

Focus Group Summary: Persons with Disabilities

We Need to Speak Up

People with intellectual and/or developmental disabilities (IDD) are sexually assaulted seven times more often than people without disabilities. Lesbian, gay, bisexual, transgender, queer, and questioning (LGBTQ) individuals with disabilities also face high rates of sexual violence.



“I didn’t tell anyone because he threatened me, I didn’t feel safe until police wanted to save my life. I didn’t even trust my parents.”

Because of this, medical providers must talk about sexual abuse with their patients and offer support. Unfortunately, many medical providers do not have the tools or training to help them have these important conversations.

[Talk About Sexual Violence](#) centers on **conversation groups of medical providers and people with disabilities, including survivors of sexual assault**. It was important to hear from them about how medical appointments can be more supportive.

What We Did

Conversation groups were held as live, online video sessions to hear from people with IDD about their appointments with medical providers.

Participants were assured that nothing would be recorded and written notes would not include names. Participants were free to leave the session or move offline to talk with a support person, if they felt uncomfortable. The names and logos of participating agencies can be found on the last page.

HEARD AND BELIEVED

Do you feel listened to and believed at your medical appointments?

“It depends upon the doctor, there is a gap in understanding disability”

- I am not listened to, and not always believed when I talk about important things.
- My provider knows me, I do feel listened to and believed.
- I feel rushed – there isn’t time for explanations.
- My doctor does not understand that I need to be told some things again.

Is your medical provider comfortable talking about personal health issues?

“Depends on the doctor or how well you know them.”

- When I change doctors, it’s hard to explain the whole story and open up to them.
- I train them, patients need to ask questions.

If there is a support person with you, does your medical provider talk to you, or the other person?

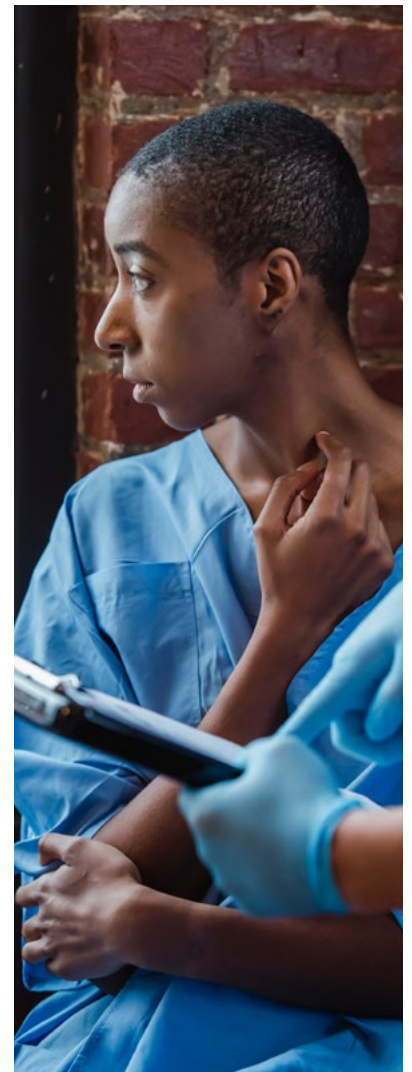
“They often talk to support person, in the beginning.”

- [They] talk to both of us.
- My support person asks for information, then the medical provider talks to me.
- They don’t explain things to me, like what a rape kit is.
- My doctor talks to me, but I don’t talk.
- The support person explains what was said.
- Doctors talk to others—they see the disability first, [and] assume it is worse than it is.

Does your medical provider ask if you want to talk alone?

“Yes and no. Depends on the provider and their comfort level with me.”

- The doctor had my mom leave so he could talk with me.
- I didn’t want to be alone, because of what happened.
- My doctor doesn’t ask me if I want to talk alone.
- The doctor leaves it up to me.



REPORTING

Has your medical provider ever talked to you about mandated reporting?

“Sometimes”

- No, he never told me about what this is.
- I understood when I was told, but it was hard hearing about it.
- My doctor talked to my parents but should have talked to me.
- On occasion, when I was asked questions about being or feeling safe.
- He used understandable explanations, not jargon.

Did your medical provider discuss what would happen after reporting?

“Back then it was not talked about, I just went where they told me.”

- All depends on the doctor.
- No, never talked about it. It should be mandatory to talk to us.
- I would have to prompt the doctor about what is next.

Did your medical provider listen to what you wanted to do next?

“My doctor listens, gives me information and points me in the right direction.”

- It was my decision to do something after the report was made.
- Parents made the decisions for me in my day.

EDUCATION AND TRAINING

What training or materials can help medical providers and patients feel confident when talking about personal things and sexual assault?

“Training about different disabilities”

- Train medical students about sexual assault and disabilities
- Trainings on plain language and how to listen.
- Trainings that include peer advocate survivors on being respectful.

“See sexual assault prevention as part of health and wellness”

- Webinars and conversation guides for patients and doctors.
- Resource website to help patients with IDD who are LGBTQ or transgender.
- More partnerships with health care organizations and disability service systems.

SUMMARY

Participants were generous with their experiences and suggestions. The value of being heard, believed, and seen as a person first was a theme repeated across conversation groups.

Their suggestions pointed to the need for training on the impact of disabilities and trauma.

Just as important was how medical providers can build a supportive relationship with their patients using effective communication.



WHO PARTICIPATED

