First, family caregivers play a crucial role in facilitating access to sexual and reproductive health services and information for women with IDD, and their attitudes and perspectives can significantly impact the level of access available to these women (Carter et al., 2022; Powell et al., 2020). The study's findings reveal that some participants held restrictive attitudes and perspectives, suggesting a need for increased access to information and resources for family caregivers regarding the importance of sexual and reproductive health services and information for women with IDD. It is essential to provide guidance that addresses potential negative attitudes and perspectives, equipping family caregivers with the necessary tools to support women with IDD effectively (Carter et al., 2022). Furthermore, family caregivers require information about accessible sexual education, as some participants doubted the comprehension of women with IDD on these topics. Additionally, disability service providers should prioritize educating family caregivers about sexual and reproductive health to ensure comprehensive support for women with IDD. By imparting such knowledge and guidance, caregivers can better advocate for and assist women with IDD in accessing appropriate sexual and reproductive health services and information.

Moreover, it is crucial to address the influence of family caregivers' attitudes and perspectives on sexual and reproductive health services and information for women with IDD within broader systems. For example, despite the recommendation for sexual education for people with IDD, family caregivers' attitudes may hinder access to such education (Carter et al., 2022; Ginn, 2021). This study revealed divergent viewpoints among participants, with some emphasizing the importance of accessible sexual education for all women with IDD, while others deemed it unnecessary. Restrictive attitudes sometimes stem from outdated beliefs that people with IDD are unwilling or unable to engage in sexual relationships (Azzopardi-Lane, 2021; Azzopardi-Lane &

Callus, 2015). These findings align with existing research, highlighting the conservative attitudes of family caregivers toward people with IDD forming sexual relationships (Carter et al., 2022; Cuskelly & Bryde, 2004; Evans et al., 2009). Previous studies also suggest that some people with IDD avoid sexual relationships due to discouragement from family caregivers who consider it risky or emphasize abstinence to prevent parenthood (Nayak, 2016). Additionally, inadequate provision of sexual and reproductive health information for people with IDD by schools and service providers has been documented (Barnard-Brak et al., 2014; Borawska-Charko et al., 2017). Hence, the study findings and prior research suggest that some women with IDD lack adequate sexual and reproductive health information. Consequently, policymakers should prioritize expanding comprehensive and accessible sexual education for individuals with IDD, covering essential topics such as anatomy, consent, healthy relationships, puberty and development, sexually transmitted infections (STIs), pregnancy and reproduction, and safety (Rushbrooke et al., 2014; Turner & Crane, 2016).

The study's findings underscore the importance of alternatives to guardianship, such as supported decision-making (Davidson et al., 2015). Supported decision-making occurs when one person receives support from others to make a decision and communicate to others: "This could be through helping them to obtain and understand information relevant to the decision, talking through the pros and cons of different available options, or helping a person to communicate with others" (Series, 2015, p.85). While some participants in the study reported enabling their family members to make their own sexual and reproductive health decisions, others restricted access to such services and information, including making decisions about contraception without involving their family members. Given that most participants in this study were guardians and previous research indicates that guardianship laws can limit sexual decision-making among individuals with IDD (Friedman et al., 2014), policymakers should adopt laws that allow for alternatives to guardianship, such as

supported decision-making. Further, additional research is needed to understand the interplay between sexual decision-making and guardianship.

Finally, sexual abuse against women with IDD remains a significant issue warranting greater consideration by policymakers and practitioners (Carter et al., 2022; Hughes et al., 2012; Byrne, 2018). A recent investigation by National Public Radio revealed that people with IDD are victims of sexual abuse at a rate almost seven times higher than nondisabled people, with family and paid caregivers being among the perpetrators (Shapiro, 2015). Many participants in this study expressed deep concerns about the possibility of their family members experiencing sexual assault, which aligns with previous research (Carter et al., 2022). These concerns often led participants to support access to sexual and reproductive health services and information as a means of protection. It is essential for women with IDD to have access to comprehensive and easily understandable sexual and reproductive health services and information to empower them in recognizing and identifying sexual abuse. Thus, policymakers must establish and enforce measures that safeguard women with IDD from sexual abuse, such as enhanced oversight and accountability. Additionally, healthcare providers should make efforts to directly communicate with women with IDD regarding their sexual and reproductive health and inquire about potential sexual abuse, particularly considering the significant number of perpetrators who are family or paid caregivers (Shapiro, 2015).

This study has several limitations to consider. First, the sample may not represent the attitudes and perspectives of all family caregivers of women with IDD, as it relied on voluntary participation, potentially leading to a bias towards strong positive or negative attitudes. Second, recruitment through social media and disability-related organizations may have resulted in a sample of caregivers well-connected to disability supports and services. Third, the overrepresentation of non-Hispanic White participants who spoke English limits the generalizability of the findings to diverse racial or ethnic backgrounds. Fourth, the study relied on family caregivers' assertions without validation from their family members with IDD. However, this study is part of a larger project that

includes interviews with women with IDD. Fifth, social desirability bias may be present, despite the anonymous survey. Sixth, using measures without established validity requires caution in interpreting the findings. Seventh, caution should also be exercised in interpreting the results due to missing data, despite the majority of participants answering most survey questions. Eighth, due to the nature of the online survey used in this study, there were limitations in terms of the ability to engage participants for further information or clarification. Therefore, it is essential to conduct additional qualitative research to obtain more in-depth insights on the topic. Last, the study focused exclusively on women with IDD, emphasizing the need for future research to include the experiences of all people with IDD who need sexual and reproductive health services. Nevertheless, despite these limitations, this study holds important implications for policy, practice, and research.

Conclusions

The participants in this study reported a range of attitudes and perspectives about sexual and reproductive health services and information for women with IDD. These findings add depth to a growing body of research on the sexual and reproductive health of women with IDD and suggest that some women with IDD continue to be constrained in accessing sexual and reproductive health services and information because of their family caregivers. Thus, greater attention to systems-level changes, including universal and accessible sexual education for women with IDD, supported decision-making, and sexual abuse prevention measures, are urgently needed.

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Table 1. Participant characteristics

Characteristic	<i>N</i>	%
Relationship with family member		
Parent	118	89
Sibling	9	7
Grandparent	1	1
Other ^a	4	3
Gender ^b		
Female	118	89
Male	1	1
Race and ethnicity ^b		
Latinx	6	5
American Indian or Alaska Native	1	1
Asian	1	1
Black	2	2
White	112	85
Other ^c	3	2
Relationship status ^b		
Married	85	64
Living with partner, not married	3	2
Partnered, not living together	2	2
Single	13	10
Divorced	14	11
Widowed	3	2
Educational attainment ^b		
Less than high school	1	1
High school or GED	8	6
Some college	38	29
Bachelor's degree	42	32
Master's degree or beyond	28	21
Employment status ^b		
Full-time	55	42
Part-time	23	17
Student	2	2
Unemployed, looking for work	4	3
Unemployed, not looking for work	11	8
Retired	24	18
Household income ^b		
Less than \$25,000	4	3
\$25,000-\$34,999	8	6
\$35,000-\$49,999	11	8
\$50,000-\$74,999	22	17
\$75,000-\$99,999	18	14
\$100,000-\$149,999	26	20
\$150,000-\$199,999	8	6
\$200,000 or more	11	8

^a Includes cousin and guardian.^b Missing data due to non-response.

^c Includes multiracial and one response of “human.”

Table 2. Family member characteristics

Characteristic	<i>Mean</i>	<i>SD</i>
Age	27.3	6.6
	<i>N</i>	<i>%</i>
Residence		
With family	96	73
Independently	12	9
Group home	8	6
Supervised apartment	9	7
State-supported foster care	1	1
Other ^a	6	5
Disability type ^b		
Intellectual disability	76	58
Down syndrome	42	32
Autism	44	33
Cerebral palsy	19	14
Other disability ^c	19	14
Educational attainment ^d		
Less than high school	26	20
High school or GED	81	61
Some college	10	8
Bachelor’s degree	6	5
Master’s degree or beyond	6	5
Health insurance ^b		
Medicaid	104	79
Medicare	45	34
Private	67	51
Uninsured	2	2

^a Includes family member living independently part-time and with parents part-time, and family member owning her home.

^b Categories not mutually exclusive.

^c Includes visual impairment, hearing impairment, seizure disorder, fetal alcohol disorder, microcephaly, heart defect, and genetic syndromes.

^d Missing data due to non-response.

Table 3. Family caregiver roles

Characteristic	N	%
Ever helped family member access SRH ^a		
Yes	99	75
No	28	21
Currently help family member access SRH ^a		
Yes	84	64
No	9	7
Types of SRH assisted with ^{a, b}		
Pap test	39	30
Sexually transmitted infection screening	7	5
Birth control or contraception	57	43
Sterilization	8	6
Pregnancy health care	3	2
Sexual education	34	26
Mammogram	10	8
Other ^c	19	14
Number of SRH types assisted with ^a		
0	39	30
1	45	34
2	27	20
3 or more	21	16
Tasks assist with ^{a, b}		
Find provider	77	58
Schedule appointments	81	61
Attend appointments	85	64
Communicate with provider	80	61
Make decisions for family member	54	41
Other ^d	5	4
Others also assist family member access SRH ^a		
Yes	35	27
No	86	65
Encountered problems helping family member access SRH ^a		
Yes	33	25
No	60	45
Family member uses or has used contraception ^a		
Yes	59	45
No	61	46
Requester of contraception		
Participant	32	24
Family member with IDD	5	4
Support staff	1	1
Physician	17	13
Other ^e	4	3
Reason for contraception ^b		
Expectation family member would be sexually active	15	11
Family member was sexually active	4	3
Fear of pregnancy	14	11

Management of menstruation	43	33
Fear of sexual abuse	13	10
Other ^f	11	8
Guardian or conservator ^a	77	58

Notes: SRH = sexual and reproductive health.
^a Missing data due to non-response.
^b Categories not mutually exclusive.
^c Includes gynecological exam or evaluation, yeast infection treatment, and discussion of upcoming medical procedures.
^d Includes discussing medical procedures and options with family member and assisting family member in making informed decisions.
^e Includes participant and family member's physician requesting together, participant and family member requesting together, and participant using to manage family member's menstruation.
^f Includes acne, family member behavior or mood regulation, endometriosis, and migraines.

Table 4. Participant attitudes and perspectives

Characteristic	<i>N</i>	%
SRH is important for women with IDD ^a		
Yes	114	86
No	3	2
Women with IDD should receive sexual education ^a		
Yes	114	86
No	3	2

^a Missing data due to non-response.

Table 5. Themes, codes, and definitions

Theme	Definition	Code	Definition
Supportive attitudes and perspectives	Family caregivers' attitudes and perspectives that indicate support for women with IDD accessing SRH services and information	"Knowledge is power"	Participants support universally available and accessible SRH services and information for women with IDD because it will empower them to understand their bodies and sexual needs
		Supported decision-making	Participants support their family members' autonomy in making informed decisions about their SRH

		Protection against sexual abuse	Participants believe SRH services will help to protect their women with IDD from being assaulted by others
Restrictive attitudes and perspectives	Family caregivers' attitudes and perspectives that indicate restricting women with IDD from accessing SRH services and information	Dependent on the individual	Participants believe that women with IDD do not universally need SRH services and information
		Lack of autonomy	Participants restrict their family members' sexual and reproductive autonomy by making decisions on their family members' behalf
		Placing responsibility on disability	Participants believe their family members cannot receive SRH services and information due to their disabilities
