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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 disabled youth (physical disabilities)

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Health Canada Santé Canada

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PROJECT OVERVIEW

Disabled youth and Autistic 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 *Enhancing Effective Sexual Health Promotion with Autistic and Disabled Youth* project aims to improve service providers' knowledge and skills to effectively promote the sexual health and well-being of disabled youth with physical disabilities and Autistic youth. This project is funded by Health Canada's Health Care Policy and Strategies Program (Sexual and Reproductive Health Fund).

To achieve this goal, SIECCAN is 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 to October 2022. **Service providers, for our purposes, is defined as anyone in a formal position to provide sexual health information and/or services to disabled and/or Autistic 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.

A total of 137 service providers participated in the consultation survey, of which 89 indicated that they work with disabled youth or both disabled youth and Autistic youth (the remaining 48 participants indicated that they only work with Autistic youth). This report summarizes key findings from those 89 participants. The percentage of the 89 service providers who responded to each of the survey questions ranged from 37% to 100%.

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 disabled youth. These findings will inform the development of the capacity-building toolkit focused on the needs of disabled youth.

Importance of language

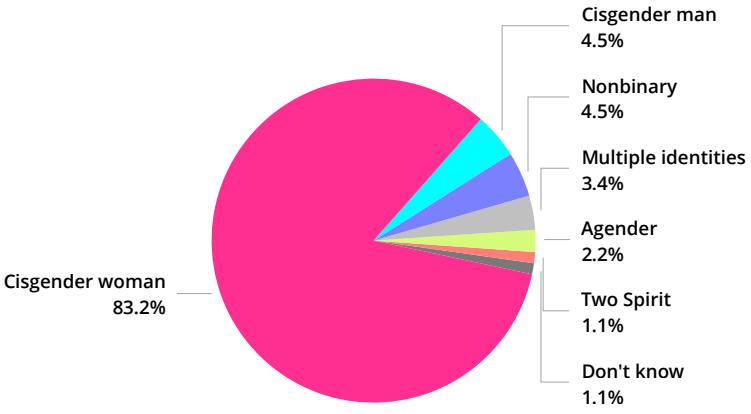
There is currently no consensus regarding preferred language to talk about disability and/or autism either among people with lived experience (i.e., disabled people or Autistic people) or across other stakeholder groups (i.e., service providers and family members). Existing literature along with first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

WHO PARTICIPATED IN THE CONSULTATION?

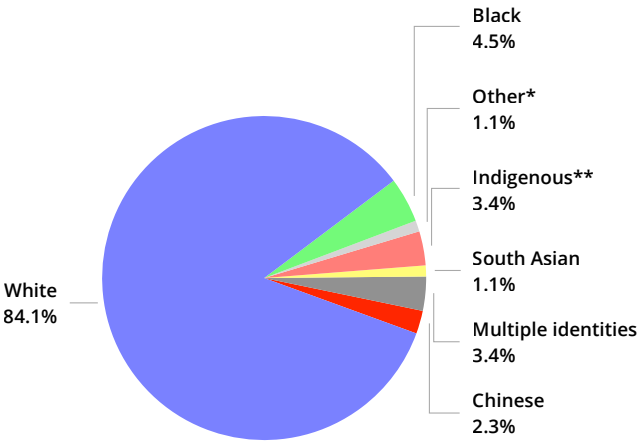
Most respondents identified as white, as a cisgender woman, and as being heterosexual (see pie charts below for detailed breakdown). Few respondents (6.7%) either reported having an autism diagnosis or self-identified as Autistic, while 13.5% indicated they had a physical disability (data not shown).

Demographic information (n=89)

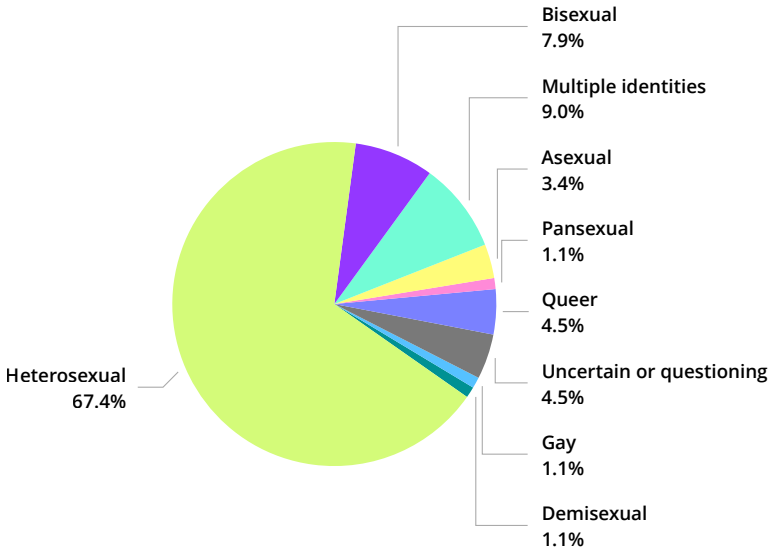
Gender



Race/ethnicity



Sexual orientation



* *Other responses included European.*

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

The majority of participants worked in Quebec, Ontario, and Alberta (see Figure 1). Unfortunately, there were no participants from the territories. Just under 20% of participants completed the French version of the survey (data now shown).

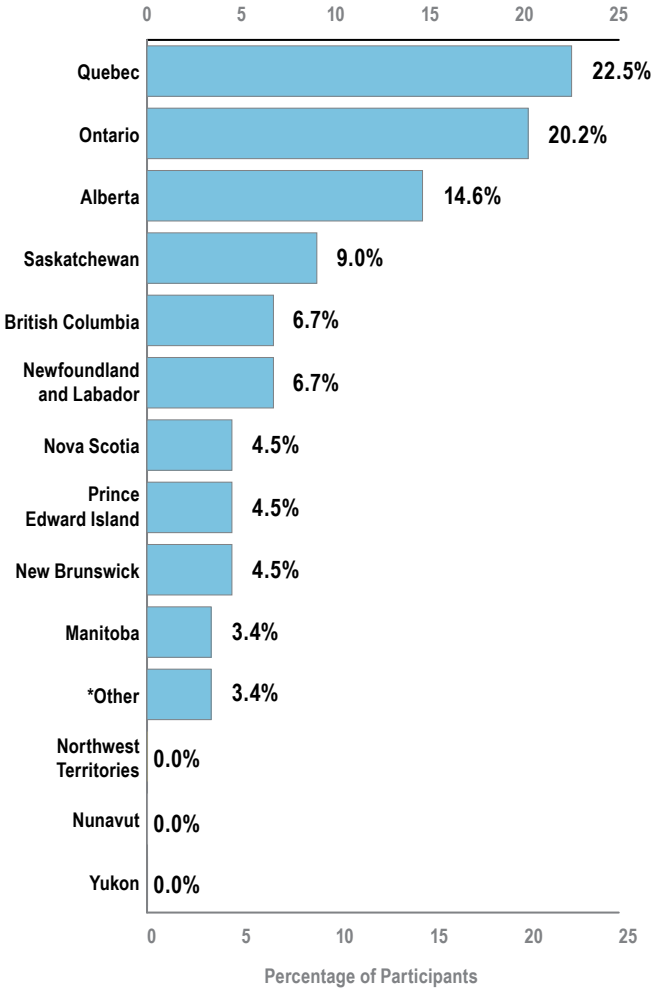


Figure 1: Region of work (n=89)

*Other responses included British Columbia and Manitoba, Southwest, and the United-States.

Participants worked in a wide range of professions with educators (18.2%), social workers (15.9%), community organization staff (10.2%), and public health professionals (8%) being the most represented (see Figure 2).

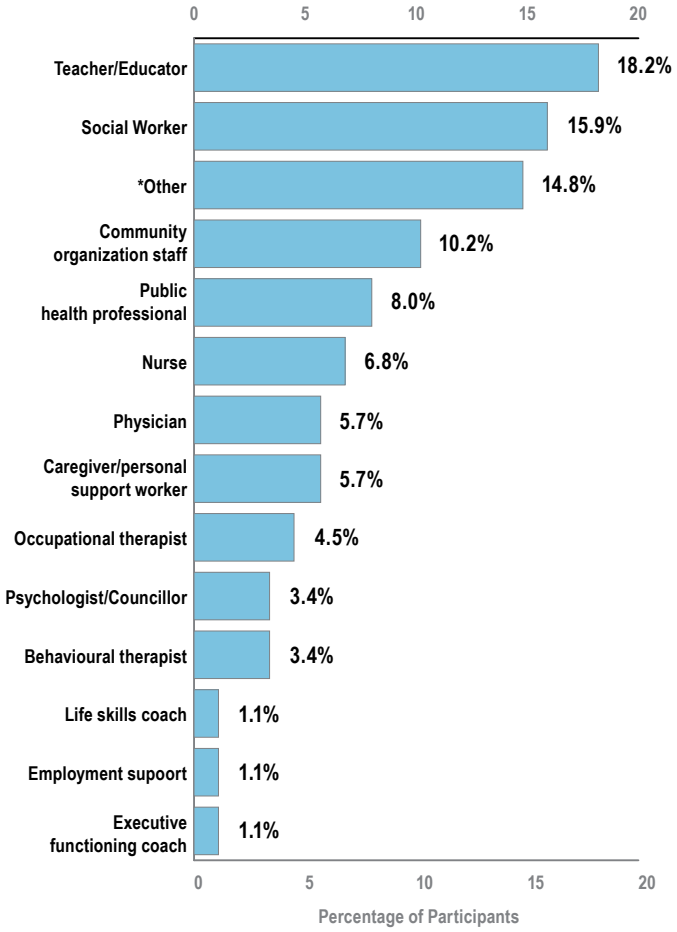


Figure 2: Area of work (n=89)

*Other responses included speech and language, sexual health educator, child and youth counselor, behaviour analyst/consultant, auxiliary nurse.

Participants worked in a variety of settings notably within schools, community organization/groups, homes, as well as community health centres, and supported disabled youth across all age groups (see Table 1). While English (84.3%) and French (32.6%) were the languages most used in their places of work, about 6.7% of participants also used American Sign Language (data not shown). Over half of the participants worked in large urban centres and about one fifth in medium population centres (see Table 1).

Table 1: Workplace information (n=89)

Age of disabled youth participant supports	
4 years old and under	**22.5 %**
5 - 8 years old	**40.4 %**
9 - 12 years old	**56.2 %**
13 - 16 years old	**68.5 %**
17 - 20 years old	**76.4 %**
21 - 24 years old	**56.2 %**
25 - 28 years old	**44.9 %**
29 years and over	**38.2 %**
Setting where participant supports disabled youth	
School	**44.9 %**
Community organization/group	**25.8 %**
Home	**24.7 %**
Community health centre	**19.1 %**
Other*	**13.5 %**
Rehabilitation centre	**11.2 %**
Workplace	**11.2 %**
Community living facility/group home	**7.9 %**
Hospital	**7.9 %**
Size of community where participant works	
Large urban centre	**57 %**
Medium population centre	**22.1 %**
Small population centre	**14 %**
Rural area	**7 %**

*Other responses included youth shelters, safe-consumption sites, various community settings depending on activity being carried out (e.g., shopping, taking the bus, developing peer relations in the community), online, private office.

WHAT DID WE LEARN FROM THE CONSULTATION SURVEY?

Part I: Sexual health promotion experience

Participants were asked questions about their sexual health promotion experiences more broadly, and specifically with disabled youth.

Questions covered the following topics:
The ways in which service providers promoted sexual health in their current work;
Reasons for not discussing sexual health with the people service providers support;
Barriers and challenges service providers experienced in promoting sexual health;
Service providers' comfort level in addressing sexual health; and
Whether or not service providers received training in the area of sexual health.

Comfort level

About 80% of participants reported feeling comfortable or very comfortable addressing sexual health as part of their work. Participants predominantly engaged in sexual health promotion through education (77.5%), referrals (64%), and counseling (43.8%) (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 disabled youth in your work?", service providers in our sample generally reported feeling quite comfortable addressing a wide range of sexual health topics with disabled youth (see Table 2).

The topics that participants reported feeling the LEAST comfortable addressing included (see Table 2 for the full list of topics):
1. Adapting sexual behaviours to accommodate for physical disabilities
2. Adapting sexual behaviours to accommodate for sensory differences
3. Sexual function, problems, and concerns (including the use and impact of medication)
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 disabled 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

A large majority of participants (78.5%) indicated receiving training on the topic of sexual health (data not shown). Some participants (21.7%) received training on the topic of sexual health as part of their degree requirement, 41.7% received training through a professional development opportunity, and 36.7% received training as part of both their degree requirement and through a professional development opportunity (data not shown).

Only 8.1% of participants who received training on the topic of sexual health indicated that this training addressed the needs of disabled youth specifically (data not shown).

Table 2: Comfort level discussing various sexual health topics with disabled 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 disabled youth in your work?	
Topic	**Mean (Average)**
Safer sex methods (e.g., condom use)	**4.46**
Sexually transmitted infections (STIs), including HIV	**4.39**
Self-image and self-esteem	**4.34**
Birth control methods	**4.33**
Sexual orientation	**4.29**
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)	**4.24**
Relationships, including different types of relationships (e.g., romantic, sexual, friendships) with single/multiple partners, initiating relationships and dating	**4.24**
Gender identity and expression	**4.24**
Puberty changes (e.g., physical, biological, psychological, emotional, social)	**4.20**
Pregnancy options (e.g., parenting, abortion, adoption)	**4.20**
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)	**4.20**
Sexual rights and advocacy	**4.15**
Love and intimacy	**4.12**
Reproduction and birth	**4.10**
Legal aspects of sexual behaviour (e.g., consent, cyberbullying, harassment, assault, and sexting)	**4.05**
How to access sexual health and reproductive resources and services	**4.05**
Sexual behaviours (e.g., masturbation, oral sex, intercourse)	**3.95**
Family planning, fertility, and parenting	**3.93**
Media literacy related to sexual content in advertising, TV, pornography etc.	**3.93**
Sexual pleasure	**3.88**
Sexual function, problems, and concerns (including the use and impact of medication)	**3.54**
Adapting sexual behaviours to accommodate for sensory differences	**3.53**
Adapting sexual behaviours to accommodate for physical disabilities	**3.49**

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 do not bring up the topic of sexual health, sexual health is not always a key part of the service providers' job, and service providers often do not have enough time to discuss sexual health with the people they support.

Analysis of the qualitative responses from participants indicated the following four categories of barriers to sexual health promotion with disabled youth:

1. **Stigma and stereotypes:** Participants noted that stereotypes about disabled youth being disinterested in sexual activity contributes to the infantilization and desexualization of disabled youth, which could result in disabled youth feeling ashamed about their sexuality. One participant stated that media representations also posed a challenge to effective sexual health promotion because youth may internalize and imitate sexual/relationship behaviours they see in media without being provided with information to understand these behaviours.
2. **Discomfort with discussing/addressing sexuality:** Participants noted that both service providers and disabled youth may experience discomfort in discussing and addressing sexuality and sexual health. Service providers often lack training or resources about disability and sexuality, and/or have internalized harmful stereotypes about the sexuality of disabled youth. Participants acknowledged that disabled youth may be uncomfortable discussing sexuality with health service providers due to past negative experiences with service providers.
3. **Parents/caregivers as potential "gatekeepers":** Participants indicated that parents/caregivers can sometimes act as "gatekeepers" for the provision of sexual health education and services for disabled youth. For instance, participants noted that some parents/caregivers did not think it was necessary to proactively discuss sexual health with disabled youth and that parents/caregivers would "sort it out as it comes." Some parents/caregivers may also assume that the school system alone would adequately address sexual health with disabled youth.
4. **Structural barriers:** Participants also highlighted various structural barriers that limit their capacity to promote sexual health with disabled youth, including a lack of:

    - Time (e.g., having to prioritize "more pressing concerns")
    - Training
    - Sexual heath resources for health service providers and for youth that are tailored to the needs of disabled youth (e.g., communication devices that are programmed with sexual health vocabulary)
    - Organizational and/or staff support to address sexuality with disabled youth (i.e., service providers/ service agencies not knowing how to or not wanting to address sexuality with disabled youth)

Ableism

A strong majority (82.9%) acknowledged (*agree* and *strongly agree*) that ableism significantly impacts how disabled youth are taught about sexuality and sexual health (data not shown). In addition, most (74.4%) have also reflected upon how ableism might affect the ways service providers address sexuality and sexual health with 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 disabled youth;
Identify important considerations for sexual health resources focused on the needs of disabled youth; and
Elaborate on the types of resources and resource formats that would be the most useful to service providers and to the disabled youth they support.

Age groups with the most significant knowledge gaps

Participants indicated that all age groups of disabled youth have sexual health knowledge gaps, with some noting that sexual health education in schools is often lacking for disabled youth. Further, some participants highlighted that disabled youth with co-occurring conditions, such as developmental disabilities, often have even less access to sexual health information.

Sexual health topic priorities

Resources for service providers supporting disabled youth

The top four topics that service providers indicated should be prioritized within sexual health promotion resources for service providers supporting disabled 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 physical differences, and
4. Legal aspects of sexual behaviour

Participants also indicated a need for more information about (see Table 4 for the complete list):
Common misconceptions regarding the sexuality and sexual health needs of disabled youth
Navigating possible resistance from families/ caregivers in addressing sexual health among disabled youth
How specific physical disabilities may impact experiences of sexuality and sexual health

Table 3: Sexual health topics to prioritize in sexual health resources for service providers working with disabled youth

Question: What sexual health topics do you think should be prioritized within sexual health resources for service providers working with disabled 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 %**
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)	**34.1 %**
Adapting sexual behaviours to accommodate for physical differences	**29.5 %**
Legal aspects of sexual behaviour (e.g., consent, cyberbullying, harassment, assault, and sexting)	**22.7 %**
How to access sexual health and reproductive resources and services	**15.9 %**
Adapting sexual behaviours to accommodate for sensory disabilities	**13.6 %**
Relationships, including different types of relationships (e.g., romantic, sexual, friendships) with single/multiple partners, initiating relationships and dating	**13.6 %**
Gender identity and expression	**11.4 %**
Birth control methods	**11.4 %**
Media literacy related to sexual content in advertising, TV, pornography etc.	**11.4 %**
Family planning, fertility, and parenting	**9.1 %**
Safer sex methods (e.g., condom use)	**9.1 %**
Puberty changes (e.g., physical, biological, psychological, emotional, social)	**6.8 %**
Sexual behaviours (e.g., masturbation, oral sex, intercourse)	**2.3 %**
Love and intimacy	**2.3 %**
Sexually transmitted infections (STIs), including HIV	**2.3 %**
Sexual rights and advocacy	**2.3 %**
Self-image and self-esteem	**2.3 %**
Pregnancy options (e.g., parenting, abortion, adoption)	**2.3 %**
Sexual pleasure	**0.0%**
Sexual orientation	**0.0%**
Reproduction and birth	**0.0%**
Sexual function, problems, and concerns (including the use and impact of medication)	**0.0%**

Table 4: Information to cover in sexual health resources for service providers supporting disabled 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 disabled youth (select up to 3 responses)?	
Topic	**% of participants**
Common misconceptions regarding the sexuality and sexual health needs of disabled youth	**45.5 %**
Strategies for navigating possible resistance from families/caregivers in addressing sexual health among disabled youth	**43.2 %**
Information about how specific physical disabilities may impact experiences of sexuality and sexual health	**40.9 %**
Strategies to support service providers in communicating more effectively with disabled youth about sexual health	**31.8 %**
Information demonstrating the need for sexual health promotion among disabled youth that service providers can use to advocate for improved sexual health promotion in their place of work or in their profession more broadly	**25 %**
Information about the role of different service providers in promoting sexual health among disabled youth that service providers can use to advocate for improved sexual health promotion in their place of work or in their profession more broadly	**25 %**
Strategies to support service providers in initiating conversations about sexual health with disabled youth	**15.9 %**
Strategies for making my place of work more physically accessible	**11.4 %**

Resources for disabled youth

Within participants' qualitative responses, the sexual health topics that were recommended for sexual health promotion resources for disabled youth included:
The use of sex toys
Birth control safety
Pregnancy and childbirth
Parenting
Dating, communication, and disclosing disability in a relationship
Online safety
Hygiene
Body image and self-esteem

Type of physical disabilities that service providers encountered

When asked about the types of physical disabilities that participants encountered in their work, cerebral palsy was the disability most frequently reported.

Other types of disabilities participants reported encountering in their work included:
Spina bifida
Mobility/motor coordination challenges, requiring mobility aids (e.g., wheelchair users)
Neuromuscular disorders
Quadriparesis
Brain injury
Multiple sclerosis
Muscular dystrophy
Epilepsy
Hearing impairments
Visual impairments
Spinal cord injuries
Genetic disorders and chromosomal differences
Chronic pain
Chronic fatigue
Ehlers- Danlos syndrome
Diabetes
Provisional Tic Disorder
Degenerative diseases (e.g., Friedreich's ataxia)
Immune disorders (e.g., Guillain-Barré syndrome)
General physical impairment
Limb amputations
Complex physical needs (e.g., requiring feeding tubes)

*Note: The disabilities indicated above are not listed based on the frequency they were mentioned.

Co-occurring conditions to consider

Participants noted the following co-occurring conditions to consider in the development of sexual health resources for disabled youth:
Cognitive disabilities
Intellectual and developmental disabilities
Mental health challenges (e.g., depression, anxiety)
Fetal alcohol spectrum disorder
Autism
Behavioural disorders
Neuromuscular conditions (i.e., mobility and sensory challenges)
Impaired skin integrity
Bowel and bladder management
Drug use and other addictions

*Note: The conditions indicated above are not listed based on the frequency they were mentioned.

Resource formats

A strong majority of participants indicated that resources covering sexuality and physical disabilities broadly would be useful to them in their practice, but that these resources would be most useful if used in combination with other resources that focus on specific physical disabilities.

Overall, participants agreed with our proposed format for the physical disability toolkit resources (data not shown). Specifically, we proposed to develop a guide for service providers (i.e., written document that provides information and strategies for service providers to promote sexual health with disabled youth) and handouts that service providers could give to disabled 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 resources in alternative formats.

Other suggested resource formats included:
Videos
Brief modules that address specific sexual health topics or that challenge misconceptions
Pamphlets and fact sheets
Workshops
Social stories and other visuals
Workbooks
Audio versions of materials for people with a vision impairment
Conferences
Online communities
Podcasts

Participants emphasized the importance of providing disabled youth with resources in easy read and other accessible formats. Additionally, participants noted that having resources for disabled youth made available online can promote their accessibility, particularly in contexts where in-person trainings and education may not be possible (e.g., COVID-19 and other barriers to in-person services).

Helpful supports

Participants identified several helpful supports that could enable service providers to improve sexual health promotion with disabled youth in their work:
1. **Tailored resources:** Participants expressed a need for up-to-date resources focused on how specific types of disabilities impact different aspects of sexual health (e.g., common concerns that disabled youth might have, how to promote positive relationships for disabled youth, supporting youth in navigating physical changes to their body following a diagnosis). Participants also noted that resources tailored to specific geographical regions would be beneficial (e.g., being able to access local services, knowing where to refer youth for accessible and effective care and information).
2. **Training and education:** Participants expressed a need for additional training and education focused on physical disabilities and sexual health.
3. **Professional collaboration and support:** Some participants emphasized the importance of being able to connect and collaboration with other professionals who can provide recommendations for disabled youth to enhance their sexual heath (e.g., determine physical positioning for sexual activity; suggest sex toys that are accessible).
4. **Family and community support:** Some participants noted that parents/caregivers and other community members can contribute to improving sexual health promotion for disabled youth by actively providing youth with sexual health information and services, as well as supporting disabled youth in accessing opportunities to socialize with their peers.
5. **Structural supports:** Participants highlighted several structural supports that are needed to improve sexual health promotion with disabled youth, including: • Implementing policies that encourage sexual health promotion with disabled youth; • Prioritizing evidence-based sexual health education in schools and ensuring that disability is integrated within school-based sexual health education; • Ensuring that service providers are allocated enough time to provide disabled youth with the support they need; • Greater funding for accessible sexual health education programs and services, as well as trauma support services; and • Instilling institutional cultures that promote disability awareness and acceptance, as well as challenge ableist assumptions about the sexuality of disabled youth.

CONCLUSION AND RECOMMENDATIONS

Service providers participating in this survey reported high degrees of comfort in addressing sexual health with youth, in general. Yet, service providers identified some important barriers to addressing sexual health with disabled youth, specifically.

These barriers included:
Misconceptions about the sexuality of disabled youth (e.g., the belief that disabled youth are not interested in sex);
A lack of training in addressing sexual health with disabled youth;
Parents/caregivers who are hesitant about providing disabled youth with sexual health information; and
Limited organizational/workplace support for addressing sexuality with disabled youth (e.g., lack of time, limited support from other staff).

Service providers expressed a desire to learn more about how physical disabilities can impact the sexuality and sexual health of disabled youth. Specifically, service providers reported both a lack of comfort in supporting disabled youth in adapting sexual behaviours to accommodate for physical disabilities, as well as a need for more information on this topic. Service providers also acknowledged that societal stigma and prevailing misconceptions about the sexuality of disabled youth could contribute to disabled youth feeling ashamed about their sexuality.

Service providers noted that resources addressing the sexual health needs of disabled youth more generally are needed, but that these resources would be best used in combination with additional resources that are tailored to specific physical disabilities. Service providers also emphasized the importance of ensuring that resources designed for disabled youth are accessible to them (e.g., having resources in easy read formats, using video and/or audio to provide information, making resources available online).

Based on the findings from the service provider consultation survey, SIECCAN recommends the following for the physical disability toolkit:
1. Describe how existing **stigma and misconceptions about the sexuality of disabled youth** impact the sexual health of disabled youth and identify ways that these can be addressed (e.g., include disability within sexual health curricula for both disabled and non-disabled youth; guide disabled youth in working through internalized stigma);
2. Provide service providers with **information about the sexual health related experiences and needs of disabled youth** as well as the supports that disabled youth may require;
3. Provide service providers with educational material to help guide disabled youth in **adapting sexual behaviours to accommodate for physical disabilities** (e.g., sex positions that are more comfortable/do not cause pain; the use of accessible sex toys);
4. Provide service providers with tools to guide disabled youth with **sexual decision-making and communicating in sexual/romantic relationships** (e.g., asking for and giving consent, negotiating boundaries, choosing to engage or not engage in sexual activity, communicating needs and desires); and
5. Provide service providers with strategies for **communicating with parents/families about the importance of sexual health education for disabled youth** and addressing misconceptions parents/families may hold.