

SEXUAL HEALTH PROMOTION:

A Guide for Service Providers Working with Disabled Youth



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PREFACE

The *Enhancing Effective Sexual Health Promotion for Autistic and Disabled Youth* project was made possible through a financial contribution from Health Canada. Through this project funding, the Sex Information and Education Council of Canada (SIECCAN) led the development of two capacity-building toolkits aimed at improving service provider knowledge and skills to promote the sexual health and well-being of Autistic youth and disabled youth with physical disabilities, respectively.

Sexual Health Promotion: A Guide for Service Providers Working with Disabled Youth is one component of the capacity-building toolkit focused on the sexual health needs of disabled youth, which also includes the *Canadian Guidelines for Sexual Health Promotion with Disabled Youth* and sexual health resources for disabled youth.

Suggested citation:

SIECCAN. (2024). *Sexual health promotion: A guide for service providers working with disabled youth*. Toronto, ON. Sex Information and Education Council of Canada (SIECCAN).

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ACKNOWLEDGEMENTS

Funding

Financial contribution from



Health Canada Santé Canada

The views expressed herein do not necessarily represent the views of Health Canada.

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INTRODUCTION

Sexual Health Promotion: A Guide for Service Providers Working with Disabled Youth was developed based on findings from a consultation process (<https://www.sieccan.org/ady-physicallydisabledyouth>) that included an online survey with service providers, as well as focus groups with disabled youth. **In the context of this project, disabled youth refers to individuals with physical disabilities aged 29 and under.**

The topics included in this guide were selected based on findings from our consultation process, as well as through discussions with working group members. Information presented in this guide reflects the best available published evidence drawn from both scientific and grey literature. Quotes from the focus groups with disabled youth have been integrated throughout the guide to reinforce important messages with lived experience perspectives.

This guide provides service providers with recommendations for adopting a disability-affirming and sexual health enhancement approach to promoting sexual health with disabled youth and for making sexual health education and services more accessible. This guide also offers strategies for supporting disabled youth across a wide range of sexual health topics.

The following sexual health topics are covered in this guide:

- Cultivating self-determination and bodily autonomy
- Developing positive sexual esteem
- Adapting sexual scripts to be more inclusive of the needs of disabled youth
- Delivering 2SLGBTQINA+ inclusive sexual health education and services
- Responding to abuse
- Sexually transmitted infection (STI) prevention
- Cervical cancer prevention
- Reproductive justice

SIECCAN has also developed sexual health information sheets for youth which complement the content outlined in this guide. The information sheets can be accessed on the SIECCAN website at the following links:

Sexual health information sheets for Autistic youth¹:
www.autismsexinfo.ca

Sexual health information sheets for disabled youth:
www.physicaldisabilitysexinfo.ca

1 These information sheets were developed for Autistic youth but can also be useful for disabled youth.

Who is this guide for?

This guide is for anyone in a formal position to provide sexual health information, education, and/or services to disabled youth. This can include educators, social workers, public health professionals, community organization staff, psychologists/counsellors, nurses, caregivers/personal support workers, behavioural therapists, occupational therapists, physiotherapists, physicians, group home staff, and others.

Defining physical disability

Note: There are many different definitions of physical disability. Some definitions are broader than others and some definitions focus on how the environment contributes to experiences of disability (i.e., social model of disability), while others focus on how an individual's body contributes to experiences of disability (i.e., medical model of disability). **We chose to adopt the World Health Organization conceptualization of disability, which acknowledges the complex interplay between individual bodies and their social/environment context. Further, we decided to focus on physical disabilities related to mobility, flexibility, and dexterity** in order to provide more specific recommendations.

The World Health Organization's International Classification of Functioning, Disability, and Health (ICF) defines disability as a person's level of functioning (e.g., activity limitation or participation restriction) that results from the interaction between a person's impairments (i.e., conditions affecting the body structure and/or function) and their context (i.e., environmental and personal factors; Kostanjsek, 2011; World Health Organization, 2001).

Accordingly, we have conceptualized physical disability as limitations in activity or restriction in participation that occur due to the interaction between impairments affecting a person's bones, muscles, joints, and central nervous system development, and the person's environmental (e.g., physical, social, and attitudinal environment) and personal factors (e.g., identity, age, motivation, life habits).

Physical disabilities may include:

Acquired brain injury

Amputation

Arthritis (e.g., osteoarthritis, rheumatoid arthritis, fibromyalgia, gout, lupus)

Cerebral palsy

Multiple sclerosis

Muscular dystrophy

Osteogenesis imperfecta

Poliomyelitis

Physical disabilities may include:

Scoliosis

Spina bifida

Spinal cord injury

Carehome.co.uk (2023); Centers for Disease Control and Prevention (2023a); Rutgers School of Arts and Science (2023)

Based on this definition, it is the interaction between impairments and contextual factors, not the impairment itself, that contributes to limitations in activity or restrictions in community participation (Eisenberg et al., 2015). As such, these limitations and restrictions can be alleviated through the use of assistive devices and aids, the provision of necessary accommodations and adaptations, and more inclusively built social environments.

In this document, the term *disabled youth* will be used to refer primarily to individuals aged 29 and under with physical disabilities, according to the definition of physical disabilities that has just been outlined.

When we are referring to existing research, the term *disabled people* may include disabilities other than physical disabilities as we have defined it. When relevant and possible, we have indicated the specific disabilities that are mentioned in the referenced studies. The recommendations in this guide focus on the needs of disabled youth with physical disabilities but may also be relevant for individuals with other disabilities.

Explanation of language choices

There is currently no consensus regarding preferred language to talk about disability either among people with lived experience (i.e., disabled people) or across other stakeholder groups (i.e., service providers and family members). Existing literature and first-person narratives suggest that identity-first language (i.e., disabled youth), which views 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 (Andrews et al., 2022; Liebowitz, 2015). This contrasts person-first language (i.e., youth with a disability), which views disability as an attribute of a person rather than a defining feature of who they are. As such, we have chosen to primarily use identity-first language for this project, but we recognize this is not preferred by all. In some cases, person-first language is used to specify the type of disability being discussed (e.g., individuals with spina bifida) or when we are referring to the title of a policy or report that uses person-first language (e.g., *Convention on the Rights of Persons with Disabilities*).

DELIVERING SEXUAL HEALTH EDUCATION AND SERVICES TO DISABLED YOUTH

Challenging misconceptions and addressing stigma

What is ableism?

Ableism is a way of thinking that is based on negative beliefs (e.g., false assumptions, stereotypes) and feelings (e.g., discomfort, negative attitudes) about disabled people (Ontario Human Rights Commission, 2016).

How people think affects how they act. Sometimes, negative ways of thinking about disabled people can lead to harmful behaviours enacted towards disabled people, such as discrimination, social exclusion, and limiting opportunities for disabled people to fully participate in society.

Ableism can be both conscious and unconscious – this means that people are not always aware of the harmful stereotypes and attitudes they might hold about disabled people, as well as their potential consequences.

Many of these negative ways of thinking about disabled people have become so deeply ingrained in society that individuals may not always notice when they have internalized these harmful ways of thinking.

Impact of ableism on the sexual health and well-being of disabled youth

False assumptions being made about the ability and desire of disabled youth to date, be in relationships, have sexual experiences, and become parents;

Not having discussions about sexuality and sexual health with disabled youth because disabled youth are believed to not have the capacity to make their own decisions about their sexuality;

The sexual health needs and experiences of disabled youth not being included in sexual health education programs;

Sexual and reproductive health services not being offered to disabled youth because they are believed to be irrelevant to them; and

Not respecting the right of disabled youth to autonomously make decisions about their own sexual health and well-being.

Benoit et al. (2022); Chan et al., (2022); East & Orchard (2014); Giles et al. (2023)

Watch this video about common false assumptions non-disabled people have about disabled people:

https://www.youtube.com/watch?v=W6c6JLbczC8&ab_channel=VICE

“There’s this kinda stereotype...they [people in society] feel sexual/romantic desires should be the last stuff on my list.”

- Focus group participant: Disabled youth

While addressing ableism within society is a big task, there are some ways you, as a service provider, can contribute to making society more inclusive of disabled people.

What can you do to address ableism?

1. Reflect on your own assumptions:

- In supporting disabled youth, do I provide them with the same opportunities and choices as I would to non-disabled youth? If not, what assumptions am I making about disabled youth? Are these assumptions accurate? Where do these assumptions come from?
- Am I supporting disabled youth in achieving the goals **they** want to achieve or am I making assumptions about what goals they **should** pursue based on the types of goals that non-disabled people often pursue? If I am **not** supporting disabled youth to achieve a self-determined goal, why not? Whose goal should take precedence – mine or theirs?
- Am I truly listening to disabled youth and trusting their perspectives as experts of their own lives?

2. Question and challenge what we think we know about disability:

- Is what I think I know about disabilities really true? Is it always true or am I generalizing what I know about a few disabled people to all disabled people?
- Where does my knowledge come from and what is it based on?
- How have ideas about disability changed over time?

3. Actively challenge misconceptions, acts of discrimination, and exclusion:

- Do I treat disabled youth differently than non-disabled youth? Why or why not?
- How can I make my workspace more inclusive of disabled people? What can I do to create a safe and comfortable space for disabled people?
- Are there ways I could support disabled youth in accessing necessary accommodations?
- Are there opportunities for me to engage in open and honest discussions with colleagues about ableism?

4. Broaden conceptualizations of sexuality to be more inclusive of diverse bodies and preferences:

- Intentionally include representations of disabled people (e.g., images, stories) within discussions and resources about sexuality and sexual health.
- Encourage disabled youth to explore and define their own sexual identities, which do not have to conform to non-disabled experiences or expressions of sexuality. See *Promoting More Diverse Sexual Scripts* section for ways to diversify sexual scripts.

What can you do to address ableism?

5. Seek out opportunities to interact and collaborate with the diverse communities of disabled people:

- Engage/consult with disabled people from diverse backgrounds and with different support needs, as well as provide appropriate compensation for their contributions.
- Learn from disabled self-advocates through books, online blogs, or social media.

Fostering a safe and trusting environment

Adopting a disability-affirming approach in your practice

Ask disabled youth what their goals are and how you can help them achieve their goals rather than making assumptions or imposing goals onto them based on non-disabled norms.

Here are some examples of questions you can ask:

- What are the things that are important to you in your life/your relationships?
- What are the challenges you experience in your life/your relationships that you would like me to support you with?
- Do you have some ideas of the kinds of supports that would be helpful to you?
- I would like to propose some supports that could be helpful. You let me know if any of these could work for you?

Support disabled youth to **address positive aspects of sexuality** (e.g., positive identity formation, healthy interpersonal relationships, safe sexual exploration) in addition to the prevention of outcomes that can have a negative impact (e.g., sexually transmitted infections, unintended pregnancies, sexual abuse, feelings of sexual/relationship distress or worry).

Provide encouragement and support to disabled youth in **navigating the challenges of romantic/sexual relationships**.

Dating and relationships often involve taking some risks (e.g., being open and vulnerable with one's feelings, putting one's trust in another person) and these risks may not always result in desired outcomes. However, the process of dating and forming relationships can involve many positive experiences and can enable individuals to learn about their needs and desires, which can be applied to future relationships or sexual experiences. Disabled youth should be supported (e.g., by proactively discussing potential risks, taking measures to prevent potential harm) to try out new experiences so that they can learn about themselves, develop important life skills, and have positive dating/relationship experiences.

Take a strengths-based approach by supporting disabled youth in identifying their strengths and ways they can use these strengths to acquire new knowledge and skills.

Adopting a disability-affirming approach in your practice

Be willing to **make accommodations** or offer supports, considering that environments are often not designed with the needs of disabled people in mind.

Work to **remove social and environmental barriers** that limit opportunities for disabled youth.

Design spaces in consideration of the accessibility needs of disabled youth.

Bahner (2012); Eglseider & Webb (2017); Eisenberg et al. (2015); Powers et al. (2002)

Building trust

Get to know the individual you are supporting as everyone's needs and experiences are different. Listen with the goal of understanding disabled youths' perspectives.

Cultivate self-determination by giving disabled youth choices and encouraging youth to make their own decisions. Support youth in carrying out these decisions (e.g., work with families to support the self-determination of youth, support youth in thinking about potential risks and rewards with making a particular decision and how to mitigate potential harms).

Ask disabled youth if they are comfortable discussing their sexual health with you and if there is anything you can do to make them feel more comfortable.

Communicate directly with disabled youth, even when they are accompanied by a support person (e.g., parent, family member, caregiver).

Protect the confidentiality and privacy of disabled youth.

Tell youth clearly who will and will not hear the conversation they have with you. Also tell youth when confidentiality must be broken (e.g., if they report an incident of abuse).

If a support person is present, you can say to the disabled youth, "This is the point where I usually ask parents/caregivers to step outside so you can get used to asking me any questions you like or where we can talk about things you might want to keep private. Is that okay with you?"

Remain flexible and be willing to adapt and make accommodations to better meet the needs of disabled youth.

Bonder et al., (2021); East & Orchard (2014); Hough et al. (2020); Lung et al. (2022); Magoon & Meadows-Oliver (2011); Tylee et al. (2007)

Initiating conversations about sexuality with disabled youth

Obtain disabled youths' consent to talk about sexual health.

For example, you can say, "It is important that we all take care of our sexual health. Many young people have questions about relationships, dating, and sex. Is it okay if I ask you a couple of questions about some of these things?"

Ask disabled youth about their sexuality-related concerns, barriers they encounter to sexual health and well-being, and supports they need.

If a disabled youth is not sure about their concerns, barriers, or support needs, you can provide examples of questions other disabled youth sometimes have (e.g., how to engage in sexual activity, how to meet potential partners, how to protect themselves from negative experiences, how to navigate accessibility barriers).

Assume that disabled youth can have a 2SLGBTQINA+ (Two-Spirit, lesbian, gay, bisexual, transgender, queer, intersex, nonbinary, and asexual) identity.

For example, say, "Are you dating anyone?" instead of "Are you dating any girls or any boys?"

Also remember that it is possible youth may have a gender identity that is different from the gender identity indicated in their medical records.

See *Delivering 2SLGBTQINA+ Inclusive Sexual Health Education and Services* section for more information.

Work with disabled youth to identify appropriate solutions to address their needs. It is okay to not have all the answers but be willing to investigate further and/or provide referrals as needed.

Adjust the language you use according to each disabled youth's needs and existing knowledge about sexual health.

Have multiple and relevant ways to engage with disabled youth.

For example, gather resources from reputable social media sources (e.g., disabled adults) that discuss sexuality and sexual health.

Visit the Disability and Sexuality Resource Hub for examples of conversation guides and other resources that can be helpful to service providers: <https://hollandbloorview.ca/disability-sexuality-resource-hub/sexuality-guides>

Giles et al., (2023); Hough et al., (2020); Rowen et al., (2015)

“...I think they [health service providers] 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.”

- Focus group participant: Disabled youth

Implementing trauma-informed practice

Recognize that disabled youth may have past experiences of trauma that can continue to impact how they interact with service providers.

Consider how social and environmental factors (e.g., physical barriers to accessing services, stigma) may contribute to experiences of trauma and/or impact how disabled youth cope with trauma.

Promote physical and psychological safety and predictability (e.g., work with disabled youth to establish expectations, offer opportunities for youth to ask questions anonymously).

Work with disabled youth to identify helpful self-regulation strategies (e.g., practical ways of managing and reducing feelings of distress).

Foster opportunities for disabled youth to exercise personal choice and agency (e.g., collaborate with youth, encourage youth to define own goals).

Ballan & Freyer (2017); Berger et al., (2021); Dorado et al., (2016)

Adopting an intersectional approach

Learn about intersectionality. Here is a video that helps to explain intersectionality:
<https://youtu.be/MOaGxtY5d4g?si=0agB9xJabFg4MY6m>

Adopting an intersectional approach

Acknowledge your positionality. Positionality refers to one's social location, meaning where one is situated in relation to different social identities (e.g., race, ethnicity, gender identity, sexual orientation, geographical location, disability). The intersection of these identities shapes one's knowledge, perspective, and understanding of the world, which can be different from how others, who have a different positionality, view and engage with the world.

Acknowledging your positionality allows you to:

- Identify the spaces where you experience power/privilege;
- Reflect on how the advice or services you offer are shaped by your own personal worldview;
- Recognize that the disabled youth you support may experience a different reality than your own; and
- Be open to the perspectives of disabled youth in guiding decisions made about their sexual health and well-being.

Ask disabled youth how they see themselves and how they experience their identities.

For example, you can ask youth:

- What are some things you want people to know about you?
- What are some things that are important to you?
- What are some things you are really good at?
- Could you tell me a bit about your family and/or your upbringing?

Ask disabled youth about the barriers they may experience to sexual health and well-being and discuss ways these barriers could be addressed.

Inform yourself about the intersection of disability with other dimensions of identity (e.g., gender identity, sexual orientation, race/ethnicity), particularly its implications for accessing education, services, and opportunities for sexual health and well-being.

When referring disabled youth to supports, **consider their intersecting identities in the types of supports you offer.**

For example:

- What additional barriers might compound their experience?
- Could it be beneficial to refer youth to communities of shared identities?
- How can resilience be fostered when resources that address intersecting identities may not exist?

Hudson & Mehrotra (2021)

Applying Inclusive Design for Learning to sexual health education

Taking an Inclusive Design for Learning approach to sexual health education can better meet the learning

needs of disabled youth. Inclusive Design for Learning is a practice that begins with an understanding that there is no one-size-fits all approach to teaching that will meet the needs of all learners (Watkins et al., 2020). This approach embraces diversity and aims to develop individualized teaching approaches within an integrated learning environment.

Inclusive Design for Learning is an ongoing process, rather than a set of criteria, where service providers collaborate with learners to co-create solutions that meet diverse learning needs so that everyone can benefit.

Inclusive approaches to providing sexual health education

Obtain feedback from learners, particularly those whose needs are often not met within standardized learning environments, about how they are doing and challenges they may be experiencing.

Ensure that learners whose identities have traditionally been underrepresented and/or marginalized are being reflected within sexual health education.

Promote the self-determination of learners by **offering choices** (e.g., having materials in multiple formats, providing options for how students demonstrate their learning).

Create a learning environment that **encourages learners to try new and different approaches** to determine what works for them.

Watkins et al. (2020)

Promoting accessibility

Physical accessibility considerations:

Access to **parking** (e.g., having a parking lot, having accessible parking spots located close to the building).

Access to **transportation** (e.g., supporting disabled youth to book adapted transportation services, supporting disabled youth to obtain funding to cover the cost of public transportation/taxis/rideshare services).

Buildings to be equipped with automatic door openers, doors that are wide enough to accommodate wheelchairs and scooters, elevators, ramps, smooth floor surfaces, continuous handrail, accessible washroom facilities (e.g., sufficient space, grab bars, emergency call bells, sinks/soap/paper towel at wheelchair-accessible height). It is also best to have multiple accessible entrances, in case one accessible entrance does not work.

Health care examination rooms that are large enough to accommodate wheelchairs/scooters and equipped with height-adjustable examination tables that are located near a wall, ceiling and/or mechanical lifts, railing or straps to support individuals with getting onto an examination table, and portable examination equipment.

Physical accessibility considerations:

Clear and simple **signs** (e.g., use of contrasting colours, graphics, Braille) to indicate the location of buildings, offices, rooms, elevators, washrooms, and emergency exits.

Chan et al. (2022); Pritchard et al. (2014)

Information and communication accessibility considerations:

Offer youth different options of ways to interact with you (e.g., in-person, by phone, by TTY/TDD devices², over a videocall, by email, or via text message).

Use the communication method(s) that work best for the youth you are supporting (e.g., talking, writing, or typing).

Familiarize yourself with augmentative and alternative communication (AAC) methods and how to communicate with AAC users.

Support youth in adding sexuality-related symbols into their AAC devices. Here are some examples of symbols that can be helpful to youth: https://www.learningdisabilityservice-leeds.nhs.uk/easy-on-the-i/image-bank/?symbol_keyword=sex&symbol_category&symbol_show_sensitive=yes

Offer easy read versions of written materials, as well as in large print and Braille.

Use a combination of text and visuals (e.g., animation).

Caption audio content.

Describe visual content.

Offer sign language or interpretation services.

Check in with youth regularly to see if they have questions about what is being discussed.

Ask youth to repeat what they have learned in their own words.

Provide opportunities for youth to practice what they have learned.

Be creative and open to trying new ways of doing things (e.g., using arts-based approaches, using models to demonstrate concepts, having hands-on material that youth can touch and manipulate).

Communication Disabilities Access Canada (2018); European Agency for Special Needs and Inclusive Education (2015); Sequenzia & Grace (2015); Rajan (2011)

2 TTY (Teletypewriters) and TDD (Telecommunications Devices for the Deaf) are telecommunication equipment that are alternatives to telephones that enable conversations to be typed and displayed on screens.

Allocating enough time:

Embrace a more flexible concept of time. *Crip time* is a term that emerged from the disability and chronically ill communities that refers to disabled people's different experiences of time and demands of time. Acknowledging *crip time* involves making accommodations that account for the additional time disabled people may require to travel to a health care facility, to complete a health care procedure, or to complete an assignment in school. It is also about understanding that certain times of the day may work better for appointments or for carrying out certain tasks (e.g., when the person has more energy) and that sometimes disabled people may have to cancel an appointment at the last minute (e.g., when they unexpectedly do not feel well).

Book longer appointments so that supports and services (e.g., health procedures) can be carried out safely and successfully.

Allow enough time for youth to process and reflect on the information they are given, with adequate time for questions (e.g., provide information in advance of a meeting or appointment).

Offer breaks during longer activities or procedures.

Chan et al. (2022); Communication Disabilities Access Canada (2018); Schumm (2022)

The following are some additional resources that you might find helpful:

- Resources for service providers by the Disability and Sexuality Resource Hub, including online simulations and conversation guides: <https://hollandbloorview.ca/disability-sexuality-resource-hub>
- Resources for service providers who support individuals with neuromuscular conditions: <https://hollandbloorview.ca/services/programs-services/neuromuscular-services>
- Resources for supporting disabled youth by Talking about Sexuality in Canadian Communities (TASCC), including practical tips and strategies: <https://tascc.ca/supporting-youth-with-disabilities/>
- Resources for caregivers by the Disability & Sexuality Lab, including tips for talking to disabled youth about sexuality: <https://www.disabilitysexualitylab.com/>
- Resources for disabled youth in accessible formats by Scarleteen that cover a wide range of sexual health topics: <https://www.scarleteen.com/article/disability>

SEXUAL HEALTH PROMOTION TOPICS

Cultivating self-determination and bodily autonomy

At the core of sexual rights is the right to bodily autonomy and self-determination (Sexual Rights Initiative, 2018; UN General Assembly, 2006).

Definitions:

Self-determination Self-determination refers to the ability of making things happen in one's own life and being able to pursue freely chosen goals (Wehmeyer, 2015).

Bodily autonomy Bodily autonomy refers to having agency (i.e., having control over one's actions) and the power to make choices about one's own body, free of violence or coercion (Moore, 2016; United Nations Population Fund, 2021). This includes having the freedom to choose to engage in sexual activity or not and to have children or not.

Disabled youth have the right to make decisions about and have control over their bodies and their lives, as well as pursue freely chosen goals, without violence or coercion.

Too often decisions are made for disabled youth without the meaningful input of youth themselves (Giles et al., 2023). While the intention is often to protect, restricting disabled youths' opportunities for self-determination is not only a violation of their fundamental human right, but it also encourages unquestioning compliance. Consequently, disabled youth are not given opportunities to develop the necessary skills and confidence to assert their own choices or to assess if choices that are being made for them are in their best interest. This, in turn, makes disabled youth more vulnerable to abuse and coercion (Hollomotz, 2011).

Cultivating disabled youths' capacity for self-determination is critical to effectively promoting disabled youths' safety.

It is important that youth understand that they have choices and develop the necessary skills to understand their needs, identify goals, and determine appropriate actions to take to achieve desired goals. Developing these important skills can enable youth to protect themselves from being taken advantage of or forced into decisions that make them feel unsafe or uncomfortable.

Cultivating the self-determination of disabled youth

Ask disabled youth to identify their own sexuality-related goals and needs and work with them to determine the types of supports that would help them achieve their goals/address their needs.

Communicate directly with disabled youth, even when they are accompanied by a support person.

When supporting disabled youth to make decisions about their sexual health, **provide youth with all the information they need to make autonomous and informed choices.**

Let disabled youth know that the choices they make may not always result in desired outcomes and be available to support them when that happens.

Encourage parents/families to provide regular opportunities for disabled youth to make choices about their lives, across all life domains (e.g., what activities they want to try, what classes they want to take, who they want to spend time with), and to be ready to support disabled youth when their choices do not result in desired outcomes.

Create or seek out opportunities for disabled youth to hold leadership roles (e.g., paid opportunities to contribute to the development and implementation of sexual health initiatives, opportunities to serve as a peer mentor).

Connect disabled youth with communities of people with similar lived experiences for mutual learning and support.

Angell et al. (2010); Bryant et al. (2022); Giles et al. (2023); Powers et al. (2002); Wehmeyer & Palmer (2000)

Refer youth to SIECCAN's *Setting and Maintaining Boundaries: Information Sheet*:
www.physicaldisabilitysexinfo.ca

Communicating consent

Consent means permission for something to happen or for someone to do something when it involves more than one person.

To consent, a person must have all the information they need to fully understand what will happen if they agree to something before choosing to agree or not.

Communicating consent is important in all aspects of a person's life when more than one person is involved. For disabled youth, consent is especially important in the context of sexual activity, care provision, and using mobility aids.

Communicating consent for sexual activity

Communicating consent for sexual activity is critical for anyone but may be particularly important for disabled youth. For some disabled youth, engaging in partnered sexual activity may involve having their partner help them with things like getting undressed, positioning, and accessing community and private spaces, which disabled youth need to consider when they give their consent to another person to engage in sexual activity. It can be helpful to discuss or remind disabled youth of these considerations before they decide to engage in partnered sexual activity.

Things to remind disabled youth about consent to sexual activity	Examples
When a person is giving their consent to sexual activity, it needs to be an enthusiastic consent. Enthusiastic consent means that a person clearly says yes or clearly expresses that they want to engage in sexual activity. It is not sufficient that a person has simply not said “no.”	<p>If an individual asks another person if they want to engage in sexual activity and the person responds with “yes, let’s have sex” or smiles and nods, then it is okay to engage in sexual activity.</p> <p>If the person does not respond or says, “okay” but looks unsure, that is not an enthusiastic consent. It is not okay to engage in sexual activity with this person.</p>
A person should not be pressured to consent to something they do not want to do.	If someone says “no” to engaging in sexual activity, the other individual should not pressure the person to change their mind.
A person can withdraw their consent at any time. Asking for consent should be an ongoing process, even after someone has given consent.	A person can agree to engage in sexual activity with someone, but while engaging in the sexual activity, decide that they no longer want to continue with that experience. Their decision to not continue with the sexual activity must be respected.
Consent should not be assumed.	Being in a relationship with someone does not mean that the person will always want to be touched by their partner.
Consenting to one thing does not imply consent to something else.	If someone says that they want to be kissed, that does not mean they automatically consent to engaging in sexual activity.
In some situations, a person may not be able to provide informed consent. In these cases, it should be assumed that the individual does not give consent.	If someone is intoxicated or high (i.e., under the influence of alcohol or other substances) or asleep, they are not able to provide informed consent.

Things to remind disabled youth about consent to sexual activity	Examples
<p>In some situations, supported decision-making may be necessary. Supported decision-making means helping the individual make an informed decision. Supported decision-making does not mean other people making decisions for the individual.</p>	<p>If someone is unable to fully understand the situation that they are asked to consent to, it may be helpful to obtain support from someone (or a few people) who knows the individual well and can help explain the situation in a way that the individual can understand.</p> <p><i>See Supported Decision-Making section.</i></p>
<p>If someone does not consent to something, their decision must be respected.</p>	<p>If someone says “no” to engaging in sexual activity or their body language clearly demonstrates that they are not interested, then the other individual should not engage in any form of sexual activity with that person.</p>
<p>Kids Help Phone (2023); RAINN (2024)</p>	

Refer youth to SIECCAN’s *Communicating Consent: Information Sheet*: www.autismsexinfo.ca. This information sheet was initially developed for Autistic youth, but the information provided can be useful to all youth.

Consent in the context of care provision

Disabled youth who receive support with personal care needs from a young age may learn to comply with all forms of personal touch, which can contribute to a lack of bodily autonomy (Public Health Agency of Canada, 2013). It is critical that care providers, including family members, services providers, and intimate partners, support disabled youth in building their consent capacity and promote their bodily autonomy, particularly in the context of care provision.

The following are some ways care providers can support disabled youth in building their capacity for consent
<p>Do not assume that disabled youth will necessarily want your help or advice.</p>
<p>Always ask disabled youth for their consent prior to doing anything to them or for them.</p>
<p>For example, you can say, “Can I help you with this?” or “Is it okay if I support you with this?”</p>
<p>Before touching disabled youth, ask them if it is okay to do so and how – there is a chance you could physically hurt someone if you do not consult with them first. This is important for promoting the bodily autonomy of disabled youth and to ensure their safety.</p>

The following are some ways care providers can support disabled youth in building their capacity for consent

Before asking disabled youth personal questions, including questions about their disability, ask them if they are comfortable sharing personal information with you.

Always respect disabled youths' choice to say "no."

Intentionally provide opportunities for disabled youth to practice setting boundaries with you and giving consent to you.

Communicate the importance of asking disabled youth for their consent with other care providers, including parents/family members, other service providers, and intimate partners.

Levis (2012); Reilly (2021); Silverman (2017); Williams (2019)

Consent and mobility aids

Mobility aids, such as a cane, service dog, wheelchair, walker, scooter, or crutches, are often experienced as extensions of disabled youths' bodies. Before touching or manipulating someone's mobility aid, it is critical to ask the person for their consent to do so (Levis, 2012).

Touching or manipulating someone's mobility aid without their consent is not only a violation of that person's right to bodily autonomy, but doing so can potentially result in serious harm or injury, or damages to the mobility aid.

Supporting/assisting someone who uses a mobility aid

Always ask disabled youth for their consent before touching or manipulating their mobility aid.

If you see someone who may need help, ask them if they want your help before taking any action.

If a disabled person has asked you to help them with their mobility aid, ask them how to do so safely and carefully.

Inform other people about the importance of asking disabled people for their consent before touching or manipulating their mobility aids.

Mingus (2017); Peters (2019)

Supported decision-making

In some instances, disabled youth may require support to consent and/or to make other choices about their lives. In these cases, supported decision-making should be used instead of guardianship or substitute decision-making.

According to Article 12 of the United Nations' *Conventions on the Rights of Persons with Disabilities*, disabled people should “enjoy legal capacity on an equal basis with others in all aspects of life” and “[all] parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity” (UN General Assembly, 2006).

Supported decision-making is about enabling disabled people to make choices about their lives with the support of a team of people that is chosen by the disabled person (Center for Public Representation, 2024).

A supported decision-making team should consist of people who

The disabled youth trusts and chooses.

Know the disabled youth well.

Are able to support the disabled youth for an extended period of time.

Are committed to honoring the disabled youth's decisions.

Provide the disabled youth with all the information they need to make their own choices (e.g., the benefits and potential risks of making a particular decision, things to consider); and

Meaningfully involve the disabled youth in decision-making processes.

Center for Public Representation (2024)

Help disabled youth build a team of supporters by

Informing the disabled youth about supported decision-making and how it is different from guardianship/substitute decision-making.

Working with the disabled youth to identify appropriate people to include in their supported decision-making team.

Determining how the disabled youth wants to work with their team of supporters (e.g., do they want to engage with the entire team or only a few people depending on the decision that needs to be made, is there a hierarchy of who they want to consult with first).

Informing the team of supporters about what supported decision-making is and their role in supporting the disabled youth.

Working with the disabled youth to draft an agreement with their team of supporters.

Visit this link for more information about choosing supporters and working with them: <https://supporteddecisions.org/getting-started-with-supported-decision-making/>

Center for Public Representation (2024)

Developing positive sexual esteem

Sexual esteem describes a person's perception of themselves as a sexual being, including the degree to which the person feels sexually appealing and sexually competent, which can impact their sense of self-worth (Hassouneh-Phillips & McNeff, 2005).

Disabled people often believe that they are less sexually desirable than non-disabled people and/or that they are not able to have or worthy of positive sexual experiences (Connell et al., 2014; Dune, 2014a; Taleporos, 2001; Taleporos & McCabe, 2001; Tepper, 2000).

The development of negative sexual esteem is in large part due to prevailing stigma and negative discourse around the sexuality of disabled people, which become internalized by disabled people.

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

- Focus group participant: Disabled youth

Low sexual esteem can have a negative impact on disabled youths' mental health, as well as impact their relationship and sexual behaviours (McCabe & Taleporos, 2003). For instance, negative sexual esteem can discourage disabled people from pursuing romantic/sexual experiences and may make disabled people more reluctant to set boundaries and communicate their needs in relationships (Dune 2014a; Hassouneh-Phillips & McNeff, 2005).

Supporting disabled youth to develop positive sexual esteem:

Work to address ableism by **challenging negative and/or false beliefs and assumptions** that service providers, parents/families, non-disabled peers, and disabled youth may hold about the sexuality of disabled youth (See *What Can You Do to Address Ableism?* section).

Have sexuality-related discussions with disabled youth so that disabled youth are aware of their capacity to have romantic and sexual experiences if they choose to have them.

Include accurate and diverse representations of disabled youth and their experiences within sexual health discussions with:

- Disabled youth, so that disabled youth see themselves as potential sexual beings; and
- Non-disabled youth, so that the sexuality of disabled people is recognized by non-disabled youth.

Expand sexual scripts to be inclusive of disabled bodies and experiences and encourage disabled youth to engage in sexual exploration to identify sensations that they find pleasurable and ways of engaging in sexual activity that work for them (see *Promoting More Diverse Sexual Scripts* section).

Supporting disabled youth to develop positive sexual esteem:

Connect disabled youth with peers and mentors, who have shared lived experiences and can serve as positive role models.

Cultivate self-determination by providing disabled youth with regular opportunities to set goals, make their own decisions, and advocate for their needs so that disabled youth can build confidence and develop feelings of competence (See *Cultivating Self-Determination and Bodily Autonomy* section).

Work with disabled youth to **develop the language and strategies for communicating their needs, desires, and boundaries** with potential sexual partners.

This includes supporting disabled youth to understand their disability and to develop scripts to be able to disclose their disability and/or needs to their sexual partners.

Work with disabled youth to **identify their strengths** and ways they can leverage these strengths to make positive contributions to improving their sexual health.

Support disabled youth when they experience rejection, which is a difficult, but somewhat inevitable part of dating/relationships.

This can include:

- Pre-emptively discussing the different kinds of emotions that can be experienced when one's feelings are not reciprocated;
- Reassuring youth that their feelings are valid;
- Letting youth know that they are not the only ones to have these experiences;
- Letting youth know that there could be many reasons someone does not like them back or stops talking to them (e.g., the person is busy or not emotionally ready to date) and that it does not mean that there is anything wrong with them or that they are not desirable; and
- Reassuring youth that after some time has passed, they will feel better and that it is better to connect with someone else who is more compatible.

Work with disabled youth to **engage in positive self-talk**.

The Student Wellness Centre at the University of Saskatchewan provides some recommendations for engaging in positive self-talk: <https://students.usask.ca/articles/positive-thinking.php>

Baylor College of Medicine (2023); Consortium for Spinal Cord Medicine (2010); Esmail et al. (2010); Heller et al. (2016); Lee et al. (2020); Rowen et al. (2015); Student Wellness Centre (2023)

Adapting sexual scripts to be more inclusive of the needs of disabled youth

Sexual scripts refer to narratives about sexuality that are socially constructed and that become internalized by individuals to guide their own behaviours related to expressing or experiencing their sexuality (e.g., what kind of behaviours are appropriate, how one should conduct themselves in a particular situation, expectations for how others might act; Simon & Gagnon, 1986).

Contrary to prevailing misconceptions about the sexuality of disabled youth, many disabled youths are interested in and/or are engaging in sexual activity. In a SIECCAN survey of youth (ages 16 – 24) in Canada, about two-thirds of disabled youth³ reported having been sexually active: 65% had touched a partner's genitals for pleasure; 59% have had penis-vagina sex; 42% have had penis-anal sex, and 58% have had oral sex (SIECCAN, 2023a).

However, sexual activity involving disabled people can look and feel different than for non-disabled people and these ways of experiencing sexual activity have traditionally been excluded from dominant sexual scripts (Rubinsky & Hudak, 2022). When disabled people internalize dominant sexual scripts that do not account for or align with their needs and wants, sexual interactions can be unfulfilling or possibly harmful.

"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."

- Focus group participant: Disabled youth

Promoting more diverse sexual scripts

Dominant sexual scripts rarely include empowering narratives about disabled people's experiences of sexuality, which contributes to non-disabled people overlooking disabled people as potential sexual partners and disabled people internalizing false beliefs that they cannot be sexual.

Expanding sexual scripts to be more inclusive of diverse bodies and preferences allows for all people to experience rich, diverse, pleasurable, and consent-centered sexual interactions (Gunning et al., 2023).

3 These statistics refer to the 110 disabled youth who indicated having a disability related to mobility, dexterity, and/or flexibility.

The following are some ways to expand current conceptualizations of sexuality and sexual activity to be more inclusive of disabled bodies and experiences. These can be used to reflect on your own assumptions about what sexuality and sexual activity can/should look like, as well as to inform both disabled and non-disabled youth about the many ways sexuality can be experienced.

Diversifying sexual scripts:	
Disabled people can be sexual.	Include accurate, diverse, and empowering narratives of the many ways disabled people experience and express their sexuality within discussions about sexuality and sexual health with both disabled and non-disabled youth.
Sexual activities include more than just penetrative sex.	Encourage disabled youth and their partners to explore different ways of engaging in sexual activity. Penetrative sex may not always be possible or desirable for everyone. Other ways to be sexual with a partner include cuddling, showering/bathing together, touching, kissing, massaging, lying naked together, oral sex, and other activities that feel good to the partners involved. The use of sex toys and other equipment can enhance sexual pleasure for both individual and partnered sexual activity.
Partnered sexual activity can centre around pleasure and connection.	Shift the focus of partnered sexual activity away from carrying out specific sexual acts towards finding ways to make each partner feel good and connected.
Sexual satisfaction can occur without experiencing orgasm.	Encourage partners to explore diverse ways of experiencing sexual satisfaction, including promoting feelings of desirability, affection, trust, closeness, as well as reciprocal respect and friendship between partners.
Planned sexual activity with a partner can be rewarding.	Remind partners that planned sexual activity can be exciting and rewarding. Planning ahead allows all partners to prepare, feel ready and energized, and prioritize time spent together.
Communication is central to safe, consensual, and pleasurable partnered sexual experiences.	Support disabled youth and their partner(s) to have ongoing and honest discussions about needs, boundaries, consent, and desires before, during, and after sexual activity. Effective communication contributes to establishing expectations between partners and enables partners to better respond to each other's needs.
Dune (2014b); Gunning et al. (2023); Kattari (2015); Leibowitz (2005); Morozowski & Roughley (2020)	

Refer youth to SIECCAN's *Disability and Sexual Activity: Information Sheet*: www.physicaldisabilitysexinfo.ca

Partner acceptance and support

In partnered relationships, having a partner who is understanding, supportive, and non-judgemental can allow disabled youth to feel more comfortable exploring different strategies for enhancing sexual experiences.

"I'm hoping to meet with a partner whose gonna understand and love me for who I am."

- Focus group participant: Disabled youth

Providing partners with information on how they can support disabled youth during sexual activity can foster more positive sexual experiences (Browne & Russell, 2005; Eisenberg et al., 2015; Jungels & Bender, 2015; Tellier & Calleja, 2017).

It is important that all partners involved in a relationship understand the mutual responsibility they have for making their relationship experiences positive for everyone involved.

Ways that sexual partners can better support disabled youth

Address internalized ableism (See *What Can You Do to Address Ableism?* section for some guiding questions that can be used to engage in self-reflection about internalized ableism).

Ask disabled youth about their support needs (e.g., putting on a condom, getting undressed, getting into a comfortable position, using assistive devices).

Listen and respect disabled youths' needs and boundaries.

Respect *crip time* (e.g., the additional time disabled people may need to get ready, last minute cancellations or change of plan, that certain times of the day may be better for sexual activity).

Be open to diverse ways of engaging in sexual activity.

Identify ways that each partner can make significant and meaningful contributions to the relationship/sexual experience.

Morozowski & Roughley (2020)

Delivering 2SLGBTQINA+ inclusive sexual health education and services

The *Canadian Human Rights Act* (Canadian Human Rights Act, 1985) and legislations in all provinces/territories prohibit discrimination based on sexual orientation or gender identity. Sexual health education and services that are relevant to and incorporate the needs of Two-Spirit, lesbian, gay, bisexual, transgender, queer, intersex, nonbinary, and asexual (2SLGBTQINA+) disabled youth are, therefore, consistent with established human rights in Canada. Access to relevant and inclusive sexual health education and services is a right for all 2SLGBTQINA+ disabled youth.

"I also find that as a queer disabled person it's more difficult to be queer and disabled at the same time, it's almost like you can't be both of those things in the same time."

- Focus group participant: Disabled youth

How to provide 2SLGBTQINA+ inclusive sexual health education and services:

Be upfront about being a safe space for 2SLGBTQINA+ individuals (e.g., put up a pride flag). In doing so, it is also important that you take the necessary steps (i.e., suggestions in this table) to fulfill your commitment to making your office, classroom, or organization safe for 2SLGBTQINA+ individuals.

Assume that the disabled youth you are supporting could have a 2SLGBTQINA+ identity.

Familiarize yourself with 2SLGBTQINA+ terminology. You can find definitions for some 2SLGBTQINA+ terminology here: <https://women-gender-equality.canada.ca/en/free-to-be-me/2slgbtqi-plus-glossary.html>

Ask youth about the pronouns they use and use the pronoun they provide. You can share your pronouns before asking youth for their pronouns to create a safe space for youth to share their pronouns.

If an individual is not comfortable sharing this information with you, do not pressure them to do so. You can use the person's name or a gender-neutral pronoun, such as "they/them."

When referring to people in general, it can be helpful to **use gender-neutral pronouns**, such as "they/them", instead of "she/her" or "he/him."

For example, instead of saying, "if a person wants to have sex with his or her partner, it is important for him or her to ask for consent," say, "if a person wants to have sex with their partner, it is important for them to ask for consent."

How to provide 2SLGBTQINA+ inclusive sexual health education and services:

Avoid using the honorifics “Mr.,” “Ms.,” “Mrs.,” and “Miss.” if you are unsure about the person’s pronouns. Refer to individuals by their names.

When talking about anatomy, **avoid associating body parts with sex or gender.**

For example, instead of saying, “when a man has an erection” say, “when the penis is erect.”

Also, be aware that some people may use non-medical/slang terms to refer to their genitals that is different from medical terminology.

Ask everyone to respect the names, pronouns, and identities that an individual has shared.

Be open to learning from people with diverse gender identities and sexual orientations.

Be willing to apologize if you make a mistake, such as using the wrong pronoun or making a false assumption.

For example, if you say, “She went to the store.” and then realize or find out that the individual goes by “they,” you can simply say, “Sorry, **they** went to the store.”

Making mistakes will happen. What is important is that you are willing to acknowledge and fix your mistake. You may feel bad when you make a mistake but avoid placing responsibility on the other person to make you feel better. Instead, accept responsibility for your mistake and learn from it.

Cortes et al. (2016)

How to support disabled youth who may be exploring or questioning their gender identity and/or sexual orientation

Remind youth that **being 2SLGBTQINA+ are valid ways of being.**

Reassure youth that **it is okay to take the time they need to figure out their gender identity and/or sexual orientation** and that for some people, gender identity and sexual orientation can change throughout their life.

Recognize that **disclosing a 2SLGBTQINA+ identity may be a difficult decision for youth to make** as it may not always be safe to do so. Support youth in assessing the potential benefits and risks of disclosing a 2SLGBTQINA+ identity.

Recognize that navigating society as someone who identifies with a 2SLGBTQINA+ identity can be challenging, given that these identities continue to be stigmatized. Refer youth to appropriate **mental health supports** if needed.

How to support disabled youth who may be exploring or questioning their gender identity and/or sexual orientation

Provide disabled youth with information about how they can **connect with 2SLGBTQINA+ communities**, including identifying accessible queer spaces and events (e.g., queer events that are physically accessible, communities specifically for 2SLGBTQINA+ disabled people).

If a disabled youth discloses their gender identity or sexual orientation to you, it is important to **respect that person's privacy and choice** regarding who else they may or may not want to share this information with.

Kosciw et al. (2015); National LGBT Health Education Center (2016)

Refer youth to SIECCAN's *Gender Identity and Sexual Orientation: Information Sheet*: www.autismsexinfo.ca. This information sheet was initially developed for Autistic youth, but the information provided can be useful to all youth.

Responding to abuse

Disabled people are more likely than non-disabled people to be targets of violence (Cotter, 2018; Statistics Canada, 2021; Savage, 2021). According to the 2019 Canadian *General Social Survey on Victimization*, disabled people were almost three times more likely to experience violent victimization (i.e., sexual assault, robbery, or physical assault) compared to non-disabled people (141 incidents per 1,000 vs. 53 incidents per 1,000) and disabled women⁴ were at greater risk (184 violent incidents for every 1,000 disabled women vs. 84 violent incidents per 1,000 disabled men; Statistics Canada, 2021).

Disabled people are also more likely to experience some form of intimate partner violence (IPV) in their lifetime compared to non-disabled people (Savage, 2021). According to the 2018 Canadian *Survey of Safety in Public and Private Spaces*, more than half of disabled women (55%) who had ever been in an intimate relationship had experienced some form of IPV in their lifetime and were more likely than non-disabled women (37%) to experience IPV. Disabled men were also more likely to experience some form of IPV in their lifetime compared to non-disabled men (44% vs. 32%).

Recent population-based research from Ontario indicates that disabled women of reproductive age (15 to 44 years) are more likely to report having been assaulted compared to non-disabled women of reproductive age (Tarasoff, Lunsky et al., 2020).

“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.”

- Focus group participant: Disabled youth

Disabled people are more likely to be targets of abuse and violence largely due to prevailing stigma and the social devaluation of disabled people, as opposed to an inherent vulnerability associated with disabilities (SIECCAN, 2023b).

⁴ In describing gender differences, the referenced studies do not differentiate between cisgender and transgender individuals.

Recognizing abuse

Disabled youth need to be informed about different forms of abuse so they can recognize when abuse has taken place.

Types of abuse that disabled people can experience	Examples
Systemic	<ul style="list-style-type: none">• Ableism• Racism• Prejudice
Psychological/verbal	<ul style="list-style-type: none">• Being insulted or laughed at• Being threatened• Being controlled and forced to engage in behaviours that the person does not want to engage in• Having false accusations made about the person
Cyber	<ul style="list-style-type: none">• Online bullying• Being exploited or taken advantage of on social media• Having false information about the person being shared on social media
Financial	<ul style="list-style-type: none">• Having money stolen by a care provider• Having money poorly managed by other people• Being told what to do with the person's own money• Having items stolen from the person's home
Denial of services and supports	<ul style="list-style-type: none">• Being refused necessary personal care support• Accessibility aids being withheld
Neglect	<ul style="list-style-type: none">• Failure to have basic needs met by a care provider (e.g., food, medicine, safe and clean shelter)• Failure to have health care needs met by a care provider (e.g., medical treatment plan not being followed, not being provided with necessary medication, not being taken to medical appointments)• Service animals not being properly cared for
Isolation	<ul style="list-style-type: none">• Being held in confinement with limited social contact

Types of abuse that disabled people can experience	Examples
Physical	<ul style="list-style-type: none"> • Being hit, kicked, choked, pinched • Use of physical restraints • Inappropriate use of drugs/medication • Violence resulting in severe injuries
Sexual	<ul style="list-style-type: none"> • Inappropriate touching • Being forced to engage in unwanted sexual behaviours
Destruction of property	<ul style="list-style-type: none"> • Damages to accessibility aids • Destruction of home or car
Rajan (2011)	

Supporting disabled youth who have experienced abuse

“Support us when we need to talk about negative situations. I would also suggest that there should be empowerment for when we are ready to report any type of sexual abuse to the authorities.”

- Focus group participant: Disabled youth

How to respond if a disabled youth reports an incident of abuse to you

Believe them and do not dismiss their concerns.

Identify and be aware of services/organizations in your area that provide support to disabled youth who have experienced abuse. Support disabled youth in connecting with these services/organizations.

Advocate for the accessibility needs of disabled youth within shelters and abuse support services.

Disability Rights Wisconsin's (United States) *Self-Assessment Tool for Ensuring Access for People with Disabilities* (<https://safehousingpartnerships.org/node/205>) can be a helpful resource for assessing the accessibility of assault and violence support programs and services.

Support disabled youth to report an incident of abuse to local authorities if they wish to do so.

Disabled youth may require you to support them as there are many cases where the police do not believe disabled youth who report an incident or do not take any action.

Support disabled youth to assess immediate risks and develop a safety plan.

The following resources can be helpful to conduct a risk assessment and develop a safety plan:

- Canadian Domestic Homicide Prevention Initiative's *Creating Safety Plans with Vulnerable Populations to Reduce the Risk of Repeated Violence and Domestic Homicide*: <https://cdhpi.ca/creating-safety-plans-vulnerable-populations-reduce-risk-repeated-violence-and-domestic-homicide>
- Safe and Equal's (Australia) *Safety Planning and Risk Management* (with specific disability considerations): <https://safeandequal.org.au/working-in-family-violence/tailored-inclusive-support/people-with-disability/safety-planning-and-risk-management/>
- Washington State Coalition Against Domestic Violence (United States)'s *Model Protocol: Safety Planning for Domestic Violence Victims with Disabilities*: <http://wscadv.org/wp-content/uploads/2015/06/Protocol-disability-safety-planning-rev-2010.pdf>
- Victim Rights Law Center (United States)'s *Safety Planning with LGBTQ Sexual Assault Survivors: A Guide for Advocates and Attorneys*: <https://victimrights.org/wp-content/uploads/2020/11/WTSToolkit-Safety-Planning-with-LGBTQ-Sexual-Assault-Survivors.pdf>

Connect disabled youth with crisis helplines (e.g., <https://findahelpline.com/ca/topics/sexual-abuse>) and/or local mental health supports.

Support disabled youth to access safe and reliable personal care support.

Fear of losing personal care support can prevent disabled youth from leaving an abusive situation.

Identify services/organizations that can support disabled youth with financial planning (e.g., obtaining education and/or employment opportunities, applying for disability benefits).

Experiences of abuse have been shown to be linked to experiences of poverty. Further, fear of losing financial support can often prevent disabled people from leaving an abusive situation.

Bader et al., (2019); Barrett et al., (2009); Ellsberg et al., (2015); Rajan (2011)

Sexually transmitted infection (STI) prevention

Disabled people have higher rates of sexually transmitted infections compared to non-disabled people, largely due to barriers in accessing necessary and relevant sexual health information and services (Brennand & Santinele Martino, 2022; Parekh et al., 2023). Providing disabled youth with information about reducing risk of getting or transmitting sexually transmitted infections (STIs), STI testing, and STI treatment can enable disabled youth to make more informed decisions about their sexual health (SIECCAN, 2019).

The information-motivation-behavioural skills (IMB) model can be a helpful behavioural change approach to supporting disabled youth in reducing their risk of getting or transmitting an STI

(SIECCAN, 2019).

Information	Provide disabled youth with relevant information that will enable them to adopt behaviours to enhance their sexual health.
Motivation	Support disabled youth in understanding the importance and personal benefits of adopting sexual health promoting behaviours.
Behavioural skills	Provide disabled youth with actionable steps they can take to adopt sexual health promoting behaviours.

Information, motivation, and behavioural skills to prevent STIs

Information	<p>Inform disabled youth about:</p> <ul style="list-style-type: none">• STIs and their symptoms. It is important for youth to understand that many cases of STIs do not have symptoms and that symptoms can be different for people with penises and people with vulvas.• The ways STIs can be passed from one person to another.• How and when to get tested for STIs.• Treatments. All STIs are treatable and many are curable.
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Information, motivation, and behavioural skills to prevent STIs

Motivation

Discuss with disabled youth:

- The effectiveness of condoms and dental dams in preventing the transmission of STIs.
- The importance of talking to sexual partners about safer sex practices.
- The importance of accessing STI testing for sexually active youth.
- The importance of getting vaccinated against HPV and hepatitis.
- Their personal beliefs and attitudes about STI prevention, as well as that of their families, peers, and society more broadly.

Behavioural skills

Provide disabled youth with information about:

- How to bring up and talk about using condoms or dental dams with sexual partners before engaging in sexual activity.
- Where they can get condoms and dental dams.
- How to use condoms and dental dams.
- Asking a partner to help them put on a condom/dental dam if they experience challenges opening condom/dental dam packages or putting on the condom/dental dam themselves.
- The steps to accessing STI testing, treatment, and vaccination.

SIECCAN (2019)

Refer youth to SIECCAN's *Preventing Sexually Transmitted Infections (STIs): Information Sheet*: www.autismsexinfo.ca. This information sheet was initially developed for Autistic youth, but the information provided can be useful to all youth.

Cervical Cancer Prevention

People with a cervix are at risk of cervical cancer (Centers for Disease Control and Prevention, 2023b). Most cervical cancers are caused by the human papillomavirus (HPV).

The HPV vaccine and preventative cervical cancer screenings are effective ways of either preventing cervical cancer or detecting it early. However, disabled people experience many barriers to accessing these preventative health services, which may place disabled people at greater risk of developing cervical cancer (Baruch et al., 2022; Iezzoni et al., 2021; O’Neill et al., 2020).

HPV vaccination

The HPV vaccine is highly effective in preventing most cases of cervical cancer, particularly when administered before an individual becomes sexually active (Canadian Partnership Against Cancer, 2020).

Note: HPV can also cause cancer in other parts of the body (e.g., throat, vulva, penis, anus; SIECCAN, n.d.). The HPV vaccine can reduce the risk of developing HPV-related cancers for individuals of all gender identities and sexual orientations.

Disabled youth may experience the following barriers to receiving the HPV vaccine

Parents believing that their disabled child does not need the HPV vaccine;

Health service providers not recommending the HPV vaccine to disabled people; and

Concerns about the safety of the vaccine.

O’Neill et al (2020)

In a SIECCAN survey of youth (ages 16 – 24) in Canada, a significantly higher percentage of disabled youth⁵ assigned female at birth indicated not knowing if they had received the HPV vaccine (24%) compared to non-disabled youth assigned female at birth (15%; SIECCAN, 2023a). This finding indicates that many disabled youths are not fully informed about the HPV vaccine and how to access it.

5 These statistics refer to the 516 disabled youth who indicated having any type of disability, not just those related to mobility, dexterity, and/or flexibility.

The IMB model can be used to promote the uptake of the HPV vaccine among disabled youth by informing disabled youth and their parents about the importance and effectiveness of the HPV vaccine. See *Sexually Transmitted Infection (STI) Prevention* section for a description of the IMB model.

Information

Inform disabled youth and their parents about:

- Cervical cancer (e.g., who can develop cervical cancer, what causes cervical cancer, how cervical cancer can be prevented).
- HPV infections (e.g., who can get HPV, how HPV can be transmitted from one person to another, what kind of health problems HPV can cause, how HPV can be prevented).
- The HPV vaccine (e.g., how the vaccines protect against certain types of HPV, Canadian guidelines for receiving the vaccine).

Motivation

Discuss with disabled youth and their parents:

- The importance of the HPV vaccine for preventing genital warts and cancers caused by HPV.
- The effectiveness of the HPV vaccine in preventing cervical cancer.
- The value of the HPV vaccine, particularly for disabled youth who experience barriers to accessing cervical cancer screening (e.g., HPV testing and Pap tests).
- The safety of the HPV vaccine.

Behavioural skills

Provide disabled youth and their parents with information about:

- How disabled youth can receive the HPV vaccine.
- Publicly funded school-based HPV immunization programs.
- Eligibility for publicly funded catch-up programs for individuals who are not eligible for school-based HPV immunization programs.

Canadian Partnership Against Cancer (2021); Indigenous Services Canada (2020); Public Health Agency of Canada (2024); Rowe et al. (2017); SIECCAN (2019)

Cervical cancer screening

The Papanicolaou (Pap) test and HPV testing are two ways to screen for cervical cancer. The Pap test can detect precancers (i.e., cell changes on the cervix that could become cervical cancer) and is currently the primary cervical cancer screening test used in Canada (Cancer Care Ontario, n.d.).

Barriers disabled youth encounter to accessing the Pap test

Misconceptions that disabled youth do not require Pap tests;

Disabled youth receiving limited information about the Pap test, including the importance of regular screening and how to access these services;

Health service providers not recommending the Pap test to disabled youth;

Pap test procedures not adapted for disabled youth;

Physical inaccessibility of health care facilities; and

Lack of adaptive equipment in health care facilities.

Chan et al. (2022); Iezzoni et al. (2021); McRee et al. (2010); Ramjan et al. (2016)

“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 [health service provider] couldn’t fit the tool in me and so they just decided I probably didn’t need a pap smear.”

- Focus group participant: Disabled youth

HPV testing is used to detect high-risk strains of HPV in cervical cells (Nguyen et al., 2018). Some provinces/territories are considering implementing HPV testing as the primary cervical cancer screening method (Canadian Partnership Against Cancer, 2022). British Columbia has recently launched a cervix self-screening program, which includes the option to do the HPV test at home (BC Cancer, 2024).

Improving the uptake of cervical cancer screening among disabled youth

Provide disabled youth with information about Pap tests:

- Why: The Pap test is a screening test that can detect precancers (i.e., cell changes in the cervix that can become cervical cancer) before a person has any symptoms. This test helps to detect cancer early so that the cancer can be treated.
- Who: Individuals with a cervix, beginning at age 21 or 25 (or depending on when the person becomes sexually active) until age 65 to 70, are generally recommended to receive the Pap test every 2 – 3 years. Specific cervical cancer screening guidelines vary across provinces and territories.
- Where: Pap tests can usually be done at a health clinic by a doctor or nurse practitioner.
- How: A health service provider will open a patient's vagina using a tool called a speculum so that they can see the patient's cervix. The health service provider will then use a soft brush to take cells from the patient's cervix.

Support disabled youth in determining if they are eligible to receive the Pap test by checking their local provincial/territorial guidelines for Pap tests.

Support disabled youth in finding a suitable and accessible health clinic where they can receive the Pap test.

Recommendations for health service providers to make Pap tests more accessible:

- Ensure that enough time is allocated for the appointment so that the test can be administered safely and successfully;
- Adopt a trauma-informed approach (See *Implementing Trauma-Informed Practice* section);
- Prior to administering the test, ask youth what types of adaptations they may need (e.g., using a smaller speculum);
- Ensure that your health care facility is physically accessible (See *Physical Accessibility Considerations* section for recommendations for making your health care facility more accessible); and
- Offer home visits as an option, if possible.

Offer HPV testing as an alternative to the Pap test.

For some disabled youth, undergoing a speculum examination may be challenging or not possible. In these cases, consider administering an HPV test instead of the Pap test. HPV testing does not require the use of a speculum and may be a more accessible cervical cancer screening method for some disabled youth.

Cancer Care Ontario (n.d.); Chan et al. (2022); Clark & Horton (2021); Iezzoni et al. (2021); Nguyen et al. (2018)

Reproductive justice

Reproductive justice refers to each individual's right to choose whether or not they want to have children and if they do, when and with whom. To make informed choices, disabled youth require access to information about pregnancy and contraception that is tailored to their needs.

The reproductive rights of disabled youth must always be respected.

Contraceptive methods

All youth should be provided with the opportunity to learn the relevant information and skills to make informed choices about pregnancy prevention or birth control.

According to research from the United States, disabled women are more likely than non-disabled women to have unintended pregnancies (i.e., pregnancies that are either unwanted or mistimed), which underscores the importance of supporting disabled youth with pregnancy planning and contraceptive use (Horner-Johnson et al., 2020).

“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.”

- Focus group participant: Disabled youth

Disabled youth should not, in any way, be coerced or persuaded into using any form of birth control that they do not want to use or that they do not fully understand.

Respecting disabled youths' choice to use birth control or not and which birth control method to use is fundamentally about supporting their right to bodily autonomy. If the disabled youth does not fully understand their birth control options, supported decision-making should be offered, rather than guardianship or substitute decision-making (See *Supported Decision-Making* section).

The IMB model can be used to support disabled youth in choosing birth control methods. See *Sexually Transmitted Infection (STI) Prevention* section for a description of the IMB model.

Information	Inform disabled youth about: <ul style="list-style-type: none">• What birth control is.• Reasons for using birth control (e.g., preventing pregnancy, managing menstruation, managing hormonal dysregulation).• Different birth control methods.
Motivation	Discuss with disabled youth: <ul style="list-style-type: none">• Their right to choose if they want to use birth control or not, and which birth control method they want to use.• The effectiveness of different birth control methods in preventing pregnancies and possible side effects.• The advantages and disadvantages of different birth control methods (See the table, <i>Important Things for Health Service Providers to Consider When Providing Contraceptive Counselling to Disabled Youth</i>, below).
Behavioural skills	Provide disabled youth with information about: <ul style="list-style-type: none">• Where they can get information about different birth control methods.• How to obtain and use their birth control method of choice.• How to bring up and talk about birth control with their sexual partners.

Refer youth to SIECCAN's *Birth Control Methods: Information sheet*: www.autismsexinfo.ca. This information sheet was initially developed for Autistic youth, but the information provided can be useful to all youth.

Important things for health service providers to consider when providing contraceptive counselling to disabled youth:

Some disabled youth may be more susceptible to bone fractures or developing blood clots, which need to be considered when choosing contraceptive methods.

Individuals with spina bifida are more likely to have latex allergies and should be encouraged to use non-latex condoms.

Disabled youth may be taking other medication, which can interact with the birth control pill to have unintended effects (e.g., reduced effectiveness of either medication).

Some disabled youth may have dysphagia (i.e., swallowing difficulties), which can make taking oral contraceptives more challenging.

Important things for health service providers to consider when providing contraceptive counselling to disabled youth:

Speculum insertions can be challenging for some disabled youth, which can make inserting an intrauterine device (IUD) more difficult.

Individuals who experience challenges with dexterity may require help from another person to use certain contraceptive methods such as condoms, the vaginal ring, the patch, and the birth control pill.

Baylor College of Medicine (2020); Dragoman et al. (2018); Fasen et al. (2020); Houtchens et al. (2017); Jansheski (2024); Spinal Cord Injury BC (2024); Stoffel et al. (2018); TASC (2024); Taylor & Erkek (2004); Welner & Hammond (2009); Williams (2014)

The following are some additional resources about contraception and disability that you might find helpful:

- Contraception and Disabilities by Baylor College of Medicine: <https://www.bcm.edu/research/research-centers/center-for-research-on-women-with-disabilities/a-to-z-directory/reproductive-health/contraception>
- Contraception by Spinal Cord Injury BC: <https://scisexualhealth.ca/contraception/>

Planning for pregnancy

Pregnancy is common among disabled people. According to population-based data from Ontario, one in eight pregnancies are to a disabled person (Brown et al., 2020). However, compared to non-disabled people, disabled people are at an increased risk for perinatal (i.e., during pregnancy and/or childbirth) complications (Brown et al., 2021; Tarasoff, Ravindran et al., 2020).

Social inequities such as barriers to education, employment, and accessible health services, as well as higher rates of poverty, abuse, and chronic illness may contribute to disabled people's increased risk of adverse perinatal outcomes and poorer perinatal care experiences (Shah et al., 2024; Tarasoff et al., 2023; Tarasoff, Ravindran, et al., 2020). Further, false assumptions made about disabled people's desire or ability to have children contribute to poor quality reproductive health services and experiences of discrimination within the health care system (SIECCAN, 2023c; Smeltzer et al., 2017).

"Yeah, I get laughed at when I say I wanna have kids. Everybody is like, well focus on everything else because you don't know if you're gonna be able to take care of kids..."

- Focus group participant: Disabled youth

Disabled youth who are considering the possibility of getting pregnant should receive preconception counselling that is tailored to their unique needs and circumstances so they can make informed choices about pregnancy.

“...pregnancy and disabled people, and understanding how different that looks in certain people. Being able to advise, because every pregnancy is obviously going to be different [...] I don’t think enough doctors take that into account and understand how to address it, so it doesn’t make pregnancy a safe experience for people with disabilities when it should be.”

- Focus group participant: Disabled youth

While the choice to get pregnant or not is ultimately that of the person who can get pregnant (i.e., the person who has a uterus and ovaries), partners have an important role to play in respecting and supporting that decision.

Important things for health service providers to consider when counselling disabled youth prior to or during pregnancy:

Fertility

For many physical disabilities (e.g., cerebral palsy, multiple sclerosis, spina bifida, spinal cord injuries), there is currently no evidence that they have an impact on fertility. Contraception should be used if disabled youth, who are sexually active, do not want to get pregnant (See *Contraceptive Methods* section).

People of all genders, with or without disabilities, can experience challenges with fertility. If someone is experiencing challenges getting pregnant, they should speak with their health care provider to better understand their options.

Possible impact of pregnancy on disabled youths’ bodies

Body changes during pregnancy can, in some cases, impact a person’s impairment(s). For example, weight change can have an impact on mobility and balance. The use of mobility aids (or the use of a different mobility aid for those who already use a mobility aid) can be helpful. In some cases, disability-related symptoms (e.g., spasms) can increase during pregnancy.

Body changes during pregnancy should be monitored and addressed as necessary as part of prenatal care. Rehabilitation professionals (e.g., occupational therapists) can support disabled youth in managing potential changes to body functioning.

Important things for health service providers to consider when counselling disabled youth prior to or during pregnancy:

Medication use and potential changes to medical treatments/therapies

Certain medications and/or medical treatments/therapies that disabled youth may be using before getting pregnant may not be safe to use during pregnancy. Health service providers should advise disabled youth on potential changes needed to their medical treatments/therapies.

Changes to medication use can, in turn, impact disabled youths' functioning. Rehabilitation professionals (e.g., occupational therapists) can help to anticipate potential environmental safety risks and identify potential solutions.

Delivery options

Many disabled people can have vaginal deliveries. However, there may be cases where Caesarean section (C-section) is necessary. Health care providers should discuss potential risks and advantages of each delivery option with disabled youth.

Pain management during labour

For some disabled youth, receiving an epidural may be challenging. Disabled youth should be consulted by an anesthesia team early on during pregnancy so they can make informed decisions about pain management during labour.

Potential pregnancy- and birth-related complications

Compared to non-disabled people, disabled people are at an increased risk of pregnancy- and birth-related complications including increased risk of gestational diabetes, urinary tract infections (UTIs), thromboembolism, cardiovascular events, hemorrhage, preeclampsia, and maternal death.

It is important to note that disabled people experience significant health inequities due to barriers accessing important social determinants of health (e.g., financial insecurity, discrimination, physical inaccessibility of health care facilities), which contribute to and/or exacerbate challenging pregnancy experiences. Health service providers should ensure regular monitoring of disabled youths' health and collaborate with necessary health and/or social service providers.

Brown et al. (2021); Gleason et al. (2021); Iezzoni et al. (2015); Johns Hopkins Medicine (2024); Krysko et al. (2020); Provincial Council for Maternal and Child Health (2023); Smeltzer et al. (2017); Stoffel et al. (2018); Visconti et al. (2012); Warmbrodt (2024)

Approaches to perinatal and postpartum care for disabled youth:

Involve disabled youth in shared decision-making about their care and labour/delivery plans;

Engage a multidisciplinary health team (e.g., family doctor, obstetrician, anesthesiologist, urologist/nurse specializing in urology, rehabilitation professionals);

Offer more frequent and longer health care visits before, during, and after pregnancy;

Include rehabilitation and mental health services as part of perinatal and postpartum care.

Brown et al. (2021); Deeksha et al. (2023); Iezzoni et al. (2015); Provincial Council for Maternal and Child Health (2023); Stoffel et al. (2018); Tarasoff, Ravindran, et al. (2020); Visconti et al. (2012); Warmbrodt (2024)

Additional resources:

- Clinical practice guidelines on perinatal and postpartum care for disabled people, *Labour, Delivery, and Postpartum Care for People with Physical Disabilities* (development was led by Dr. Anne Berndt from the Accessible Pregnancy Care Clinic at Sunnybrook Hospital in Toronto, Ontario): <https://pubmed.ncbi.nlm.nih.gov/33631321/>
- Resources for health service providers and for disabled people about pregnancy and postpartum care for disabled people (developed by the Ontario Provincial Council for Maternal and Child Health in partnership with researchers from the University of Toronto): <https://www.pcmch.on.ca/disability-and-pregnancy/>

Access to abortion care

Another important component of reproductive justice is the voluntary choice to terminate a pregnancy legally and safely (Kirby, 2017). However, ableist assumptions about disabled people's capacity to have children can contribute to disabled people who become pregnant to be unwillingly pushed towards or even coerced into getting an abortion due to the belief that they are not fit to become parents (Hassan et al., 2023; Nguyen, 2020). On the other hand, barriers to accessing reproductive health services (e.g., unavailable or unreliable health information, physical barriers, negative attitudes held by health service providers) can limit disabled youths' access to appropriate and safe abortion care (Nguyen, 2020).

**Disabled youth should never be coerced into getting an abortion if that is not what they want to do.
Disabled youth who wish to get an abortion should have access to appropriate and safe abortion care.**

Youth wanting support to access abortion care can call (1-888-642-2725) or text (613-800-6757) Action Canada for Sexual Health & Rights' Access Line for support.

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