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Hoosier Women with Intellectual and Developmental Disabilities Lack Access to Sexual Health Education

Don Dumayas, MPH, Lydia Hamilton, MPH., Jane Harlan-Simmons, MA.,
& Jae Chul Lee, PhD

Center for Health Equity, Indiana Institute on Disability and Community,
Indiana University Bloomington

Project Background

The Center for Health Equity, part of the Indiana Institute on Disability and Community at Indiana University – Bloomington, started a two-year research project about sexual health education for Hoosier women with intellectual and developmental disabilities (IDD) in October 2018. This project was supported by the Indiana Governor’s Council for People with Disabilities. This project aims 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 achieve this goal, the project team conducted the following research activities: comprehensive literature reviews of sexual health needs of and sexual health education for individuals with IDD; key informant interviews, and focus groups. We conducted 14 key informant interviews with women with IDD, professionals serving this population, and parents of adult daughters with IDD, from a variety of Indiana locations, to increase our understanding of the sexual health needs of Hoosier women with IDD and related barriers and resources. We then conducted three focus groups – two with adult women with IDD and one with parents of adult daughters with IDD.

Overview of Sexual Health Education for Women with IDD

There are greater concerns for women with IDD related to sexual health than for those with other disabilities and those without disabilities. An estimated 68% to 83% of women with IDD are sexually abused in their lifetime, and less than half seeks services for it (Murphy & Elias, 2006). Both adult men and women with IDD are more likely to have unsafe sex compared to people without IDD (Baines et al., 2018). In addition, women with IDD experience greater disparities in obtaining sexual and reproductive health services, including preventive screenings, compared to their counterparts without disabilities (Havercamp et al., 2004).

Research indicates that there are positive effects of sexual health education on the knowledge, skills, attitudes, and behaviors of adults with intellectual disabilities (Schwartz & Robertson, 2019). However, research shows that people with IDD do not have equitable access to sexual health education (Barnard-Brak et al., 2014; Cheng & Udry, 2003; Rohleder, Braathen, & Carew, 2019). Students with moderate or profound intellectual disabilities (ID) receiving special education services in public schools receive significantly lower rates of sexual health education compared to their counterparts without ID and those with mild ID (Barnard-Brak et al., 2014). Students with ID receive both less sex education in school and at home than their counterparts without disabilities (Cheng & Udry, 2003; Schaafsma et al., 2015).

Along with inadequate opportunities to receive sexual health education, there is a limited number of evidence-based sexual health curricula available for adult women with IDD. The currently available resources do not provide sufficient focus on development of sexual health literacy and advocacy skills as well as women's health and wellness. As a result, women with IDD face considerably more risks and barriers in developing sexuality in a healthy way, including higher rates of sexual abuse (Greenwood & Wilkinson, 2013), and lower rates of well-woman exams, specifically cervical and breast cancer screenings (Havercamp & Scott, 2015).

In the state of Indiana, sexual health education is not comprehensive and not required for all students. Parents are allowed to remove their children from sexual health education courses (Sexuality Information and Education Council of the United States [SIECUS], 2018). There are currently no requirements for sexual health education programs to teach about violence prevention, child sex abuse, consent, sex trafficking, communication skills, and decision-making skills (SIECUS, 2018). Schools are only required to promote marriage and abstinence and HIV/AIDS prevention (Indiana Department of Education, 2020). Additional health and wellness topics such as contraception; abortion; and lesbian, gay, bisexual, transgender, and queer (LGBTQ) topics are not required in courses (SIECUS, 2018). Teachers are not required to have training in sexual health education topics (SIECUS, 2018).

Findings

Through discussions with women with IDD and parents of women with IDD it is apparent that many women with IDD in Indiana have received little to no formal sexual health education. If any formal education was received, it focused predominantly on puberty, anatomy and physiology, and sexually transmitted infections (STIs). For some, the emphasis was on abstinence. Education lacked information on the emotional aspects of relationships, communication, or consent.

It was the sex video. So, like just how to be safe when having it and all of that good two shoes. Making sure you're on birth control and stuff like that.

It was particularly evident that there is an unmet need for education about healthy, consensual relationships, including sexual self-advocacy. Sexual education that was provided omitted topics such as emotions, communication, and intimacy. There is an inadequate understanding of the concept of consent and of the characteristics of a healthy intimate relationship.

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

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.'

These findings suggest the very limited availability and scope of sexual health education for grades K-12 in the state of Indiana. Most of the participating women with IDD had not received any education outside of school. Some women noted that they obtained information from unreliable sources, such as television shows and movies, and the internet.

TV show was—it was like a teenager TV show and it was like Glee. It's called Glee. Like a singing TV show type of thing, so and they did episodes like that. So, I watched that too.

As well as limited sexual health education in schools, parents from our focus groups reported that they struggled to find reliable and appropriate information to help educate their daughters with IDD.

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.

In addition to limited opportunities for formal and informal education, there is an absence of educational materials on sexual health that are suitable for women with IDD. There are promising sexual health education programs for individuals with disabilities, but very few have

been empirically evaluated. In our review of sexual health curricula for individuals with disabilities, we found only four curricula that have undergone an evaluation with results published in peer-reviewed literature. Along with limited research available on the efficacy of curricula, we found that research conducted in this area has lacked rigor. Studies have had small sample sizes, lacked control groups, lacked detailed descriptions of their methods and materials, and have not operationalized definitions, which makes it difficult to generalize the findings. The delivery of sexual health education without empirical evidence of effectiveness may have significant impacts, potentially harmful and lifelong, on people with IDD and their families (McDaniels & Fleming, 2016).

Conclusion

Our findings from key informant interviews and focus groups of women with IDD and parents confirm and amplify existing research regarding the sexual health and related educational needs of this population. As their peers with IDD across the U.S., these Hoosier women with IDD received little, if any, sexual health education in school and limited parental instruction on sexual health. There were evident misconceptions about the sexuality of people with IDD. Many of our participants demonstrated an inadequate understanding of the concepts of consent and of the characteristics of healthy relationships. It was apparent that women with IDD need more knowledge about the importance of preventive screenings, as well as other information about their sexual health.

Insufficient access to, and limited scope of, sexual health education for grades K-12 in Indiana, as well as a lack of official, evidence-based, sexual health curricula for individuals with IDD, suggest that there is reason for concern regarding adverse impacts on the sexual health and well-being of women with IDD in Indiana. Our research suggests that, due to inadequate sexual

health education, Hoosier women with IDD may face long-term, negative consequences identified by existing research. The risks include unsafe sex and STIs; fewer preventive sexual health screenings (with related implications for health care costs); and sexual abuse and violence.

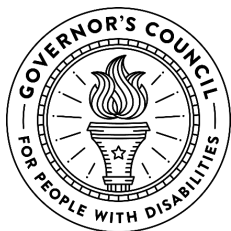
Recommendations

On the basis of the findings of comprehensive literature reviews, key informant interviews, and focus group, we make the following recommendations:

- 1) There is a need for accessible, comprehensive sexual health education for women with IDD in Indiana. This education should emphasize the topics of consent and the characteristics of healthy intimate relationships. It should include information about preventive sexual health screenings, as well as sexual self-advocacy and how to cultivate skills required to communicate with sexual health care providers.
- 2) An evidence-based sexual health curriculum should be developed for women with IDD. The curriculum must meet the needs and learning styles of women with IDD.
- 3) Women with IDD should participate in the development and delivery of sexual health education for those with IDD. Their input is valuable and necessary to make the content and learning formats meaningful and appropriate for the target audience.
- 4) Indiana's students with IDD need access to more comprehensive sexual health education in grades K-12. This information should be presented by trained educators and be tailored to these students' learning styles. The content of sexual health education should include the topics of consent and the characteristics of healthy relationships.

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