**Sharing Intimate Stories: How Young Adults with Intellectual Disabilities Navigate Sexual Communication Opportunities and Challenges in Sweden**

**Hart, A., Carlström, C., Löfgren, C. & Elmerstig, E. (Year)**

# **Abstract**

Everyone, including young adults with intellectual disabilities, should have the opportunity to express their sexuality. It is an essential aspect of their overall well-being. However, they may face challenges in comprehending the intricate social norms associated with sexual contexts. In such situations, caregivers and peers can offer support and guidance to help them decipher these norms. Previous research has primarily concentrated on the viewpoints of family members or care providers when addressing sex and relationships with individuals who have intellectual disabilities. This study aims to gain an in-depth understanding of the perceptions of young adults with intellectual disabilities concerning conversations about sexuality and intimacy. The sample comprises 22 young adults aged 18-35 with intellectual disabilities who participated in qualitative interviews conducted in a semi-structured format. A thematic analysis of the interviews was conducted. The results are discussed using Ken Plummer's theoretical framework on sexual narratives and power dynamics. The results suggest that trust is crucial for participants when discussing sexual situations, and that transparent and honest communication is necessary. Additionally, the study highlights the challenges that young adults with intellectual disabilities may encounter when seeking such support, as they must balance autonomy and safety concerns. Formal support, such as sex education and counseling services, can provide individuals with intellectual disabilities the necessary tools to navigate sexual situations. However, informal support networks, such as friends and family, are also crucial for emotional support and guidance.

**Keywords** Intellectual disabilities, Sexuality and intimate relationships, Sexual Storytelling,

Sexual communication

# **Introduction**

Expressing one's sexuality is an important aspect of overall well-being, and this principle applies to young adults with intellectual disabilities as well (WHO, 2022:2015). Although many young adults with intellectual disabilities desire sexual relationships, they often lack access to accurate information and resources regarding sexuality (Löfgren-Mårtenson, 2020; Dinwoodie et al., 2020; Schaafsma et al., 2017).

Recent findings from a study by Kammes et al. (2020) provide valuable insights into the experiences of parents in providing socio-sexual education to individuals with intellectual disabilities. The research indicates a growing involvement of parents in supporting adults with intellectual disabilities in sexual education. Similarly, international studies, such as the work by Shtarkshall et al. (2007), have highlighted the struggles parents face in determining the appropriate level of sex education to offer. These findings emphasize the central role of society, where care providers play a central role in providing social skills and support for young adults with intellectual disability in navigating these experiences, and highlight the need for training programs to assist parents in effectively addressing the sexual education needs of individuals with intellectual disabilities (Bane et al., 2012; Retznik et al. 2022).

Both international and national research findings consistently demonstrate that young adults with intellectual disabilities share similar desires for relationships and socio-sexual knowledge as their peers (Frawley et al., 2016; Löfgren-Mårtenson, 2012). In the broader societal context, specific attitudes and norms regarding sexuality and intimate relationships hold particular relevance for young adults with intellectual disabilities, who often rely on daily support and guidance in matters of sexuality and intimacy (Frawley and Wilson, 2016; Gomez, 2012). Studies focusing on the sexual relationships and intimacy of young adults with intellectual disabilities frequently overlook the perspectives of the individuals themselves, relying instead on insights from family members and staff. This approach can lead to biased depictions of sexual activity as risky rather than pleasurable, and an exaggerated emphasis on the vulnerability of this group (Hollomotz, 2011; 2018). In addition, stakeholders argue that sexual education is necessary for individuals with intellectual disabilities throughout their lives, from early childhood to adulthood, to have safe and non-abusive sexual experiences (McGilloway et al., 2018).

A meta-synthesis of qualitative studies by Black and Kammes (2019), found that individuals with intellectual disabilities expressed a desire for friends and peers with whom they could openly discuss sexuality and intimate relationships. These conversations are central to promoting empowerment, informed decision-making, and protection from exploitation among young adults with intellectual disabilities, ultimately contributing to their sexual health and overall well-being. Providing opportunities and information to improve problem-solving skills and navigate challenges in developing safe sexual relationships is also essential (Ferrante & Oak, 2020).

Research by Frawley and Wilson (2016) revealed the significant obstacles young adults with intellectual disabilities face when seeking comprehensive information about sexuality and relationships. Despite barriers that may indirectly or explicitly restrict their access to such information, these individuals exhibit a strong desire and need to engage in discussions about romantic relationships and sexual experiences (Retznik et al, 2022; Löfgren-Mårtenson, 2020). While it is well-established that young adults with intellectual disabilities tend to participate in conversations about sexuality and relationships, there remains a gap in scholarly research regarding their ability to express concerns about sexual consent directly within these discussions (Azzopardi-Lane & Callus, 2015).

# **Objective and research question**

This study seeks to gain an in-depth understanding of the experiences and perceptions of young adults with intellectual disabilities regarding conversations about sexuality and intimate relationships. The research questions are:

*With whom do young adults with intellectual disabilities engage in conversations about sexual experiences and intimate relationships?*

*What enables or hinders young adults with intellectual disabilities to engage in conversations about sexuality and intimacy?*

# **Sexual stories**

According to sociologist Ken Plummer (1995), sexual stories are based on the idea that individuals construct and share their narratives on sexuality. Sexual storytelling emphasizes the richness and diversity of human sexual experiences. It moves beyond traditional academic or clinical approaches that may oversimplify or stigmatize certain aspects of sexuality. Sexual storytelling pertains to the narrative of intimate life, with an emphasis on the erotic, gendered, and relational aspects (Plummer, 1995:6). This approach involves acknowledging people's stories about their sexual lives, fostering empathy, and recognizing the complexity and diversity of human sexual experiences. It promotes a more inclusive and compassionate approach to studying and discussing sexuality. Plummer (1995) aimed to create a space where people's unique experiences, desires, and challenges related to sexuality can be acknowledged and understood through storytelling. This approach recognizes that sexuality is a complex and multifaceted aspect of human life, influenced by various cultural, social, and personal factors. Plummer (1995) emphasized the importance of comprehending diverse and frequently marginalized voices in the realm of sexuality.

Although sexuality is significant in the lives of young adults with intellectual disabilities, it has often been overlooked or stigmatized (Kullick and Rydström, 2015; McCarthy, 2014). The narratives of the right to sexuality have historically been linked to societal views based on a strong population, dating back to Plato's time, with restrictions on who could marry. "There should be a law that no child with disabilities is raised." cripple child shall be reared' (The Politics 439-44 in Stainton, 2017). The sexual experiences of this population have been neglected and require attention and understanding (Kullick and Rydström, 2015; Löfgren-Mårtenson, 2012). The connection between the tale and its time and the ability to tell, feel, and legitimize the 'sexual history of an intellectual disability' (Plummer, 1995:26) is closely tied to power.

Power is a process that weaves its way through embodied, passionate social life and everything in its wake. Sexual stories live in this flow of power. The power to tell a story, or indeed not to tell a story, under the condition of one’s own choosing is part of the political process*.* (Plummer, 1995:26)

Sexual storytelling is often associated with narrative analysis. Although this study does not use the narrative method, it incorporates some of Plummer's ideas regarding how power can impact one's sexual narrative. The use of sexual narratives as a theoretical framework in the discussion can provide a deeper understanding of the needs and desires experienced by individuals with intellectual disabilities in this context.

# **Methods**

This study utilized a qualitative research approach, conducting 22 semi-structured individual interviews (five males and 17 females), to gain in-depth knowledge on the sensitive research topic of sexuality among individuals with intellectual disabilities. It is important to consider the challenges that come with interviewing this population (Hollomotz, 2018). The study's first author, who conducted all interviews, had experience working with the targeted population on sensitive topics such as sexuality. To maintain ethical standards, individuals with whom the first author had contact in a clinical setting were excluded due to their state of dependency (Godwill, 2015). Additionally, those with severe intellectual disabilities were excluded as their participation would have presented a significant hindrance to the interviews (Semple and Smyth, 2019).

## ***Recruitment***

This study included participants aged 18-35 years with intellectual disabilities who could express themselves verbally in Swedish or English and had experience talking about sexual experiences with someone else. Traditionally, the term young adults applies to the period between the late teens and 30s, but it is difficult to specify definitive age thresholds (Hudson, 2006). As the development of individuals with intellectual disabilities can vary individually, the decision was made to include participants up to the age of 35 years. Ethical approval (Dnr 2021-04974) was granted by the Swedish Ethical Review Authority and recruitment was conducted nationwide in 2022. Given the participants’ cognitive impairments and the sensitive nature of the topic, an explicit explanation of the interview process was crucial during the recruitment and interviews. The first author initiated contact with organizations that facilitated discussions about sexuality and intimate relationships among people with intellectual disabilities. The aim was to provide information in advance so that potential participants could meet the researcher separately. However, this was performed as a secondary outcome during the scheduled interviews. Other participants were informed by the gatekeepers and given additional details during the interview, which resulted in a snowball effect in the recruitment process. All the participants who agreed to participate completed the interviews. This suggests a general interest among the participants in sharing their experiences.

## ***Interview Procedure***

Interviewing individuals with intellectual disabilities can pose several challenges for the interviewer. For instance, participants may provide brief responses or exhibit loyalty toward their supporters (Hollomotz, 2018). Previous research suggests that researchers should ensure participants with intellectual disabilities fully understand the implications of participating in a research project. Information should be adapted to the individual's needs (Caldwell, 2014; Hollomotz, 2018). Before being interviewed, participants received information about the project and gave written or verbal (recorded) consent to participate. Control questions were adjusted to the individual needs and used to confirm that the participants understood and wanted to participate (Hollomotz, 2018). The interviewer used an interview guide that covered the project topics and prioritized reflexive and participant-centered interviews that lasted 20-60 minutes (most lasted an hour). Open-ended questions were utilized to accommodate the range of understanding of the participants and to encourage contextualized answers (Caldwell, 2014; Emerson, 2012). The interviews commenced with general questions, such as 'Please tell me about yourself' and 'Are you currently in a relationship?' The responses were used to formulate questions about sexuality and intimate relationships, which enabled the participants to relate to the context (Hollomotz, 2018). The participants' responses were summarized either during or after the questions to promote mutual understanding and allow for modification or elaboration of their answers.

## ***Analysis***

The interviews were recorded and transcribed verbatim. The transcriptions were then imported into NVivo, a software tool used for qualitative data analysis (Dhakal, 2022). To effectively answer the research questions (Creswell & Poth, 2018; Bryman, 2016), the coding and analysis procedures followed the guidelines outlined by Braun and Clarke for thematic analysis, which incorporated elements of both inductive and deductive approaches (Braun & Clarke 2022; 2006). Thematic analysis is a systematic approach to identifying, interpreting, and organizing recurring patterns in qualitative data (Braun & Clarke, 2006). The coding process involved an extensive examination of both latent and semantic codes, including both semantic content and subtlety communicated through non-linguistic cues (Braun & Clarke, 2006; Trainor et al., 2020). The development of initial thematic constructs was achieved through a meticulous process of code review and refinement (Braun and Clarke, 2022). The analysis resulted in the following themes 1) Sharing is caring- Initiating conversations about sexuality and intimacy, 2) Safe Space - Facilitator of sexual and intimate communication, and 3) Barriers to effective sexual Communication. Throughout the analysis process, the authors held rigorous discussions to increase the credibility and rigor of the analysis (Nowell et al., 2017). The first author translated quotes from Swedish to English, which were then proofread by a linguistic editor.

# **Results**

Table 1 provides general information about the respondents. To protect the identities of the participants, pseudonyms and approximate ages were used. All of the participants have talked to someone about sexuality and intimacy and the results are based on the participants' reflections and experiences about having these conversations.

**Table 1** general information about the participants (n=22)

|  |  |
| --- | --- |
|  |   |
| Participants | **Number of participants** |
| Gender |  |
| Women | (n=17) |
| Men | (n=5) |
| AGE |  |
| 18-23 | 7 |
| 24-29 | 5 |
| 30-35 | 10 |
| LOCALITY |  |
| Urban area | 16 |
| Rural area | 1 |
| Suburb | 5 |
| RELATIONSHIP STATUS |  |
| Single | 14 |
| In a relationship | 8 |
|  |  |
| ACCOMMODATION |  |
| Own flat | 6 |
| Service accommodation | 1 |
| Living with parents | 9 |
| Accommodated living | 6 |
| CONVERSATIONS WITH OTHERS ABOUT SEXUALITY AND INTIMATE RELATIONSHIPS |  |
| Formal conversations with others | 18 |
| Informal conversations with others | 19 |

The results of the study are structured according to three different themes, namely *Sharing is caring- Initiating conversations about sexuality and intimacy; Safe space - facilitator of sexual and intimate communication* and *Barriers to effective sexual communication*.

## **Sharing is caring- Initiating conversations about sexuality and intimacy**

This theme explores participants' motivations for sharing their intimate stories and sexual experiences with others. Sharing can be explained as, where the participants get the opportunity and space to share their experiences or concerns about sexuality and intimacy with someone who cares, and whom they trust. For many of the participants, it was not easy to talk about sexual and intimate relationships with someone else. This could have consequences for the individual. However, conversations were initiated and opportunities arose, but there were also barriers for participants to engage in conversations with others, as will be shown in the following themes.

### ***Reasons for wanting to talk about sexual experiences***

For many participants, the reason for talking to someone else could be a result of experiencing challenges in the relationship. These challenges included difficulty interpreting their partner's social cues, which they were hesitant to discuss directly with their partner. Several participants reported discussing challenges in their relationships with someone they trusted, such as parents, housing staff, or secondary school staff. One instance is exemplified by Eric, a young adult aged 24-29:

My mom and dad would call me sometimes and I couldn't believe they thought she [girlfriend] was dangerous for me. So, my dad and mom said that she [girlfriend] is dangerous for you. But, we must try and give the boy a chance. And I tried, and it was no problem, but then I didn't understand that she was dangerous for me, because she made it so I wouldn't be with my friends.

Eric's dialogue with his parents regarding his girlfriend's perceived threat encapsulates a delicate balance of parental care and support for personal exploration. This is exemplified by Tove aged 18-23. Her exposure to a TV drama depicting sexual assault can be seen as a trigger for individuals to disclose personal negative experiences. Tove shares:

I told my mum after a year or so. After I told my mum, she helped me to break up. So, it ended after a year. I think I was afraid that my parents would be angry if I told them, although my mum later said that she would never be angry if I told them, but it felt like she would be angry with me. She doesn't think you should be doing things like that, uh, when you're so young. But it wasn't really like I wanted to do that kind of thing.

Tove's disclosure to her mother, followed by supportive actions leading to a breakup, underscores the impact of external stimuli on sharing intimate stories and the role of loved ones in providing support and understanding, which was the case for several participants.

Some participants automatically mentioned their use of contraception at the start of their narratives. Britt, aged 24-29, emphasized the importance of using contraceptives in her own sexual experiences to avoid negative consequences, despite preferring to discuss sexuality and intimate relationships with parents or care providers.

In Britt’s own words:

But then I have to use protection. Otherwise, it becomes a backlash both from here [care providers] and from my parents.

Although some participants used the contraceptive confession as an entry point, several of them were able to initiate conversations that led directly to the topic they wanted to talk about. They selectively choose whom to confide in, such as Suzy who is in her 30s, seeking guidance from her sister, a mother herself, when contemplating parenthood. Suzy explains:

I have my mum, I have my sisters. I have a sister who has a daughter so I can talk to her. Talk about the whole thing.

### ***The sexual issue influences the choice of whom to talk to***

The decision of what to share and whom to confide in is intricately linked to the nature of the sexual issue being discussed. Participants often grappled with the dilemma of what to disclose and how much to share, a common thread reflecting their protective instincts towards their parents, leading them to withhold certain information. For instance, some participants prioritized their parents' emotional safety when navigating challenging discussions, particularly concerning instances of sexual abuse. In some cases, however, parents were drawn into the situation. Mona, aged 30-35, experienced persistent sexual harassment at a day activity center, underscoring the key role of family support in addressing such sensitive issues. Mona opens up:

(…) Every morning when I came there, he stood there and lurked around as soon as I came inside the door. Then he jumped at me straight away and started [sexually offend], and when I was about to go home, he followed me out to the car, to dad, and started humping and wanting to get hold of me (…). Dad got angry got out of the car [and said] “This stops now!” “Enough! I know what you’re up to!” The daycare attendant] ran back and cried. Then the staff got angry at me.

Despite reporting the harassment to staff, the lack of intervention prompted Mona's father to intervene, highlighting the protective stance parents may adopt in safeguarding their young adult's well-being.

Many of the participants demonstrated a nuanced approach to initiating sexual conversations with others, considering the interplay of sexual issues, familial dynamics, and external influences. Their communication choices were influenced by a range of factors, such as seeking relationship advice, sharing concerns about negative experiences, or discussing intimate topics. This highlights the multifaceted considerations that shape their decisions on whom to trust with their intimate narratives, which brings us to the second theme.

## **Safe Space - Facilitator of sexual and intimate communication**

In this theme, participants reflected on what made the sexual and intimate conversations possible. The concept of trust and safety is a central pillar for participants to share their sexual and intimate experiences with someone else. This includes both physical aspects, such as ensuring a private and secure environment, and personal factors, such as the personality and trust in the confidant. Participants emphasized the importance of these two components in creating a safe space. Many participants made a conscious decision to confide their intimate concerns to trusted friends. These confidants, often individuals with whom a deep bond existed, provided a supportive platform for discussing sensitive topics. Moreover, the choice of confidant was influenced not only by familiarity but also by the friend's own sexual experiences. This contributed to the participant's comfort level in sharing personal sexual issues.

Supportive friends played a pivotal role in nurturing a sense of security among participants. Tom's experience exemplifies how friends can offer invaluable support during challenging relationships, recognizing behavioral changes and providing guidance to navigate negative situations. Their intervention and care ultimately empowered Tom to end a harmful relationship, underscoring the importance of external support networks in promoting well-being. Their support was invaluable. In Tom's own words:

She was very much like that. Well, she wanted to keep me [to herself]. They [friends] noticed right away, and they wanted to take care of me and stuff. […] We broke up, so yes. They [friends] wanted to be with me make me happy and so on.

Additionally, many of the participants found digital platforms to be another safe avenue for sharing intimate information. Utilizing digital spaces strategically, participants exercised caution in timing and disclosure, highlighting a thoughtful approach to safeguarding confidential details. Judith's account exemplifies how digital platforms can serve as a strategic tool for sharing personal experiences in a controlled. This is what Judith, aged 30-35, says about experiencing the digital world.

It would be someone I feel safe with. So, it's not something that I would talk about the first time, but if you felt that you had this security with a person, you could have talked about it, then you could have asked how to do it on a date. Uh, how do you, how do I ask someone if they want to go on a date? What is a good relationship, what is not, and things like that.

Another way for individuals to have a safe space to communicate is through group discussions. Many participants had experience with these forums. Typically, the discussions are structured around different themes related to relationships and sexuality, but they can also lead to private conversations with the facilitators later on.

### ***Establishing trusting relationships for sexual conversations***

Establishing a supportive atmosphere for conversations about sexuality and intimate relationships requires a basis of trust and mutual understanding between individuals and their chosen confidants. For the younger participants who were attending secondary school, their keyworker would be a person they would turn to for sexual advice or concerns. Per, aged 18-23s involvement in discussions with a key worker during his time in secondary school exemplifies the importance of a trusted relationship in enabling meaningful dialogues on personal sexual topics. Per said:

 Eh, we used to work with those, sex sometimes with Kalle (staff), a long time ago. Then we used to talk about them and uh, body, how, based on how the body will feel good otherwise if you infect someone, they will not be good.

Receiving sex education differs from having a confidential conversation about sexuality. Per's decision to confide in a particular employee highlights the significance of confidentiality and trust when sharing personal and intimate concerns.

Most participants emphasized the importance of being heard and understood by their confidants. Many participants emphasized the importance of mutual understanding in these conversations as a means of promoting security. A narrative, that was shared by some participants, further exemplifies the transformative impact of professional support in navigating abusive relationships. This is exemplified by Daisy, aged 30-35:

I almost think it was her, uh, the nurse who saved me, otherwise, I would have, like, I didn't have anything in me. She called me and asked me where I was. She hadn't seen me for some time. Luckily, he was out shopping and then she called an ambulance in the meantime and I had the opportunity to go away, to the psych ward.

The nurse who intervened at a critical moment not only provided physical safety but also served as a lifeline, offering the opportunity to seek necessary care and support, ultimately leading to a critical decision to prioritize her well-being.

### ***Safe environment prior to sharing sexual experiences***

Creating a safe environment means making sure the space in which one communicates is appropriate and professional. Before engaging in discussions about sexuality and intimate relationships is crucial to fostering open and honest communication.

Among the participants who spoke with their parents, diverse experiences and motives were prompting their openness about their sexual and intimate issues. For a considerable number, it was a matter of trust and the sense of genuine empathy which made her feel safe. Some participants choose to confide in their mothers. For instance, Nellie, aged 30-35 years, shares that she talks to her mother when she cannot discuss certain issues with her boyfriend.

She is always close to me, mum. However, I don't do it as much when dad is home. I don't dare talk about it then. I feel safer with Mom (...). She has always been by my side in everything since I was little.

Participants' reliance on their parents for emotional security underscores the significance of familial bonds in creating safe spaces for discussing sensitive topics. Nellie's preference for confiding in her mother reflects a desire for a trusted and empathetic listener, indicating the pivotal role parents play in providing a sense of safety and support. In other cases, participants chose to shield their parents from distressing details, particularly related to experiences of sexual abuse, out of concern for exacerbating parental distress. One of the participants, Lina, aged between 24-29, was reluctant to discuss her abuse with her parents. Instead, she chose to confide in a psychologist. This illustrates the delicate balance between transparency and protection within family relationships. Lina shared:

I could talk to mum and dad, but not really about it [sexual abuse]. I felt that mum and dad didn't need to know about it. I mean, they knew about it. But, to talk about it might (...) Dad will get even angrier than he already is, and then I thought it would be better to talk to the psychologist.

### ***Reciprocal communication and mutual trust in conversations***

In formal conversations about sexual experiences, mutual trust, and understanding are essential prerequisites for productive dialogues. Suzi explains:

When I want to ask a question like that, I want, someone to listen to me and also, that they see themselves in me.

Suzi's perspective highlights the importance of feeling heard and understood by the listener, emphasizing the need for reciprocal communication based on empathy and shared experiences. Eric's contrasting experiences with his mother and stepfather underscore the impact of different communication styles on emotional well-being. While his stepfather's calm and empathetic approach helps alleviate distress, his mother's more interrogative demeanor may hinder effective communication. Eric explains:

He's as calm as he can be. He understands me. He listens to me. He feels my body that I am shaking, and I am starting to hyperventilate, so his calm makes me calm. My mother becomes more like a police interrogator.

In this second theme, participants shared their requirements for enabling conversations about sexuality and intimacy with another person. The environment, personality and competence are identified as key factors for successful discussions. But it is important to note that conversations are not always successful, which leads to the third theme.

## **Barriers to effective sexual Communication**

Many participants found it difficult to discuss sexuality and intimacy with others due to various factors that did not always result in successful communication. For instance, the issue could pertain to feeling unheard during a conversation, or it could involve experiencing unequal treatment based on sexual norms. During the interviews, participants reflected on instances where sexual conversations did not unfold positively, potentially influencing their future disclosure decisions.

Rosa aged, 30-35 shares that there are times when she needs to talk to a friend about her sexual experiences and her concerns. She reveals that she sometimes talks to her mother, but that she keeps some things to herself.

Well, sometimes it goes a little too fast, so I talk to my friend and sometimes to my mother (...). If I feel bad, I don't tell them. I keep everything inside.

Rosa's experience exemplifies the nuanced approach several participants take when navigating conversations about sexual experiences and concerns. While occasionally confiding in her mother and friend, she withheld certain aspects when feeling overwhelmed. This highlights the internal struggles individuals face in deciding what to share and what to keep private within their support networks.

Participants reported varied unfavorable conversations, often feeling overlooked and not listened to in formal settings. In family situations, participants may have felt insulted when they shared their questions and concerns about sexuality and intimacy. Some of the participants also shared that the professionals should have explained a bit more about the practicalities or procedures surrounding the aftermath of sexual abuse, i.e. what is involved in a hospital setting, and how investigations will take place to ensure predictability. Elsa exemplifies:

That you are calm and focused, not just sitting down and taking notes, but keeping, eye contact. (…) Perhaps explained a bit more to ensure I am in a safe environment. You can also take a little break because then I go into more detail.

Although many participants reported receiving good professional counseling support, some found it difficult to access such help and were negatively impacted as a result. Gunnel, a participant, aged 30-35, reported struggling to find professional support, but turning to her caregiver.

I want to [talk to someone].And I've tried, but the health care system won't give it to me, so it feels pretty hopeless. (...). I talk to my support person once a week and she helps me as much as she can.

Although obtaining professional counseling contacts can be challenging, it seems that recurring conversations with caregivers occur and are important, as noted by other participants.

#### **Support Systems and Communication Strategies**

Some participants shared experiences where conversations with their parents about sexuality were overshadowed by parental fears of potential risks, such as pregnancy. Felica, aged 24-29 exemplifies how she tries to discuss her worries about sexual reproductive health concerns with her mother.

Maybe I shouldn’t have said what I said about my stomach, rather kept my mouth shut. She got worked up, and I even told her before ‘Don’t get either angry or disappointed at me. I am ashamed of what I have done, so please!’But still, she got annoyed and then you get a lot of feelings of shame and guilt.

Communicating with her mother leaves Felicia with no answers. Instead, she feels a lot of self-blame and does not want to raise these questions with her mother again. Similar to some of the other participants, Felicia’s account exemplifies the challenges individuals face in discussing sexual reproductive health concerns with family members. She expressed regret over-sharing personal worries with her mother, leading to feelings of shame and guilt. Despite seeking understanding, Felicia encountered a lack of supportive dialogue, reinforcing her reluctance to revisit these sensitive topics with her mother. Similarly, Lisa's experience underscored the complexities of navigating conversations about sexual matters within the family. Feeling uncomfortable discussing such issues with her mother, Lisa, aged 30-35 turned to her aunt as a trusted confidante. However, in an attempt to navigate societal taboos and fears surrounding sexually transmitted diseases, Lisa felt compelled to withhold certain details, highlighting the barriers individuals encounter in open communication within familial settings. Lisa, shares:

My aunt. She's the only one I can talk to about situations like this. So I was kind of the first one to tell her that I slept with Fred [boyfriend] and that he took my virginity. Then she said he sounded like a good guy. Then I said he was cool, but I lied about not using a condom. I lied. My mom and aunt are afraid of sexually transmitted diseases, so I had to lie that we had a condom when we didn't even have one.

For some participants, communicating with parents about sexual matters proved challenging and served as a significant barrier. This discomfort may stem from a lack of open-mindedness at home or feelings of embarrassment when broaching topics related to sex and relationships, as articulated by Tove:

I find it a bit embarrassing to talk about these things with my parents. My parents want me to talk about it. I think it's a bit difficult.

Expressing difficulty in discussing such matters with her parents, Tove's narrative reflects the internal and external obstacles individuals face in engaging in candid conversations about sexuality within the family dynamic.

# Taken together, the themes highlight the complexity and nuance faced by participants when talking about sexual and intimate issues, and underscore the importance of trust, support, and understanding in promoting productive dialogue.

# **Discussion**

The purpose of this study was to gain a comprehensive understanding of the experiences and perceptions of young adults with intellectual disabilities regarding discussions about sexuality and intimacy. The findings emphasize the significance of establishing a supportive and comprehensive atmosphere that enables individuals to express their sexual concerns, acquire information, and make knowledgeable decisions regarding sexuality and intimacy. This is exemplified in the theme *Sharing is caring - Initiating conversations about sexuality and intimacy.* Based on Ken Plummer's concept of sexual storytelling (1995), this safe space allows individuals to express their thoughts and emotions freely without fear of judgment or negative reactions. Engaging in these conversations helps establish trusting relationships, enabling individuals to explore and understand their sexual identity and expression. These discussions are important in sexual healthcare as they provide a platform for individuals to express their sexual concerns and contribute to an open and supportive dialogue.

As earlier described, Plummer's (1995) concept of sexual storytelling highlights how societal norms can limit self-expression in matters of sexuality and intimacy, particularly affecting young adults with intellectual disabilities whose experiences are often ignored. The results draws parallels between the narratives of individuals with intellectual disabilities and the 'coming out' stories of the LGBTQ+ community, demonstrating how power dynamics affect the expression of sexuality in different contexts (Löfgren-Mårtenson, 2008; Stoffelen et al. 2013).

In residential settings with constant staff support, hierarchies and established patterns shape the possibilities for sexual activity among young adults with intellectual disabilities. Plummer (1995) emphasizes the role of personal power in determining whether these narratives are shared or suppressed, underscoring how social power influences the spaces available for these stories to be articulated (Swango-Wilson, 2008).

The results indicate that young adults with intellectual disabilities strategically manage the disclosure of sexually appropriate practices, such as safe sex, to conform to perceived expectations and facilitate open discussions on intimate topics. This strategic storytelling approach reflects the power dynamics at play in shaping how narratives are presented, as individuals adapt their stories to align with perceived interviewer preferences.

The findings suggest that many participants found it difficult to identify and articulate the content of their conversations, including what information to share and how to share it, in the theme of *Safe spaces- facilitators of sexual and intimate communication*. This difficulty can be attributed to the power dynamics at play, as described by Plummer (1995), which underscores the intricate relationship between disclosing information and ensuring safety in familial contexts. This sheds light on parental narratives that frequently stereotype individuals with intellectual disabilities as sexually vulnerable. Additionally, external influences, where some participants' experiences demonstrate that the sexual narrative (Plummer, 1995) can serve as an external influence and be included as a trigger element. This highlights the significance of creating safe spaces where individuals can share their sexual narratives (Plummer, 1995) freely, without fear of judgment or negative reactions.

As demonstrated in the theme *Barriers to Effective Sexual Communication*, the findings reveal that discussions about sexuality with parents often revolve around the possibility of pregnancy. This hesitance to disclose intimate details resonates with Ken Plummer's (1995) theory of sexual storytelling, where individuals may withhold information to prevent burdening others with uncomfortable narratives, especially in cases of negative sexual experiences. Participants highlighted the importance of non-judgmental support systems and effective communication strategies in empowering individuals to navigate their sexual experiences.

The participants' reluctance to share intimate details demonstrates a conscious effort to avoid imposing potentially uncomfortable or inappropriate information on their friends, which aligns with Plummer's (1995) theory. In cases of negative sexual encounters, individuals often choose not to disclose these experiences to their social circle, even if they feel emotionally secure in those relationships. This reluctance is evident in the selective sharing of specific details, which allows participants to exercise agency and control over their sexual narratives as a protective measure to preserve their relationships and prevent discomfort.

This passage demonstrates the active utilization of sexual agency (Gill, 2015) by participants, as they carefully decide what information to disclose and when to disclose it. It highlights their sense of autonomy and decisiveness in shaping their sexual narratives. This strategic approach safeguards their close relationships from potential discomfort or inappropriate revelations, influencing how they frame and share their sexual experiences.

The study revealed that parents of young adults with intellectual disabilities play a critical role in shaping their social development by imparting basic knowledge about healthy relationships, boundaries, and consent. Although parental support is advantageous, it is important to address the potential risks of dependency that may arise from excessive reliance on familial relationships for emotional security (Shtarkshall et al., 2007). Conversations about sexuality within the family unit can empower children to navigate intimate relationships with confidence and understanding. McCartney's (2022) research highlights the need for open and honest dialogues while also being mindful of potential negative influences where this group does not need to be shielded from natural relationship ups and downs.

Collaborative efforts between caregivers and peers are necessary to establish formal and informal support networks for young adults with intellectual disabilities. Collaborative efforts between caregivers and peers are necessary to establish formal and informal support networks for young adults with intellectual disabilities. These networks provide emotional support, guidance, and access to resources. Collaborative efforts between caregivers and peers are necessary to establish formal and informal support networks for young adults with intellectual disabilities. Balancing autonomy with safety considerations is key, enabling individuals to make independent decisions while receiving guidance and protection when necessary.

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Recognizing that societal attitudes and norms can affect how individuals with intellectual disabilities are perceived and treated in their intimate relationships emphasizes the importance of approaching these relationships with sensitivity, respect, and a focus on empowerment to safeguard the well-being and autonomy of individuals. Empowering individuals to express their concerns and experiences directly during sexual encounters promotes their sexual health and well-being. A holistic approach that values empowerment, agency, and inclusivity in all facets of sexual education is necessary to promote sexual health in this population.

# **Implications to practice**

The PLISSIT model (Annon, 1976) can provide valuable guidance to caregivers when providing sexuality education to young adults with intellectual disabilities. The model promotes empowerment in social work through four stages: The acronym stands for Permission, Limited Information, Specific Suggestions, and Intensive Therapy. The first two levels do not require sex education, but the lower levels may require collaboration with professionals such as psychologists or sex therapists for specialized support (Annon, 1976). By following the PLISSIT model, care provider may enable young adults to make informed choices, develop healthy relationships, and claim their sexual rights.

# **Limitations of the study**

Certain limitations of this study should be acknowledged. Firstly, challenges with gatekeepers presented barriers to participant access, which impacted the intended briefing of potential participants before the interview plan did not materialize. However, the first author successfully conducted 22 interviews, yielding substantial empirical data that underscores the willingness of participants to share their experiences. For future studies involving the same demographic, it is important to explore alternative strategies for circumventing gatekeeper barriers. It is also noteworthy that the study had a gender imbalance, with 17 out of 22 participants being women and only 5 men. The overrepresentation of women in qualitative research on sexuality may be due to a number of factors. These include the gender of the researcher, the dynamics inherent in face-to-face interviews (Gougeon, 2009), or the dissemination of information by the organizations contacted. It is important to note that this does not mean that men's sexual experiences are neglected. However, subsequent studies should actively seek to achieve gender balance.

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# **Declarations**

All the authors declare there is no conflict of interest.

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