

**Focus Group of Participants
from Pilot In-Person Sexual Health Trainings for
Women with Intellectual and Developmental
Disabilities in Indiana:
Feedback and Suggestions for Improving the Training**

SEPTEMBER 2022



INDIANA INSTITUTE ON DISABILITY AND COMMUNITY
CENTER FOR HEALTH EQUITY

Focus Group of Participants from Pilot In-Person Sexual Health Trainings for Women with Intellectual and Developmental Disabilities in Indiana: Feedback and Suggestions for Improving the Training

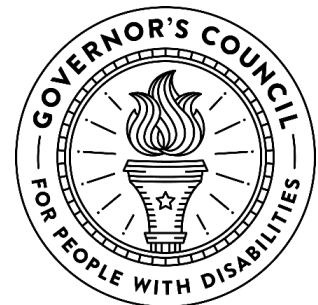
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ACKNOWLEDGMENT

We would like to express our sincere gratitude to the focus group participants. This project is funded by the Indiana Governor's Council for People with Disabilities. The content of this report does not necessarily represent the views of the Indiana Governor's Council for People with Disabilities.



BACKGROUND

While women with intellectual and developmental disabilities (IDD) in Indiana have a considerable need for sexual health education about healthy relationships and sexual self-advocacy, they encounter a significant challenge of lacking formal and accessible sexual health education (Dumayas et al., 2020; Hamilton et al., 2020; Lee et al., 2020b). The issue of the dearth of sexual health education for women with IDD in Indiana is further compounded by the fact that Hoosiers with disabilities do not receive comprehensive education at school or from their caregivers (Dumayas et al., 2022; Lee et al., 2020a; Lee et al., 2020b). To address this critical issue, the Center for Health Equity (CHE) at the Indiana Institute on Disability and Community at Indiana University Bloomington has been working to develop evidence-based sexual health education accessible to Hoosier women with IDD since October 2018, with funding from the Indiana Governor’s Council for People with Disabilities.

Based on recent experience in the development and delivery of pilot online sexual health education for women with IDD, as well as the findings of previous research activities (Dumayas et al., 2020; Hamilton et al., 2020; Hamilton, Lee, & Harlan-Simmons, 2022; Lee et al., 2020b), CHE developed a pilot in-person sexual health curriculum for Hoosier women with IDD in two-day and four-day formats. The pilot trainings were designed to improve the sexual health literacy and sexual health advocacy skills for Hoosier women with IDD. In particular, the four-day training was developed to help the participants comprehend broad critical topics and learn sexual health advocacy skills. The four-day pilot training consisted of 15 sessions covering the following topics: relationships; establishing relationships; communication and setting boundaries; healthy and unhealthy relationships; sexual anatomy; reproduction and birth control; taking care of pelvic area; sexually transmitted infections; preventive care; and intimate relationships. Each day was 5 hours long, with 15-minute breaks between sessions and a 30-minute lunch. The four-day pilot in-person sexual health trainings were delivered in Fort Wayne between July and August 2022.

Regarding the eligibility for the training participation, women with IDD needed to: 1) speak English; 2) be between the ages of 18 – 49 years old; 3) be a current resident of Indiana; 4) be able to stay engaged during the trainings; 5) be able to read at higher than a first-grade level; and 6) be able to meet a criteria for reciprocal conversation (talk with two or more people back and forth). Each participant was compensated with a \$50 Walmart electronic gift card for each day they had attended. After the delivery of the pilot training, one virtual focus group was conducted to gain a deeper understanding of the participants’ perspectives, experiences, and suggestions regarding trainings and curricula. A total of 8 women participated in the pilot in-person trainings. This report summarizes the findings of the focus group with participants from the four-day pilot in-person training.

METHODOLOGY

Participant Recruitment

Focus group participants were a subset of the participants who attended the four-day pilot in-person sexual health training. Participants were provided information about the focus group



during the last session of the training and via email. Participants needed to have access to the internet and to a computer, laptop or tablet with microphone and camera, in order to participate in the focus group. Participants were given a \$30 Walmart electronic gift card in appreciation of their participation.

Focus Group Protocol

The focus group was conducted on September 8, 2022, through Zoom video conferencing. The focus group lasted approximately one hour. The focus group was facilitated by a female CHE staff member and was assisted by a male CHE staff member both of whom had not been involved in the delivery of the pilot training. Before starting the focus group, the CHE moderator informed the participants that their participation was voluntary, that they did not have to answer any question they did not want to, and that they could withdraw at any time without consequence.

The facilitators used a discussion guide including the following questions:

- What do you think is the best thing about the training?
- What was your least favorite thing about the training?
- What would you add to the training that wasn't covered?
- What part would you take out of the training?
- If we could make the training better, what do you think we should do?
- If we do this training again, what should we do differently?
- What did you think about the session topics?
- What topics would you like to spend more time on?
- What topics would you like to spend less time on?
- How did you find the length of the training day?
- How did you find the length of the breaks?
- What activities did you like the best?
- Would you like more activities?
- How did you like the workbook?
- What did you like or not like about it? Was it useful?
- Was there enough note-taking space in the workbook?
- Did you like the pictures and images in the workbook? In the slides on the screen?
- Were the pictures helpful? Would you like more/less pictures?
- What did you like about attending the training in person?
- Would you have preferred to attend this training online, using Zoom?

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. They discussed codes they found during their review, grouped related codes, and combined related codes into potential themes. Staff reviewed the themes and codes to ensure that they were accurate and distinguishable from one another. Lastly, they defined and named the themes and the narrative structure with accompanying descriptions added.



RESULTS

Participants

A total of five women between the ages of 27 – 41 participated in the focus group. The average age was 32.8. All participants were white and lived in northern Indiana.

Key Findings

Six primary themes emerged: 1) There are ambiguous opinions on anatomy; 2) effective relationship skills are critical for sexual health education; 3) interactive activities increase engagement in sexual health education; 4) comprehensive training materials enable accessible learning; 5) there is a preference for in-person trainings; and 6) training duration was enough to cover the information.

Theme 1. There are ambiguous opinions on anatomy.

1.a. Discussions about anatomy and the body are uncomfortable.

- Participants were often negative about their experience with lessons on anatomy and the body. They found the topic uncomfortable and gratuitous. Discussions about and images of anatomy and the body appeared to conjure up negative perceptions and reinforced their discomfort in engaging in the topic.

- *“The maybe uncomfortable part is talking like how they do those pelvic exams maybe. That video was uncomfortable on how those work.”*

“The talking about it, it felt uncomfortable, and then I felt weird because I’m almost in my 40s, and then I’ve never had a, what do they call them? Mammogram done. That kind of felt a little uncomfortable talking about it, because hearing that it hurts a little bit and all that kind of felt uncomfortable.”

1.b. Learning about anatomy can be valuable despite reservations on the topic.

- Even though participants were uncomfortable discussing anatomy, they also saw the value of learning about anatomy for situations like health care appointments. It could help them identify where on their body they may experience health conditions and help them explain their conditions to healthcare professionals by using the correct terminology.

- *“I mean some of sexual anatomy, I mean, I guess that can be uncomfortable, but I think it’s good for people to know, because like, in the future, they may go to the doctor, and they ask them questions.”*

- Some participants indicated that they had previously discussed topics related to the body and anatomy with individuals outside of the trainings. They were more comfortable discussing these topics with people they had relationships with. This suggests the importance of creating a safe and nonjudgmental environment to lessen discomfort and encourage questions and discussion on anatomy among participants.

- *“I am able to talk to other people [about the body], especially if we’ve known each other for a long time and have the same friends. That always makes it easy to be comfortable.”*



Theme 2. Effective relationship skills are critical for sexual health education.

1.a. There was an eagerness to learn more about improving relationship skills.

- Women raved about discussions and activities on the different aspects of relationships. They appeared to value it overwhelmingly compared to other topics. They may be looking for opportunities to improve their education in this topic because they have not had sufficient learning opportunities in school and other educational setting.
 - *“I think probably less pictures of the female parts maybe and more pictures of the relationships and communication stuff.”*
 - *“I feel like it's very useful, because we could this training in everyday life, too. We can use this in everyday life...In the relationships training, you need to have class [inaudible]. So, I took that stuff from that class to this class. It helped us.”*
 - *“I feel like we need to have like, even if it's not with boyfriend and girlfriend, like with friends. I think we need to like have a discussion about like having relationships like with friends and families and like classmates and all that.”*
- Participants want more time to discuss and learn about relationship issues. They were particularly interested in lessons about the following:
 - Communication: *“more group discussion maybe on healthy relationships and how to communicate better with each other”*
 - Conflict Resolution: *“...like what's a good way to resolve a conflict? And you could pick that, and then you could say what you think is the best way to make sure that you don't have a conflict in the future or something.”*
 - Boundaries: *“I think, a lot of people, some people, not everybody, but some people have problems with boundaries and think if they learn about boundaries, maybe they can be better at setting boundaries, because some people may not -- may have problems with that or they may have problems like communicating and stuff like that.”*

Theme 3. Interactive activities increase engagement in sexual health education.

3.a. Role playing helps practice skills in different areas of relationships.

- Participants indicated their interest in doing role playing as a form of engaging in the topics and practicing skills. They noted the utility of role playing in teaching effective strategies in forming healthy relationships with intimate partners, friends, and families. Role playing could also be helpful in learning about effective communication and conflict resolution.
 - *“Sometimes people don't know the difference between healthy and unhealthy stuff. So, I think role-playing with like of friendships, relationships, and maybe communication. Like a bad way to have communication would be where you just let on person talk, and you never say anything.”*



- *“My favorite was the role playing. When I was in school, they wanted us to do a lot of role-playing, and they would always ask me to do it because they knew. I was always in small classes. So that worked best.”*

3.b. Playing games can help to retain information.

- Participants explained how games could be an effective and enjoyable tool for learning about sexual health. It could help make it easier to review the different concepts in the trainings. They were enthusiastic about suggesting types of games (e.g., Jeopardy and the Game of Life) that could help others engage in the sexual health materials.
 - *“You better understand something like if you made up a game, and it was about -- or where you make up your own game about like what you think is best in a way to resolve conflicts and stuff?”*
 - *“When I began thinking like I kind of like the Jeopardy idea, because like, for example, they could have categories, and about like what's a good way to resolve a conflict? And you could pick that, and then you could say what you think is the best way to make sure that you don't have a conflict in the future or something.”*
 - *“I understood everything pretty well, but I think if there was [games] people who didn't understand, that it would make it easier them.”*

Theme 4. Comprehensive training materials enable better access to learning.

4.a. The workbook provided well-rounded information.

- Participants were generally positive about their opinions of the workbook. They thought it was useful for learning about sexual health. They said it was appropriate for people with disabilities, specifically for those with intellectual disabilities.
 - *“Very well understanding and educational, and to lead people the right way, especially the people who are fully disabled and not able to understand.”*
 - *“The workbook really focused well on everything that we needed to know about our body and relationships.”*

4.b. The workbook is useful as a reference material.

- Participants stated the workbook would be beneficial when visiting a health care professional. They could use pictures in the workbook (e.g., body parts) to explain to health care providers what health conditions they may be having.
 - *“If I need a special discussion with my doctor, I can refer back to the workbook and be like, ‘Well, I think I need this done or I need that done.’ You know, I could like help the doctor know that I think something's wrong and, and I think it should be checked.”*

4.c. The workbook needs more space for notetaking.

- Some participants explained that they would like more available space in the workbooks for



them to take notes. The areas in the workbook for notes could serve as a way of helping participants express their thoughts and help them reflect on what they learned.

- *“I wish like there was a little bit more writing involved...so like because you maybe sometimes writing just helps me better express how I feel. So, I think it would be better if I could like write about stuff, and then it would be better for me, because then maybe I could read what I wrote, and then, I'd be better able to express my feeling about sort of...”*

4.d. Pictures and videos enhance participants' understanding of sexual health topics.

- Pictures and videos serve as additional learning tools for participants to better understand different sexual health topics. Some of them learn better when information is communicated through images and graphics.
 - *“Some people are better like visual learning. So, it was like seeing the videos could help. Where some people are more like hearing. So, like hearing her talk or hearing the videos could work too. Or I mean, everybody has different ways that they learn... So, I'm good at either like seeing, visual or hearing. I'm good at either. So, I think it was good that they had both, especially for people who are better at visual and stuff.”*
 - *“The pictures were helpful because I really didn't know a lot about it, and I think it's better to get a visual, because it's better -- I mean, because I could see it.”*
 - *“Yeah, it was really -- it gave us a good overview on how our body works and things and how we [inaudible] gave us a lot of good visual aids. So, I think that helped and sometimes, visual aids are better than just hearing about it, I think.”*

Theme 5. There is a preference for in-person trainings.

5.a. In-person trainings provide more opportunities to engage in active learning.

- The participants generally preferred to participate in in-person trainings over online formats. They noted that in-person trainings allow them opportunities to get to know others on a personal level. Participants shared that they retain the information better by participating in-person. Additionally, this training was conducted over 2 years after the start of the COVID-19 pandemic. This may have affected their perceptions about in-person and remote trainings. In-person trainings afforded participants with the personal and face-to-face interactions that they could not do during the early period of the pandemic.
 - *“You can interact better with people in person than over like Zoom”*
 - *“I like it in person to really see you and have a better feeling of receiving new people and having fun in the training.”*
 - *“I do better in person, as well, because during COVID, I had to do telemed a lot, work stuff, and I just prefer person because you learn a lot more.”*
- There are fewer issues with learning experiences through in-person trainings. Online



trainings sometimes have technical issues.

- *“...better to do it in person, because sometimes over video, sometimes things don't work out the way you want them to.”*
- *“It's better to talk to people in person than over Zoom, because sometimes Zoom will mess up, and you can't like hear the person, and then it's just like better to like see people.”*

Theme 6. Training duration was enough to cover the information.

6.a. A four-day training was feasible for women with IDD to learn about sexual health.

- Participants stated the four-day training provided adequate time to go through the workbook and slides. They also stated that the length of each session and the allotted breaks were appropriate.
 - *“It [Four-day training] was perfect. We covered a lot in those number of days. I felt like we got a lot accomplished.”*
 - *“I think it was good. I think it was just right. It covered a lot in that week of time...”*

Limitations

The findings of the focus group need to be carefully interpreted taking into consideration the following limitations. First, there was a lack of geographical diversity among the focus group participants. The four-day training was held only in Fort Wayne with all participants living in the area. Second, the focus group was conducted by two CHE employees (one female and one male). Participants had not met these employees prior to the focus group. Some of the participants may not have been comfortable to share information in front of strangers, especially with a male facilitator. The question topics involved sexual health, and this is a sensitive topic for some individuals.

In spite of these limitations, the participants of the focus group were able to discuss their opinions on the successes and limitations of the trainings and provide recommendations about how to improve the trainings. The majority of focus group participants were able to engage in the questions throughout the focus. They provided valuable insights into the development of in-person sexual health education for women with IDD in Indiana.

RECOMMENDATIONS

- Despite the participants' discomfort about learning and discussing anatomy and the body, the topic is invaluable in sexual health education. It is necessary to create lessons and activities in the trainings that will address the discomfort surrounding the topic. It is also important to promote the importance of normalizing it and the benefits of learning about it. The fact that the participants have discussed this topic with individuals they trust indicate that trainings need to promote a safe and nonjudgmental environment where participants feel comfortable to openly talk about anatomy and the body.



- The incorporation of interactive learning activities appears to be important for the participants to engage in active learning and to better understand sexual health topics. More activities and games, such as Jeopardy and role playing, would be good to help participants review information covered and practice different advocacy skills.
- Although there were multiple sessions focused on relationships in the sexual health training, participants seemed very interested in furthering their education on these topics. They showed great interest in building skills needed to improve their understanding of healthy relationships. Their interest in this topic could be related to their need for more opportunities to form healthy, intimate relationships and better sexual advocacy. Their great interest may also suggest that they did not have many opportunities to learn about these topics. Future trainings should include more lessons and activities focused on healthy relationships.
- More in-person sexual health trainings should be offered across Indiana. As more people return to in-person meetings and events, there appears to be a strong preference to have sexual health trainings in this format. Participants felt they were able to get to know others better through in-person interactions than through online video conferences. In-person trainings may also provide more opportunities to engage in different ways of learning when compared to the online format.
- The participants recommended that more space in the workbooks be available for notetaking. Writing and drawing notes is an example of a learning style. Some individuals prefer to use their notes to process, understand, and retain information rather than engage in open discussions and interactive activities.



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