

Enhancing effective sexual health promotion for Autistic and disabled youth

*Findings from focus groups
with disabled youth
(physical disabilities)*

April 1, 2023

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PROJECT OVERVIEW

The Sex Information and Education Council of Canada (SIECCAN) is developing resources for service providers to improve sexual health promotion for Autistic and disabled youth¹. This project is funded by Health Canada's Health Care Policy and Strategies Program (Sexual and Reproductive Health Fund). The overarching goal of this project is to improve service providers' knowledge and skills to effectively promote the sexual health and well-being of Autistic youth and disabled youth. To inform the development of these resources, focus groups and interviews were conducted with Autistic, neurodivergent, and disabled youth to learn more about their sexual health experiences and educational needs. This report will specifically discuss the focus groups with disabled youth.

About the focus groups

In September 2022, Wisdom2Action (W2A), in collaboration with SIECCAN, conducted two focus groups with disabled youth in English². One of the two focus group sessions was open to all disabled youth between the ages of 16 and 24 (open session), while the other was specifically for disabled youth between the ages of 16 and 24 who identify as Black, Indigenous, or People of Colour (BIPOC session).

Participants were asked about their dating, relationship, and sexual health experiences including how physical disabilities might impact these experiences, as well as how others may perceive the sexuality and sexual health of disabled youth. In addition, participants were

asked about their sexual health education needs including where they receive or seek out information, any questions they may have, and any advice they would like to give service providers.

Description of participants

A total of 14 youth between the ages of 19 and 24 who indicated having a physical disability participated in the focus groups. Nine participated in the open session and five in the BIPOC session. Six participants lived in Ontario, two in Alberta, one in Quebec, one in British Columbia, and four participants did not specify. When asked about their pronouns, eight participants indicated "he/him," four "she/her," one "he/they," and one did not specify.

About this report

The following report summarizes key findings that emerged from the focus group discussions with disabled youth. W2A provided SIECCAN with an initial summary of the focus group discussions, which served as the foundation for this report. Quotes from the focus groups were then integrated throughout the report by SIECCAN.

- 1 In the context of this report, *disabled youth* refers to those with physical disabilities.
- 2 French interviews were offered as an alternative for individuals wishing to participate in French. However, we did not receive any requests for French interviews from disabled youth participants.

SUMMARY OF FINDINGS

Dating, Relationships, and Sexual Experiences

Stigma

Stigma around disability was described as negatively impacting participants' sexual and romantic experiences. For many participants, this meant being seen as undesirable, which contributed to feelings of inadequacy and a subsequent fear of rejection.

"When I've said no to friends of mine who are disabled when they've asked if I just wanted to hook up, they'll be like, 'Oh, you don't wanna sleep with me or you don't wanna be in a relationship with me cause I'm disabled or because I'm in a chair. And you're embarrassed of that. You're probably the type of girl who only dates able-bodied guys.'"

- Disabled youth

Some participants discussed being perceived as not desiring or as being undeserving of love and affection. Participants indicated that when they had professed lust, love, or attraction to another person, they were often not taken seriously and assumed to be making a joke.

"They feel we shouldn't love or be loved, they feel we should focus on surviving."

- Disabled youth

The desire for disabled people to be loved and to have a sexual partner was sometimes interpreted by others as being an uncontrollable sexual urge. Some participants felt that as a disabled person, there was a greater risk involved in being open and vulnerable about their romantic or emotional attraction to a person. This fear, in turn, often led to disabled youth remaining guarded and unwilling to express their romantic or sexual feelings towards another person.

"The fear of getting rejected or feeling not so enough for the other person to want to date or be in love with me."

- Disabled youth

Many participants also described invasive questions they have been asked by able-bodied people relating to how disabled people have sex.

Finally, some participants talked about the stigma around being perceived as incapable of parenting.

De-sexualization

One common theme emerging from the focus group discussions was the experience of being de-sexualized. Participants discussed how potential romantic or sexual partners did not view them as capable of having sexual feelings or as being sexually attractive. These attitudes were also reflected in participants' interactions with health and social service providers, who often assumed that their disabled clients were uninterested in or incapable of engaging in sexual activity.

“But it’s like to the point where able-bodied people think we just don’t have sex at all. And even my last family doctor, at first, he refused to give me birth control, because he was like you don’t need it, you can’t have sex. And I had to sit down and explain that I very much was having sex and it’ll get to the point where even my able-bodied friends will be like, wait but how do you do this, I didn’t know you could do this.”

- Disabled youth

Disability and Gender

Disability can intersect with gender to create particular experiences of marginalization when it comes to dating and sexual experiences. Participants described how disabled men are often pitied but seen as worthy of sex, whereas disabled women are often seen as undesirable. In addition, some participants discussed how being disabled and a woman or another marginalized gender identity can make an individual more vulnerable to sexual violence.

“And I feel like having the disability and being a disabled woman specifically, opens you up, in my experience, to a lot of danger with sex and dating, because you don’t know what you’re going to encounter, whether it’s going to be ableism or violence or just people who are not willing to see you as a person.”

- Disabled youth

Disability and Sex

Participants also discussed how disability can make sex look and feel different. Some mentioned experiencing pain during sex and having to put in the work to make sex pleasurable.

“Initially, though, the one question that I had was how do disabled people and able-bodied people have sex? Because my family didn’t talk about it. I never heard anything about it and I knew that two disabled people could do it. I just kind of assumed it didn’t work between able-bodied and disabled people. It does. And it just requires some figuring out, a couple injuries, you know, and some patience”

- Disabled youth

Others discussed experiencing certain limitations around movement or sensation due to their disability.

“So I kind of avoid relationships because I feel like sex is a given for people and I don’t want to have to explain why it can hurt for me or feel bad for ‘withholding’ something [sex] from someone that seems important for a lot of people.”

- Disabled youth

In general, participants expressed a need to find activities or equipment that were compatible with their bodies.

Fetishization

Many participants talked about experiences of being fetishized for their disability, particularly in the context of online dating. Specifically, participants indicated receiving inappropriate messages from people they matched with.

"...especially with things like people who are there to fetishize you or may not be willing to see you as a person and more as just whatever your disability is, so it's...it can be really hard to get around those things and kind of see yourself worthy of experiences."

- Disabled youth

Educational Needs

Health and Social Service Provider Knowledge Gaps

Overwhelmingly, participants discussed their desire for health and social service providers to be better educated about disability and sexuality.

"Why is getting access to sexual health tools and testing so difficult? Like you're supposed to have a pap smear, what? Every two years after you have sex? I have not...So yeah, they couldn't fit the tool in me and so they just decided I probably didn't need a pap smear."

- Disabled youth

Participants felt that many practitioners held misconceptions about sex and disability, which need to be addressed. Some examples of misconceptions that were mentioned included the

belief that people with certain conditions cannot have sex when they can or the assumption that intense pain during a period is not concerning when it is actually indicative of a health condition.

"...I think they just need to access more information, and in the way that they are constantly reading new studies on illnesses and keeping up with the most relevant information... Doing the same for your disabled patient."

- Disabled youth

Participants also discussed how many service providers seemed to feel uncomfortable talking about sex with disabled clients/patients/students.

Finally, participants discussed the importance of including disabled people when developing sexual health programs for disabled people.

Past Sexual Health Information Seeking

When asked how they had sought out sexual health information in the past, the majority of participants identified the Internet as their main source of information. Participants specifically discussed seeking information via Google searches, as well as anonymous question websites such as Quora and YouTube. Additionally, some participants mentioned asking their parents about their sexual health related questions, and some mentioned speaking with counselors and health care providers.

"I know a few that go to counselors (only a few), while a large number of them rather keep to themselves in order not to get mocked."

- Disabled youth

In-School Experiences

In general, participants felt the sexual health education they had received in school was limited, lacking, or completely non-existent. Many participants did not receive any sexual health education because sexual health was often taught in gym class, which disabled youth are often excluded from.

"...we're supposed to receive some basic form of sex education [...] but my school board offered me physiotherapy once a month. It also happened to be that we got sex ed once a month, but I was pulled out of those sex ed classes and instead got my physiotherapy session then, because I 'wouldn't need sex ed anyway,' you know..."

- Disabled youth

Even when sexual health education was taught, participants expressed frustration that sexuality and disability were rarely discussed.

Participants also expressed frustration with the limited scope of the curriculum. For instance, many felt that sexual health education:

Narrowly focus on (able-bodied) physical anatomy, pregnancy prevention, and sexually transmitted infections (STIs)
Had little 2SLGBTQ+³ content
Had little acknowledgement of sexual pleasure
Focused on abstinence

Some participants expressed a desire for disability-focused sexual health education resources, such as a helpline, an App, or pamphlets.

Desired Topics for Future Learning

Participants indicated several sexual health related questions they would like to learn more about including:

How disabled people can have pleasurable sex and explore what is enjoyable and what works for their bodies
Navigating self-esteem issues and pushing back against stigma and ableism from sexual or romantic partners
Whether there will be health care centers exclusively for disabled people in the future
Why disabled youth often receive negative replies when expressing sexual or romantic feelings towards an able-bodied person
Whether there is or will be a dating website for disabled people
Understanding the misconceptions that able-bodied people hold about dating a disabled person
More data on relationships among disabled people
How pregnancies are experienced by disabled people and how disabled people can be supported to have safe pregnancy experiences
Whether it is possible for disabled youth to have and raise children

3 2SLGBTQ+ is an acronym that stands for Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer or Questioning and additional sexual orientations and gender identities

CONCLUSION AND RECOMMENDATIONS

Overall, disabled youth highlighted a number of challenges they experience in having fulfilling intimate relationships and sexual experiences, as well as in accessing necessary sexual health services. Underpinning many of these challenges is prevailing stigma about disabled youth's interest and ability to have meaningful relationships and sexual experiences, as well as to have children and to parent. False assumptions that disabled youth are either not interested or unable to engage in such experiences contributed to disabled youth being removed from sexual health education courses in school, health service providers not offering needed sexual health services (e.g., pap tests, birth control), and disabled youth encountering barriers in finding suitable dating partners (e.g., disabled youth not being pursued romantically/sexually or being fetishized). These misconceptions also negatively impacted the self-esteem of disabled youth and contributed to disabled youth feeling unattractive, undesirable, or even unworthy of romantic and sexual relationships.

Based on these findings, SIECCAN recommends the following for the physical disability toolkit:

1. Emphasize the importance of **addressing stigma and ableism** within sexual health curriculum more broadly and offer suggestions on how that could be done (e.g., including disability within discussions around dating, relationships, and sexual experiences with both disabled and non-disabled youth);
2. Illuminate and **challenge common misconceptions about the sexuality of disabled youth** (e.g., the notion that disabled youth are not interested or not capable in engaging in fulfilling intimate relationships and/or sexual experiences; the belief that disabled youth cannot have or raise children; the idea that disabled youth do not need preventative sexual health care);
3. Provide services providers with tools to support disabled youth in **developing positive self-esteem and self-image** particularly when it comes to feelings of desirability and worthiness of romantic and sexual experiences (e.g., fostering greater disability representation within sexual health curriculum more broadly; supporting disabled youth in working through internalized ableism);
4. Provide service providers with educational material to guide disabled youth and non-disabled youth in **making adaptations so that sexual experiences are more pleasurable for disabled youth**;
5. Provide services providers with strategies to **foster a safe environment where disabled youth feel comfortable asking questions about sexuality and sexual health** (e.g., initiating conversations with disabled youth about sexuality and sexual health; being opened and willing to work with disabled youth to identify appropriate adaptations; embracing diversity of experiences; listening and validating the self-determined needs and desires of disabled youth).