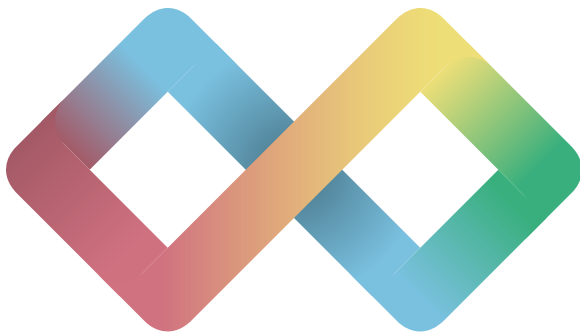


Enhancing effective sexual health promotion for Autistic and disabled youth



*Findings from focus groups
and interviews with Autistic
and neurodivergent youth*

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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 youth (with physical disabilities). The overarching goal of this project, funded by Health Canada's Health Care Policy and Strategies Program (Sexual and Reproductive Health Fund), is to improve service providers' knowledge and skills to effectively promote the sexual health and well-being of Autistic youth and disabled youth (with physical disabilities). 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 and interviews with Autistic and neurodivergent youth.

About the focus groups and interviews

Between September and October 2022, two focus groups were conducted in English by Wisdom2Action (W2A) and two interviews were conducted in French by SIECCAN with Autistic and neurodivergent youth. One of the two focus group sessions was open to all Autistic or neurodivergent youth (open session), while the other was specifically for Autistic or neurodivergent youth who identify as Black, Indigenous, or People of Color (BIPOC session).

Participants were asked about their dating, relationship, and sexual health experiences including how autism or neurodivergence might impact these experiences, as well as how others may perceive the sexuality and sexual health of Autistic or neurodivergent 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 10 Autistic or neurodivergent youth between the ages of 17 and 23 participated in the focus groups and interviews. Six participated in the open session, two in the BIPOC session, and two participated in the interviews. Four participants lived in Quebec, three in Ontario, two in Nova Scotia, and one in Manitoba. When asked about their pronouns, four participants indicated "he/him," two "she/her," one "she/they," one "they/them," one "any pronouns," and one did not specify.

About this report

The following report summarizes key findings from both the focus groups and interviews with Autistic and neurodivergent youth. W2A provided SIECCAN with a summary of key findings from the focus group discussions, which served as the foundation for this report. Findings from the interviews were then integrated by SIECCAN. Finally, quotes from both the focus groups and the interviews were added throughout the report. French quotes from the interviews have been translated into English.

SUMMARY OF FINDINGS

Dating, Relationships, and Sexual Experiences

De-sexualization

One common theme emerging from the focus groups and interviews 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 sexually attractive. These attitudes were also reflected in many participants' interactions with health and social service providers, who often assumed that their Autistic and neurodivergent clients were uninterested in or incapable of engaging in sexual activity. Several participants noted that this experience was distinct from asexuality or a lack of interest in sex.

Communication Barriers

Many participants noted that Autistic and neurodivergent youth may find it difficult to set and communicate boundaries, as well as recognize the risk of sexual assault through more subtle forms of manipulation or coercion.

"I wish we'd known that it wasn't normal, that I shouldn't have had to be receiving that or gone through that or accepted that. I had the right at that moment to take myself out of that situation. [...] I think it's extremely important to be mindful of situations that aren't the classical kind of picture of what you expect sexual assault to be."

- Autistic/neurodivergent youth

The importance of teaching Autistic and neurodivergent youth about consent was also highlighted.

A common theme which emerged was that dating and engaging in sexual relationships can involve many "unwritten rules" that may not always be clear to Autistic and neurodivergent youth. Many participants noted that Autistic and neurodivergent youth have different ways of communicating than allistic (i.e., a person who is not Autistic) or neurotypical (i.e., a person who is not neurodivergent) youth. Specifically, Autistic and neurodivergent youth often prefer to speak very directly instead of guessing through body language and facial expressions, which can lead to challenges when flirting or communicating about sex.

"But perhaps when it comes to Autistic people - one characteristic in common we share is being generally very direct, speaking very directly without necessarily using Hollywood cliches of what is meant to be romantic and seducing. And I think that especially when it is individuals assigned male at birth Autistic individuals. It is seen to be very creepy..."

- Autistic/neurodivergent youth

In the BIPOC session, participants who were in relationships with allistic or neurotypical partners noted that Autistic or neurodivergent youth were more likely to have to accommodate the needs of their partners, while having their own needs compromised.

“Because you have your disability or you’re Autistic or you’re neurodivergent, so you try to meet them halfway and that’s already outside your comfort zone but they’re like unwilling to meet you the other half of the way because they’re expecting a “normal” relationship [...] they’re not willing to put in the work or the effort to try to make the experience good for the both of you.”

- Autistic/neurodivergent youth

Additionally, some participants indicated that their allistic or neurotypical partners sometimes described their relationships as being more of a friendship due to lower levels of physical intimacy.

Stigma

Many participants discussed how stigma around autism and neurodiversity negatively impacted their sexual and romantic experiences.

“It’s only ever people’s reactions to my autism/ disability that bother me, really. Not so much the actual symptoms of autism. Stigma heavily influences all of my relationships.”

- Autistic/neurodivergent youth

Participants noted that it is not autism itself that impacts Autistic people’s ability to date or have relationships, but rather people’s lack of openness and willingness to date Autistic people, which can make these experiences more difficult for Autistic people.

Many participants discussed being perceived as “weird,” “awkward,” and/or “creepy,” which contributed to feeling or being seen as unattractive.

“...when I told him [partner] I have autism, he told me he felt lied to. So I asked him why he felt he was lied to and he said “because you’re not really like normal.” That’s the words he used.”

- Autistic/neurodivergent youth

Other youth expressed having different needs or boundaries than allistic or neurotypical partners, which led to concerns about coming across as “too much” or being described as “hard to love.” As a result, many participants felt limited in their dating or sexual experiences, specifically being excluded from the possibility of having neurotypical/allistic partners.

Some participants described how their neurotypical or allistic partners ignored their Autistic/ neurodivergent-specific traits or needs, wanting to pretend their partner was neurotypical, and/or expecting the Autistic/neurodivergent individual to perform neurotypical behaviours through masking.

“In my experience, when I become intimate with non-autistic people, they usually either pretend I’m not Autistic, or become uncomfortable.”

- Autistic/neurodivergent youth

Positive Experiences

Some participants brought up positive dating experiences, especially around dating other Autistic or neurodivergent people. These participants discussed how such connections could be validating and comfortable because of shared experiences.

Educational Experiences and Needs

Past Sexual Health Information Seeking

When asked how Autistic and neurodivergent youth had sought out sexual health information in the past, the majority of participants identified the Internet as their main source of information. Some discussed searching for information on health information websites or seeking out official government or medical sources. Others described seeking out information on Wikipedia, social media sites such as Reddit or Youtube, or sites for crowdsourced questions and answers such as Quora or Yahoo Questions. Some participants also discussed using pornography or other sexually explicit media as a way to learn about sex.

Many participants expressed frustration with these various sources of information, feeling they had not necessarily found the answers they needed, and/or that they had absorbed misinformation.

Some participants discussed how some of these platforms involved interacting with strangers online and how this could be a uniquely vulnerable experience for some Autistic and neurodivergent youth who might miss red flags or be overly trusting.

"I asked the Internet but also one thing that I noticed is because of looking that up online, it got me in a dangerous situation. A person took advantage of the situation [...] and I was then too embarrassed to talk to anybody about what was happening, I never told anyone except my current partner about what they did or who they are. It's dangerous not having someone to talk to..."

- Autistic/neurodivergent youth

In addition to the Internet, some participants also mentioned asking their parents or other family members sexual health related questions, while others turned to their friends, most of whom were also Autistic or neurodivergent.

Family Background, Culture, and Race

BIPOC participants discussed how sex is a taboo topic in some cultures, which can make talking openly and learning about dating, relationships, and sex very difficult.

"...I definitely have to confess to having been online for you know things like when it comes to your first kiss or how do you know if a guy likes you. And I think this is true for a lot of Autistics when they have nowhere else to turn to or no one else to turn to. I couldn't go to my parents because I'm from a culture where sex and dating is a no no, it's a taboo."

- Autistic/neurodivergent youth

BIPOC Autistic and neurodivergent youth also discussed how coming from mixed racial backgrounds or being in interracial relationships may lead to experiences of racism that intersect with other forms of stigma, which can make it difficult to confide in or reach out to family for support.

Additionally, experiences of racial profiling from health care providers when seeking services creates a frustrating experience for BIPOC Autistic and neurodivergent youth, whose health care needs are not met or met inadequately due to these intersecting forms of marginalization.

"It was not the abortion itself, it was the sensitivity and the stuff that came after. It was the health care provider racial profiling me that bothered me about the experience."

- Autistic/neurodivergent youth

Desired Topics for Future Learning

Participants identified up a number of sexual health topics they would like to learn more about. These included:

How to engage in casual sex in a way that is comfortable, consensual, and fun

Desire to learn more about BDSM

How to maintain a long-term relationship

How to make sex more pleasurable

How to prevent feelings of discomfort when physical changes or strong sensations occur during sexual experiences

How to feel less awkward talking about sex

Reproductive support and how to prepare for an abortion as an Autistic or neurodivergent youth - how the abortion will potentially feel and the emotional and physical effects afterward intersecting with hypersensitivity and hormonal/chemical peaks

A clear map, format, or guideline for sex, dating, and relationships instead of feeling thrown into dating while guessing how to engage (i.e., a guideline of expectations, what to do and when, how to respond to different situations)

How to know someone is interested in you and how to respond

How to know what a partner expects from you in a relationship without compromising what you're willing to share

What is a period going to feel like

Reassurance that not all sexual experiences are pain-free, reasons why that could be, as well as ways to reduce or eliminate painful sexual experiences and to make them more pleasurable

Learning the risks of sexual assault or aggression including less obvious behaviours - things said and done - that constitute sexual assault

Preventing Urinary Tract Infection or other infections

"For Autistic people, what I can say is that they can be more sensitive so then, professionals don't know how to manage these sensitivities [...] For example, they [Autistic people] can find erections to be strong sensations. So it's not that they hurt, but it's strong sensations that could cause sensitivities."

- Autistic/neurodivergent youth

"Sometimes in sexual health, it hurts down there. You're not moist down there because you're not turned on because if you're asexual, and you're having that physical relationship because you care about the other person. [...] but it's painful and you don't want to tell them it's painful because then they get turned off and then they say you're not enjoying it."

- Autistic/neurodivergent youth

In-School Experiences

In general, participants felt the sexual health education they had received in school was limited, lacking, or completely non-existent.

Autistic and neurodivergent youth identified multiple reasons for finding the content and structure of school-based sexual health education as inadequate including:

Focus on physical anatomy, pregnancy prevention, and Sexually Transmitted Infections (STIs)

Lack of trauma-informed approaches

Little 2SLGBTQ+¹ content

Little acknowledgement of sexual pleasure

Little discussion of reproductive health disorders such as Polycystic Ovary Syndrome (PCOS)

“We need to teach more about prioritising pleasure, being able to define sex in various ways, deconstructing virginity/purity culture and publicising info on intimacy that isn’t inherently sexual.”

- Autistic/neurodivergent youth

Additionally, some participants discussed being separated from their neurotypical/allistic classmates into a “special class” in school, including for their sexual health courses.

Finally, it was suggested that giving students the opportunity to write down their questions anonymously and have these questions answered in sexual health courses would be helpful as some students might not feel comfortable asking their questions out loud in front of the entire class.

1 2SLGBTQ+ is an acronym that stands for Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer or Questioning and additional sexual orientations and gender identities

Health and Social Service Provider Knowledge Gaps

Overwhelmingly, participants discussed their desire for health and social service providers to be better educated on the intersections of neurodivergence and sexuality. Participants identified a number of key reasons for this:

To be able to have an open and very honest conversation about sex regardless of anyone's age to help Autistic and neurodivergent youth have safe, consensual, and comfortable sex

"...one of the meetings was very cool because it was sexual health related and it was full-on explanatory, it was great that it didn't make blowjobs feel taboo. It was nice having a very honest conversation regardless of anyone's age because a lot of people are having sex at a very young age, and the most important thing is that they're protected and having safe consensual comfortable sex if they want to be having sex and not if they don't want to be."

- Autistic/neurodivergent youth

To be able to answer questions and dispel awkwardness with Autistic and neurodivergent youth

To be able to teach all youth how to have pleasurable and respectful sex with Autistic and neurodivergent youth

To trust and believe Autistic or neurodivergent youth and try to adapt to them

To be open-minded to everyone's experiences, recognizing that people from different communities and ethnic backgrounds may have different understandings and experiences of sexual encounters, of what might feel good to them, and of what might fit with their needs

"The advice I would give to service providers would be you don't know everything and in life that's fine. [...] it doesn't mean you can't learn [...] Like if someone who has autism is telling you this is how best to help their personal experience, take it and run with it. Give that advice to someone else too."

- Autistic/neurodivergent youth

To be able to provide clear directives to Autistic and neurodivergent youth, and have an actual list of possible options that Autistic and neurodivergent youth can use when experimenting

To stop talking about autism and neurodivergence as diseases needing to be cured - talk from a strengths-based and trauma-informed lens

To be as neutral as possible in the advice service providers provide without assuming that service providers know how the Autistic person will experience a particular situation

"But maybe don't change the question. For example, if it's about ejaculating, don't say 'but maybe after you won't like to ejaculate' or 'maybe after you'll get used to the feeling and after you won't want to do it'...saying things like they were the Autistic person."

- Autistic/neurodivergent youth

To stop offering various types of medication as the primary solution for making sex more pleasurable and listen to what the Autistic or neurodivergent youth are explaining about their needs and issues - to provide alternative options instead of medication, making solutions more client-centred

To reach out to Autistic and neurodivergent people with lived experience to expand their knowledge, in order to provide advice that is better tailored to the needs of Autistic and neurodivergent youth

To be as clear as possible and avoid complicated language when talking to Autistic people. Service providers should also verify that they appropriately interpret the questions that Autistic people ask them before providing an answer

CONCLUSION AND RECOMMENDATIONS

Overall, Autistic and neurodivergent youth discussed the many challenges they encountered when it comes to dating, relationships, and sexual experiences. **In particular, Autistic and neurodivergent youth highlighted challenges they experienced in communicating their needs with their partners, in understanding subtle and more implicit forms of communication, and in navigating their sensory, sexual, and intimacy needs.**

Underpinning much of these challenges was prevailing stigma about Autistic and neurodivergent people, which contributed to:

Misconceptions about Autistic and neurodivergent youth's desire for relationships and intimacy,

Lack of openness from non-autistic people to adapt to the needs of their Autistic partners,

Limited avenues for Autistic and neurodivergent youth to safely seek out reliable sexual health information that account for their unique needs and experiences.

This lack of support and information, in turn, placed Autistic and neurodivergent youth at an increased risk of being taken advantage of and having negative experiences.

BIPOC Autistic and neurodivergent youth, as well as gender and sexual minority Autistic and neurodivergent youth, may be more susceptible to experiencing multiple forms of stigma that contribute to even greater disadvantages and vulnerability.

Based on the findings from the focus groups and interviews, SIECCAN recommends the following for the autism toolkit:

1. Emphasize the **impact of prevailing stigma and ableism** on sexual health education, services, opportunities, and experiences for Autistic youth and offer some ways in which these can be addressed (e.g., promoting autism awareness and acceptance within sexual health education curriculums more broadly, training and education for service providers about the diverse ways Autistic people experience sexuality and sexual health);
2. Highlight the **diversity of experiences** that Autistic people can have (e.g., in terms of sexual interest, gender identity, sexual orientation, how intimacy can be experienced, how relationships can be experienced, communication styles, sensory sensitivities and preferences);
3. Provide service providers with tools to support Autistic youth in **navigating more subtle and implicit forms of communication** (e.g., dating conventions, identifying potential harm and danger);
4. Provide service providers with strategies to guide Autistic youth in **identifying and expressing their needs, desires, and boundaries** (e.g., related to sensory sensitivities, sexual desires, and intimacy);
5. Provide service providers with educational material to guide Autistic youth in safely **navigating online sexual health information.**