

**Critical Need for Sexual Health Education
about Healthy Relationships
and Sexual Self-Advocacy
among Women with Intellectual and
Developmental Disabilities
in Indiana**

Focus Group Final Report

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INDIANA INSTITUTE ON DISABILITY AND COMMUNITY
CENTER FOR HEALTH EQUITY

Critical Need for Sexual Health Education about Healthy Relationships and Sexual Self-Advocacy among Women with Intellectual and Developmental Disabilities in Indiana

FOCUS GROUPS FINAL REPORT

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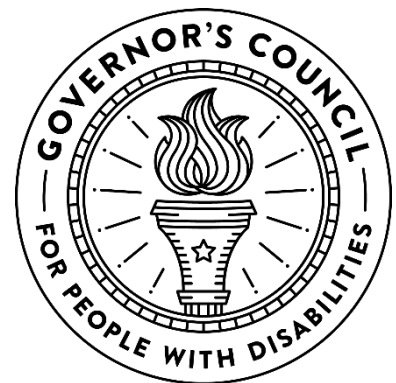


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INDIANA INSTITUTE ON DISABILITY AND COMMUNITY
CENTER FOR HEALTH EQUITY

EXECUTIVE SUMMARY

In November and December 2019, the Center for Health Equity at the Indiana Institute on Disability and Community at Indiana University-Bloomington conducted three focus groups to better understand the sexual health needs of adult women with Intellectual and Developmental Disabilities (IDD) in Indiana. A total of eight adult women with IDD participated in two focus groups, and three parents (all mothers) of women with IDD participated in another focus group. Women with IDD who participated in the focus groups were not daughters of the mothers participating in the parent focus group. Focus group discussions revealed two primary themes, both of which included several subthemes.

THEME 1: Women with IDD received little formal sexual health education, had fairly negative views of sex, and reported a number of negative sexual health experiences.

■ **Women with IDD received little formal sexual health education, and their knowledge related to healthy relationships was particularly lacking.**

One of the sexual education topics women with IDD said had been taught in school concerned birth control. Because formal opportunities for sexual health education for women with IDD were limited, they instead

learned from their families, from watching television, and from their direct experiences, which included relationships.

■ **Women with IDD were often involved in unhealthy relationships. While this may be partially related to insufficient knowledge about healthy relationships, it's also likely a result of cultural norms and societal treatment of women and individuals with IDD.**

Women with IDD discussed how they needed to “be safe” and make sure they “get to know someone” before getting too involved with them. Parents shared that, in the past, their daughters had easily “fallen for” someone who gave them attention, and then labeled this attention as “love”. They also recognized that their daughters had been manipulated or taken advantage of by others. Although women with IDD did not reference cultural norms and societal views of people with IDD as direct causes of aggression and violence towards them, it's important to note that they recognized they were often treated differently and expected to behave differently than other women their age.

■ **Women with IDD reported negative views of sex and negative sexual experiences, including assault and teenage pregnancy.**

Overall, women with IDD expressed a number of negative views of sex and

sexuality. In several instances, sex was portrayed as dangerous, and something that led to disease. Several women with IDD directly acknowledged they had been victims of sexual assault. In addition, there was a notable absence of conversation among women with IDD around the idea that sex could be pleasurable, or that women should self-advocate in order to feel satisfaction within a sexual context. Parents of women with IDD also described episodes of sexual assault their daughters had experienced. In their descriptions, they suggested that their daughters had often known, and in some cases had relationships with, the perpetrators of these incidents.

■ **Women with IDD lacked information on the rationale for, and procedures related to, preventive screenings, and how to advocate for themselves in the healthcare setting. They reported infrequent screenings and negative experiences.**

It was apparent that few of the women with IDD had received sexual health screenings on a regular basis. Some of the women acknowledged that they had avoided seeing health care practitioners for sexual health screenings due to fear or previous negative experiences, including poor treatment by healthcare providers. It was notable that women with IDD did not describe their interactions with healthcare providers to include self-advocacy. For example, they did not

mention if they had been able to ask questions or state their preferences during screenings.

THEME 2: There is a critical need to teach women with IDD about healthy relationships and to provide opportunities for them to develop healthy relationships.

■ **Self-Advocacy skills are needed for women with IDD to be in healthy relationships.**

Women with IDD reported that self-advocacy and communication are important skills that would benefit themselves and other women like them. Parents shared concerns that their daughters would continue to be “taken advantage of” by others, and that they lacked the knowledge and skills to recognize disingenuous intentions of men.

■ **Women with IDD need opportunities to develop healthy relationships.**

Parents of women with IDD wanted their daughters to have genuine companionship and opportunities to develop relationships that are healthy and mutually supportive. In addition, they recognized that opportunities to socialize with similar-aged peers were often limited after graduation from high school. Parents of women with IDD also recognized the challenges of helping their daughters navigate romantic relationships, sexual health, marriage, and the desire to have children.

RECOMMENDATIONS FROM FOCUS GROUP PARTICIPANTS: Content & Delivery Strategies for Sexual Health Education for Women with IDD

Suggested Sexual Health Topics

Topics suggested by women with IDD included learning how to assertive (or “strong”), protecting yourself by not giving out personal information, communication skills (including body language), being able to say no (assertiveness skills), hygiene, reasons for abstinence, and how to use birth control. Parents’ suggestions included safety, healthy relationships, using social media responsibly, and exploration of different types of relationships. Parents noted that their daughters needed to learn about healthy relationships in general – not just romantic relationships. After high school, many saw their daughters become more isolated from peers their age, and they didn’t know how to help them form friendships.

Ideal Learning Environments for Women with IDD

Women with IDD recognized that their peers may not feel comfortable asking questions or sharing ideas about sensitive topics such as sexual health. Therefore, they suggested that trainings should include opportunities to ask questions and share ideas anonymously. Women with IDD also noted that individuals with disabilities may require more time to genuinely

understand certain concepts or they may need additional clarification, and that they preferred learning environments that “didn’t feel like school”. They commented that facilitators should “make it fun, but still serious”, hold group discussions, include breaks, and use language that normalizes sexual concepts. Visual learning strategies were preferred by a couple of the women with IDD, as well as by parents of women with IDD. Parents of women with IDD also encouraged the research team to consider online modules, in-person sessions limited to 1-2 hours, and smaller in-person training groups (including no more than 2-3 people).

INTRODUCTION

In November and December 2019, the Center for Health Equity at the Indiana Institute on Disability and Community at Indiana University-Bloomington conducted three focus groups to better understand the sexual health needs of adult women with Intellectual or Developmental Disabilities (IDD) in Indiana. Two focus groups included adult women with IDD, and a third focus group included parents of adult women with IDD. Participation in the focus groups was completely voluntary, and participants were recruited through outreach efforts to disability organizations, disability advocates, and state agencies. Financial assistance for the project is provided by the Indiana Governor's Council for People with Disabilities.

OBJECTIVES

The findings of the focus groups will be used to inform the development of training sessions to help Hoosier women with IDD learn about their sexual health. In addition, the trainings will be designed to help Hoosier women with IDD to advocate for their sexual health needs. Each focus group included the same discussion topics, and questions were modified slightly for parents of women with IDD. Focus group topics of discussion included:

- **When and from whom did women with IDD first learn about sexual health?**

- **What kinds of experiences have women with IDD had with romantic relationships?**

- **What problems have women with IDD faced in receiving health care related to sexual or reproductive health** (e.g., gynecological exams, mammograms or Pap smears).

- **How have women with IDD learned to advocate for themselves, and what do other women with IDD need to learn about self-advocacy** (e.g., communicating needs to their partner, their family, or their doctor).

- **What are the most important topics to include in sexual health education for Hoosier adult women with IDD?**

- **In which ways do women with IDD learn best** (e.g., viewing pictures, reading text, watching videos, having discussions).

METHODOLOGY

Participant Recruitment

Preparation for participant recruitment began in late July and August 2019. Potential participants for both the parent and women with IDD focus groups were identified by consulting with stakeholders, including disability and disability advocacy organizations, as well as government agencies. A total of 17 organizations were initially consulted for assistance with the project:

- The Indiana Governor’s Council for People with Disabilities
- Indiana Bureau of Developmental Disabilities Services
- The Arc of Indiana
- Self-Advocates of Indiana
- Easterseals Arc of Northeast Indiana (Fort Wayne)
- Rauch, Inc. (New Albany)
- Sky Point Service (Fort Wayne)
- Partners in Autism (Fort Wayne)
- Passages (Columbia City)
- Pathfinders (Huntington)
- Easterseals Crossroads (Indianapolis)
- Village of Merici (Indianapolis)
- Noble, Inc. (Indianapolis)
- accessABILITY (Indianapolis)
- Down Syndrome Family Connection (Bloomington)
- Stone Belt Center (Bloomington)
- LIFEDesigns, Inc. (Bloomington)

The final stages of the recruitment process occurred over four weeks, beginning in late October when locations and dates for the groups were finalized. Through contacts with the organizations listed above, Easterseals Arc of Northeast Indiana (Fort Wayne), and Easterseals Crossroads (Indianapolis) emerged as

willing partners for recruitment and meeting space. Although targeted locations were all cities, the research team attempted to reach potential participants in surrounding rural counties as well.

Following approval from Indiana University’s Institutional Review Board (IRB), project staff provided each organization with IRB-approved information sheets that described the project and the purpose of the focus groups. Several organizations then provided project staff with contact information for potential participants (who had all agreed to have their information shared with the project team). Prospective participants were contacted by a member of the project team via email or phone, using IRB-approved scripts. Project staff confirmed with them that they met the inclusion criteria and understood the purpose of focus groups. Project staff encouraged adult women with IDD to consult with their friends, family, or trusted caregivers prior to making decisions about participation. When potential participants agreed to attend a focus group, they were sent IRB-approved consent forms and encouraged to contact the Center with any questions.

Recruitment Challenges

Overall, recruitment for the Indianapolis and Bloomington focus groups resulted in fewer participants than desired. The Indianapolis focus group location for women with IDD proved challenging for transportation, and two potential participants could not participate because they did not have staff available to assist them with transportation, or they were unfamiliar with the bus system. A second challenge to recruitment was likely related to the subject matter of the focus groups. Many eligible women with IDD were reluctant or altogether unwilling to speak openly about sexuality in a group setting. Feedback from a recruiting partner in Fort Wayne supported this hypothesis. Additional barriers to recruitment may have been the time of day the focus groups for women with IDD were scheduled (2:00 pm). Fort Wayne agency contacts reported that several interested participants worked during the day and were therefore unable to attend.

Recruitment for the parent focus group was also challenging, and low recruitment numbers resulted in a week's postponement. Scheduling the parent focus group near the Thanksgiving holiday season was also likely a barrier to higher levels of participation. Staff members at agencies supporting parent recruitment also reported that parents appeared reluctant to discuss the topic of sexuality as it related to their daughters. Initially, the research team

had targeted only parents of adult women with IDD for these focus groups, but later broadened the recruitment criteria to include parents of high school age girls in order to increase the number of potential participants. The focus group was scheduled in the evening (at 6:30 pm) in order to allow working parents to attend.

Participants

Overall, eight adult women with IDD participated in the focus groups, three of whom were in their 20's, two of whom were in their 30's, and three of whom were in their 40's. Among the adult women with IDD, all had an intellectual disability. Additional disabilities were identified for three participants: autism; hearing impairment; ADHD and PTSD. All parents of women with IDD were women between the ages of 50-64. Their daughters were not participants in the focus groups for women with IDD. Participants in the parent focus group all had daughters who were 25-39 years old. Their daughters' disabilities included developmental disability, mild mental disability due to epilepsy, and autism.

Given the significant challenges with recruitment, it is possible that participants may not be representative of all women with IDD and all parents of adult individuals with IDD. Instead, it is likely that focus group participants are more vocal about their opinions and more willing to talk about topics

related to sexual health. It is also possible that focus group participants are more active in addressing issues related to sexual health in their own lives.

Focus Groups

Two focus groups included adult women with IDD, and a third focus group included parents of adult women with IDD. Participation in the focus groups was completely voluntary, and participants were provided with a \$30 electronic gift card as a token of appreciation. All focus groups were facilitated by a female Research Associate from the Center for Health Equity. She was assisted by a second female Research Associate from the Center who served as the co-facilitator. Focus group sessions were held in conference and/or meeting rooms that provided confidentiality and quiet environments. Upon arrival to the focus group, participants were greeted by the facilitators and provided with a handout that provided an overview of the topics included in “sexual health”. The handout for women with IDD was illustrated with explanatory drawings. Participants were given time to review the handout before the discussion began. Each focus group was audio-recorded and transcribed later for the sake of accuracy, with consent from the participants.

Focus Group Dates and Locations

The three focus groups were held on the following dates at the following locations:

- November 21, 2019
Easterseals Crossroads, Indianapolis. This group included two adult women with IDD.
- November 25, 2019
Easterseals Arc of Northeast Indiana, Fort Wayne. This group included six adult women with IDD.
- December 9, 2019
Indiana Institute on Disability and Community, Bloomington. This group included three parents of women with IDD.

KEY FINDINGS

Main Themes

Focus group discussions among women with IDD and parents of women with IDD revealed two primary themes, both of which included a number of sub-themes. A summary of the themes and sub-themes is presented in the pages that follow, along with relevant quotes from focus group participants. In addition, focus group participants provided a number of useful suggestions related to the content and delivery of sexual health education to women with IDD in the future. A summary of those suggestions is also presented below.

THEME 1: Women with IDD received little formal sexual health education, had fairly negative views of sex, and reported a number of negative sexual health experiences.

1a: Women with IDD received little formal sexual health education, and their knowledge related to healthy relationships was particularly lacking.

Women with IDD reported that they had received little formal sexual health education, especially from schools. However, one of the sexual education topics women with IDD reported was taught in school concerned birth control:

“It was the sex video. So, like just how to be safe when having it and all of that goody two shoes. Making sure

you're on birth control and stuff like that.”

“Yes, to learn how to put on a condom on the guy, if they didn't know how to put one on, I guess, I don't know. [Laughter] Or birth control, learn about birth control too, yeah.”

Because formal opportunities for sexual health education for women with IDD were limited, they instead learned from watching television, even though they acknowledged that perhaps it wasn't an ideal source of information:

“I learned it on TV which is kind of like a bad thing to know now, but...my family didn't even talk about it. So, growing we didn't even talk about it...I learned about it on TV shows that I watched.”

Women with IDD also reported learning about sexual health and relationships through their direct experiences, including their relationships. At several points during the discussions, they described these past relationships as “bad” even though they recognized they had learned from them (more information on unhealthy relationships is presented in the next section).

Parents of women with IDD reported that the information their daughters learned in school related to sexual health was limited, and did not include information specific to women with IDD:

“... I'd say the school had some, you know, just like the period type starting things. But as far as actual sex, they didn't really teach it.”

“I found very little, very little that was suitable for someone like my daughter. And so, it was very discouraging. And I talked to teachers, and they said, ‘We haven't been able to identify really great materials either. We use these books from the library that are for young girls and during puberty.’ But those are totally not adapted for special needs people who, like my daughter, who are not able to read and not able to grasp what's being addressed there.”

As a result, many parents of women with IDD took responsibility for teaching their daughters about sexual health:

“...at different stages of her life, as she matured, I gave her the information she needed, you know, and I explained it to the best of her understanding, that what was going to be happening with her body and how she had rights over her body and how certain things had to be kept privileged and confidential and not shared with others, particularly males.”

“I did get an anatomy book and brought it home for my own daughter and I explained male and female anatomy...So, I had to do it myself.”

1b. Women with IDD were often involved in unhealthy relationships. While this may be related to

insufficient knowledge about healthy relationships, it's also likely a result of cultural norms and societal treatment of women and individuals with IDD.

Women with IDD were aware that they had been overly-trusting of men in the past, and they discussed how, in the future, they needed to “be safe” and make sure they “get to know someone” before getting too involved with them.

“I've had 15 relationships and I've -- all of them have been bad except the current one I'm in right now.”

“[M]ine (my boyfriend) was pretty controlling. So, -- I mean, I told him to stop and he wouldn't listen so, and he kept doing it. So, mine was kind of hard to do. So, I had to get my parents involved and stuff like that.”

Parents were concerned that, in the past, their daughters had easily “fallen for” someone who gave them attention, and then labeled this attention as “love”. One parent expressed this by commenting:

“... she's so trusting with every boy that comes in and says, ‘Oh, I like your hair today. You look nice today.’ She's in love. I mean, they're going to get married in two months, you know. I mean, that's love to her when somebody gives her a compliment.”

Although parents acknowledged that their daughters may have been somewhat naïve in the past about what healthy romantic and sexual

relationships should look and feel like, they also recognized that their daughters had been manipulated or taken advantage of by others, some of whom were disabled, and some who were not disabled.

“... the people that molested my daughter were disabled. But they function up here and my daughter is down here. And they knew just what to say and do. They already knew that...”

“Once she [my daughter] got out of school and just got to working and was out in the workforce then...she always seemed to pick the ones that treated her like dirt...in fact, I know for a fact that she's been raped, she's been abused, she's been hit. You know, we've had a sheriff investigate. But we can't get [my daughter] to stand up and say, 'This was wrong'...she says, 'But he loves me, mom, he loves me. That's why he did it, he loves me.’”

Although women with IDD did not reference cultural norms and societal treatment of individuals with IDD as direct causes of aggression and violence towards them, it's important to note that they recognized that they were often treated differently and expected to behave differently. As such, women with IDD acknowledged societal views and cultural norms as having an impact on their experiences. In several different instances, women with IDD articulated that, just because they were different, didn't mean they should be denied the experiences available to all others:

“I told her I'm like, we just like normal people. Just do things differently, you know, we need how to speak up for ourselves, we do the same things that you do. Like we can get married, we can have family, we can have a job. We just do things differently.”

“Hey, we're just like you guys, but we just do things different. We have a right to get married, have kids, have a job, learn how to drive a car.”

1c. Women with IDD reported negative views of sex and negative sexual experiences, including assault and teenage pregnancy.

Overall, women with IDD expressed a number of negative views of sex and sexuality.

In several instances, sex was portrayed as dangerous, something that leads to disease. In addition, there was a notable absence of conversation among women with IDD around the idea that sex could be pleasurable, or that women should self-advocate in order to feel satisfaction within a sexual context.

“Because some people should not have sex. Some people should not have sex. That's breaking the rules.”

“Don't have sex, get disease in you, and pray about it to God.”

Several of the women with IDD also directly acknowledged they had been victims of sexual assault:

“I have been through abuse, sexual assault, when I was young.”

“After I was raped, my mom talked about like [inaudible] you did [inaudible] like HIDs and all this other stuff and infections and all that stuff.”

Although it was unclear how common this experience was among women with IDD, at least one focus group participant described her experience with pregnancy when she was a teenager:

“I got pregnant when I was 17. When I had to baby, he was only 3 or 4 months, I mean 3 or 4 pounds when he was born. And he was put into an incubator, his lungs didn’t develop properly, and he die, and I haven’t had another kid since...it’s hurt me all my life...”

Parents of women with IDD also described episodes of sexual assault their daughters had experienced. In their descriptions, they suggested that their daughters had often known, and in some cases had relationships with, the perpetrators of these incidents:

“Later when she [my daughter] got to high school, there were a couple of incidents where boys were very aggressive and actually took advantage of her sexually, not intercourse but they managed to get her into dark spaces at the high school and touch her private parts.”

“And then the one boy that I know raped her (my daughter) but I can’t get her to say it...”

1d. Women with IDD lacked information on the rationale for, and procedures related to, preventive screenings, as well as how to advocate for themselves in the healthcare setting. They reported infrequent screenings and negative experiences.

When women with IDD were asked about their experiences with sexual health screenings and preventive care, it was apparent that few of them received sexual health screenings on a regular basis. Some of the women acknowledged that they had avoided seeing health care practitioners for sexual health screenings due to fear or previous negative experiences:

“No, I have not been for a pap smear or anything like that because I have a fear of doctors going in there...And also, you don’t have to go unless you’re super, super, super sexually active and I’m not super sexually active.”

“I had a very nasty incident happen when I recently had my last pap smear. The doctor was a gentleman and he snapped at me inside of my private area with the pap smear. A very painful, I cannot, I had to leave for a whole week, I had to stay home.”

Several of the women with IDD reported they hadn’t been treated well by healthcare providers during earlier screening experiences, and a few noted they felt more comfortable with female practitioners rather than male practitioners. Although this preference

was not explained by all of the women who noted it, one of the women recounted a negative experience with a male doctor:

“[W]hen I was like 17 or 18, I had a male doctor but he kind of just shoved the metal thing up my out my thing and it wasn't very pleasant. And, so then I got a female doctor and ever since I've seen a female instead of a male.”

When asked if they had been told why they needed sexual health screenings or whether the exam procedures had been explained to them prior to their appointments, some of the women reported the screenings were related to “cancer prevention” and “birth control”. However, none of the women said that details of the specific procedures had been explained to them prior to their appointment.

During the focus groups, it was notable that women with IDD did not describe their interactions with healthcare providers as including self-advocacy. For example, they did not mention if they had been able to ask questions or discuss their preferences during screening visits with healthcare providers. As such, it is possible that some of the experiences reported by women with IDD would have been less negative if the women had been able to express their preferences and feelings to their healthcare providers.

THEME 2: There is a critical need to teach women with IDD about healthy relationships and to provide opportunities for them to develop healthy relationships.

2a. Self-Advocacy skills are needed for women with IDD to be in healthy relationships.

Women with IDD reported that self-advocacy and communication are important skills that would benefit themselves and other women like them. When they described what it meant to advocate for oneself, one of the women noted that girls/women “can't just be nice about it” because no one listens to girls/women when they are nice. Instead, they need to be “strong with their voice” or even “mean” in certain circumstances. Another focus group participant observed that self-advocacy will continue to be a challenge for women with IDD:

“People that don't have disability don't really understand how hard it is...they will take advantage of us if they can. And that's something we got to make sure that we're ahead of. Especially today. And the society is changing faster than we can catch up to it. And yes, it's going to be harder for us women with disabilities to meet what we need and what we need to do to stand up for other people with disability especially women.”

Parents shared a common concern: that their daughters would continue to be “taken advantage of.” They shared

that their daughters lacked the knowledge and skills to recognize disingenuous intentions of men. Therefore, they continue to be more likely to be preyed upon:

“So, our girls have none of the tools, you know, most girls don’t have the tools they need to protect themselves against predatory males whose testosterone level is up to head.”

2b. Women with IDD need opportunities to develop healthy relationships.

Parents of women with IDD expressed a strong desire for their daughters to have genuine companionship and opportunities to develop relationships that are healthy and mutually supportive. In addition, they recognized that opportunities to socialize with similar-aged peers were often limited after graduation from high school.

“My daughter has had two dates in her entire life... So, I think in a lot of ways that concerns me a great deal because I don’t know what kinds of relationships she’s going to have in her life long-term if any ever. So, she has no friends here. So, girlfriends, guy friends, any friends. So, what does that mean for her long-term that she doesn’t know how to have a romantic relationship or how to engage with other people?”

“She wants a family, she wants a husband, she wants the little white house and the dog, and, you know, the

whole bit. She wants it. And she should be able to have it . . . And as a parent, you want to give your child what they want. But I can’t give it to her because I don’t know how.”

Parents of women with IDD also recognized the challenges of helping their daughter navigate romantic relationships, sexual health, marriage, and their daughter’s desire to have children. These concerns were pragmatic (e.g., their daughters could lose all or some of their financial benefits if they were to get married) as well as ethical (e.g., would their daughters be able to raise a child if she were to get pregnant?). The parents who participated in the focus group, all of whom were mothers themselves, recognized that as parents of women with IDD, they were going to be involved in helping their daughters navigate these decisions and life events for the most (if not all) of their lives.

“That’s always been my thing, you know, what happens when I’m gone? Who’s going to be sure that all this [is] taken care of...?”

“The thing that our community of people has to overcome is that even if our daughters found the perfect guy for them, they can’t get married because they lose their benefits if they get married. Maybe that was just in [state]. I bet it’s true here in Indiana too. But when you become legally married, it gets cut in half. And so, they can’t get married.”

“I think I have those concerns about my daughter because she does not have, and will not ever have, a staff or someone to watch out for those kinds of things for her... So, when I'm not around, what will happen? Will she continue to see her doctor? Will she make those calls on her own?”

Recommended Content and Delivery Strategies for Sexual Health Education for Women with IDD

During the latter part of each focus group, the facilitator asked women with IDD and parents about the topics that should be included in sexual health education trainings for women with IDD. In addition, focus group participants were asked to describe how women with IDD learn best (e.g., viewing pictures, reading text, watching videos, having discussions).

Suggested Sexual Health Topics

Overall, topical suggestions made by parents of women with IDD were somewhat more detailed than those made by women with IDD. In particular, suggestions made by women with IDD were often very succinct:

- Be assertive (“strong”).
- Protect yourself by not giving out personal information.
- Communication skills (including body language).

- Being able to say no – assertiveness skills (“no means no”).
- Hygiene – “keeping yourself clean and stuff like that.”
- “Don’t have sex – you’ll get diseases.”
- Always use birth control: “lots of condoms.”

Parents, on the other hand, provided more detailed suggestions that included topics such as safety, healthy relationships, using social media responsibly, and exploration of different types of relationships. Several parents noted that “safety” (sometimes described as “personal safety” and “adapted safety”) was important to include in sexual health education for women with IDD:

“I think that safety for all girls but especially adapted safety, some kind of manual, a handbook, a guidebook, some kind of training that we can do for my daughter.”

“... all young people need safety and guidance on what is healthy and what is respectful and what is appropriate and how to protect themselves against predatory people. And even people who are merely being opportunistic, they might not even be predatory, you know.”

Parents noted that their daughters with IDD needed to learn about healthy relationships in general – not just romantic relationships. After high school, many saw their daughters

become more isolated from peers their age, and they didn't know how to help them form friendships:

"... how do you continue relationships, how you grow relationships, not necessarily romantic relationships, just relationships of the kind that are healthy. "

"...what's a healthy relationship, how it starts out. No, you don't go right to the sex, you don't submit yourself to the control of other people. If they do that, that should be a warning to you to walk away from them."

One parent suggested that exposure to a variety of different types of relationships would be helpful to include in sexual health education for women with IDD:

"... it would be good if ... there could be some kind of unit or segment that would help people, you know, explore their own sexuality safely, non-judgmentally, and without any expectations that the person would feel like they need to act on it if it..."

Another parent suggested that sexual health training for women with IDD include guidance on pornography and using social media responsibly:

"Another thing that I think young adults need help with at early or middle school, we've talked about this a little bit with the exposure to pornography early on. But I think there needs to be some guidance with social media."

Ideal Learning Environments for Women with IDD

Both women with IDD and parents of women with IDD provided detailed comments in response to questions about learning strategies and learning environments for women with IDD. Women with IDD recognized that their peers may not feel comfortable asking questions or sharing ideas about a sensitive topic. Therefore, they suggested including opportunities to ask questions and share ideas that don't require people to say things out loud. For example, training participants could write down questions and/or ideas they would like to contribute that would then be shared in an anonymous manner.

Women with IDD also noted that individuals with disabilities may require more time to genuinely understand certain concepts or they may need additional clarification:

"... it's a lot harder for us...women with disabilities to actually get our word out there and tell you guys, 'Hey, we don't know what you're saying.'"

Women with IDD also expressed a preference for learning environments that "didn't feel like school". They commented that the training setting should not be set up like a classroom with tables and desks. Facilitators should "make it fun, but still serious", hold group discussions, include breaks, and use language that normalizes sexual concepts.

Several of the women in the focus groups used the internet as a source of information (one in particular noted she watched videos on YouTube). This type of “visual learning” was acknowledged as a preference by a couple of the women with IDD, as well as by parents of women with IDD:

“Something very visual that girls can watch, young women can watch and see healthy relationships and not healthy relationships and then actually identify the behaviors. I think it would be helpful.”

“... I think visual learning is the easiest across all different abilities. So, I think that that would be a good place to start with investing because I know you have limited funding. But most people can learn visually the way they can't learn in other ways.”

Parents of women with IDD also encouraged the research team to consider online modules (for privacy). If training sessions were to be offered in-person, then 1-2 hours per session would be the maximum length per session. In addition, parents suggested that in-person training groups should be small - ideally including 2-3 people.

Not all parents or women with IDD commented on their ideal gender composition of potential training groups for sexual education, but some of the women with IDD agreed that it could be useful to have some of the information provided in same-sex groups, while other information could

be delivered in co-ed groups. One of the parents recommended same-sex groups.

CONCLUSIONS

Throughout the focus groups, women with IDD shared important experiences and insights into their priorities related to romantic relationships and sexual health. In addition, parents of women with IDD described their daughters' experiences during high school and their young adult years that set the course for their sexual development and their romantic relationships. These discussions revealed that women with IDD had experienced limited formal training on sexual health through their schools or other community providers. In addition, women with IDD often lacked opportunities to develop healthy relationships (romantic as well as platonic) with others, especially after they completed high school. As a result, women with IDD had relatively less experience with healthy relationships (outside of their family members), and they didn't always recognize when they were in an unhealthy relationship.

Women with IDD recognized the value of self-advocacy skills and recommended that future trainings on sexual health and relationships for women with IDD should include this topic. Parents also communicated the importance of self-advocacy skills for their daughters, but also worried that their daughters may need the support of others (e.g., advocates, guardians, family members) to ensure their ongoing safety and well-being.

A number of potential topics for sexual health trainings for women with IDD were also proposed by focus group participants including communication, assertiveness skills, hygiene, healthy relationships, and using social media responsibly. Parents noted that their daughters needed to learn about healthy relationships in general – not just romantic relationships.

For the interpretation of the findings, it should be noted that participants of the focus groups, who were willing to discuss sexual health topics and express their opinions on those topics, may not be generally representative of women with IDD and parents of adult women with IDD. These individuals may be more active in addressing their own sexual health than those who declined the opportunity to participate. Despite these limitations, the findings of the present study are consistent with the results of similar research efforts aimed at better understanding the sexual health needs of women with IDD. As such, they offer valuable insights into the sexual health training needs of women with IDD in Indiana.