

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

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Virtual Focus Group of Participants in Pilot Online Sexual Health Trainings
for Women with Intellectual and Developmental Disabilities in Indiana:
Feedback and Suggestions for Improving the Pilot Online Training

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BACKGROUND

This report summarizes the findings of a focus group discussion held with five women with intellectual and developmental disabilities (IDD) in Indiana who had participated in pilot online sexual health trainings. In August-October 2021, the Center for Health Equity (CHE) at the Indiana Institute on Disability and Community at Indiana University Bloomington piloted a 6-week online, synchronous sexual health training with two cohorts. Participants met for about two hours (two sessions of 45 minutes with a 15-minute break) during the daytime per week. A total of 10 women with IDD who live in Indiana completed the trainings. The first cohort had six participants, while the second had four.

The purpose of the focus group was to collect feedback and suggestions from the participants in order to revise and improve the pilot online sexual health training curriculum and materials that were developed for women ages 18-49 with IDD in Indiana. To participate, women with IDD needed to meet the following additional criteria:

- Speak English
- Have Internet access
- Have access to a computer, laptop, or tablet with microphone and camera
- Be able to stay engaged for two 45-minute training sessions with a 15-minute break in between
- Be able to read at higher than a first-grade level
- Meet our criteria for reciprocal conversation (talk with two or more people back and forth): score between 9-15 in total

The online training included the following sessions: sexual anatomy; reproduction and birth control; taking care of my pelvic area; preventive health care; relationships; establishing relationships; communication and setting boundaries; healthy and unhealthy relationships; and intimate relationships.

Since 2018, the CHE has been working to develop evidence-based sexual health education in an accessible format for Hoosier women with IDD to enhance their sexual health literacy and advocacy skills, thereby improving their health and well-being. As a foundation for developing the pilot sexual health curriculum, CHE completed a comprehensive literature review, conducted 14 key informant interviews of Indiana stakeholders (6 women with IDD, 1 partner of a woman with IDD, 2 family members, and 5 professionals serving adults with IDD), as well as 3 focus groups (2 focus groups of women with IDD and 1 focus group of parents of women with IDD in Indiana).

From the interviews and focus groups we learned that many of the women with IDD had adverse sexual experiences such as abusive relationships or sexual violence (Dumayas et al., 2020; Hamilton et al., 2020; Lee, King, Hamilton, Dumayas, & Harlan-Simmons, 2020). They also had negative interactions with sexual health care providers (Hamilton et al., 2020; Lee, King, Hamilton, Dumayas, & Harlan-Simmons, 2020). Hoosier women with IDD received limited formal and informal sexual health education, while encountering common misconceptions about their sexuality (Dumayas et al., 2020; Lee, Dumayas, Dubie, & Hamilton, 2020; Lee, King, Hamilton, Dumayas, & Harlan-Simmons, 2020). The women faced additional barriers such as a

lack of autonomy and/or skills needed for decision-making about sexual health, and for setting boundaries regarding unwanted sexual activity (Hamilton et al., 2020). This research has demonstrated that there is an unmet need for Hoosier women with IDD to have accessible, effective education about their sexual health. The most needed topics include healthy relationships, with an emphasis on sexual self-advocacy, the concept of consent, and communication skills in intimate relationships (Dumayas et al., 2020; Hamilton et al., 2020; Lee, King, Hamilton, Dumayas, & Harlan-Simmons, 2020).

METHODS

Focus group participants were a subset of participants from the two sexual health training cohorts. Participants were provided information about the focus group during the last session of the training and via email. A total of seven women expressed an interest in participating, two of whom were unavailable on the date selected. One focus group was held on October 27, 2021, using Zoom video conferencing. The focus group lasted for approximately one hour. The focus group was facilitated by a female Research Associate from CHE. She was assisted by a second female Research Associate from the Center who served as the cofacilitator. A third male Research Associate took notes during the focus group and provided technical assistance for the Zoom platform. These facilitators did not deliver the pilot sexual health training.

The facilitators used a discussion guide, which included the following questions about the participants' experience and suggestions about the online training in general:

- What were your overall impressions of the training?
- What did you think was 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 should we 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 sessions: Were they too long? Too short?
- How did you find the length of the breaks?
- How was the balance between the instructors talking while showing slides on the screen and the time spent on doing activities?
- What activities did you like the best?
 - Watching video clips
 - Practice saying anatomy words out loud
 - Matching vocabulary with anatomy diagram in workbook
 - Sharing experiences with others (e.g., visiting the doctor using medical terms)
 - Group discussion
 - Small group discussion
 - Role play

- Thumbs Up Thumbs Down for signs of abuse
- Writing information about themselves which could be used to find friendships and dating relationships
- Identifying two close individuals to be their safe person.
- 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 online, using Zoom?
- What did you not like about attending this training using Zoom?
- What would have made Zoom easier for you to use?

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. Although the focus group was granted exempt status by the Indiana University Institutional Review Board, participants and/or their guardians completed signed informed consent forms prior to the focus group. Participants were provided with a \$30 electronic gift card as a token of appreciation.

Analysis

The focus group was audio recorded and transcribed verbatim. A content analysis was conducted to explore common views and experiences among the participants (Hsieh & Shannon, 2005). The focus group was analyzed using five predetermined categories (Topics, Activities, Workbook, Zoom, Instructors), and emergent categories through inductive coding. ATLAS-ti Web was used to manage the analysis.

RESULTS

Participants

A total of five women between the ages of 22-31 (mean = 27.6) participated. One participant had completed the first pilot training cohort and four participants had completed the second cohort training. All the participants were white and lived in the northern region of Indiana.

Key Findings

This section presents findings from the focus group discussion in the form of a summary of what respondents said in response to specific questions.

A. Overall Impressions

All of the focus group participants gave positive feedback about the pilot online training and were happy they had participated. When directly asked what they liked best about the training, the first response was that they enjoyed getting to know one another. One participant noted that *“I think we’re going to try to get something together of hanging out, outside of the training sometime.”* They found the training beneficial and *“liked how they talked about a lot of different*

things... ” Several content topics were mentioned, as described in the next section. One person responded that the activity of roleplay was her favorite aspect of the training.

The women contrasted the training with previous sexual health education they had received, pointing out that they learned *“some of the things that usually you wouldn't find in your casual or your traditional kind of sexual health class.”* A participant shared that her previous sexual health education had included being given *“packets of like pads, like to all the girls. And some of us haven't even started our like periods yet.”* Another participant commented that *“the sexual health classes where I grew up were very like gross and very sexist and rude because one of the things that they would teach is basically imagine a woman as a cupcake, you wouldn't want to eat a cupcake that's already been bitten into, that's what sex is like.”*

One participant cited the quality of the instruction as what she liked best about the training: *“I like how easy it was to understand the way that they explained it.”* Participants were also happy with the instructors in particular, sharing that *“if we did do the training again, [...] and [...] would be awesome to instruct it again,” “they're really good,”* and that *“if we did not understand it, they would have an example in their own way.”*

Participants were asked about the length of the 45-minute sessions with 15-minute breaks. Participants were uniform in their responses that the sessions and breaks *“were just fine,” “they were just right,”* and *“they were good.”*

B. Training Topics

Each focus group participant was able to share a topical area of the training that they learned new information or enjoyed learning about. Participants shared that they liked learning about *“what's bad and what's good for your body,” “different diseases and stuff and how you can get them and how to prevent it because I didn't know,”* and *“the stages from strangers to acquaintances, to dating, to all that stuff, to body parts.”*

When asked about which topic/s participants would like to spend more time on during the training, they noted they would like more attention given to healthy relationships, communication, setting boundaries, and navigating dating. Participants remarked *“I think probably the communication and setting boundaries one,”* and *“healthy relationships too.”* Participants noted that they want to know how to respond to certain situations. For instance, *“like if you're fighting with your partner, like how to set your boundaries like to walk away or stay and how to talk about it.”* In terms of dating, participants wanted to know more about online dating sites and how to determine when you are dating someone or when to introduce someone to your family. Two of the participants' responses illustrated their inexperience in relationships sharing:

“I know it would be inappropriate to start dating someone after only three days of talking to them because they still don't know me. But I've never been in a relationship before. So I don't really know a whole lot. So it's like I would like to know what's the appropriate amount of time to wait to date someone and like stuff like that.”

“...how long you would be dating a person and then like if they want to meet like their family because I'm kind of going through that right now. So and I'm like how long would it take for them to meet your family and what do you do and stuff because I'm kind of struggling through that right now.”

One participant was interested in expanding the content about *“the different sexualities or orientations of people. And even talking about some sexualities that aren't as common as gay, bi, trans, or whatever, like things like asexuality or pansexuality...”* Another mentioned that she wanted to learn more about *“different symptoms that you have and relationships. Like if you get a partner and if you have a history of let's just say STIs or whatever, HIV and if you want to find out if you are a carrier to your child or the partner that you have has carried it, would it damage to your child...”*

The least favorite topic for the focus group participants was anatomy. They shared that they were uncomfortable with the topic, and especially disliked starting the training with that topic. *“It was kind of awkward with just starting about like talking about your anatomy when it should have been like what's your hobbies.”* Another noted *“That was kind of a little bit uncomfortable, to be honest. For a minute, I was like, is this going to be the whole training talking about our body.”* Additionally, compared to other topics anatomy was the one topic that most participants wished less time was spent on. *“Like I didn't mind the anatomy. I just felt like we were talking about it and talking about it and talking about it. It's like, okay, we already know. We're uncomfortable. Move on.”* *“I kind of felt like it was like sex ed just a little bit. Like when you were like little in like middle school [inaudible] and they like what is a pad and what is a tampon.”* Several participants mentioned being uncomfortable with repeating out loud the names of sexual anatomical parts.

Regarding where to place anatomy within the order of the training topics, *“I think getting to know people beforehand, your hobbies. It would be a little bit better to know the people, then to go into like relationship maybe, then like go right into the body parts...”* Similarly, another participant suggested *“starting about like getting to know everybody, and then all your hobbies, and then starting with relationships, and then probably in the middle like talking about the sexual and what the likes and dislikes, and then like if you go to the doctor and all the diseases.”*

C. Activities

The responses to the question about the balance between having information presented on slides and activities were mixed. There was a preference among the participants for more activities, for example, *“I would say probably less info, more like activities.”* However, one participant shared that *“I think it was okay, depending on the topic that we're covering.”*

When asked about their favorite types of activities of the training, role-play, videos, and discussion were mentioned the most. Participants stated *“...roleplay, that's okay. Then watching the video clips. And sharing experiences with others,”* and *“I liked watching the video clips...The group session, definitely. And then sharing our experience.”* A couple of participants also noted that they enjoyed writing down information in their workbooks. *“I liked...[to] write down information about yourself and [inaudible] to find some friendships....”*

Regarding activities, participants noted their enjoyment of the opportunity to share their experiences and learn about themselves and each other. For example, a participant liked *“the group discussion. And then sharing experience with others.”* She remarked that she appreciated *“talking about what do you like, and then, like just what's your hobbies, and what do you do in your daily life...”* Another participant mentioned she valued *“get[ting] to know the girls.”*

D. Workbook

Participants enjoyed having the workbook as a supplement to the lectures, PowerPoint slides, and activities. A few shared that they were visual learners and would like to have more pictures.

“I would say probably more pictures to kind of go along with like whatever is being discussed. That way it kind of, okay, this is what's being discussed, kind of visually, like kind of visually see what's actually being discussed and everything.”

Another added, *“I had to like see what is actually being explained in order for me to actually like okay, so this is what they're trying to explain.”*

E. Online Training Using Zoom

All of the focus group participants relayed that they had enjoyed doing the training online. Logistically, they found Zoom was quick and easy, noting that *“like you click on your email and it just pops up.”* Zoom also allowed ease in taking a break or eating. Participants enjoyed that if needed they *“can shut off our camera for our meal because if we're actually in a class, we can probably just go out in the hallway and can't do that.”* Zoom also removed any transportation barriers of attending a training. They shared that there was no need to *“get on a bus or get in the car. I like that”* and that *“it's quicker than like having to like wait for somebody to pick you up or anything like that.”* A participant with some health conditions also shared that doing the training online was *“less stressful”* on her body physically. The main downside of an online setting was not being able to have personal one-on-one time, alone with other participants. For instance, you could not *“just informally talk to somebody in the hall and outside the training.”*

Limitations

Findings of this focus group must be considered in the context of several limitations. The focus group comprised only five members (the total number of participants in the two cohorts of the online pilot training was 10). Additionally, the two training cohorts were not equally represented in the focus group; four out of the five participants were from the second cohort. Furthermore, the lack of racial and geographical diversity should be noted; all focus group participants were white, and all lived in the northern region of Indiana.

Recommendations

Several insights were gained from the focus group participants regarding the refinement of the current online sexual health curriculum for women with IDD in Indiana.

1. **Rearrange the order that topics are presented.** Participants reported that they would like to get comfortable with the training more before delving into the topics. It is suggested to begin the training topics after getting to know each other, with relationships

rather than anatomy being the first topic. Anatomy was the least favorite topic of the focus group participants and the one topic they wished to spend less time with. Addressing anatomy later in the training may reduce unease about the topic.

2. **Place more of an emphasis on developing healthy relationships.** Of all the training topics, participants really wanted to be able to spend more time on relationships: how to cultivate healthy relationships, how to communicate in relationships, and how to set boundaries. Regarding intimate relationships, a few of the focus group participants noted that this is something that they have little to no experience with and would like more knowledge on how to date and what a timeline of an evolving dating relationship might look like.
3. **Allow for more time for sharing of personal experiences.** Participants noted that they had enjoyed discussion as an activity, and throughout the focus group it was noted that they liked sharing experiences and getting to know one another. In many ways the participants enjoyed fostering relationships with one another, in addition to learning about themselves and the topic of sexual health.
4. **Provide online training opportunities in addition to in-person offerings.** Although the COVID-19 pandemic necessitated the need for an online training, the delivery of a sexual health training using Zoom appears to be a feasible modality to use for future trainings. Participants found the platform to be easy to use, and an online training removed barriers of attendance, including transportation, for participants.

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