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**ISSUE BRIEF**

## **Hoosier Women with Intellectual and Developmental Disabilities Need Opportunities for Healthy Intimate Relationships and Sexual Self-Advocacy**

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### **Project Background**

Lack of formal and accessible sexual health education, coupled with myths about their sexuality, can make individuals with intellectual and developmental disabilities (IDD) vulnerable to inaccurate sexual health information, unsafe sexual practices, sexually transmitted infections (STIs), and sexual abuse. To address these issues, the Center for Health Equity at the Indiana Institute on Disability and Community at Indiana University Bloomington embarked on a research project about sexual health education for Hoosier women with IDD in October 2018, with funding from the Indiana Governor's Council for People with Disabilities. The goal of this project is to improve the health and well-being of Hoosiers with disabilities by enhancing sexual health literacy and advocacy skills for adult women with IDD through the creation of evidence-based sexual health education in an accessible format. To this end, the project team has identified the current landscape of sexual health needs of women with IDD in Indiana and sexual health education curricula for individuals with IDD through the following research activities: comprehensive literature reviews; 14 key informant interviews with women with IDD, parents,

and professionals serving people with IDD; and three focus groups (two with adult women with IDD and one with parents of adult daughters with IDD).

### **Overview of Intimate Relationships and Sexual Self-Advocacy in Women with IDD**

Individuals with IDD do not have adequate opportunities to learn about sexual health and experience it. People with IDD have lower levels of knowledge about sexuality and fewer opportunities to learn about sexuality; fewer experiences with dating and intimacy; and more negative attitudes toward sexuality (Di Giulio, 2003). They do not receive equitable access to sexual health education (Barnard-Brak et al., 2014). The consequences of inequitable sexual health education and experiences include higher risks for sexual abuse and sexually transmitted infections (STIs). For example, it is estimated that around 68% to 83% of women with IDD are sexually abused in their lifetime, and that less than half seeks services for it (Murphy & Elias, 2006). Adolescent females with IDD are at high risk for STIs (Mandell et al., 2008).

There are many misconceptions about individuals with disabilities including those with IDD and their sexuality: people with disabilities are asexual; they have a lack of need for physical intimacy; and they are not able to have satisfying sexual experiences (Milligan & Neufeldt, 2001; Rohleder, Braathen, & Carew, 2019; Rowen, 2013). Many desire intimacy and romance like other people, and they have diverse viewpoints about their sexuality. Some prefer nonsexual relationships; some want physical intimacy but not sexual intercourse; and others want satisfying sexual relationships (Eastgate et al., 2011). Additionally, sometimes people with IDD are viewed as asexual or hypersexual or only interested in heterosexual relationships (Bernert & Ogletree, 2013).

Women with IDD lack autonomy to make decisions about their sexual health. People with IDD sometimes feel that their service providers and families prevent them from developing

intimate relationships (Sitter, et al., 2019). Parents may put women with IDD on birth control to prevent pregnancy, but many of those under 18 years old have little knowledge about contraception (Ballan & Freyer, 2017).

Self-advocacy is an important skill, especially for vulnerable populations. Self-advocacy can be defined in many terms. It is concerned with the following: speaking up for yourself, standing up for your rights, making choices, being independent, and taking responsibility for yourself (Azzopardi-Lane & Callus, 2015). Encouraging sexual self-advocacy may increase sexual esteem and help women manage their sexuality in sensual, satisfying, and safe ways (Bernert & Ogletree, 2013). Sexual self-advocacy can help improve access to information and sexual health services (Friedman, et al., 2014). Given poor communication and self-advocacy skills among individuals with IDD, it is imperative to improve their health literacy and advocacy skills, which will help address their health care access, illness prevention, and health promotion among women with IDD.

## **Findings**

Our key informant interviews and focus group discussions reveal that many women with IDD in Indiana have negative experiences and perceptions related to relationships and sexual health. Many shared adverse sexual experiences such as abuse, harassment, or violence. Women with IDD acknowledged their history of unhealthy relationships, although they did not appear to understand the reasons why they may have been involved with boys and men who did not treat them well.

*[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.*

*It was kind of hard at first. After a year of being married because he became abusive. And I actually had to put a restraining order against him.*

Women shared 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. Parents were also concerned that their daughters had easily “fallen for” someone who gave them attention, and labeling this attention as “love.” One parent shared:

*... 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.*

Additionally, parents can sometimes feel at a loss as to how to help their children have healthy romantic relationships:

*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.*

Self-advocacy is important for effective communication with health care practitioners, as well as accurate sexual health information. Many women with IDD in focus group discussions lacked knowledge of the rationale for and procedures related to preventive screenings related to sexual and reproductive health. Focus group participants with IDD reported infrequent screenings and negative experiences with providers of sexual health care.

*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.*

As described by participants, their communication with these providers did not involve advocating for themselves. Some 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.*

Several of the women with IDD also noted they felt more comfortable with female rather than male practitioners. Although it was not clear why this was the case for all of them, 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 were getting sexual health screenings or if the exam procedures had been explained to them prior to their appointments, some of the women knew that the screenings were related to “cancer prevention” and “birth control.” However, none of the women reported if the specific procedures had been explained to them prior to their appointment or not. Participants with IDD lacked understanding on how to protect themselves from abuse and STIs.

Our interviews and focus group discussions suggest that women with IDD in Indiana are not receiving equitable information nor support for healthy intimate relationships. In addition to a lack of education and knowledge about healthy relationships, women with IDD have not had the opportunity to develop healthy sexual relationships. As one woman noted:

*[W]e 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.*

These women need and want to develop the self-advocacy skills that are essential for healthy relationships. They shared the importance of knowing what you want and using your voice, but many noted that they want to learn how to communicate in the context of relationships and how

to say “no.”

Despite negative experiences and limited opportunities, participants demonstrated the resilience and coping skills that will allow them to be effective self-advocates and engage in positive, healthy relationships.

*I have been through literally pretty much everything. But I think just from my past kind of taught me to stay strong in the future.*

They communicated an awareness of barriers to their sexual health that they face as women with IDD. They expressed a determination to overcome these obstacles and a willingness to support one another.

*People that don't have disability don't really understand how hard it is for people... they will take advantage of us if they can. And that's something we got to make sure that we're ahead of.*

*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.*

## **Conclusion**

With key informant interviews and focus groups, we learned from women with IDD, from parents, and from professionals that women with IDD in Indiana are facing similar or greater sexual health challenges as identified by studies using national surveys or other states' data. They are receiving insufficient education and support necessary to develop and maintain healthy intimate relationships. Many have had adverse experiences such as abuse or other types of unhealthy relationships, resulting in negative perceptions of sexuality and of intimacy. These women need support to develop a broad range of social relationships in order to make healthy choices regarding relationships that involve sexual intimacy. This kind of support can be provided by a network including friendships and mentors, as well as supportive service

providers, health professionals, and family members. Women with IDD can be encouraged and provided with opportunities to safely explore and develop intimate relationships, to practice communication skills, and to make informed decisions.

Although research suggests that self-advocacy by women with IDD can help improve their experience of sexuality as well as their access to sexual health information and services, many Hoosier women with IDD do not have the autonomy required to make decisions about their own sexual health. Along with their personal strengths and resourceful coping abilities, they need greater knowledge of their rights and self-advocacy skills to assert their rights in intimate relationships. Those skills are equally vital for interacting with health care practitioners, acquiring accurate sexual health information, and having a more positive experience of sexual health care.

### **Recommendations**

The following are suggested for Hoosier women with IDD based on comprehensive literature reviews, key informant interviews, and focus groups:

- 1) Women with IDD require and deserve opportunities to explore and develop friendships and healthy social relationships of all kinds.
- 2) Women with IDD need improved access to sexual health education that includes the topics of healthy intimate relationships and sexual self-advocacy.
- 3) Women with IDD should be supported in their right to have intimate relationships, which may or may not include sexual relations.
- 4) Women with IDD should have opportunities to learn how to advocate for themselves in intimate relationships and in interactions around sexual and reproductive health services. They need opportunities to practice these self-advocacy skills.

- 5) Appropriate sexual health education should be available to adults as well as K-12 students with IDD.
- 6) Indiana needs to build improved, sustainable social support networks that empower women with IDD to have healthy intimate relationships.

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