



Romantic Relationships and Adults with IDD in Inclusive Supported Living: Considerations, Complexities, and Opportunities

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Abstract

The love and companionship provided from romantic relationships is a right for all adults, yet many adults with intellectual and developmental disabilities (IDD) have been unable to experience these forms of relationship. This study investigates the experiences and perspectives on romantic relationships regarding adults with IDD involved in an inclusive supported living program. We asked residents with IDD, their parents, graduate student residents (without disabilities), and organization staff for their insights into the romantic relationships of adults with IDD and how the organization could better support those relationships. The residents with IDD described romantic relationships in various ways, but all emphasized their importance. Participants discussed an array of challenges in this area, including difficulty meeting people to date, challenges with social skills, and a lack of comprehensive sexual education. Likewise, the study noted a number of tensions that arise when supporting adults with IDD to pursue romantic relationships, including their comfort addressing this area, navigating dignity of risk, and acceptance from family members. The residents, parents, and staff members also provided helpful recommendations for how supported living organizations can most effectively support individuals with IDD in romantic relationships.

Keywords Supported living · Intellectual disability · Developmental disability · Romantic relationships · Sexual education

Supported living programs and services have become more available for adults with intellectual and developmental disabilities (IDD) over the past two decades [2]. These programs provide supportive environments in which individuals can live as independently as possible and in community with others. Although living away from family brings many new opportunities for adults with IDD, it can also be accompanied by new challenges. One of these

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opportunities and challenges relates to navigating romantic relationships. A growing body of research and literature now addresses these relationships among transition-age youth or adults with developmental disabilities [8, 12, 13, 17]. However, no studies have explored the perceptions and experiences of adults with IDD on this topic who are living in independent and inclusive housing apart from their families.

Individuals with IDD are more likely to experience sexual abuse than youth and adults without disabilities. Wolf et al. (2019) found that children with disabilities are four to eight times more likely to experience sexual violence than children without disabilities. Although these statistics are well known within the disability community, data from the National Longitudinal Transition Study–2 found that almost 84% of students with intellectual disability did not receive any sexual education [16]. Romantic relationships for individuals with IDD remain a challenging and often overlooked topic. Moreover, individuals, families, and professionals often hold different—and sometimes competing—views on the importance and support of these relationships [1, 3]. Likewise, families and professionals often approach this area using a wide variety of approaches. Therefore, it is imperative that these perspectives be explored, as adults with IDD should have access to safe and satisfying romantic relationships.

Much of the research on romantic relationships for individuals with IDD centers on sex education provided when they are still students receiving public education. In contrast, the experiences and education of young adults (21 and older) who have left their homes and live independently has received scant attention. However, it is during this time of young adulthood when romantic relationships take on a particular salience. Nelson and colleagues (2020) discussed how professionals who work with adults with IDD tend to adopt a more protective approach that can sometimes infringe on privacy and autonomy. It is important to understand the perspectives and experiences of support staff in order to guide the future work of residential programs. Additionally, Pugliese et al. (2020) emphasized the importance of addressing sexuality and identity among young adults with IDD. Like anyone else, young adults with IDD are entitled to information regarding the wide range of romantic relationships.

A growing number of studies have examined the perceptions of service providers and staff members who serve adults with IDD. These studies include rehabilitation counselors, group home staff, paid caregivers, and employees from leisure programs [3, 4, 6–8, 11]. Four of these studies were conducted outside of the United States and discuss themes related to lack of training on this topic, personal belief systems, and tensions between safety and autonomy. Deffew et al. (2021) found that staff members in Ireland who received training regarding sexual and intimate relationships had more positive attitudes regarding romantic relationships among young adults with intellectual disability. Overall, staff members also took a more reactive versus proactive response when approaching issues involving romantic relationships and their residents. An overarching theme among staff in this study was the issue of safety versus autonomy. Staff expressed support for individuals with IDD having romantic relationships, but they also stated concerns about individuals with moderate to severe intellectual disability and their capability to understand sex and romantic relationships. Meaney-Tavares and Gavinia-Payne (2012) found that staff employed in day programs, community-based services, or residential settings in Australia had overall positive attitudes towards sexuality and individuals with intellectual disability. Younger participants reported more positive attitudes and higher levels of training. Rushbrooke and colleagues

(2014) completed a meta-synthesis in the United Kingdom of difficulties caregivers face in relation to the sexuality of people with intellectual disability. Some of the identified difficulties included fear and uncertainty, the impact of their views on sexuality, balancing the roles of protector and facilitator, and conditional support for sexual and romantic behavior based on specific parameters such as intellectual capacity and ability to perform sexual and romantic behavior without staff support.

Another line of research has examined the relationships between young adults with IDD and their parents with regards to romantic relationships [10, 17]. For example, a study by Ballan (2012) found that parents of children with autism spectrum disorder (ASD) needed more communication about this topic from educators and service providers. They also raised concerns about their child's ability to comprehend conversations about sex and romantic relationships. Likewise, Holmes and Himle (2014) found that parents of individuals with ASD tended to cover certain topics (e.g., privacy, sexual abuse prevention, hygiene, puberty) with over others (e.g., relationships, sexuality, sexual health) with their children.

A third line of research has addressed teachers' perspectives on providing sexual education to students with IDD [8, 15]. In their study on sexual education for individuals with intellectual disability, Nelson et al. (2020) found that sexual education in Sweden is often taught from a risk-based perspective without highlighting the positive aspects of a romantic relationship. They also found that topics such as LGBT+ identities among students with intellectual disability were often ignored. Wilkenfeld and Ballan (2011) found that educators tended to have positive attitudes toward the sexual rights of individuals with IDD, but they expressed concerns related to capacity to consent, approaching the topic educationally, and the risk of pregnancy.

The present study seeks to contribute to the literature by gathering information about the perspectives and experiences of romantic relationships among the following stakeholders: residents of a supported living program, their parents, the graduate students who reside in the inclusive community, and the organization's director. It also explores how to best serve and prepare this population of young adults as they seek opportunities to connect with others in romantic relationships. This qualitative study is designed to provide new insights into the importance and complexities of supporting romantic relationships. Our research questions are as follows:

RQ1: How do stakeholders view the romantic relationships of adults with IDD and their importance?

RQ2: What challenges do adults with IDD experience in the area of romantic relationships?

RQ3: What tensions can arise when supporting adults with IDD who are pursuing romantic relationships?

RQ4: How can inclusive supported living programs better address romantic relationships?

Method

Participants

To be included in this study, participants must have been either: (a) an adult with IDD residing in the inclusive, supported living community with whom we partnered; (b) a graduate student also residing at one of the organization's multiple houses; (c) a staff member work-

ing for the organization; or (d) the parent of an adult with IDD involved in the study. To be served by the non-profit supported living organization, residents with disabilities must have (a) been 18 years of age or older, (b) had an intellectual or developmental disability (e.g., Down syndrome, intellectual disability, ASD), (c) possessed strong daily living skills and required minimal support, and (d) not exhibited significant behavior challenges. We relied on the organization's verification of these admission standards; no additional assessments were conducted. All residents worked in the local community and lived on their own. Moreover, each was their own guardian and capable of consenting to participate in the study. We included graduate students because of their day-to-day involvement in the lives of the residents with disabilities and their observations of challenges and opportunities. We included parents to better understand the backgrounds and experiences of the residents with disabilities related to romantic relationships. We included staff members to better understand the organization's procedures and challenges.

Overall, two staff members, 30 residents with IDD, 40 student residents, and nine parents of residents with IDD were invited. We held 21 individual interviews as part of this study: ten residents with IDD (one of whom had very recently left the program), six graduate student residents (one of whom had very recently left this role), three parents, and two staff members (i.e., director, assistant director). Participant demographics were collected for all but one participant, a resident with IDD. Full demographic information is shown in Table 1.

Recruitment

All study procedures were approved by the university's Institutional Review Board. I worked with the organization's director to recruit participants. She emailed out approved study invitations on our behalf to all graduate student residents ($n=6$) and the residents with IDD ($n=10$). The residents with IDD expressed their interest in participating by sending the lead author an email. She then scheduled a time to review the study information form, obtain informed consent, and complete the interview. Graduate student residents filled out an online consent form and then scheduled an interview with her. Parents of residents with IDD were invited only if their daughter or son gave me permission to do so. All participants received a \$25 VISA gift-card for their participation.

Supported Living Program

Participants were involved with a non-profit supported living organization in a large southern city. The organization operates four houses for residents with and without IDD, with eight more opening soon. Some of the houses consist of individual one-bedroom apartments in an apartment complex, while others live in homes and share common kitchens and living areas. At the time of the interviews, the organization provided affordable and inclusive housing for 30 residents with IDD, 40 student residents, and 10 older adults. The student residents received a small stipend and paid a reduced housing cost but were otherwise not given official responsibilities. It was the expectation that student residents would step in to support the residents with IDD as needed, especially when safety concerns come up. However, the residents with IDD were not monitored by staff or the student residents.

Table 1 Participant Demographics

	Residents with IDD (n=10)	Student residents (n=6)	Staff (n=2)	Par-ents (n=3)
Age				
20–29	33%	66%	50%	0%
30–39	55%	33%	0%	0%
40–49	0%	0%	0%	0%
50–59	11%	0%	0%	0%
60–69	0%	0%	0%	33%
70 or older	0%	0%	50%	67%
Gender				
Female	33%	50%	50%	100%
Male	55%	33%	50%	0%
Non-binary	11%	17%	0%	0%
Race/Ethnicity				
Asian/Pacific Islander	0%	33%	0%	0%
White	88%	17%	100%	100%
Hispanic/Latinx	0%	17%	0%	0%
Black	11%	33%	0%	0%
Marriage status				
Single	100%	66%	50%	0%
Married/living with partner	0%	17%	50%	100%
Prefer not to answer	0%	17%	0%	0%
Highest level of education				
High school or less	22%	0%	0%	0%
Some college	11%	0%	0%	0%
Certificate program	22%	0%	0%	33%
Associates degree	33%	0%	0%	33%
Bachelor's degree	11%	17%	50%	0%
Master's degree	0%	50%	50%	0%
Doctoral degree	0%	33%	0%	33%
Self-identified disability*				
Autism spectrum disorder	44%	-	-	-
Learning disability	67%	-	-	-
Mental illness	22%	-	-	-
Intellectual disability	11%	-	-	-
Other	67%	-	-	-

*All participants met the organization's eligibility criteria as having IDD. However, we asked residents with disabilities to self-describe their one disability; more than one disability could have been noted. IDD=Intellectual and developmental disabilities

Procedure

Once informed consent was provided, the lead author scheduled a one-on-one interview with each participant. All interviews took place via Zoom and were audio recorded. The interviews averaged 33 min (range, 12–69 min) in length. The shortest interviews took place with the residents with IDD who were fairly brief in their responses. We created a semi-structured interview protocol (see Appendix) to address the four research questions. In addition to a common set of questions for all participants, we also developed follow-up questions related to each participant's responses. The interview protocol started with introductory questions addressing the interests, hometown, and occupation of the participants. It

asked how long they (or their daughter or son) were part of the supported living program. The second section of the protocol consisted of questions about the stakeholders' experiences with sexual and romantic relationship education as well as what aspects of this topic are important to the stakeholder. The third section addressed how the stakeholders felt about discussing, teaching, and learning about this topic. The fourth section included questions about what aspects of romantic relationships stakeholders may be neglecting to teach or learn about. We anticipated that these aspects might be sexual orientation, gender identity, and birth control and having children. The fifth section asked about how the supported living program addressed and supported romantic relationships with their residents with IDD. The final section asked wrap-up questions including what advice stakeholders would give for other supported living programs on this topic.

Positionality Statement

The first author is a graduate student in the special education department concentrating in low-incidence disabilities. She has a B.S. and M.Ed. in special education, as well as teacher certification in special education (K-12). She is an educated, neurotypical, and non-disabled individual. She believes individuals of all abilities have the right to love and romantic/sexual relationships. She spent nine years with individuals with IDD in educational, employment, social, and family contexts. Her personal experiences and beliefs may have influenced her approach and analyses. The second author is a faculty member with more than 25 years of experience working with youth and young adults with IDD. His expertise is the transition to adulthood and the ways community programs can support the flourishing of individuals with IDD. He believes adults with IDD should have the same opportunities as anyone else to pursue valued relationships and that needed supports should accompany such pursuits. Throughout the data analysis process, we strived to highlight the participants' voices, beliefs, and opinions rather than our own.

Data Analysis

We used a general inductive approach to analyze the qualitative data from the interviews [14]. The analysis involved multiple readings of each interview transcript, identification of overarching themes, and categorizing responses. Data analysis occurred in multiple stages. First, all interviews were transcribed using an online software, checked, and de-identified electronically. During the second stage, the first author read each transcript carefully and identified segments relevant to each of the four research questions. She then created category names within each overarching research question for the relevant transcript segments. Coded responses in each transcript ranged from a few words to entire paragraphs. As similarities between codes were found, she grouped them together under the relevant research question. New categories were added as she read through each transcript; however, she first reviewed all existing categories for relevance before a new category was added. She discussed the initial list of categories and definitions with the second author and solicited input; additional revisions were made. The first research question did not produce any underlying themes, while the other three research questions contained a total of 18 themes.

Findings

How Do Stakeholders View Romantic Relationships and Their Importance?

Participants with IDD were asked what a romantic relationship means to them and about their importance. Responses to this question centered around romantic relationships as companionship. Many of the participants used practical, action-oriented phrases to describe what a romantic relationship means to them. Bill, a resident with IDD, said, “Like dating someone means like going out, like going out to the movies, out to eat, or hanging out together.” Another resident with IDD, Samuel, explained, “Someone that loves every fiber of your being. And of course, someone that you kiss. French kiss or just kiss in general.”

Others incorporated past experiences into their understanding of romantic relationships. For example, Daniel, a resident with IDD, noted:

It means togetherness. It means not being alone. It means being the company of someone you really, really feel attracted to. Someone who doesn't have an ex-boyfriend that they want to go back. An ex-boyfriend that I'm not aware of. Someone who's deceitful. Someone who gets you going. And then just suddenly drops you.

All ten residents with IDD affirmed that romantic relationships are indeed important to them. Other stakeholder groups also emphasized the importance of romantic relationships based on their own experiences. Parents communicated the importance of romantic relationships for their children and shared how difficult it can be to watch them remain unsuccessful in finding a romantic partner. Martha, a parent of a resident with IDD, explained, “All the times that we would talk with him, he wanted very, very much to have a girlfriend. That's a big deal to [son]. And we encouraged him in that.”

The student residents also described why this topic is important for the residents with IDD. The student residents and staff refer to the residents with IDD as the “friends.” Abby, a student resident, said, “We have these longings. We have these needs to connect at that level. And again, I ask...what do we do to nurture that part of our friends' lives?”

What Challenges Do Adults with IDD Experience in the Area of Romantic Relationships?

Collectively, the four stakeholder groups raised six themes addressing the challenges adults with IDD face in the area of romantic relationships (see Table 2).

Interpersonal Skills

One staff member, three parents, one student resident, and four residents with IDD mentioned how difficulties with interpersonal skills leads to challenges with romantic relationships for adults with IDD. Interpersonal skills were referred to as social skills such as introducing yourself, carrying a conversation, and reading body language among others. Several of the residents with IDD expressed their difficulty understanding social cues and understanding the nuances of how to begin a romantic relationship. Emmett, a resident with

Table 2 Themes Associated with Research Questions

Themes	Definition
What challenges do adults with IDD experience in the area of romantic relationships?	
Interpersonal skills	Difficulty connecting and communicating with others in order to develop a romantic relationship (may be due to a specific disability or more general challenges)
Lack of comprehensive sexual education	Skewed or incomplete understanding of the topic based on where the individual with IDD received education on romantic and sexual relationships
Conceptualization of topic	Areas of romantic relationships that adults with IDD need more training in or have trouble understanding; general understanding of romantic and sexual relationships
Difficulty assessing risk	Challenges assessing the riskiness of a certain decision or behavior especially when it comes to romantic or sexual relationships
Difficulty meeting people	Difficulty forming relationships based on challenges meeting other individuals who may be interested in a romantic relationship
One-sided relationships	Difficulty surrounding an asymmetrical relationship where one side has a different conceptualization of the relationship than the other
What are the tensions surrounding romantic relationships among adults with IDD?	
Comfort discussing the topic	The stakeholder's overall comfort in engaging in conversations on romantic relationships among individuals with IDD
Safe relationships and sex	Difficulty determining what type of relationships and sexual activities are safe for individuals with IDD; issues surrounding consent
Dignity of risk	Difficulty balancing the autonomy of individuals with IDD to make their own decisions (esp. risky decisions) with ensuring that individual's safety
Who to date	Tensions surrounding whether individuals with IDD should date individuals with disabilities or individuals without disabilities
Acceptance from family members	Lack of acceptance from family members with regards to romantic relationships contribute to difficulty for individuals with IDD to have healthy, romantic relationships
Lack of training	Student residents feel as though they could benefit from more training/education around the topic of individuals with IDD and romantic relationships
How should supported living programs address and support romantic relationships?	
Establish organizational rules	Discussion surrounding the rules that the organization has put into place with regards to romantic and sexual relationships
Define student resident role	Description of the roles and responsibilities of the graduate student residents in regard to supporting the residents with IDD in romantic relationships
Utilize outside resources	The resources and individuals the organization uses to educate their residents and families on the topic of romantic and sexual relationships
Offer workshops and classes	The workshops and classes that the organization offers their residents and how that programming influences the understanding and behavior of the residents
Organization leadership	How the organization approaches policies surrounding romantic relationships among their residents with IDD including when to intervene, call parents, and ask residents to leave
Suggest new ideas	Ideas for how the organization or other organizations can improve their policies and programming surrounding romantic and sexual relationships among adults with IDD

IDD, stated candidly, "I have the social cue ability of a soggy napkin... but social cues is one of my struggles."

The three parents all mentioned their adult children's difficulty with interpersonal skills and the unique challenges they faced when it comes to meeting others. Two of the parents said their child tended to become overly attached to a potential romantic interest without considering the other person's feelings. This behavior made it difficult to sustain a relationship and get to know people they might be interested in dating. Donna, a mother of a

resident with IDD, explained, “And so, my son has a tendency to, if he sees that anybody’s interested in him, he just pounces on them, and he’ll start calling and calling and calling.”

The student residents and staff also discussed the challenge they saw in this area. Among the other challenges, difficulty with social skills was perceived to be the main reason that very few of the residents have had successful, long-term romantic relationships. Justin, the associate director of the supported living program, explained:

Yeah, I think mostly it’s the social cues. The social cues are a big one that I think everybody, because a lot of, I mean, when we were working with intellectual disabilities and we’re working with people that are capable of living on their own, a lot of people just kind of have that kind of quiriness and this kind of lack of social understanding. And so, I think that’s probably most specific to our population.

Lack of Comprehensive Sex Education

One staff member, two student residents, and three residents with IDD discussed how the lack of good quality, comprehensive, and unbiased sex education contributes to challenges in the area of romantic relationships. Few of the residents with IDD could remember anything from their high school sex education courses, or they had never actually received such education. When asked about the importance of sex education, the residents with IDD did acknowledge the need for education in this area. Staff emphasized that the residents with IDD often learned about sex and romantic relationships from unrealistic, non-educational sources like media and pornography. Claire, the director of the supported living organization, explained:

A lot of our folks learn about sex from movies and TV shows...And if they see a woman that’s available, if pornography is all they’ve seen, the pornography is extremely dangerous because the woman has become so objectified in pornography that they think that that’s the behavior that they should model. So, the pornography is bad, not because it’s bad, the pornography is bad because of the modeling.

The two student residents felt the residents with IDD had a history of biased sexual education from school or family members. This lack of a comprehensive idea of biology, sex, and healthy relationships was said to impede overall understanding and the ability to form a healthy relationship. Tori, a student resident, shared:

And I think sometimes that comes from family expectations being in the south. Again, that shame culture around sex and sex education and, you know, people not knowing how to talk about pleasure and people not knowing how to talk about safe pleasure and safe sex in a healthy way.

The supported living organization also holds classes and workshops for the residents around a variety of topics, including daily living skills, employment skills, and romantic relationship. Tori also described the impact of the organization’s speakers and classes on the residents with IDD’s understanding of romantic relationships.

Another challenge was that the only programming happening around it, which was happening with our Monday night classes was a volunteer couple that was not educated to have those conversations. And in a lot of cases that created more harm and things that needed to be undone on the back end than it did on the front end. There was a Planned Parenthood person who came in. She was wonderful.

Overall, the residents with IDD have only piecemeal ideas about how healthy romantic and sexual relationships should look.

Conceptualization of Topic

Two staff members, three parents, three student residents, and eight residents with IDD addressed how adults with IDD conceptualize the idea of romantic and sexual relationships. They indicated that the lack of comprehensive sex and healthy relationships education contributed to a skewed or incomplete understanding of what constitutes a safe, healthy romantic relationship. Some of the adults with IDD were unfamiliar with terms related to romantic relationships such as sexuality, gender identity, and birth control. Claire, the director of the supported living organization, explained:

That's just the reality of it. But they have to deal with it with a different deck of cards and a different set of understanding. Some of our guys do understand exactly what's involved in a romantic and sexual relationship. Some of our guys, we're not sure what exactly they understand.

Along with social-related challenges, an incomplete understanding of romantic relationships can lead to difficulty with starting a romantic relationship. Justin, the associate director, explained this connection:

I think they understand companionship really well, so maybe I'm answering this with what they are able to understand. They, you know, companionship and that love and acceptance. It's something that almost everybody that I've come in contact to understands and wants. And then I think the connection between that and then what the world says—a relationship or a marriage or a dating relationship or love or sex or whatever that is—there's almost like a disconnect of the practical side of how to get that companionship.

Some of the participants also commented on how the disabilities of residents with IDD may play a role in their conceptualization of romantic and sexual relationships. Tori, a student resident, explained:

A lot of times too there are a lot of complex emotions that are happening that are hard to navigate for anyone at all, but also especially hard to navigate without some advanced, complex thinking skills and ability to think abstractly.

During each interview with the residents with IDD, I asked about their experience in sex education and what concepts they remember from any education on this topic. Many of the

residents could not remember anything from their sex education courses or they said they did not receive any formal education on romantic relationships. However, all the residents with IDD expressed that sex education is important. Jacob, a resident with IDD, explained why sexual education is valuable:

Yes, because that taught me how, like how like safe sex and how it's not like good to like, just go around, like having random sex with other people and just yeah. Yeah. It really taught me a lot. It was very, very valuable.

Difficulty Assessing Risk

One staff member and one student resident discussed the difficulty residents with IDD have when assessing the riskiness of a certain decision or behavior. This challenge may have contributed to the fact that most residents with IDD had not found healthy romantic relationships at the time of the interviews. Claire, the director, explained how this relates to the risk of online dating:

That actions lead to consequences is not a straight line and that there could be a jeopardy to physical safety is really hard to communicate. And when it comes to online dating, which has been an up and down problem, that's the concern is that the risk is not understood.

According to the staff and student residents there was a disconnect for some residents with IDD between their decisions and the consequences of their actions. This was a challenge for creating healthy relationships and presented a safety concern for the organization. Overall, difficulty assessing the risk of a given situation made it difficult to trust the residents with IDD and give them the freedom to pursue romantic relationships without supervision. Tori, a student resident, shared:

Like thinking about risky behaviors, you know, online dating and meeting up with someone, or having sex in a room with someone else watching, and you know, the logistics and the legalities. And, I think as far as an impact, it's very impulsive.

Difficulty Meeting People

One staff member, two parents, two student residents, and four residents with IDD shared that a difficulty in meeting people had hindered the ability to form romantic relationships. Many of the residents with IDD expressed that they have struggled to meet other individuals with or without disabilities who they may be interested in dating. They often had a small social circle and limited opportunities to meet new people. The COVID-19 pandemic also exacerbated loneliness and created difficulty meeting people. Daniel, a resident with IDD, mentioned:

I mean, I could take a whole bunch of classes and speakers. It's finding that person that's difficult. You can take any kind of romantic relationship class or courses. Now it's just a matter of finding that person. And even if you're lucky enough to find that person, they may be in a relationship already.

Despite this challenge, many of the residents with IDD held out hope they would find the perfect romantic partner. The student residents, parents, and staff also named meeting people as a challenge for residents with IDD. It can be very difficult for residents with IDD to watch their friends and siblings start romantic relationships and get married when meeting people seems so insurmountable for them. Claire, the director of the supported living organization, commented on this challenge:

But for all of the ones who see their sisters and their brothers and their schoolmates all developing relationships, all getting married, all starting to have children, it's just real hard. They feel left out and it's not a feeling left out. They are left out.

Tori, a student resident, raised this same point:

And, yeah, it is really hard for them to meet people. And that goes back to the need for belonging and, you know, that need for intimacy that we all have. And it's hard for everyone, but especially for people with IDD.

One-sided Relationships

Three parents, two student residents, and two residents with IDD shared that one-sided or imbalanced romantic relationships were a challenge. The two residents with IDD shared that they had started romantic relationships only to find out the partner was exploiting them for money or favors. The parents also said that certain individuals had taken advantage of their sons' disability, friendliness, and desire for a romantic relationship. One parent shared a story of when her son met a young woman at work who asked the son to drive her to another state and he happily complied that same day. Martha, a parent of a resident with IDD, shared a similar story:

There were a couple of times when he was not making a wise decision, where some young woman would catch his interest and he was not quite sure how to handle it. And that he probably would have been exploited by them. One young woman thought that she could use him as a way to be taken out to dinner and basically wined and dined, but had no interest in him just, just wanting him to spend money on her.

Both stories suggested that the resident with IDD's intense desire for a romantic relationship could cloud their judgement regarding a person's genuine interest in the relationship. Catherine, a parent of a resident with IDD mentioned, "He thinks if they're friends that they want to go out with him. And that's been his whole, most of his problems throughout his whole life."

The parents said they had seen these scenarios play out for their children with IDD throughout their adolescence and adulthood; however, one of the student residents also mentioned this challenge affecting the residents with IDD at his house. Stuart, a student resident, mentioned:

And, you know, for you, it's a meaningful friendship relationship with a friend. But for the friend, you know, if there is a, you know, a strong emotional dependency for instance, or a strong, not sexual platonic, but maybe romantic interest, for instance, how would you want to approach that? And how do you sort of deal with asymmetry of power understanding, you know, in these situations? I think including that might also just be helpful in general.

Outside of commenting on this issue, Stuart also expressed his desire for more support in handling this kind of situation with a resident with IDD.

What Tensions Arise When Supporting Individuals Pursuing Romantic Relationships?

The four stakeholder groups discussed six themes under this category (see Table 2).

Comfort Discussing the Topic

Two staff members, five student residents, and four residents with IDD mentioned their comfort discussing the topic of romantic relationships. All but one of the residents with IDD shared that they felt comfortable discussing romantic relationships with the interviewer. These residents also shared that they had discussed romantic relationships with their friends and family members; however, they did not share which topics those conversations covered. Five of the ten residents with IDD had also discussed it with the staff and student residents. One resident with IDD mentioned that she felt a bit uncomfortable with the topic due to lack of experience with romantic relationships, but that she was working on feeling more comfortable.

All six student residents felt comfortable discussing romantic relationships with the residents with IDD given the right circumstances (e.g., privacy, topic naturally came up in conversation, resident with IDD was comfortable). Stuart, a student resident, shared:

I think I would also be comfortable with talking about it with them and potentially also learning from them because I feel like their own experiences might teach me a lot more than I could, you know, teach them for instance.

Overall, the student residents and staff demonstrated a positive, open-minded perspective to discussions of romantic relationships. Justin, the associate director, explained:

I want to respect them and their own what they want to talk about or what they want to divulge. I wouldn't push them into anything, but I also wouldn't necessarily shy from anything.

Other student residents recalled past experiences navigating conversations on this topic with the residents with IDD. Some of these conversations revealed the discomfort of residents with IDD with the more adult, sexual topics surrounding romantic relationships. These may have been topics that parents or educators shied away from in the past. Tori, a student resident, shared her experiences:

Basically, anything beyond holding hands, kissing, flirting, you know, directly sexual in nature, they don't want to talk about it. They don't talk about body parts. They don't want to talk about protection. Basically, anything that's taboo, you know, for society or that has shame around it. They don't want to talk about it. And so that makes it difficult.

Tori's comment demonstrates a common reaction that the student residents get when trying to discuss romantic relationships with the residents with IDD.

Safe Relationships and Sex

Two staff members, one parent, and three student residents discussed tensions related to determining what types of relationships and sexual activities were safe for the residents with IDD. They also addressed issues surrounding giving consent for sexual activities. The staff and student residents spoke to the challenges regarding making sure the residents with IDD were engaging in safe romantic and sexual relationships. The organization's overall goal was to give residents with IDD the most independent life possible, while also keeping all residents safe. Claire, the director, explained:

So, even having sex with a stranger per se would not be our business if that's how people like to have sex. Except, if it's with a stranger, it affects safety. So that's where questions come in with the disability population. That first situation actually embraced all of the problems that we could encounter in one situation and underlined that security and safety is our biggest concern and the biggest consequence for people in our community to understand.

The staff also spoke to the difficulty of teaching the residents with IDD to make smart choices regarding romantic relationships, while also enjoying their freedom. Justin, the associate director, illustrated this challenge:

We've had multiple friends, like now they're in the big, bad world. And then it's like Craigslist with people that will come and have sex with you. And it's just like, it's this kind of, you've been let loose too quickly. And so, trying to help them understand that with freedom doesn't mean you do whatever you need to still be smart about your relationships and your choices. So that has definitely been a challenge.

Additionally, the staff and student residents commented on the issue of consent with the residents with IDD. The staff and student residents shared that it can be difficult to determine whether a resident with IDD could give their consent for sexual activities. Tori, a student resident, shared her thoughts:

You know, thinking about consent, where does my right and someone else's right begin? And you know, the legality of things like what is and what isn't okay. Regardless of how innocent it is, and regardless of how much you want it and how much your body is telling you, you want it.

Dignity of Risk

Two staff members, two parents, and one student resident mentioned that “dignity of risk” was a tension related to romantic relationships. Dignity of risk is the right to take risks when engaging in life experiences, and the right to fail in those activities. Dignity of risk is a tension for individuals with IDD and romantic relationships due to the safety versus autonomy concerns. The staff, student residents, and parents felt conflicted over promoting the independence of the residents while simultaneously ensuring their safety. Both staff referenced organizational policies that strive to give the most freedom as possible, while also stepping in when safety is at risk. Claire, the director, explained:

So, in the spectrum of ability that we have, you can't have rules. All of our guys are so different. And they are independent and we don't tell them what they can and can't do. And it's not our business. The word independent means independent. It's their life, not my life. And they can do what they want with their life. You just have to try to make it as safe and secure as you can.

Claire was always concerned about the residents' safety, yet also passionate about facilitating a truly independent living experience. Justin, the associate director, explained his perspective:

But it's starting to feel like it's important to trust and to empower the friend and their community, like their friends, their parents. And even if it's not quite the direction that I would, you know, I just think of too many people are trying to take the choice away from the friend. It just becomes this battle of who has the final say of what this person does. So, I probably lean more towards giving them the free rein to make mistakes as we all had, but you're right. I mean, there is like a lot of, I don't want something bad to happen to you.

The staff and student residents said they stayed vigilant when it came to the safety of residents with IDD; yet they also strived to balance that vigilance with autonomy. Stuart, a student resident, shared, “You might want to consider potential signs of abuse or, you know, the friends being taken advantage of, but you also don't want to step on their autonomy and their own agency.”

Two of the parents also shared their thoughts on dignity of risk. They expressed their initial apprehension at the independence their children would have through the supported living program. Martha, a parent of a resident with IDD, shared:

We liked it, but we were also kind of worried about it at the same time, because there were no constraints on [him]. And I can't think of what constraints we would have

wanted, but it was matter of [him] not being under a parental eye. [Him] being on his own in an independent setting where he could have the relationship that was a romantic one without somebody looking scanted. So, that took a little bit of doing on our part, to try to adjust to that. But I wouldn't change that even though at times, I'm not quite sure. It's like just so much freedom. But I wouldn't want it any different from that.

This parent expressed her overall nervousness at the independence her son would have. Yet, at the same time, she praised the program for pushing her family to embrace dignity of risk for her son. A second parent, Catherine, also mentioned the positive aspects of the organization's approach on dignity of risk and shared her advice for other parents:

And that's part of disability, you have to give them the chance to fail in order for them to grow. And so therein lies the problem... It's going to be really hard. But the more you can give them that chance, the more they grow. I've seen it's worth it. It's not always easy.

Who to Date

Two staff members, one parent, and three student residents shared that who residents with IDD chose to date could sometimes introduce tensions. These discussions primarily surrounded whether the residents with IDD should date other individuals with IDD or individuals without similar disabilities. The staff and student residents were curious to understand more about the legal and social difficulties associated with adults with cognitive impairments establishing romantic relationships with those without disabilities. They shared stories of residents who tried to start relationships with people who could take advantage of them or who were just not interested in a romantic relationship (see the "Difficulty Meeting People" and "One-sided Relationships" sections). Justin, the associate director, explained:

I do wonder about the—and this is something I have no experience in—but the potential of dating between like kind of neuro-typical people and people with special needs and IDDs and how that would work and whether that should be limited and, you know, when that's taking advantage of somebody and [when] that's kind of that autonomy question as well.

For parents, this tension had to do with attempting to manage their adult child's expectations and prevent them from being hurt by a romantic partner. The parents wanted their children to find love and companionship; however, they also tried to help their child navigate life with as little hardship as possible. Catherine, a parent of a resident with IDD, mentioned:

But mostly our talks have been... He's always gone after the wrong person and wanting what he can't have. And so, I'm like, you know, the dream killer. I think he called me [that] once. So, it's been difficult.

Acceptance from Family Members

Two staff members, one parent, two student residents, and one resident with IDD mentioned that the views family members hold related to romantic relationships could present some difficulties. Many of the residents with IDD had lived their entire lives with their family until moving into this program. The belief systems of parents were said to have a significant influence on the residents' understanding of romantic relationships and behavior once they move into the community. Some residents created new belief systems and experimented with their new freedom after leaving home. One resident with IDD and the director both discussed issues surrounding a lack of family acceptance with LGBT plus relationships. Emmett, a resident with IDD, explained:

I am part of the LGBTQ community. So just that they're so supportive. Sadly, my parents are not that supportive. They're very traditional people, and we make things work. I kind of just have to grit my teeth and stuff, but I am trans.

Emmett felt very accepted and welcomed at the supported living community and had spent time educating neighbors about the LGBT plus community. Several other residents with IDD also identified as a member of the LGBT plus community. All three parents interviewed were supportive of their adult children with IDD having romantic relationships; however, one parent expressed a lack of confidence on the topic. Catherine stated, "But honestly they don't, for the most part, have healthy relationships. They just don't." Staff also emphasized their role in assisting residents with unsupportive parents and the tensions that could subsequently arise. Claire, the director, explained:

And we can't run interference with families per se. I'm smack in the middle of parents and one of our residents right now with this issue. I don't like being in the middle and they need a translator, and they need somebody kind of as a referee. And it's a very yucky place to be right now. But I think that would be without an IDD involvement, the IDD just complicates it. So those are some of the sexual issues.

Claire worked closely with the families of residents but said that different belief systems regarding sexuality and romantic relationships can make her job difficult. Staff tried to not get in the way of a family and their values, yet it could be difficult when immersed in the day-to-day life and decisions of residents with IDD. Justin, the associate director, added:

So that's difficult because some people coming from really conservative, kind of strict family backgrounds around dating. And they haven't been empowered to have relationships before, or they haven't been allowed to. So, there is a fine line, especially around sexuality, gender identity that we have to walk in terms of what supporting a resident, supporting a person versus getting in between their own family dynamics.

As discussed in previous sections, the values and belief systems of families have a direct impact on the knowledge and beliefs of residents with IDD. Family culture and geographic location also played a role in how the student residents approached the topic of romantic relationships with a resident with IDD. Tori, a student resident, shared:

And because of the shame culture that we have around sex in the United States, it's like, you don't talk about those things with your parents. You don't talk about those things with anyone. So, you know, in not trying to normalize those conversations also became difficult.

Lack of Training

Five student residents felt as though they could benefit from more training around the topic of romantic relationships in order to support residents with IDD more effectively. The supported living organization did not provide extensive training to the student residents before they began living in the community. The overarching hope of the organization was that the residents would provide natural support to one another without the need for formal training. Five of the six student residents felt as though they would be more effective members of the community with some education on how to support individuals with IDD both broadly and in the context of romantic relationships. Yvonne, a student resident, explained:

I don't think I got a lot of training of how to work with someone or an adult with intellectual disability. I kind of figure things out, like what are some approaches to work with each individual person, because they are very different. Not *very* different, but they all have their own style and stuff.

Yvonne felt she would benefit from some formal education on how to work with adults with IDD generally, which would in turn help her support their romantic relationships. The other student residents also expressed their curiosity surrounding how to appropriately engage the residents with IDD on the topic of romantic relationships. Stuart, a student resident, mentioned:

So I guess I would want to understand, you know, just what it means for them in general and, you know, how it might coincide or be different with things like, you know, a-romanticism or pan-romanticism amongst even, you know, able-bodied or able-minded individuals. And if there is any point of similarities or strong point of differences and how sort of that understanding can help in a more liberating view of romance and sexuality than a very constricted one.

The interviews revealed that the student residents cared deeply about their fellow residents with IDD and wanted to do their best to support them in every aspect of their lives. However, they also raised many questions about how romantic relationships function among adults with IDD and how the organization could support them in those relationships. Abby, a student resident, shared:

What's being done to introduce them into a love and romantic space both physically, like physically sexually engaging and also emotionally? What are the things to look out for or to know in terms of that development process? How does it go? Like, what's the pace? What's the rhythm? Is it different? Is it not from what we experience? I

suspect no, it's probably just more time and more communication. Right. But I don't know.

How Can Supported Living Programs Address Romantic Relationships?

All stakeholders commented on the supported living organizations' roles and responsibilities related to romantic relationships. Six themes emerged in this area (see Table 2).

Establish Organizational Rules

Two staff members, two parents, four student residents, and eight residents with IDD discussed the rules the organization had put in place related to romantic and sexual relationships. For example, the organization did not allow dating or a sexual relationship among any of the residents; overnight guests were not allowed in any of the houses; and residents with IDD could not engage in online dating or bring a stranger over to the house in order to protect the safety of all residents. Some of the residents appreciated these rules and the boundaries they offer; others wished they could have more freedom in terms of who they could date. Claire, the director, explained one of the reasons why these rules were put in place:

We don't let people within our houses date because it just gets too complicated when you live with each other, especially when you break up and that's been a complication that we've had to deal with and will continue to have to deal with.

Many of the residents with IDD mentioned that they were not on board with the rules. However, one resident with IDD did share that she appreciated the rule and it made her feel safer. Samantha, a resident with IDD, shared:

Okay. So, for some of those guys, like, I'm kind of glad that there's a rule that is set in place there. I also like, because there's guys in my house too, you know, because it is coed. I'm just glad that rule is in place.

Two parents also expressed their appreciation, while recognizing how the rules impacted their children's lives. Donna, a mother of a resident with IDD, explained:

I think the hardest part is that he might possibly be trying to kind of distance himself or emotions from getting too involved with any of the females there because he knows he can't really date or be with them romantically. I don't understand all the rules and regulations, but I do get that because you can really run into some big problems in an environment like that.

As referenced earlier, it could be difficult for some residents with IDD to meet other adults they were interested in dating. For that reason, some of the residents disagreed with rules against dating another resident in the community. Abby, a student resident, related that point to her own life:

Okay. Yeah. And so, and I understand it in terms of like how quickly it can be problematic because of the living space. But then I think like, well, where have I met people that have I've been romantically engaged with, like, maybe it wasn't my neighbor, you know. But it was for sure someone I went to school with, or that I worked with, right? Like it's people that are very close. And so it's, again, I understand the precaution, but it's difficult because it's like, well, where else are they going to meet folks?

The residents with IDD expressed a similar frustration with the rule regarding dating among the community members. Daniel, a resident with IDD, noted:

Actually, I don't see why we can't. You know, if you're living with a bunch of people and you feel attracted to someone, why can't you develop a relationship with that individual? Okay. It's just like, if I were a neighbor living at a house, you know, there was another neighbor who happened to be single and I feel attraction to. What's wrong with hooking up with that person?

Define Student Resident Role

Two staff members and two student residents commented on the lack of clarity regarding the roles and responsibilities of student residents related to romantic relationships. The student residents have few outlined roles other than informally supporting the residents with IDD throughout their day-to-day life. The staff rely on the proximity of student residents to ensure the residents with IDD are doing fine. Claire, the director, explained how she sees the student residents' role, "It's like my biggest protection in the two first houses is the students. And that protection is I have that many more pairs of eyes that see things." Claire also described her perspective when it comes to the student residents:

Proximity will make things happen. And by living together, depending upon the example that's been created already, when that community is built, then it does work. Because you care for the other person and none of us has the right answers necessarily. So, it's when you care for somebody that pretty much covers it and whatever comes out of your mouth is going to be useful if you care for the person.

The idea of proximity and caring for each other is at the core of how the organization engages the student residents as natural, informal supports for the residents with IDD. However, many of the student residents stated that they had received no training on how to work with adults with IDD generally or specifically in the area of romantic relationships. They expressed a willingness to learn more in order to better support the residents with IDD. Abby, a student resident, explained:

I don't know what I can't open up or not, you know. And I also don't know what kind of leverage or responsibility would be assigned back to me when and if I open up these conversations, right. So, then it goes back again to like our capacities and our time availability. I'm not shying from the work, please don't hear that. Like I am for

it, but it would require for me more deliberate conversations, more workshops, more training around, like, how can we handle this?

Utilize Outside Resources

Two staff members, one parent, and two student residents commented on the types of outside resources and professionals that the organization used to educate the residents and families on the topic of romantic and sexual relationships. The supported living organization did contract out education on romantic relationships to other professionals for support. The staff and student residents were not experts on the topic and so they hosted other professionals to educate their residents whenever possible. Claire, the director, explained some of the outside resources they had utilized:

We've had the sex educator from Planned Parenthood talk to our folks about once a semester. And there's always some people who seem to be informed and some people who are really surprised. Some people who couldn't begin to say something without dying of mortification and somebody else who's not going to be thoroughly repulsed. The responses are like you would get with kids where the kids are like, "Ooh, girl or boy, I'm going to get cooties."

The outside resources also showcased the resident with IDD's understanding of the topic and how the professionals could support their understanding. Claire described some of the resources she recommends for her residents and their families:

Some stuff when it relates to romance and sex is anger management. And I found a clinical psychologist that I really like who has experience with IDD and who also has a subspecialty in anxiety and depression. And he's working with three or four of our folks. I've sent people for one-on-one sex counseling with Planned Parenthood. I'm not going to be the right person to talk about that because that's just not my job to go into how do you do it and how do you do it safely? And that's just detail that I don't want to misspeak.

These resources were considered a great addition to the more informal supports that the staff and student residents provided to the residents with IDD. One parent, Catherine, shared her son's experience learning more about safe, romantic relationships from an outside resource, "He even had a one-on-one conversation with somebody from Planned Parenthood. At one point I had set up for him for risk and benefits and, you know, things that can go wrong."

Offer Workshops and Classes

One staff member and three student residents discussed the workshops and classes that the organization provided on the topic of romantic relationships and how that programming influenced the understanding and behavior of the residents. These classes and workshops typically took place one evening each week and were structured for the residents with IDD (although any member of the community could attend). These classes addressed social

skills, independent living skills (e.g., cooking), employment skills, or any other relevant topic. Justin, the associate director, explained more about these classes and workshops:

In terms of teaching, we've done classes on like the specific, the biological, the kind of medical side of things in terms of, you know, pros and cons of, of entering the relationships, but then also like social dynamics. How do you talk to the person? How do you get to know them? You know, how do you initiate those conversations? And then what's appropriate when you're in a relationship.

Both the staff and student residents discussed how these workshops and classes could be structured to better support the needs of the residents with IDD. Justin discussed a new direction for the classes:

In the future, I mean, we've, we've talked a lot about the classes that are more practical medical and like the Planned Parenthood people and talking about birth control and talking about those kinds of things. But I think one thing that we would like to build more into, and especially as COVID now is letting up a little bit is kind of the social aspect of, you know, dances or date things and kind of like healthy places to meet people.

Others mentioned ways in which the classes and workshops may not be serving the residents with IDD in optimal ways. Tori, a student resident, shared:

I would say that there's been some effort to have those conversations in the Monday night classes, but the Monday night classes are not mandatory, which also creates some knowledge gaps among our friends. And like I said, like some of the conversations that they are having aren't necessarily helpful, which also undoes some of the good stuff. I think conversations that aren't happening are basic anatomy conversations too.

Organization Leadership

Two staff members and three student residents discussed how the organization approached policies surrounding romantic relationships. Some of these policies include when to intervene, call parents, or ask a resident to leave the organization. The organization's overarching leadership approach when it comes to challenges involving romantic and sexual relationships was to be responsive instead of proactive when monitoring residents and their safety. Claire, the director, described her philosophy:

And when one of my resident friends expresses interest or express curiosity about something, then I'll try to address it. I don't try to bring it up. I try to be responsive. So that's that I typically am responsive...So in the spectrum of ability that we have, you can't have rules. All of our guys are so different. And they are independent, and we don't tell them what they can and can't do. And it's not our business. The word

independent means independent. It's their life, not my life. And they can do what they want with their life. You just have to try to make it as safe and secure as you can.

Claire worked closely with the residents with IDD and their parents to facilitate a safe community and intervened only when she felt a resident was at risk. Some of the student residents also work closely with parents, while others felt it was an infringement of privacy. Yvonne, a student resident, shared how she handled a safety concern with a resident with IDD:

I call the parents because [they] probably know their kids better...[The director] told me that whatever I see in the house of the friends, the parents have seen them all. So the parents would be the expert of their kid's behavior. Right? So that day I called [the director] and I called parents just to have a better understanding of how I should approach this.

In contrast, Tori, a student resident, said:

I would never call their parents because that, unless they explicitly said they wanted their parents involved and I got their permission for that, I would never call their parents. Because that's not, unless they're being harmed or there's a reason to call their parents. That's not fostering their own independence and that's a breach of confidentiality to me.

As the organization continues to expand and evolve, the staff and student residents shared some of their goals for the future. Justin, the associate director, shared:

Yeah, I think one thing that I'm very passionate about right now is clear expectations and, and then being able to use those expectations for accountability purposes. And so really setting like clear boundaries where possible in terms of what, what the community needs or desires or can accommodate.

Suggest New Ideas

One staff member, two parents, three student residents, and five residents with IDD presented ideas for how the independent living organization and other organizations could improve their policies and programming surrounding romantic and sexual relationships for adults with IDD. Many of the participants shared their ideas for how the independent living program could improve in terms of offering more social opportunities for the residents with IDD to meet other adults with disabilities. Several of the residents with IDD mentioned planning a social event, such as speed dating or a formal dance. Yvonne, a student resident, gave her thoughts on the same idea:

One thing I can think about is to have maybe like speed dating night or something like those social, like those fun events where they can explore, you know, get to know each other, provide them space to develop like romantic relationships. I thought that'd be

fun. They just really need the opportunity to meet new people. I think that it just seems to me, their pool for dating is quite small.

Other participants mentioned the structure of the organization and how its mission could be strengthened by different types of support. Some residents suggested potential changes to the organization's policies or living arrangement. Tori, a student resident, shared her thoughts on adding more staff to the organization: "I think that the organization needs more support in terms of social workers, in terms of a special education specialist, in terms of a lot of things, independent living consultants."

Some of the participants also offered ideas for improving the education residents receive around romantic and sexual relationships. Abby, a student resident, proposed a shift in mindset regarding the way this topic is discussed in classes at the organization: "Sex ed, starting a romantic relationship, but like make it fun. I think setting the tone in an exciting way is also important. It's not just about precaution all the time."

Finally, two residents with IDD suggested how to structure a course on romantic and sexual relationships for the residents. Samantha recommended "a class that goes for multiple weeks. Just because there's a lot to talk about. And I think if you throw it all at us at one time, I would get overwhelmed." Emmett discussed several ideas for a sexual education class:

I don't know if they'd done this yet, but it would be nice if they got like an actual, like maybe grouped like one or two people like medical professionals to come to explain sexualities and the different ways kind of like a sex ed class, but for adults obviously some people who are going to be disabled.

Discussion

Individuals with intellectual and developmental disabilities have the right to romantic and sexual relationships just like any other adult. Romantic relationships provide companionship, support, and love that are crucial to the human experience [9]. This study explored the multiple perspectives on romantic relationships for adults with IDD. These staff, student residents, residents with IDD, and parents of residents with IDD raised many themes related to romantic relationships and the roles of supported living organizations in this area. These findings expand the research base on romantic relationships for adults with IDD in several ways.

First, this study illustrates how stakeholders view romantic relationships for individuals with IDD and their importance. All ten participants with IDD emphasized that romantic relationships were important to them. Likewise, parents, student residents, and staff all expressed positive views regarding the importance of romantic relationships for adults with IDD. The student residents discussed the universal need for love and connectedness and emphasized that residents with IDD must not be excluded from such experiences. It is imperative that supported living organizations consider the place and priorities of romantic relationships in the lives of their residents. Romantic relationships for adults with IDD should not be ignored.

Second, this study documented the various challenges that individuals with IDD can face in the area of romantic relationships. The interviews revealed a variety of beliefs and understandings that residents with IDD had developed over time and that were influenced by family, friends, and teachers. These beliefs and understandings involved saving sexual relationships for marriage, incorrect understandings of anatomy and sex, and how to give consent. It can sometimes be difficult to navigate differences between the belief systems of residents and their parents. The organization involved in this study promoted a supportive, positive outlook towards romantic relationships of all kinds that sometimes differed from what families espoused as the individual with IDD was growing up in their home. Just as past studies have shown that staff perspectives play a role in adults with IDD's decisions and lifestyle, the families of the residents also have an immense influence. Additionally, most residents with IDD came to the supported living organization with an incomplete understanding of safe sexual and romantic relationships. Therefore, it is important to connect residents to unbiased and accurate education related to romantic relationships. Another challenge discussed by many of the participants focused on difficulties related to the social skills needed to start and maintain romantic relationships. The residents with IDD identified their need for support learning social skills and gaining opportunities to practice the conversation skills needed for dating.

Third, this study identified a variety of tensions that may arise for stakeholders when supporting individuals with IDD in romantic relationships. Consistent with findings from Deffew et al. (2021), who interviewed day program and residential staff, the student residents and staff in the current study took a largely reactive approach to supporting their residents with IDD in romantic relationships, rather than a proactive approach. Staff at the independent living organization tended to respond to emerging challenges and safety concerns related to sexuality, rather than training the student residents in this area or developing regulations for scenarios that were likely to emerge. However, the student residents felt that organized training and education related to IDD would clarify their roles in this area and prepare them to face complex scenarios involving romantic relationships among adults with IDD. Striking the right balance between thorough preparation and relying on natural supports was an area of tension for independent living organizations supporting their residents in romantic relationships.

Many of the themes that emerged from this study related to those found in previous studies examining the roles of staff in supporting the romantic relationships of individuals with IDD, [3, 4, 6, 7, 9, 11], including dignity of risk, lack of training and education, and a variety of personal belief systems. These topics are tensions and challenges that also arose in our interviews. The right to dignity of risk and the organization's commitment to safety for all their community members is a significant challenge. Weighing the resident's with IDD's personal autonomy with safety can be difficult for staff, parents, and student residents; however, the participants supporting autonomy by providing ongoing education experiences for the residents with IDD. This may include classes on sexual education topics from experts, opportunities to practice social skills at speed dating or other social events, and open conversations with the staff and student residents.

Providing training to student residents could also help student residents and staff feel more confident in their conversations with and support of fellow residents with IDD. The student residents expressed their desire to support the residents with IDD in romantic relationships, but they

felt unprepared for some conversations or safety concerns that occasionally arose. Training may include role playing scenarios and education from an expert in sex education.

Fourth, the conversations with staff members, student residents, residents with IDD and their parents brought forth a multitude of recommendations for organizations that provide housing to adults with IDD. These included providing high-quality education on romantic relationships by outside experts and offering training for residents without IDD in this area. Other recommendations included providing opportunities for residents with IDD to meet other individuals with similar disabilities (e.g., social dances, speed dating etc.) since meeting individuals they may be interesting in dating was identified as a serious challenge for the residents. Overall, providing a positive environment in which residents with IDD feel comfortable coming to the other residents or staff for support in their romantic and sexual relationships was considered crucial. Open communication, increased education, and using outside resources could also help the organization avoid safety concerns and best support all residents in romantic relationships.

Limitations and Future Research

There are several limitations to the present study. First, the study explored the experiences of stakeholders from one independent living organization in a large, southern city. The organization serves individuals with IDD who can perform most daily living skills independently. Therefore, we did not speak to the perspectives of individuals with more complex support needs or communication challenges. The main support system at the organization is natural supports with the student residents and a few staff members. As a result, studies with a broader range of disability types and service providers may give a more complete picture of experiences and perspectives on romantic relationships within a variety of independent living organizations.

Second, the diversity of the sample was limited to the population served by this organization. Specifically, only one fourth of the participants were non-white. Studies with more diverse samples are needed (e.g., age, race/ethnicity, geographic location) in order to look at the associations between demographic factors and people's experiences and perspectives on romantic and sexual relationships.

Third, participants self-selected their involvement in the study and thus we heard from individuals with fairly positive views on romantic and sexual relationships. All the interviewed residents with IDD, student residents, staff, and parents supported romantic relationships for adults with IDD. Most conversations stressed the importance of supporting individuals with IDD to have successful, safe romantic relationships while living at the independent living organization. Future studies should look for a broader diversity of opinion.

Implications for Practice

This study has several implications for the field of disability services and special education. First, the findings should inform independent living organizations on possible approaches for supporting their residents with IDD in having safe romantic relationships. This may include offering classes and workshops for the residents, opening conversations between residents and staff/support individuals, providing residents their dignity of risk when it comes to romantic relationships, and using outside resources to support the residents' under-

standing of romantic and sexual relationships. Organizations should also have clear rules and regulations for romantic relationships and communicate those to all stakeholders.

Second, the study identifies suggestions for families as they support their adult children with disabilities in the area of romantic relationships. The parents suggested starting conversations on romantic and sexual relationships early with their children with disabilities in order to devote enough time to making sure the concepts are clearly understood. They also mentioned providing social outlets for children and adults with disabilities as much as possible to strengthen social skills and build a broad social network for their children. The parents we interviewed made it clear how important it is for parents to allow their child as much freedom as possible to explore many types of relationships and be given the chance to fail in order to learn.

Third, this study has implications for special educators in terms of providing sexual education and supporting their students through romantic relationships. Many of the participants with IDD remembered little from their sexual education courses or they never received any formal education at all on the topic. It is essential that thorough and engaging sexual education should be provided to all students regardless of disability. Alongside the facts of sexual education, teachers should provide social skills lessons to support their students in meeting new people and navigating social networks. The participants with IDD in the study referenced difficulties with social skills especially when it comes to meeting people they may be interested in dating.

Conclusion

This study provides new insight into romantic and sexual relationships for individuals with IDD living in supported independent living. Although many questions arose from this research into experiences and perspectives regarding romantic relationships for individuals with IDD, many participants affirmed that providing education and support on this topic is imperative for adults with IDD. All adults have the right to experience love and companionship yet adults with IDD have been systemically excluded from that part of life. Given the proper environment and support, individuals with IDD regardless of their needs and challenges can experience successful, safe romantic and sexual relationships.

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Ethics Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki

Declaration and its later amendments or comparable ethical standards. The study was approved by the IRB Committee of Vanderbilt University (No. 210648).

Consent to Participate Informed consent was obtained from all individual participants included in the study.

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