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Heidi Adams Rueda

Anne Woodruff Jameson

Maggie Neujahr

Amber Godsey

Lynda Hayes

See next page for additional authors

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Authors

Heidi Adams Rueda, Anne Woodruff Jameson, Maggie Neujahr, Amber Godsey, Lynda Hayes, Jessica Johnson, Sam Montemarano, and Carly De Bruin

Sexual Health and Dating with Disabilities: Understanding the Perspectives of Parent Resource Coordinators (PRCs)

Collaborators:

Grace Abbott School of Social Work at the University of Nebraska, Omaha:

Heidi Rueda, MSW, PhD John E. Christensen Community Chair in Child Welfare

Munroe-Meyer Institute:

Woodruff Jameson, Anne, PT, DPT, Physical Therapist

Neujahr, Maggie, CSW, Care Coordination Program, Manager

Godsey, Amber J, MSW student, Specialty Program Operations Supervisor

Hayes, Lynda, PhD, Assistant Professor, Department of Psychology

Johnson, Jessica, CSW, Care Coordination Program

Montemarano, Sam M, MOT, OTR/L, Occupational Therapy

De Bruin, Carly A, MPA, CTRS, Department of Recreational Therapy

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BACKGROUND :



Young people with disabilities have unique needs concerning dating and sexuality compared to their peers without disabilities. Research supports that young people with intellectual and developmental disabilities (I/DD) desire more education and support. However, young people with I/DD often lack formal and informal sex education and dating information. Despite these barriers, youth with disabilities report feeling empowered when they receive information on sexual and dating health, and when they are included in discussion with community members, family, and close friends about their dating and sexual wants and needs.

This study responds to the need to better understand how to support parents/caregivers of youth with I/DD with regard to sexual and dating health by asking them directly about what they want to know, what they feel youth should know, and how to implement community-based sexual health and dating programming that would support both parents/caregivers and their youth with I/DD.

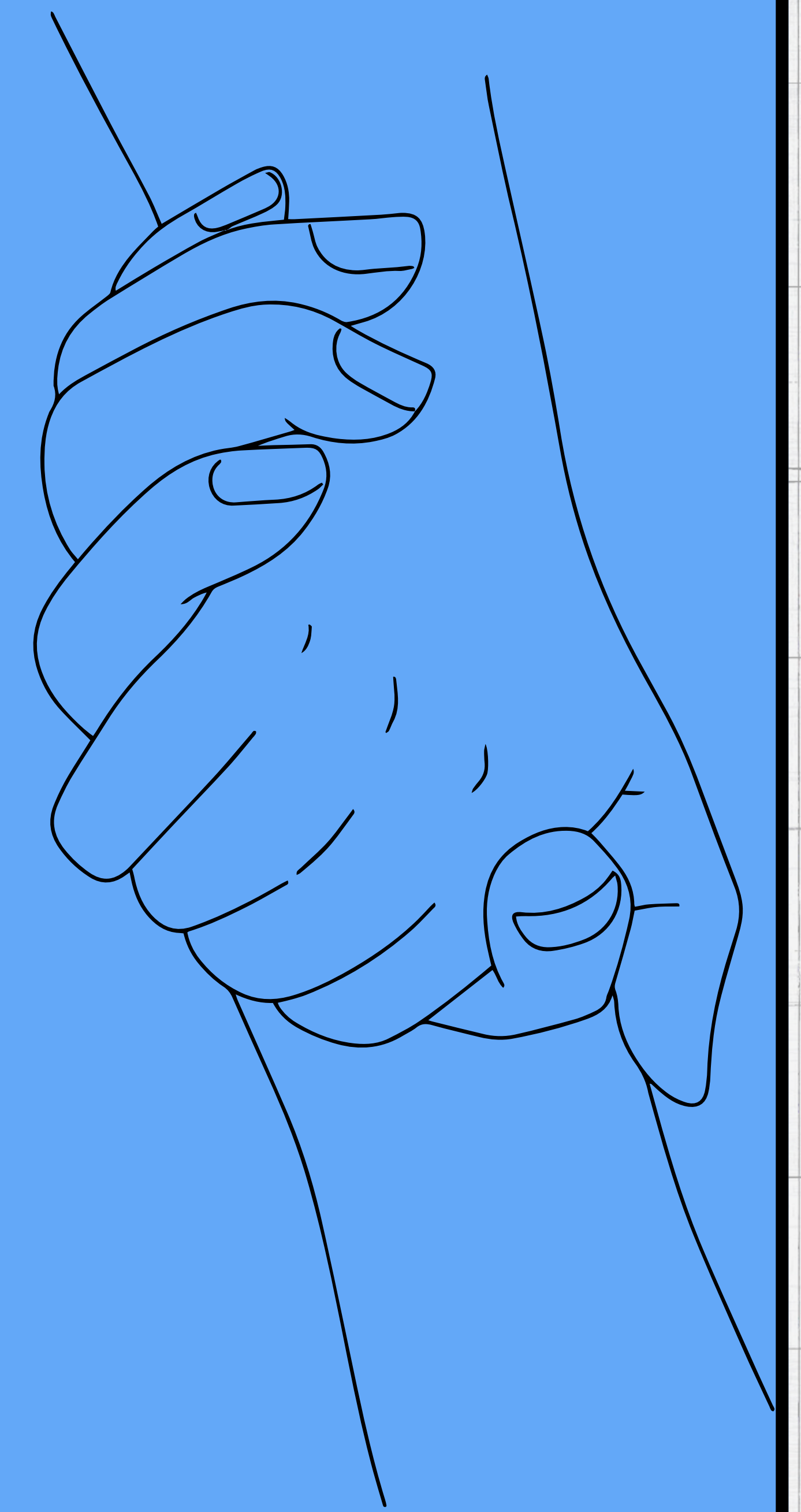
Methods

To answer our research questions, we interviewed Parent Resource Coordinators (PRCs; N=11 females; 73% White); these were mothers of adolescents or young adults with I/DD (Mchild age=18.85; SD= 5.49) who also worked for the Munroe-Meyer Institute to provide a wide range of disability support to other families in the community. In-depth semi-structured interviews were held on zoom, digitally recorded and transcribed verbatim. Key questions pertained to supporting youth in their sexuality and dating, with the aim of providing the agency with recommendations for program enhancement and development. We analyzed data using inductive content analysis, which aims to categorize and summarize persistent, recurrent, and meaningful themes across participant interviews.

Demographics Table

Table 1. Caregiver Demographics

Caregiver	N=11	%
Age		
20-29	1	9%
30-39	1	9%
40-49	4	36%
50+	5	45%
Race		
Hispanic/Latino	1	9%
Biracial	2	18%
White	8	73%
Educational Background		
Some College	2	18%
Bachelor's Degree	9	81%
Master's Degree	2	18%
Gender		
Female	11	100%



RESULTS:



The following themes emerged from Parent Resource Coordinator (PRC) interviews:

1.) PRCs perceived a number of advantages to dating for youth with I/DD.

2.) PRCs described specific topics that they felt should be taught about dating relationships to youth with I/DD.

3.) PRCs described specific topics that they felt should be taught about sexual health to youth with I/DD.

5.) PRCs voiced a number of desires that would help them to support youth with I/DD to live fulfilling lives inclusive of dating and sexual considerations.

4.) PRCs offered a number of ideas and recommendations for how dating and sexual health programming should be formatted, framed, and targeted to diverse youth with I/DD.

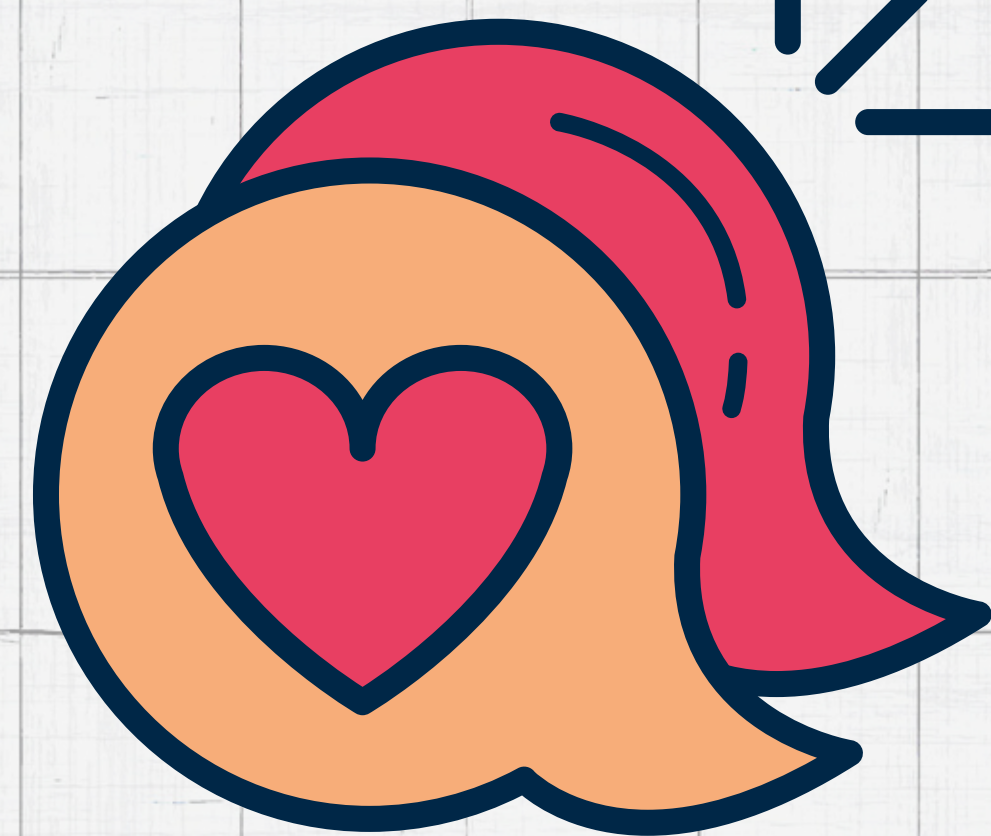
6.) PRCs listed a number of existing resources and sources of support with regard to dating and sexual health for youth with I/DD and their families, and also voiced a need for further resources.

"We all want to be loved and whatever that might look like for each individual is different. But I would like for my daughter to experience that to whatever extent is right for her."

"It's getting the chance to do things that most other people around him are doing. And to feel, you know, like he's not made different by his disability and that he can do those things just like anybody else."

"I just would hate for people to feel isolated or lonely or depressed and just to feel like they have no place in the world."

BENEFITS OF YOUTH DATING



"Their mental health would be, they would be happier, they would feel more like any other person, it's their right, it's just living a more fulfilling life."

"Meet others, interact, go to new spaces, kind of just open your eyes a little bit about other ways of life, and connecting with another family as well..."

"Building intimate relationships can just like kind of add a layer of, you know, interaction and enjoyment and experience to his life that I think is really great."

"We all are like hardwired to have that connection and to have belonging. And so the same reasons that anybody else would want to have a relationship that's what she would want too."

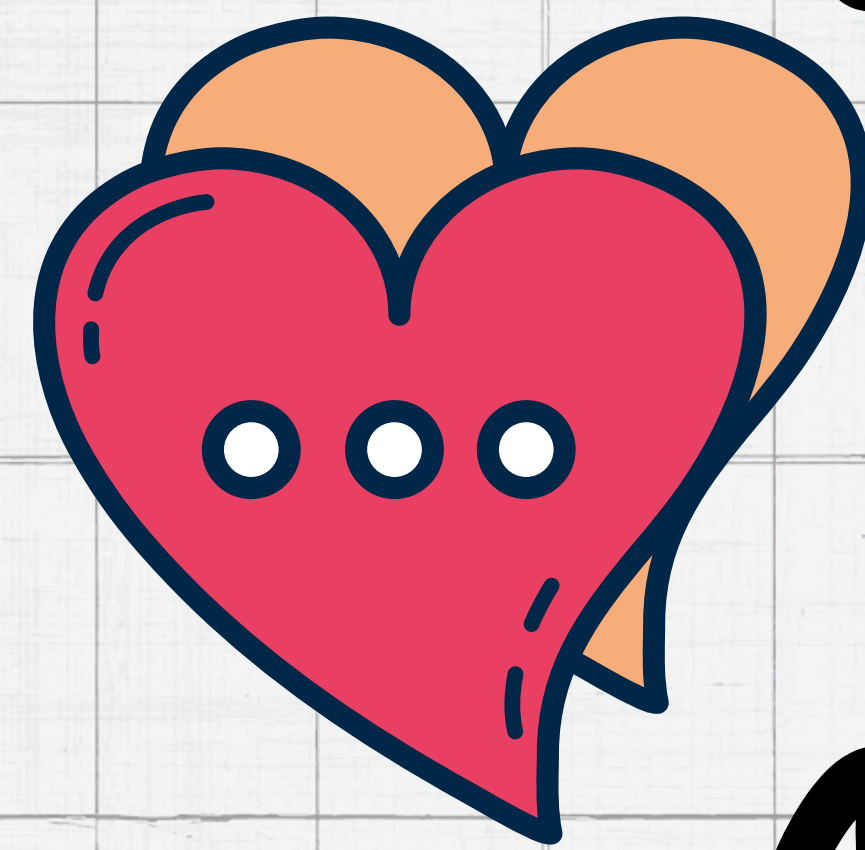
"...And just having that companionship, someone that you can count on, that you can talk to about the interests that you like, and just really be there to support each other."

"I've seen kids with intellectual disabilities who are dating someone and I can tell that they don't know the social norms of when to touch or where to go or how to keep it private."

"And then I'll hear, you know, even my kids' friends talk about, well, I'm gonna, you know, meet them in real life and you're like, not by yourself, right?"

"I think it's important to maybe talk about expectations of how a partner would treat another partner."

"Some people can take advantage of you, some people don't have the best intentions, and then at the same time there are other people who truly want a genuine relationship."



WHAT SHOULD BE TAUGHT ABOUT DATING

"But I do hear a lot about online dating and that it scares me immensely... when you don't see anyone, you have no idea who the other person is on the other end."

"And so, I struggle 'cause I'm like, you know, are you picking the person that's the right fit for you? Are you just picking a person? So, I think trying to think of like, you know, what does he want? You know, what does he value?"

"So many times individuals with disabilities are taught to comply, to do what they're told, to not push back...they need to be able to make decisions and understand that those decisions and views and wants and needs are respected."

"They don't talk about those things with them. They just talk about general things, okay, be kind to your friend, but they don't talk about romantic relationships very much."

"You know, we want them to be part of social groups and everything else. But then, you know, sometimes they don't know the boundaries between what's right and wrong."

"I will say that she has pretty significant intellectual disability, so I don't know that she would know or comprehend a lot of any kind of information. I think more of it would just be keeping her safe and protected."

"We have students that kind of represent all along the spectrum right, as far as in regards to their sexual identity or gender identity. So I think that that's important."

WHAT SHOULD BE TAUGHT ABOUT SEXUAL HEALTH

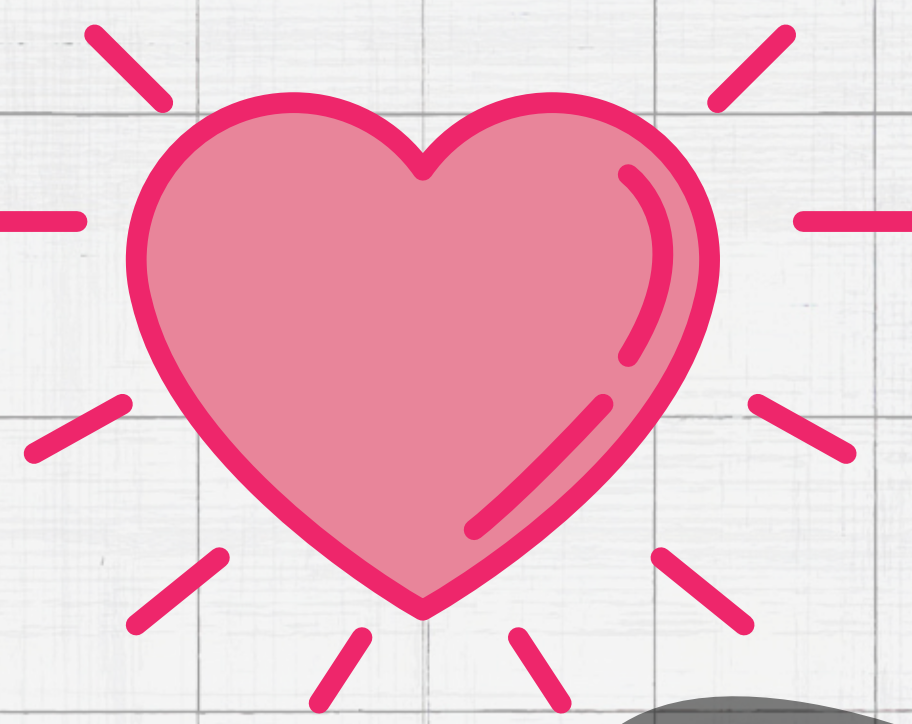
[Asked about anatomy and personal hygiene]
"Everything. Like, they should know everything."

"Just depending on abilities that I think that-just the yes or no factor would be a great thing to get across as far as consent goes."

"How important it is to, you know, have an opportunity to talk about it before it becomes a problem and then you're doing everything reactive versus proactively."

"And I think in- there's a big push in disability sex education to kind of, we want to keep our kids safe, which I agree, that's my number one goal too. But then we don't look much beyond that."

[asked about masturbation]
"I think that they should be taught that it is not something that's shameful or, you know, dirty or anything like that. I think the important pieces to talk about the public versus private spaces."



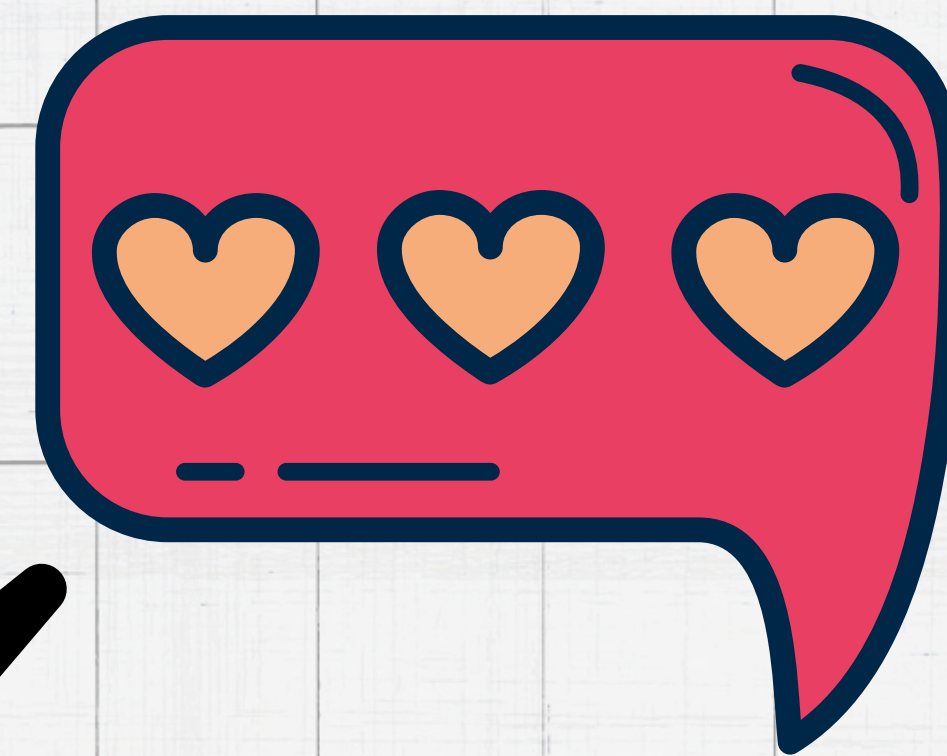
"But to me knowledge is power and to provide enough as much of that as we can to each individual when and how they are ready for it, regardless of if they have I/DD or not."

"It feels that a lot of the parents would prefer someone else to do it...I think the parents don't have the tools and are unsure of how to begin the conversation."

"I think questions are probably one of the biggest things, just a chance to ask because especially at that age, we don't know what they don't understand yet."

RECOMMENDATIONS FOR FORMAT AND FRAMING

"I think that like at least initially also a one-on-one consultation could be really good, especially thinking about him."



"I think group would be great because then they're able to interact and physically see other people, you know, others their age, kind of going through the same things."

"So maybe focusing in a situation where they actually bridge that connection and help them create those relationships with people that are really going to, that realistically can become their partner."

"I definitely think a small group is better than like a classroom-sized group. So, um... I think folks with I/DD do better in person rather than virtually."

"And then I think based off of that group, if there's some individuals that need a little bit more assistance or just need to work through something a little longer, then I think that's when the individual classes would come in hand."

"I know as a human, she has, she is a sexual being that is part of being a human being. I think for me, it would be how do I help her navigate that appropriately?"

"Because she wouldn't- she would not be able to make informed decisions. She would not be like, with the level of her disability. What would a relationship look like for her? What would a healthy, safe possibility look like for her?"

"Or even just with dating... it's like, how do you, you don't want to, you know, fix him up with anybody, you just kind of want it to happen naturally. But how do you get to that point?"

"I mean, that's, you know, it's hard. What her needs as a human being are and my needs to keep her safe and protected when I know she's at risk."

WHAT PARENTS NEED TO HELP YOUTH



"And I think it's, parents are wanting to try to learn how to navigate this because we don't know what the hell we're doing."

"I would definitely say my top is to be as informed as I can about sexual abuse or how do I, what are the signs? What do I need to watch for?"

"I think that's as he's growing up more it's just like a question mark of how do we make sure we're aware of what he's watching, that we can help him process it."

"But what if he asks, well, I do want to have kids, how do you say that that might not be a possibility for him?"

"I think it would be really helpful to have something to sort of help guide parents on how to have some of those conversations."

"And I think a lot of times parents just need like reassurance that like it's okay or just tips and tricks on how to manage even like social media with them."

"I've seen some programs that they're called, dating, speed dating or things like that. And I feel like, I don't know, I just wish I had more information about those."

CURRENT AND DESIRED RESOURCES

"I would really like to see maybe even like peer groups that could have discussions, have somebody lead some discussions, give out some good information, answer very frank questions."

"Parents want to share their information with their young adults, but then also having another place where they could be reminded of being a young adult and what goes along with that too, I think would be good."

"I wish there were more opportunities or awareness of like mental health counselors or therapists who work with people with intellectual disabilities, like that's not a list that's really out there."

"I don't think I ever found like written material that could help me figure out strategies of how to do this. It was all like on the job, learn by doing kind of a thing or talking with other parents who had kids in the same age range."

"But we want other children, other parents not to have to struggle to get all that information for their children, you know, get the information to pass on the information, the kids to get some of that information."

IMPLICATIONS AND NEXT STEPS:



Although parents/caregivers struggled to tailor sexual and dating health education to their child's needs, they viewed the provision of this education as important to supporting youth with I/DD towards well-being, development, and mental health.

PRCs voiced a number of important considerations for what should be taught to youth with I/DD pertaining to dating and sexual health, as well as how to support parents and caregivers.

The next steps of this research are 1.) to discuss research findings as a collective and 2.) determine how these results may be used to inform further research efforts and/or existing programming efforts at MMI.

For questions about this study, please contact Dr. Heidi Rueda at hrueda@unomaha.edu