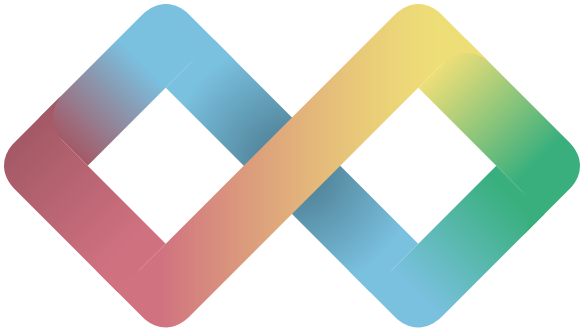
sieccan
Sex Information & Education Council of Canada
Conseil d'information & d'éducation sexuelles du Canada

Enhancing effective sexual health promotion for Autistic and disabled youth



Findings from the service provider consultation survey: Focus on Autistic youth.

December 5, 2022

Health Canada Santé Canada

Funded through a contribution agreement with Health Canada's Health Care Policy and Strategies Program (Sexual and Reproductive Health Fund).

Prepared by

Yi Wen Shao, Project Coordinator
Jessica Wood, Research Specialist
Alex McKay, Executive Director

TABLE OF CONTENTS.

Suggested citation:.

SIECCAN. (2022). *Enhancing effective sexual health promotion for Autistic and disabled youth. Findings from the service provider consultation survey: Focus on Autistic youth.* Toronto, ON. Sex Information and Education Council of Canada (SIECCAN).

PROJECT OVERVIEW.

Autistic youth and disabled youth (see section below on *Importance of language* for an explanation of our language choice) in Canada are an underserved population with respect to the provision of quality sexual health information and services tailored to their needs. 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 achieve this goal, we will be developing two capacity-building toolkits for service providers consisting of a series of online and print training materials to address the sexual health needs of Autistic youth and disabled youth (with physical disabilities), respectively. In the context of this project, youth refers to any individual aged 29 and under.

About this report

SIECCAN conducted a quantitative and qualitative online consultation with a wide range of service providers across Canada from August 2022 to October 2022. **Service providers, for our purposes, are defined as anyone in a formal position to provide sexual health information and/or services to Autistic and/or disabled youth.** Some examples of service providers include educators, therapists/counselors, occupational therapists, physiotherapists, social workers, public health professionals, community organization staff, physicians, nurses, and others.

The goal of the online survey was to better understand the experiences of service providers with sexual health promotion in general and more specifically with Autistic and/or disabled youth.

A total of 137 service providers participated in the consultation survey. This report summarizes key findings from the 127 participants who indicated that they work with Autistic youth or both Autistic youth and disabled youth. These findings will inform the development of the capacity-building toolkit focused on the needs of Autistic youth.

Importance of language.

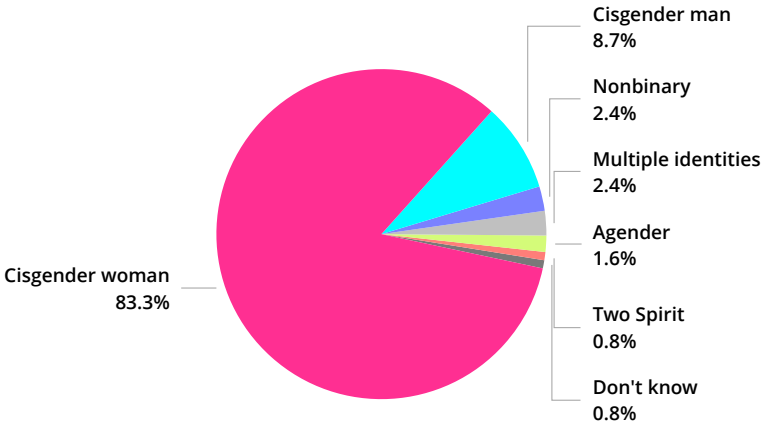
There is currently no consensus regarding preferred language to talk about autism and/or disability either among people with lived experience (i.e., Autistic people and disabled people) or across other stakeholder groups (i.e., service providers and family members). Existing literature and first person narratives suggests that identity-first language (i.e., Autistic youth or disabled youth), which views autism and/or disability as a core aspect of an individual's identity that cannot be separated from the individual, is often preferred among those with lived experience, as opposed to person-first language (i.e., youth with autism or youth with a disability), which views autism and/or disability as an attribute of a person rather than defining feature of who they are (Andrews et al., 2022; Botha, 2021; Bury et al., 2020; Liebowitz, 2015). As such, we have chosen to use identity-first language for this project, but we recognize this is not preferred by all. It is also important to note that while some Autistic people identify as being disabled, not all Autistic people identify this way. Therefore, any reference to disabled people in our project will not include Autistic people. We will specifically mention Autistic people when referring to this population. Finally, any mention of disabled youth in the context of this project will specifically refer to those with physical disabilities.

WHO PARTICIPATED IN THE CONSULTATION?

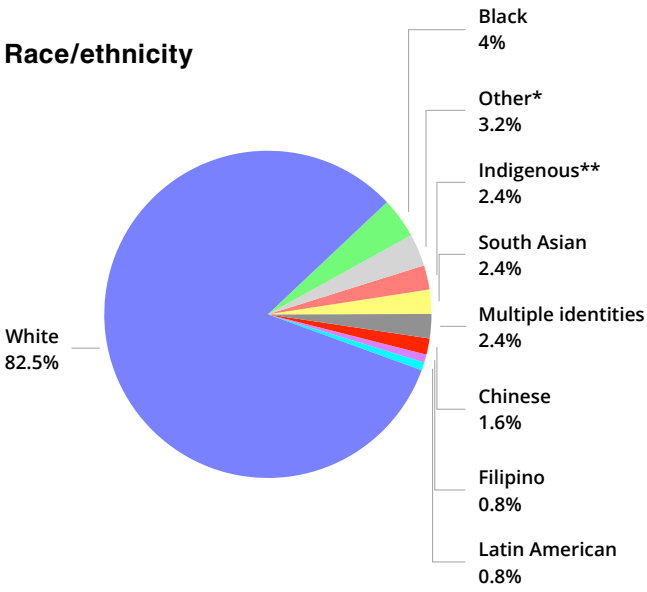
Most respondents identified as white, as a cisgender woman, and as being heterosexual (see pie charts below for detailed breakdown). Few respondents (7%) either reported having an autism diagnosis or self-identified as Autistic, while 10% indicated they had a physical disability (data not shown).

Demographic information (n=127)

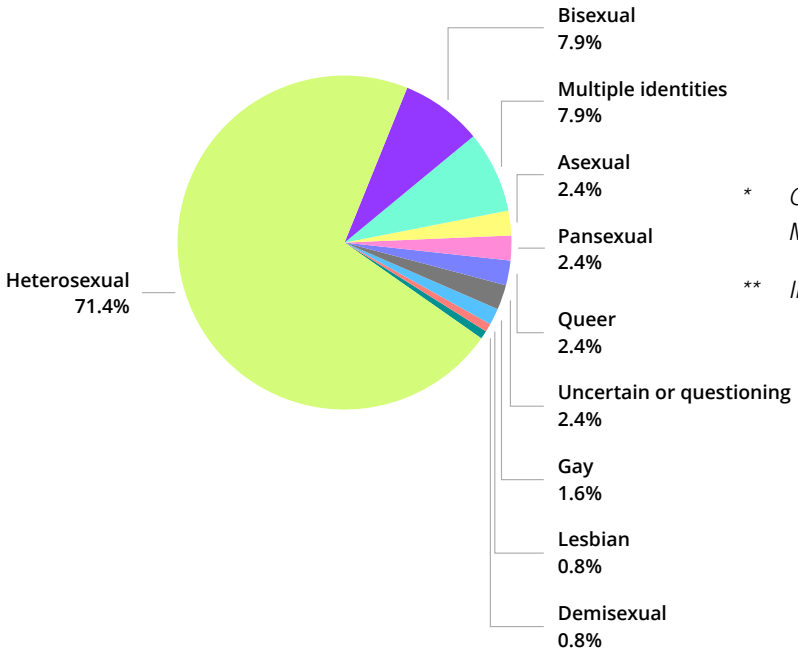
Gender



Race/ethnicity



Sexual orientation



* *Other responses included European, Jewish, Jewish Middle Eastern, Mixed (East Indian/French Canadian).*

** *Indigenous (First Nations, Métis, and Inuit)*

The majority of participants worked in Quebec, Ontario, or Alberta (see Figure 1). Unfortunately, there were no participants from the territories. Just under a third of participants completed the French version of the survey (31%), which contributed to a significant level of participation from service providers who worked in Quebec (data not shown).

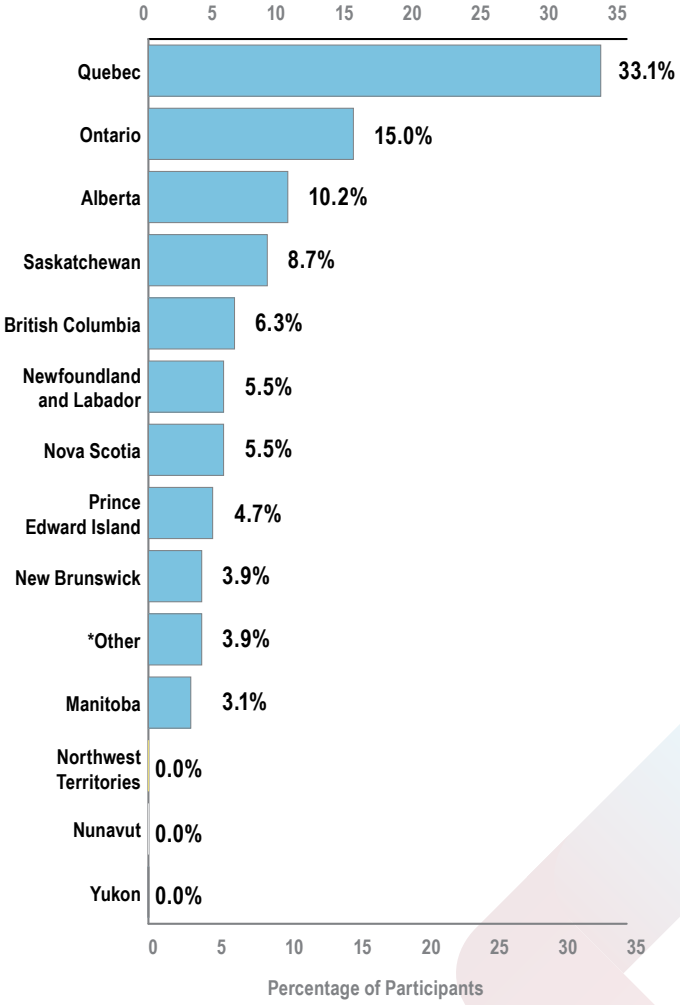


Figure 1: Region of work (n=127)

*Other responses included the United-States, working internationally, working in multiple provinces, and having previously worked in Canada but now live in the United-States.

Participants worked in a wide range of professions with educators (19%), social workers (13%), public health professionals (8%), and community organization staff (8%) being the most represented (see Figure 2).

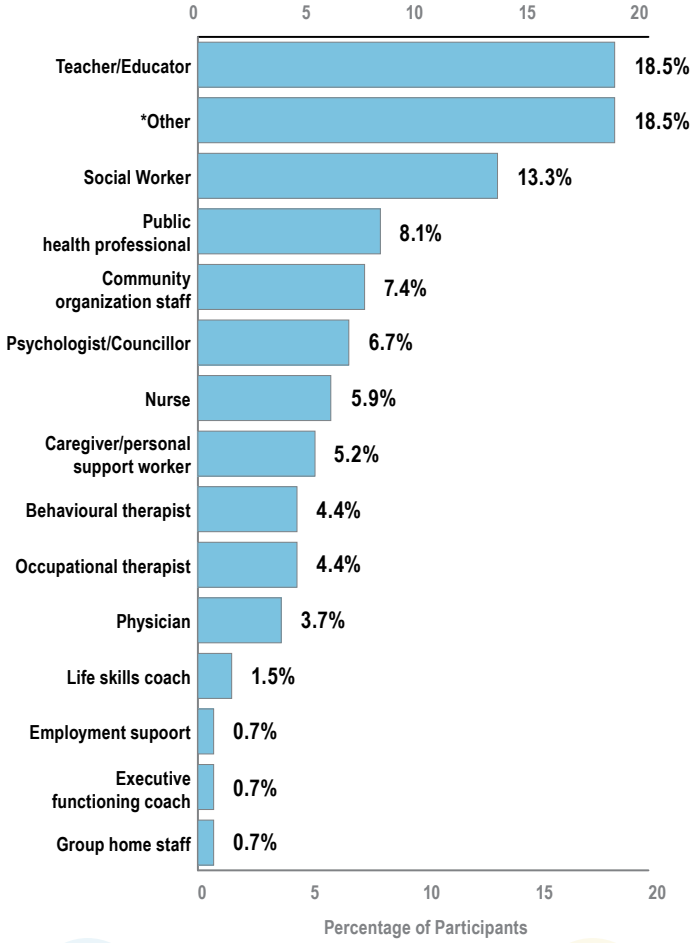


Figure 2: Area of work (n=127)

*Other responses included behaviour analyst, sexual health/sexology/sexuality educator, sexologist, sexual health education development, child and youth counsellor, developmental service worker, direct support worker, consultant, psychoeducation, personal support program educator, and having multiple roles.

About 70% of participants indicated having over 5 years of experience working with and/or supporting Autistic youth (data not shown). Participants worked in a variety of settings notably within schools, homes, community organizations/groups, community health centers, as well as rehabilitation centres and support Autistic youth across all age groups (see Table 1). While English (77%) and French (40%) were the languages most used in their places of work, about 5% of participants also used American Sign Language (data not shown). About half of the participants worked in large urban centres and a quarter in medium population centres (see Table 1)

Table 1: Workplace information (n=127)

Age of Autistic youth participant supports	
4 years old and under	**22%**
5 - 8 years old	**45.7%**
9 - 12 years old	**61.4%**
13 - 16 years old	**71.7%**
17 - 20 years old	**76.4%**
21 - 24 years old	**50.4%**
25 - 28 years old	**42.5%**
29 years and over	**38.6%**
Setting where participant supports Autistic youth	
School	**47.2%**
Home	**28.3%**
Community organization/group	**26.8%**
Community health centre	**16.5%**
Rehabilitation centre	**15%**
Other*	**14.2%**
Workplace	**9.4%**
Community living facility/group home	**8.7%**
Hospital	**7.9%**
Size of community where participant works	
Large urban centre	**54%**
Medium population centre	**25.8%**
Small population centre	**15.3%**
Rural area	**4.8%**

*Other responses included private practice, multiple community settings, group home, online, shelters, day centre, integrated health and social centres, and office settings.

WHAT DID WE LEARN FROM THE CONSULTATION SURVEY?.

Part I: Sexual health promotion experience

Participants were asked questions about their sexual health promotion experiences broadly and more specifically with Autistic youth, including questions about:
The ways in which the participant promoted sexual health in their work,
Reasons the participant may not discuss sexual health,
Barriers and challenges the participant experienced in promoting sexual health,
The participant's comfort level in addressing sexual health, and
Whether or not the participant received training in the area of sexual health.

Comfort level

The majority of individuals (79%) participating in this consultation reported feeling comfortable or very comfortable addressing sexual health as part of their work. When the participant engaged in sexual health promotion, sexual health promotion was often in the form of education (81%), referrals (65%), counseling (46%), and assessments (31%) (data not shown).

Responding to 5-point Likert scale items, "On a scale from 1 (very uncomfortable) to 5 (very comfortable), how comfortable are you discussing the following topics with Autistic youth in your work?", service providers in our sample generally reported feeling quite comfortable addressing a wide-range of sexual health topics with Autistic youth (see Table 2).

However, the topics participants reported feeling the least comfortable addressing included:
1. adapting sexual behaviours to accommodate for physical disabilities,
2. adapting sexual behaviours to accommodate for sensory differences,
3. sexual function, problems, and concerns, and
4. sexual pleasure.

It should be noted that individuals choosing to participate in this consultation survey may have been relatively more comfortable addressing sexual health with Autistic youth than those who chose not to participate. It is, therefore, possible that the comfort levels reported by the participants in this sample are somewhat higher than in the wider community of service providers.

Training

Over two-thirds of participants (72%) indicated that they received training on the topic of sexual health either as part of the education they received prior to working in their field and/or as a professional development opportunity (data now shown). However, only 19% indicated that the sexual health training they received addressed the needs of Autistic youth (data not shown). Of these participants, 27% indicated that the training was "very helpful" in making them feel more comfortable addressing sexual health with Autistic youth (data not shown).

Table 2: Comfort level discussing various sexual health topics with Autistic youth (mean/average score):

Question: On a scale from 1 (very uncomfortable) to 5 (very comfortable), how comfortable are you discussing the following topics with Autistic youth in your work?	
Topic	**Mean (Average)**
Birth control methods	**4.28**
Safer sex methods (e.g., condom use)	**4.24**
Puberty changes (e.g., physical, biological, psychological, emotional, social)	**4.19**
Sexually transmitted infections (STIs), including HIV	**4.16**
Relationships including different types of relationships (e.g., romantic, sexual, friendships) with single/multiple partners, initiating relationships and dating	**4.15**
Self-image and self-esteem	**4.12**
Sexual orientation	**4.09**
Pregnancy options (e.g., parenting, abortion, adoption)	**4.07**
Reproduction and birth	**4.06**
Sexual decision-making (including asking for, giving, and respecting consent, personal boundaries, bodily autonomy, sexual agency, choosing to engage or not engage in sexual activity)	**4.03**
How to access sexual health and reproductive resources and services	**3.91**
Love and intimacy	**3.91**
Family planning, fertility, and parenting	**3.90**
Sexual rights and advocacy	**3.85**
Legal aspects of sexual behaviour (e.g., consent, cyberbullying, harassment, assault, and sexting)	**3.84**
Media literacy related to sexual content in advertising, TV, pornography etc.	**3.83**
Sexual behaviours (e.g., masturbation, oral sex, intercourse)	**3.82**
Gender identity and expression	**3.81**
Communication skills in sexual/romantic relationships (including understanding and communicating one's emotions and needs, understanding and accommodating for communication differences, and the use of communication technology)	**3.80**
Sexual pleasure	**3.76**
Sexual function, problems, and concerns (including the use and impact of medication)	**3.46**
Adapting sexual behaviours to accommodate for sensory differences	**3.40**
Adapting sexual behaviours to accommodate for physical disabilities	**3.34**

Barriers and challenges

Despite having high levels of comfort in addressing sexual health, service providers highlighted several important reasons for not discussing sexual health in their practice including the fact that the people service providers support often do not bring up the topic of sexual health, experiencing pushback from families, and that discussing sexual health is often not a key part of their job.

Analysis of the qualitative responses from participants indicated the following five categories of barriers to sexual health promotion for Autistic youth:
1. **Stigma and stereotypes:** Participants noted that false assumptions and stereotypes about Autistic people (e.g., the assumption that Autistic people are not interested in sexual relationships and that sexual health education is not necessary for this population) held by many service providers and family members was an important barrier preventing Autistic youth from accessing sexual health information. Further, sexual health, when addressed with Autistic youth, was often done from a problem perspective and/or reflected many ableist notions (e.g., the idea that Autistic people in relationships are "cute").
2. **Lack of effective and appropriate resources:** Many participants indicated that there were limited sexual health promotion resources available that were adapted to the needs and experiences of Autistic youth. Some participants specifically mentioned a lack of resources for Autistic youth with intellectual disabilities, while others noted a lack of sexual health services that service providers could refer Autistic youth to.
3. **Structural and systemic barriers:** Among the many structural and systemic barriers that participants identified, the primary barrier discussed was a lack of relevant, trauma-informed, and up-to-date training focused on sexual health promotion needs/experiences of Autistic youth. Other systemic barriers mentioned included limited funding for sexual health promotion programs for Autistic youth, ableist notions of sexuality impacting access to services (e.g., whether services are available and account for the needs of Autistic youth), and organizational attitudes regarding sexual health promotion (e.g., working in a religious organization that does not encourage sexual health promotion).
4. **Barriers related to interacting with parents/caregivers:** Many participants emphasized that negative views held by parents and caregivers about the sexuality of the Autistic youth (e.g., not viewing Autistic youth as sexual beings and not believing Autistic youth were sexually active) often led parents/caregivers to not consent to or actively prevent the Autistic person from receiving sexual health education or information. Further, misconceptions about the sexuality of Autistic youth contributed to parents/caregivers not asking questions about sexual health during appointments with Autistic youth. Participants noted that parental/caregiver resistance also influenced how comfortable Autistic youth were asking questions to service providers about sexual health during their appointments, particularly when a parent or other caregiver was present.
5. **Barriers related to interacting with Autistic youth:** Participants noted that some Autistic youth may be embarrassed or uncomfortable and, therefore, reluctant to ask questions or talk about sexual health. Limited exposure to sexual health information and limited opportunities to meet potential partners may contribute to this lack of comfort in discussing sexual health. Participants mentioned that some Autistic youth resorted to alternative sources of information that offer more anonymity (e.g., online sites, porn, social media). Some participants recognized that these challenges were often related to a lack of provider training in fostering a comfortable environment for Autistic youth to discuss sexual health topics as opposed to placing the responsibility on the youth themselves to initiate and navigate these challenging conversations.

Ableism.

A strong majority (84%) of participants acknowledged (*agree* and *strongly agree*) that ableism significantly impacts how Autistic and/or disabled youth are taught about sexuality and sexual health (data not shown). In addition, most (73%) have also reflected upon how ableism might affect the ways service providers address sexuality and sexual health with Autistic and/or disabled youth (data not shown).

Part II: Needed resources

Participants were asked to:
Identify areas of significant knowledge gaps,
Prioritize the topics that should be covered in sexual health resources for service providers working with Autistic youth,
Identify important considerations for sexual health resources, and
Elaborate on the types of resources and resource formats that would be the most useful to service providers and to the Autistic youth they support.

Age groups with the most significant knowledge gaps.

Participants indicated that **all age groups of Autistic youth have sexual health knowledge gaps** due to Autistic youth being left out of sexual health education and experiencing challenges accessing needed information. Knowledge gaps may be more pronounced as Autistic people get older as Autistic people may spend more time online, possibly become more isolated, and their gaps in knowledge persist and accumulate over time.

There is a need for more sexual health information that is adapted to the needs of Autistic youth and that is delivered in a timely manner.

Sexual health topic priorities

The top four topics that service providers felt should be prioritized within sexual health promotion resources for service providers supporting Autistic youth included (see Table 3 for full list of topics):
1. communication skills in sexual/romantic relationships,
2. sexual decision-making,
3. adapting sexual behaviours to accommodate for sensory differences, and
4. gender identity and expression.

Additionally, participants indicated a need for more information about (see Table 4 for the complete list):
How autism may impact experiences of sexuality and sexual health,
Strategies for navigating possible resistance from families/caregivers in addressing sexual health among Autistic youth, and
Information about common misconceptions people may have about the sexuality and sexual health needs of Autistic youth.

Qualitative feedback from participants reinforced quantitative findings that communication differences (e.g., literal thinking, difficulties with metacognition and theory of mind, difficulties with forward thinking), executive function challenges (e.g., challenges with planning, organizing, and implementing information), and gender identity and sexual orientation were important topics to address within sexual health resources. Another key concept emphasized in the qualitative feedback was the importance of supporting Autistic youth to cope with and manage difficult emotions that may arise during puberty, during sexual development, and within relationships.

Table 3: Sexual health topics to prioritize in sexual health resources for Autistic youth

Question: What sexual health topics do you think should be prioritized within sexual health resources for service providers working with Autistic youth (select up to 3 responses)?	
Topics	**% of participants**
Communication skills in sexual/romantic relationships (including understanding and communicating one's emotions and needs, understanding and accommodating for communication differences, and the use of communication technology)	**40.7%**
Sexual decision-making (including asking for, giving, and respecting consent, personal boundaries, bodily autonomy, sexual agency, choosing to engage or not engage in sexual activity)	**33%**
Adapting sexual behaviours to accommodate for sensory differences	**27.5%**
Gender identity and expression	**27.5%**
Legal aspects of sexual behaviour (e.g., consent, cyberbullying, harassment, assault, and sexting)	**18.7%**
Relationships including different types of relationships (e.g., romantic, sexual, friendships) with single/multiple partners, initiating relationships and dating	**16.5%**
Birth control methods	**15.4%**
Media literacy related to sexual content in advertising, TV, pornography etc.	**13.2%**
Adapting sexual behaviours to accommodate for physical disabilities	**11%**
Love and intimacy	**8.8%**
Puberty changes (e.g., physical, biological, psychological, emotional, social)	**7.7%**
How to access sexual health and reproductive resources and services	**6.6%**
Family planning, fertility, and parenting	**6.6%**
Safer sex methods (e.g., condom use)	**5.5%**
Sexual behaviours (e.g., masturbation, oral sex, intercourse)	**5.5%**
Sexual rights and advocacy	**4.4%**
Sexually transmitted infections (STIs), including HIV	**2.2%**
Self-image and self-esteem	**2.2%**
Pregnancy options (e.g., parenting, abortion, adoption)	**2.2%**
Sexual pleasure	**1.1%**
Sexual orientation	**0%**
Reproduction and birth	**0%**
Sexual function, problems, and concerns (including the use and impact of medication)	**0%**

Table 4: Information to cover in sexual health resources for Autistic youth

Question: Which of the following would you like to see covered in sexual health promotion resources so that you can more effectively promote sexual health among Autistic youth (select up to 3 responses)?	
Topic	**% of participants**
Information about how autism impacts experiences of sexuality and sexual health (such as sensory differences, communication differences, and differences in executive function)	**62.6%**
Strategies for navigating possible resistance from families/caregivers in addressing sexual health among Autistic youth	**48.4%**
Common misconceptions regarding the sexuality and sexual health needs of Autistic youth	**39.6%**
Strategies to support service providers in communicating more effectively with Autistic youth about sexual health	**37.4%**
Information about the role of different service providers in promoting sexual health among Autistic youth that service providers can use to advocate for improved sexual health promotion in their place of work or in their profession more broadly	**33%**
Strategies to support service providers in initiating conversations about sexual health with Autistic youth	**17.6%**
Information demonstrating the need for sexual health promotion among Autistic youth that service providers can use to advocate for improved sexual health promotion in their place of work or in their profession more broadly	**16.5%**
Other, please specify*	**3.3%**

*Other responses included practical tools related to sexual health that could be use with Autistic youth (handouts, visuals etc.), trauma-informed lens on providing sexual health information, and more resources related to gender identity, maturity, and fostering self-acceptance.

Co-occurring conditions to consider

Participants noted the following common co-occurring conditions to consider in the development of sexual health resources for Autistic youth:
Sensory sensitivities (e.g., olfactory and auditory hypersensitivity; sensory processing disorder),
Behavioural diagnoses (e.g., oppositional defiant disorder),
Motor and executive function challenges,
Intellectual disability, developmental delay, cognitive challenges, and learning disabilities,
Mental health concerns (e.g., depression, anxiety, self-esteem),
Attention deficit disorder (ADD)/Attention deficit hyperactivity disorder (ADHD),
Obsessive compulsive disorder,
Language and speech challenges,
Intrusive thoughts and body dysphoria, and
Medication interactions.

Resource formats

Over 95% of participants agreed with our proposed format for the autism toolkit resources (data not shown). Specifically, we proposed to include an educator guide (i.e., written document that provides information and strategies for service providers to promote sexual health with Autistic youth) and handouts that service providers could give to Autistic youth and those that support them (i.e., infographics and/or fact sheets).

However, many respondents indicated that these resources would be best used in combination with other resources in alternative formats. In general, participants noted a need for interactive, brief, and accessible resources that integrate the use sensory objects[1] if possible, and that are made available online. Specifically, the most mentioned resource format were videos, especially short, accurate, and accessible videos that include drawings and other visuals to explain relevant concepts to youth. Participants also noted the importance of including Autistic educators in videos and avoiding abstract concepts/euphemisms, which may not be accessible to all Autistic youth.

Other suggested resource formats included:
Visuals (e.g., stories, cartoons, infographics, pictograms),
Social stories,
Guide for parents and for youth,
Information sheets,
Websites/online educational database for parents and youth,
Podcasts,
Testimonials,
Tutorials,
Conference for families, and
Online training for service providers.

1 Many Autistic people experience hypo- or hyper-sensitivity to various stimuli including sights, sounds, smells, tastes, and touch. Sensory objects can be helpful in stimulating or calming different senses.

Helpful supports

In addition to sexual health resources for service providers, participants also described several helpful supports that could facilitate sexual health promotion among Autistic youth in their work. These included:
1. **Training and education:** Participants emphasized a need for both health service professional training (e.g., through professional development courses, conferences, training in schools) and parents/ caregivers training focused on the sexual health needs of Autistic youth.
2. **Tools and materials:** Many participants expressed a need for quality sexual health promotion materials and tools that they could use in their work such as materials about online safety and relationships, pamphlets, videos, visual stories, toolkits, guidelines, teaching aids, websites, databases for youth, and educational resources to use in conversation with youth.
3. **Collaboration:** Participants noted the importance of collaborating with community partners, organizations, educators, health professionals, parents, and youth in the development and implementation of sexual health promotion programs.
4. **Access to programs and services:** Participants emphasized a need to improve access to support groups, sexual health professionals, specialized educators, quality health referrals, organizations/groups/ supports that address sexual orientation and gender identity, and counselors for youth.
5. **Structural supports:** Participants highlighted several important structural supports including supportive policies, adequate administrative support, as well as appropriate and sustained funding to promote the sexual health of Autistic youth. Many noted the need for clear, inclusive, and mandated sexual health education policies to ensure equitable access to sexual health education and information for all. Others indicated a need for stronger investments from educational ministries to prioritize sexual health education.

CONCLUSION AND RECOMMENDATIONS

Overall, the current sample was generally comfortable addressing sexual health as part of their work. However, even amongst this sample of service providers who experienced high levels of comfort, many still encountered barriers to addressing sexual health, particularly with Autistic youth. Feelings of apprehension by parents and family members remain an important barrier to sexual health education and services for Autistic youth. Further, the topics that service providers reported being the most comfortable addressing were those that are most frequently covered in school-based sexual health education and community sexual health promotion programs (i.e., birth control methods, safer sex methods, puberty changes, and sexually transmitted infections).

Areas where service providers reported requiring additional support tended to be related to how different autism characteristics (e.g., communication differences and sensory sensitivities) might impact different aspects of sexuality and sexual health for Autistic youth including gender identity and expression, communication within relationships, sexual decision-making, and sexual behaviours.

Based on the findings from the service provider consultation survey, SIECCAN recommends the following for the autism toolkit:

1. Highlight **key gaps in sexual health education and services for Autistic youth** (e.g., ways in which sexual health education has not considered the particular needs of Autistic youth);
2. Document **how prevailing stigma and ableism impact access to appropriate sexual health information and services** for Autistic youth and ways this could be addressed within sexual health education broadly (for both Autistic and non-autistic people);
3. Identify **barriers and challenges that service providers experience in promoting sexual health** with the Autistic youth they support and offer suggestions on how these barriers could be addressed;
4. Outline **the ways in which Autistic and non-autistic youth may experience sexuality and sexual health differently** (e.g., ways of communicating, sensory sensitivities) and offer strategies to foster more positive experiences for Autistic youth.
5. Provide service providers with strategies to **communicate with families about the importance of sexual health education** for Autistic youth and address misconceptions family members may hold;
6. Provide service providers with tools to guide Autistic youth in exploring their **gender identity and sexual orientation;**
7. Provide service providers with educational materials to guide Autistic youth in **identifying and communicating their preferences, needs, and boundaries.**