

**Family Caregivers and Disability Service Providers’
Perceptions and Perspectives About Sexual Health
Education for Women with Intellectual and
Developmental Disabilities in Indiana:
Focus Group Report**

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Family Caregivers and Disability Service Providers’ Perceptions and Perspectives About Sexual Health Education for Women with Intellectual and Developmental Disabilities in Indiana: Focus Group Report

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BACKGROUND

Sexual health education can provide positive effects on knowledge, skills, attitudes, and behaviors for adults with intellectual disabilities (Schwartz & Robertson, 2019). Unfortunately, people with disabilities, especially individuals with intellectual and developmental disabilities (IDD), do not have equitable access to sexual health education (Barnard-Brak et al., 2014; Rohleder et al., 2019). People with IDD have fewer opportunities to learn about sexuality and fewer experiences with intimate relationships (Di Giulio, 2003). Additionally, women with IDD experience greater disparities in obtaining sexual and reproductive health services compared to those without disabilities (Havercamp et al. 2004). In Indiana, Hoosier students do not receive comprehensive sexual health education. Schools are only required to promote marriage and abstinence, HIV/AIDS prevention, and organ/blood donation (Indiana Department of Education, 2022). Women with IDD in Indiana would benefit from comprehensive sexual health education. However, there are a limited number of evidence-based sexual health trainings available for women with IDD; many do not provide sufficient focus on topics like sexual health literacy and sexual self-advocacy (Dumayas et al., 2020). The absence of such important topics as healthy relationships and sexual self-advocacy skills leaves women with IDD vulnerable to issues like harassment and sexual abuse (Hamilton et al., 2020).

Since October 2018, the Center for Health Equity (CHE) at the Indiana Institute on Disability and Community at Indiana University Bloomington has been developing an evidence-based sexual health training program to enhance the sexual health literacy and advocacy skills of Hoosier women with IDD. As a foundation for developing the curriculum, CHE completed comprehensive research activities: literature reviews; key informant interviews with women with IDD, family members, and disability service providers in Indiana; focus groups with women with IDD and family caregivers in Indiana; and pilot online sexual health training for Hoosier women with IDD.

Family caregivers and disability service providers play significant supporting roles in the daily lives of women with IDD, including their sexual health. To learn about these two groups' perspectives regarding sexual health education and the need for sexual health training for women 18 years old and older with IDD in Indiana, CHE conducted a focus group of family caregivers and disability service providers for Hoosier women with IDD. This report summarizes the findings of the focus group discussion.

METHODOLOGY

Participant Recruitment

Participants were recruited through online platforms and contacting statewide and local disability agencies and advocacy organizations within Indiana. Recruitment was held in March and April 2022. The online platforms used to recruit participants included the CHE social media pages (i.e., Facebook and Twitter) and Indiana Resource Center for Autism's Facebook page, newsletter, and parent listserv. Participants were eligible to participate if they met the following criteria: 1) family member of a woman with IDD aged 18 or older, or disability service provider who works with women with IDD in Indiana; 2) were 18 years old and older; 3) were living in

Indiana; and 4) had access to a laptop, computer, or tablet with microphone and camera.

Recruitment Challenges

We conducted one focus group combining a small number of family caregivers and disability service providers on April 13, 2022. We had initially intended to have two distinct focus groups, but there were some recruitment limitations to this. We promoted the study through social media and multiple disability organizations and disability advocates in different regions of Indiana, but we did not generate enough interest to create a larger sample size. Also, potential participants' different schedules prevented us from finding a date and time to accommodate everyone.

Focus Group Protocol

The focus group was conducted through Zoom and lasted one hour. The focus group was facilitated by a female CHE staff member and assisted by a second female staff member. Before recording began, participants were reminded that their participation was voluntary, that they did not have to answer any question they did not want to, and that they could leave at any time. Participants were provided with a \$30 electronic gift card as compensation.

The facilitators used a discussion guide, which included pre-determined questions about family caregivers and disability service providers' perceptions and perspectives about women with IDD's experiences with sexual health education and what information is necessary in sexual health trainings:

- Has your daughter or family member had any kind of educational experiences related to health or wellness?
- From working with your clients, do you have any insights about health education and health promotion for women with IDD?
- Has your daughter/family member/client had any kind of educational experiences related to sexual health? Please tell us about those educational experiences.
- Do you think it is important for adult women with IDD to receive sexual health education?
- Given the list of topic areas we have provided, do you believe there is any content that is not appropriate to include in sexual health education for women with IDD?
 - Which content is most essential to include in sexual health education for women with IDD? Why?
- For you to feel confident about your daughter/family member/client enrolling in a sexual health education training, what would be required?
- For you to feel confident discussing with the women you support, and with their family members, the decision to enroll in a sexual health education training, what would be helpful to know?
- What kind of information about the training, if any, would be desirable for any sexual health education training provided to your daughter/family member/client?
- What are the barriers for women with IDD in Indiana to access sexual health education, if any?
 - What do you think would help reduce the barriers you identified?
- What overall recommendations would you make to us regarding sexual health education for women with IDD?

The focus group was audio recorded and transcribed verbatim. Inductive thematic analysis was used to identify themes (Braun & Clarke, 2006, 2013). Research staff read the transcript and independently coded the data that they deemed relevant to the study. Staff met together to discuss codes they found during their review. Afterwards, they worked together to group related codes and combined related codes into potential themes. The research staff reviewed the themes to ensure that the codes in each theme were appropriate and that the codes in the different themes were distinguishable. Lastly, they defined and named the themes and the narrative structure with accompanying descriptions added.

RESULTS

Participants

A total of seven participants were recruited: three family caregivers and four disability service providers. The family caregivers comprised three mothers of women with IDD, one of whom who worked as a nurse. The disability service providers consisted of one male direct support worker, one female direct support worker, one female nurse, and one female behavioral consultant. The behavior consultant was also the guardian of a woman with IDD. All the participants resided in northern and southern Indiana.

Key Findings

Four primary themes emerged: 1) sexual health education in schools is insufficient; 2) sexual health education promotes personal development, wellness, and safety; 3) external factors affect support for sexual health trainings; and 4) stakeholders also need education about sexual health.

Theme 1. Sexual health education in schools is insufficient.

- Health and sexual health education were rudimentary and inadequate.
 - According to the family caregivers, the information that women with IDD received in school related to health education and sexual health education were rudimentary and were not considered comprehensive. Family members reported that women with IDD generally received their sexual health education in middle or high school.
 - *“...in middle school, I think they had some basic health classes. I think she had one in in high school, but it would have been very general.”*
 - *“And I think it was just very general. They would have touched on some health, sexual stuff, but not very much. Maybe some anatomy and physiology, you know, but that was about it.”*
 - Participants said women with IDD would use materials outside of school, like entertainment, to get information about sexual health. One family caregiver used outside resources to provide adequate sexual health information.
 - *“[She] learned some good health instruction in school. And then unfortunately, she loves watching TV shows like ‘Vampire Diaries’ and ‘Super Girl’ and a lot of other series that do have a lot of sexual overtones. So I think her thought process is a lot different than what it*

used to be...And she doesn't quite have the skills to sort through what's real and what's fantasy.”

- *“...the behavior therapist is actually the one that has taken more of this on since [she’s] been more of a young adult. And when they get together, they go through some of these questions and scenarios. Everything like, you know, how to date, how to ask somebody out for a date, how to manage the intricacies of a relationship. And what's friendship, and what's you know, a loving relationship, and where those boundaries are.”*
- Sexual health education in schools were not disability-focused.
 - The family caregivers reported that there was no adequate and comprehensive sexual health education available in schools for school-aged girls with IDD. The information was not tailored for students with disabilities.
 - *“...there might have been a little bit again, but certainly not anything that was tailored to somebody in the class that had special needs, you know? It would have been all at the level for, you know, for the neurotypical child. And so we would have had to do that accommodation of, you know, teaching it to her at her level.”*

Theme 2: Sexual health education promotes personal development, wellness, and safety.

- Sexual health education can help improve mental health.
 - Sexual health education can be used to help women with IDD better understand their mental health and wellbeing. It can provide them with tools to better cope with issues like hormones, peer pressure, and difficulties in relationships.
 - *“...if they don't have the tools to deal with that [rejection], it can cause them to go into a very mental depressive mood and having the education would help them so much on that specific issue, yes.”*
- Sexual health education is important to explain appropriate behavior online.
 - Many of the participants spoke about the role of social media and how it was necessary to teach women with IDD about how to conduct themselves online. They noted how online behavior can lead to negative consequences (e.g., interactions with online predators).
 - *“...there’s oftentimes when we’re not around that we can help mentor her with appropriate – yeah, appropriate interactions on social media, which tend to be, you know, a little bit more risky and that’s my biggest concern.”*
 - *“One thing that I’m glad it’s in here, the public and private behavior. You know, like, with the – and the social media, that’s a good thing to talk about. Because there are predators on the social media, and there can be predators out in the public, also. But yes, to these. The social media is one thing that I’m very happy that – you know, to add that in and have that in a discussion with our ladies.”*

- Sexual health education must address sexual violence and grooming.
 - Many of the participants were concerned about how women with IDD were vulnerable to online manipulation that could lead to grooming by sexual abusers and/or sex trafficking.
 - *“I’m setting that up with my niece with my daughter. And we’re also taking the conversation of the social media a step further, and bringing up the conversation of sex trafficking, and how vulnerable the girls are and their friends.”*
 - *“And I think the sexual violence is a real important one. Because I think they’re very open to being groomed by people. Whether it’s over the internet or in person.”*

- Sexual health education is important to explain healthy relationships.
 - The participants want sexual health trainings to explore what are appropriate behaviors in relationships and what healthy relationships look like; and how to handle rejection.
 - *“I would just say too, yeah, on the bullet point on healthy relationships, you know, there – and it’s been said by other people... what are the appropriate boundaries in terms of, you know, who’s – what persons would be appropriate to have a relationship with?”*
 - The participants noted that women with IDD are exploring dating and relationships through online platforms and social media.
 - *“My daughter’s entire relationship is online. And that’s something we’ve worked very hard with her on, is what’s appropriate and what’s not on the internet.”*

- The role of sexual orientation/gender identity in relationships should be covered.
 - The topic of sexual orientation and gender identity is often glossed over with the IDD population, but participants noted the importance of this topic. Participants said there was a misconception that women with IDD were heterosexual if they were interested in romantic relationships.
 - *“I think her depression got a lot better when she realized who she really was attracted to and came out and was a much happier person.”*
 - *“...our women who do have disabilities...it might be more of a challenge for them to come and say, hi, you know, instead of, I like this guy, I like this girl.”*

Theme 3: External factors affect support for sexual health trainings.

- Families and disability service providers appreciate having input and involvement.
 - Participants said that families and disability service providers should be able to know what is in the curriculum to help increase support for women with IDD to participate in sexual health education.

- *“...I think that knowing what the curriculum is, being able to have some input to it.”*
- *“I think as a parent, I think I would appreciate if the invitation to be involved in their sexual learning skills...”*
- Sexual health education needs to avoid biases.
 - Participants said that it was important for the information in the training to be supported by evidence-based research to reduce biases.
 - *“...as a guardian of an individual and behavior consultant on the waiver, evidence-based curriculum number one, because it takes away anybody's personal views on situations 100%.”*
 - *“I think anything that's fact based, that would be -- yeah. So, whatever the research is saying is probably more accurate than what we would just come up with off of the top of your head.”*
 - Caregivers like being informed about the instructor’s background. It is important to know who the instructor is and their perspectives on the materials. They want to make sure that instructors are being fair about the materials when they are teaching it.
 - *“I think it's very important to -- for the instructors to be aware of their own biases, and to not necessarily push particular agendas. But I mean, it's important that they get the information, but there's a real fine line between presenting the information in a neutral kind of way.”*
 - *“...I would be interested in knowing a little bit about the teacher, and their background, and their attitudes...”*
- Guardians and disability services providers may not support sexual health trainings.
 - Disability service providers stated that guardians could prevent women with IDD from participating in trainings. Some guardians have antiquated perspectives on sexual health or have religious objections.
 - *“...guardians are a huge barrier to even having an intimate relationship and that's sad. And I think we just need to break that mold because that's just the -- if we're all educated.”*
 - *“And one of my clients, she has problem with her guardian. Her guardian is more like... backwards, you know? And don't believe, and they're very religious. And she's in her 30s and she's high functioning, and that's the problem that she's having. So, I think breaking that barrier with her guardian or talking about that with her guardian...”*
 - According to the participants, some residential staff object to residents having sexual relations. Some residential staff do not understand that an individual with IDD has the autonomy to make their own decisions.

“...if they're in a waiver home, the providers like -- or the staff in the home, if they're two consensual adults, they still have a real big issue with like, them having privacy alone in the individual's bedroom with nobody else around.”

- *“...sometimes in the group home setting, staff are backwards to this kind of training as well. And they don't understand what the individuals are asking for or needing to know. And they kind of sweep it under the rug. So I think staff education is a huge deal as well.”*

Theme 4: Stakeholders also need education about sexual health.

- Provide guardians and staff with sexual health information to better support women with IDD.
 - Participants indicated guardians/caregivers would be more receptive to sexual health education if they were better informed about sexual health.
 - *“...let's educate the caregiver and the guardian... So educating the parent also, and maybe bringing them out of maybe an old school mentality.”*
 - Participants discussed the importance of educating support staff about sexual health in order to enable them to be more informed on how to effectively advocate for the sexual rights of women with IDD. One way to reach people is through online training.
 - *“I think in the era of COVID, I think, you know, if webinars maybe could be -- something like this could be developed for parents, for guardians, for staff that we can begin to hit some of these topics and begin to start educating the people that need to have that.”*
 - *“It's [sexual health training] not a formal thing. It's as needed basis. The nurses will train individuals and staff as needed, but we don't have anything formally set up.”*

Limitations

The results of the focus group provide valuable insights about the perspectives of family caregivers and disability service providers on sexual health education and the need for sexual health training for women with IDD in Indiana. However, the interpretation of the results should take into consideration several limitations. First, there is limitation to infer generalizability from our study. We only conducted one focus group. This may not be enough to create data saturation and to allow for generalizable results (Guest, Namey, & McKenna, 2017). In addition, we ended up having seven participants consisting of three family caregivers and four disability service providers. Although recruitment efforts sought a variety of viewpoints on sexual health education for women with IDD, the focus group members did not represent various views of family caregivers and disability service providers. All participants supported women with IDD participating in sexual health trainings. It is likely that the individuals who participated were more willing to talk about the topic and believed in the importance of sexual health education. Also, we did not collect comprehensive demographic data such as race/ethnicity, age, location,

and years of experience working in the disability community. Such information could have helped us better understand participants' perceptions and perspectives about sexual health education for women with IDD.

Despite these limitations, the results of the focus group help strengthen the pressing need to provide evidence-based sexual health education accessible to women with IDD. People with IDD do not receive equitable access to sexual health education (Barnard-Brak et al., 2014; Rohleder et al., 2019). The participants highlighted significant challenges that women with IDD encountered in receiving appropriate sexual health education even when they had limited opportunity. The participants' overwhelming support for sexual health education for women with IDD may signal a growing awareness about the importance of sexual health among family caregivers and disability service providers in Indiana. The results also emphasize the vital role that family and professional caregivers play in women receiving sexual health education. Their support for sexual health education is critical to ensure that women with IDD are able to access sexual health resources and can voice their sexual health needs.

RECOMMENDATIONS

Several insights were gained from the focus group participants regarding sexual health education for women with IDD in Indiana. Based on the results of the focus group discussions, we have made the following recommendations to improve sexual health education for Hoosier women with IDD:

1. Sexual health education training should emphasize relevant issues affecting women with IDD. Participants noted current issues, such as appropriate behavior on social media and risks for human trafficking and grooming from online predators, as the primary topics that need to be covered in trainings. Because women with IDD are vulnerable to sexual abuse, it is vital the curriculum cover healthy relationships, private/public behavior, and appropriate use of social media.
2. Support from family caregivers and disability service providers is critical for successful sexual health education trainings. These groups are necessary allies and collaborators in implementing sexual health education programs. They have important relationships with women with IDD. Their support for sexual health education programs can make it easier for women to engage in trainings. Providing family caregivers and disability service providers with evidence-based information can bolster their support.
3. Family caregivers and disability service providers can benefit from receiving sexual health education trainings. Some of the resistance or opposition to sexual health education for women with IDD may come from lack of understanding and antiquated knowledge about sexual health. Participants in the focus group supported sexual health education, but some of them did not know how to help women with IDD address their health-related needs. Providing resources like webinars and caregiver workshops about sexual health can be used as a starting point in increasing their sexual health literacy and support for sexual health education for women with IDD.

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