

Canadian Guidelines for Sexual Health Promotion with Disabled Youth



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Consultation

SIECCAN conducted an online consultation survey with service providers to inform the development of the capacity-building toolkit focused on the needs of disabled youth. SIECCAN also worked with Wisdom2Action to conduct focus groups with disabled youth. SIECCAN would like to thank the disabled youth and service providers from across Canada who participated in the consultation.

Working group

To develop the capacity-building toolkit focused on the needs of disabled youth, SIECCAN put together a working group of individuals with diverse lived experiences and professional expertise including disabled people, researchers, community organization representatives, educators, and health service providers. Working group members were consulted at every step of the project and were integral in determining what content to include and how to present the information to best meet the needs of both service providers working in this area and the disabled youth that service providers support.

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INTRODUCTION

Project overview

Autistic youth and disabled youth in Canada are underserved with respect to the provision of quality sexual health information and services tailored to their needs. The overarching goal of the *Enhancing Effective Sexual Health Promotion for Autistic and Disabled Youth* project is to improve service providers' knowledge and skills to effectively promote the sexual health and well-being of (1) Autistic youth and (2) disabled youth with physical disabilities. To achieve this goal, SIECCAN developed two capacity-building toolkits for service providers focused on the sexual health needs of Autistic youth and disabled youth, respectively.

The *Canadian Guidelines for Sexual Health Promotion with Disabled Youth* is one component of the capacity-building toolkit focused on the needs of disabled youth, which also includes a guide for service providers and resources for disabled youth. The *Canadian Guidelines for Sexual Health Promotion with Disabled Youth* aims to inform policy and program decision-makers about the importance of promoting sexual health with disabled youth. Further, this document provides recommendations to help guide policy and program decision-makers in taking action to enhance sexual health promotion with disabled youth. **In the context of this project, youth refers to individuals aged 29 and under.**

Defining physical disabilities

Note:

In reviewing the existing literature, many different definitions of physical disability were identified. Some definitions aligned more closely with the medical model of disability (e.g., Alberta Human Rights Commission, 2024), while others reflected the social model of disability (e.g., Giles et al., 2023; See Section 2 for a more in-depth discussion about the medical and social models of disability). We chose to adopt the World Health Organization conceptualization of disability, which acknowledges the complex interplay between individual differences in body structure/function and their social/environmental context that create unique experiences of disability.

Further, some definitions of physical disability were broader than others (e.g., included mobility-related disabilities, sensory disabilities, chronic pain). For the purpose of this toolkit, we chose to focus on disabilities related to mobility, dexterity, and flexibility to provide more specific recommendations. We recognize that experiences of disability can be quite different even among those with the same disability and that we would not be able to address all aspects of these unique experiences within this toolkit. However, it is likely that some of the recommendations provided in these guidelines will also be relevant to other disabilities. The development of this toolkit is only a first step to addressing the diverse sexuality-related experiences and needs of disabled youth.

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).

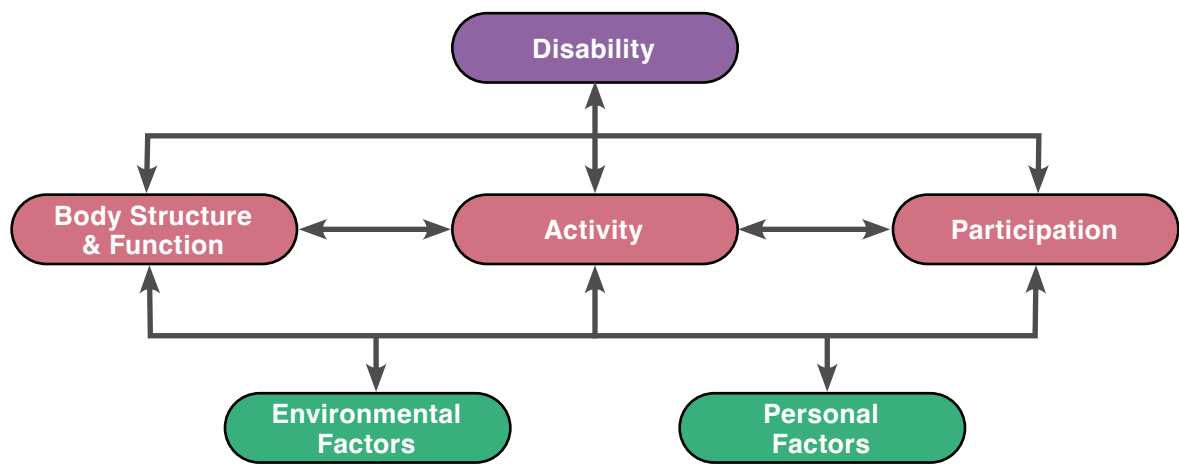


Figure 1: The World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) model

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).

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

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
- Scoliosis
- Spina bifida
- Spinal cord injury

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

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. It is important to note that existing research on the sexual health needs and experiences of disabled youth often group many disabilities together and may not always use the same definition of “physical disabilities.” When presenting existing research, the term *disabled youth* 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.

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, though we recognize this is not preferred by all. In some cases, person-first language is used to specify the type of physical disability being discussed (e.g., youth with cerebral palsy) 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*).

Defining sexual health promotion

Sexual health is “a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity” (World Health Organization, 2002). Sexual health includes matters relating to reproductive health such as ensuring that all people have the capability and freedom to decide if, when, and how often they want to reproduce (World Health Organization, 2023).

Sexual health promotion, in turn, is the process of increasing people's capacity to exert greater control over and to make positive changes to their sexual health (Khalesi et al., 2016; World Health Organization, 2002). Effective sexual health promotion requires ensuring that the sexual rights of all people, including disabled youth, are respected (World Health Organization, 2002).

Developing the Canadian Guidelines for Sexual Health Promotion with Disabled Youth

Between August 2022 and October 2022, SIECCAN conducted an online consultation survey with service providers to better understand their needs regarding sexual health promotion with disabled youth. In the context of this project, the term *service provider* refers to anyone in a formal position to provide sexual health information, education, and/or services to disabled youth.

A total of 89 service providers participated in the survey. Participants included educators, social workers, community organization staff, public health professionals, nurses, physicians, caregivers/personal support workers, occupational therapists, psychologists/councillors, behavioural therapists, life skills coaches, employment support workers, executive functioning coaches, speech-language pathologists, and sexual health educators. The *Findings from the Service Provider Consultation Survey: Focus on Disabled Youth (Physical Disabilities)* (<https://www.sieccan.org/ady-physicallydisabledyouth>) report provides a complete summary of the findings (SIECCAN, 2023a).

In September 2022, two focus groups were conducted with disabled youth (19 – 24 years old) to better understand their dating, relationship, and sexual experiences, as well as their sexual health education and service needs. One of the two focus group sessions was open to all disabled youth between the ages of 16 and 24 (open session), while the other was specifically for those who identified as Black, Indigenous, or People of Colour (BIPOC session). A total of 14 disabled youth participated: nine in the open session and five in the BIPOC session. The *Findings from Focus Groups with Disabled Youth (Physical Disabilities)* (<https://www.sieccan.org/ady-physicallydisabledyouth>) report provides a complete summary of the findings (SIECCAN, 2023b).

In May 2023, following the completion of the consultation survey and focus groups, SIECCAN held an online meeting with working group members to review key findings and identify priorities for the *Canadian Guidelines for Sexual Health Promotion with Disabled Youth*. SIECCAN then reviewed relevant scientific literature, policy documents, and grey literature to develop a draft of the Guidelines that reflects up-to-date research and knowledge. This draft was reviewed by working group members and revised by SIECCAN. The final document was approved by all working group members.

Structure of the document

The *Canadian Guidelines for Sexual Health Promotion with Disabled Youth* includes four sections. Sections 1 and 2 draw attention to the importance of and key barriers to sexual health promotion with disabled youth. Section 3 describes core principles to consider when developing sexual health promotion initiatives for disabled youth, while section 4 outlines guidelines and recommendations for the effective sexual health promotion of disabled youth.

At the beginning of each section, there are some key definitions of important words that are mentioned in that section. Some subsections end with a summary point. Quotes from the focus groups with disabled youth have been integrated throughout this document to reinforce important messages with lived experience perspectives.

SECTION 1: THE IMPORTANCE OF EFFECTIVE SEXUAL HEALTH PROMOTION WITH DISABLED YOUTH

This section outlines the sexual rights of disabled youth as enshrined within the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD) and describes the importance of sexual health promotion in reducing disabled youths' vulnerability to negative outcomes and in promoting disabled youths' overall health and well-being.

Key definitions

Ableism	Ableism refers to a belief system rooted in negative beliefs (e.g., false assumptions and stereotypes about disabled people) and feelings (e.g., discomfort in interacting with disabled people) about disabled people, which can be conscious or unconscious. These negative beliefs and feelings can manifest itself through acts of discrimination, social exclusion, and limited opportunities for disabled people to fully participate in society (Ontario Human Rights Commission, 2016).
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, 2023). This includes having the freedom to choose to engage in sexual activity or not and to have children or not.
Reproductive justice	Reproductive justice refers to the right of all people to make choices about whether or not they want to have children, when and with whom they want to have children, and to have access to necessary supports to be able to take care of their children (Fletcher et al., 2023).
Self-determination	Self-determination refers to the ability to make things happen in one's own life and to pursue freely chosen goals (Wehmeyer, 2015).
Sexuality	Sexuality is a central aspect of being human and includes sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy, and reproduction (World Health Organization, 2002). Sexuality can be experienced and expressed in many ways (e.g., thoughts, fantasies, desires, beliefs, behaviours, relationships) and can be influenced by the interaction of individual, social, and environmental factors.
Sexual rights	Sexual rights refer to an individual's rights to express their sexuality and experience sexual health and well-being, while respecting other people's rights to do the same (World Health Organization, 2002). Protecting the sexual rights of all people requires preventing discrimination and ensuring that people's broader human rights are respected.
Sexual scripts	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, social expectations; Simon & Gagnon, 1986).

Sexual rights of disabled youth

The World Health Organization describes sexual rights as “the application of existing human rights to sexuality and sexual health” and which “protects all people’s rights to fulfill and express their sexuality and enjoy sexual health, with due regard for the rights of others and within a framework of protection against discrimination” (World Health Organization, 2002). Therefore, sexual rights can only be realized to the extent that other human rights are upheld.

These human rights include, but are not limited to, the right to:

- Equality and non-discrimination
- Privacy
- Be free from violence
- Self-determination and bodily autonomy
- Equitable access to information and education
- The highest attainable standard of health

The sexual rights of disabled people are further enshrined within the United Nations’ *Convention on the Rights of Persons with Disabilities* (CRPD), which was ratified by Canada in 2010 (United Nations General Assembly, 2006).

Specifically, the CRPD outlines the rights of disabled people to:

Enjoy and exercise legal capacity on an equal basis with others and to receive appropriate support to do so (Article 12)

Privacy (Article 22)

Marry and have children, as well as have access to reproductive and family planning information and supports (Article 23)

Specifically, the CRPD outlines the rights of disabled people to:

Have equal access to quality and affordable health care, including sexual and reproductive health services (Article 25)

Yet, the sexual rights of disabled people continue to be largely overlooked and unaddressed.

At the core of sexual rights is the right to bodily autonomy and self-determination (Nguyen, 2020; Sexual Rights Initiative, 2018; United Nations General Assembly, 2006). In other words, disabled youth are entitled to make decisions about and have control over their bodies and their lives, as well as pursue freely chosen goals, without violence or coercion (Moore, 2016; United Nations Population Fund, 2023; Wehmeyer, 2015). This includes making choices about romantic/sexual partners and deciding whether or not they want to engage in sexual activity, be in a relationship, have children (i.e., reproductive justice), or get married (United Nations Population Fund, 2023).

In order to make informed decisions, disabled youth must have access to relevant and necessary sexual health information and supports.

In the past, denying disabled people the right to make their own choices has led to forced and coerced sterilization of disabled people, with many examples of similar practices continuing to occur in recent years (National Women’s Law Center, 2022; The Standing Senate Committee on Human Rights, 2022). Although explicit eugenics laws and policies are condemned today, underlying ableist assumptions and discriminatory attitudes remain prevalent in Canadian society and contribute to the ongoing exclusion of disabled youth from accessing important and necessary sexual health information, services, and opportunities (Frappier 2021; Giles et al., 2023).

"I feel like they [people in society] infantilize us a lot and think that it's weird if we want a relationship or want to be sexual."

- Focus group participant: Disabled youth

Promoting the sexual rights of disabled youth requires:

Addressing stigma and misconceptions that prevent disabled youth from sexual expression and fulfillment.

Promoting equitable access to necessary and appropriate sexual health information, services, and supports.

Adopting laws and policies that prevent forced or coerced sterilization and which outline specific requirements for ensuring that disabled youth can provide free, prior, and informed consent regarding what happens to their bodies.

Sexual Rights Initiative (2018); The Standing Senate Committee on Human Rights (2022)

Summary point:

The World Health Organization recognizes sexuality and sexual health as being integral to personhood and essential to any human life. The sexual rights of disabled youth, including their right to make choices about their sexual lives and to have fulfilling romantic and sexual relationships, are further reaffirmed within the United Nations' CRPD.

However, the sexual rights of disabled youth continue to be largely overlooked and unaddressed. Ableist assumptions and discriminatory attitudes, which underpinned eugenics laws and policies in the past, continue to contribute to the ongoing exclusion of disabled youth from sexual health education and services, as well as restricted opportunities for sexual expression.

Promoting the sexual health of disabled youth requires ensuring that the sexual rights of disabled youth, including their rights to make decisions about their bodies and to pursue freely chosen goals, are respected.

Promoting overall health and well-being and improving quality of life

Sexual well-being refers to how an individual perceives a wide range of physical, mental, emotional, and social desires and experiences related to sexuality (Laumann et al., 2006; SIECCAN, 2019). Everyone defines, experiences, and expresses their sexuality differently and, therefore, will experience sexual well-being in unique ways.

Experiencing sexual well-being requires both the prevention of negative experiences (e.g., sexually transmitted infections, unintended pregnancies, sexual and gender-based violence and discrimination), as well as the fostering of positive experiences (e.g., sexual and interpersonal relationship satisfaction, self-acceptance, feelings of belonging/inclusion; SIECCAN, 2019).

Sexuality is fundamental to personhood and essential to the overall health and well-being of all people, including disabled people
(Shah, 2017).

Greater sexual health and satisfaction are associated with overall physical and psychosocial health and well-being (e.g., reduced feelings of anxiety and depression, higher self-esteem, increased sense of belonging; Carcedo et al., 2020; Hensel et al., 2016). For disabled people, greater sexual satisfaction is associated with greater life satisfaction (Moin et al., 2009).

Similar to non-disabled youth, many disabled youths have sexual desires and want to have sexual and/or romantic experiences. In a SIECCAN survey of youth (ages 16 – 24) in Canada, about two-thirds of disabled youth¹ reported having been sexually active: 65% had touched a partner's genital for pleasure; 59% have had penis-vagina sex; 42% have had

penis-anal sex, and 58% have had oral sex (SIECCAN, 2023c). However, false assumptions made about disabled people's sexual desires, as well as sexual scripts that do not account for the unique needs and experiences of disabled people, often prevent disabled people from having the sexual and/or romantic experiences they want to have (Dune, 2014a; Sakaluk et al., 2014; Sakellariou, 2006).

"They [people in society] feel we shouldn't love or be loved, they feel we should focus on surviving."

- Focus group participant: Disabled youth

While dominant sexual scripts often emphasize physical performance and achieving orgasm, the frequency of sexual activity and achieving orgasm may not always be essential for experiencing sexual satisfaction for some disabled people (McCabe & Taleporos, 2003; Thrussell et al., 2018). Alternatively, intimacy (i.e., a sense of closeness and affection, as well as reciprocal respect and friendship within a relationship) may be more important for enhancing sexual health and well-being for some disabled people (Leibowitz, 2005; Morozowski & Roughley, 2020; Osborne et al., 2023).

It is also important to recognize, as is the case with non-disabled youth, that diversity related to gender identity and sexual orientation exists among disabled youth (Giles et al., 2023). For instance, some disabled youth identify as asexual, LGBTQ+ (lesbian, gay, bisexual, queer, and other emerging identities), or transgender (SIECCAN, 2023c). Sexual activity and/or relationships may look very different across different types of physical disabilities, between disabled and non-disabled people, across gender identities and sexual orientations, and across other dimensions of differences.

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

When the different ways sexuality can be expressed and experienced are respected and embraced, it can lead to a beneficial expansion of conceptualizations of sexual health and well-being that are inclusive of the needs and rights of all people.

Summary point:

Sexual well-being refers to how an individual defines and experiences a wide range of physical, mental, emotional, and social experiences and desires related to sexuality and contributes to a better quality of life and overall health and well-being.

Similar to non-disabled youth, many disabled youths have sexual desires and want to be in romantic relationships. However, ableist assumptions about the sexuality of disabled people, and sexual scripts that are not inclusive of disabled youths' experiences, can contribute to disabled youth not seeing themselves or not being perceived by others as sexual beings.

Disabled youth are also very diverse. Sexual activity and/or relationships can look very different across dimensions of differences (e.g., types of disability, gender identity, sexual orientation). Expanding conceptualizations of sexuality to include more diverse experiences can enable disabled youth to engage in sexual/romantic experiences and relationships in ways that better meet their needs and desires, and that are positively reciprocated.

Reducing vulnerability and mitigating negative outcomes

Abuse prevention

Disabled people² 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 women³ 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 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, Lunsy et al., 2020).

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- 2 It should be noted that much of the research referred to in the section *Reducing Vulnerability and Mitigating Negative Outcomes* also includes other disabilities such as those related to hearing, vision, pain, mobility, flexibility, dexterity, learning, developmental, memory, or mental or psychological health. In this section, we explicitly mention physical disabilities when the referenced research is specific to disabled youth with physical disabilities.
- 3 In describing gender differences, the referenced studies do not differentiate between cisgender and transgender individuals.

Gender differences in experiences of abuse

There may also be gender differences in experiences of abuse and violence. Disabled men may be more likely to experience physical violence, while disabled women are more likely to experience sexual violence (Dammeyer & Chapman, 2018; DisAbled Women's Network of Canada, 2019; Malihi et al., 2021).

According to the 2014 Canadian *General Social Survey on Victimization*, nearly 90% of disabled Canadians who had been sexually assaulted were women and among disabled Canadians who had experienced IPV, disabled women were more likely than disabled men to experience the most serious forms of violence (39% vs. 16%), be physically injured (46% vs. 29%), fear for their life (38% vs. 14%), and seek out formal support services (71% vs. 29%; Cotter, 2018).

Researchers in Australia reported that among disabled young people (14-21 years), transgender and nonbinary people were more likely to experience verbal abuse, harassment, and sexual assault compared to cisgender people (Hill et al., 2022). Further, among disabled adults, a greater proportion of nonbinary people indicated having experienced violence from an intimate partner (75%) and to have experienced violence from a family member (85%) compared to both transgender and cisgender women and men. Additional research is needed to better understand abuse and violence experienced by disabled people who are gender diverse.

Types of abuse and violence experienced by disabled people

Examples of different forms of abuse that disabled people experience:
Psychological/verbal (e.g., being insulted or laughed at; being threatened; being controlled and forced to engage in behaviours they do not want to engage in)
Financial (e.g., having their money stolen by a care provider; having their money poorly managed by other people; being told what to do with their money; having items stolen from their homes)
Denial of services and supports (e.g., being refused necessary personal care support; accessibility aids being withheld)
Physical (e.g., violence resulting in severe injuries)
Sexual (e.g., inappropriate touching by a care provider; being forced to engage in unwanted sexual behaviours)
Destruction of property (e.g., damages to accessibility aids; destruction of home and car)
Rajan (2011)

Given that many disabled people require support with daily activities, care-related forms of abuse (i.e., abuse enacted by a family member, caregiver, or intimate partner who provides personal care support to a disabled person) are particularly concerning (Dockerty et al., 2015; Findley et al., 2016; Hassouneh-Phillips & Curry, 2002).

According to the 2014 Canadian *General Social Survey on Victimization*, almost half (44%) of disabled women who were victimized reported that the perpetrator was someone they knew and almost a third of violent incidents occurred within their home (Cotter, 2018).

Disabled people who receive support with personal care needs (e.g., bathing, going to the bathroom) from a young age may learn to comply with all forms of personal touch (Public Health Agency of Canada, 2013).

Without explicit opportunities to learn and practice self-determination, disabled people may experience a lack of bodily autonomy and be unable to recognize inappropriate touching (Bahner 2012; Public Health Agency of Canada, 2013).

Further, when disabled people are abused by someone they rely on to meet their personal care needs, disabled people may feel they have to “accept” violent and harmful behaviours enacted towards them as they may not have other means of having their personal care needs met (Dockerty et al., 2015; Plummer & Findley, 2012; Rajan, 2011).

Forms of abuse that directly target disabled people (e.g., relating to accessibility aids and care provision) need to be recognized so that appropriate measures can be taken to prevent and respond to abuse (Findley et al., 2016; McFarlane et al., 2001; Robinson-Whelen et al., 2010). Further, service agencies that support individuals who experience abuse need to ensure that their services are inclusive and accessible to disabled youth (Cotter, 2018).

Factors that contribute to experiences of abuse and violence for disabled people

In thinking about the safety of disabled youth, it is important to consider the ways in which society makes disabled youth more vulnerable to abuse and violence - as opposed to viewing disabled people as being inherently vulnerable (Hollomotz, 2011).

Systemic factors that contribute to disabled people’s increased risk of abuse and violence:
Stigma and ableism
Low socioeconomic status
Limited access to social and health resources
Social isolation
Meseguer-Santamaría et al. (2021)

The social devaluation and dehumanization of disabled people within society contributes to making disabled people more likely to be targets of abuse and violence (SIECCAN, 2023d).

“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

Internalized stigma and past experiences of abuse and discrimination can contribute to poor self-esteem among disabled people, which can further increase their vulnerability to future experiences of abuse (Hassouneh-Phillips & Curry, 2002; Meseguer-Santamaría et al., 2021; Shah, 2017).

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

- Focus group participant: Disabled youth

Further, decisions are often 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 encourages compliance, including complying with decisions that are made for disabled youth by those who may not have their best intentions in mind.

Consequently, disabled youth may not develop the necessary skills to assess their own needs and the confidence to make their own choices, which, in turn, makes disabled youth more vulnerable to being abused and taken advantage of (Araten-Berman et al., 2017; Hollomotz, 2011).

Finally, limited access to sexual health education that is accessible to disabled youth and inclusive of their needs also contributes to making disabled youth more vulnerable by preventing disabled youth from acquiring the knowledge they need to make informed decisions about their sexual health and well-being (Giles et al., 2023; Hollomotz, 2011; Taylor & Abernathy, 2022).

Sexually transmitted infection (STI) and unintended pregnancy prevention

Sexually transmitted infections (STIs) are infections that can be acquired through sexual contact (Public Health Agency of Canada, 2020). Unintended pregnancies refer to pregnancies that are either unwanted or mistimed (Institute of Medicine (US) and Committee on Unintended Pregnancy, 1995). Sexual health promotion can play an important role in equipping individuals to make informed decisions about their sexual health, including choices around STI prevention and the use of contraception (SIECCAN, 2019).

However, disabled people often do not have access to necessary and relevant sexual health information and services. As a result, disabled people may be at greater risk of having an STI or an unintended pregnancy (Brennand & Santinele Martino, 2022; Parekh et al., 2023; Brown et al., 2020; 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..."

- Focus group participant: Disabled 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 is highly effective in preventing most cases of cervical cancer, particularly when given during pre-adolescent years (Canadian Partnership Against Cancer, 2020). Currently, publicly funded, school-based HPV immunization programs are offered in all Canadian provinces and territories. However, according to a SIECCAN survey of youth (ages 16–24) in Canada, 14% of disabled⁴ youth assigned female at birth indicated that they did not receive the HPV vaccine and another 24% indicated that they did not know if they had received the HPV vaccine (SIECCAN, 2023c). Compared to non-disabled youth assigned female at birth, a significantly higher percentage of disabled youth assigned female at birth indicated that they did not know if they received the HPV vaccine (24% vs. 15%). These findings indicate that many disabled youths are not fully informed about the HPV vaccine and/or how to access the vaccine.

4 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.

Papanicolaou tests (Pap tests), which can enable the early detection of precancerous lesions, are generally recommended every 2-3 years for individuals with a cervix beginning at the age of 21 or 25 until the age of 65 to 70 (Canadian Partnership Against Cancer, 2021). Specific cervical cancer screening guidelines vary between provinces and territories. However, disabled women with physical disabilities are less likely to receive cervical cancer screenings compared to non-disabled women (Baruch et al., 2022; Lofters et al., 2014; McRee et al., 2010) and are more likely to receive a cervical cancer diagnosis (Iezzoni et al., 2021).

Disabled people may have limited awareness and knowledge about the importance of and how to access cervical cancer screenings (Chan et al., 2022). In McRee and colleagues' (2010) study, disabled women with physical disabilities were just as likely to access reproductive health care services as non-disabled women, but were less likely to receive a Pap test. Health service providers may not be recommending Pap tests to disabled women to the same degree as non-disabled women. False assumptions about the sexuality of disabled people may contribute to the perception that cervical cancer screenings are not necessary for disabled people, resulting in cervical cancer screening not being equitably offered to disabled people (Cooper & Yoshida, 2007; Ramjan, 2016). The physical inaccessibility of health care facilities and a lack of necessary adaptive equipment are also important barriers to accessing cervical cancer screenings for disabled youth (Iezzoni et al., 2021; Kilic et al., 2019; Rivera Drew & Short, 2010; Story et al., 2009).

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

- Focus group participant: Disabled youth

Reproductive justice: Pregnancy, adverse perinatal outcomes, and access to abortion services

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). Further, pregnancy rates among disabled women with physical and sensory disabilities were only slightly lower than that of nondisabled women.

Reproductive justice refers to the right of all people to make choices about whether or not they want to have children, when and with whom they want to have children, and to have access to necessary supports to be able to take care of their children (Fletcher et al., 2023). However, the reproductive rights of disabled people have historically been restricted and misconceptions about the ability of disabled people to become parents continue to create barriers for disabled people to access the supports they need to make and safely carry out their reproductive choices (National Women's Law Center, 2022; Nguyen, 2020; The Standing Senate Committee on Human Rights, 2022).

Disabled people who become pregnant are at an increased risk for perinatal (i.e., during pregnancy and/or childbirth) complications such as gestational diabetes mellitus, gestational hypertension, and caesarean delivery (Tarasoff, Ravindran et al., 2020). Newborns of disabled people are also at an increased risk of neonatal complications (e.g., preterm birth, neonatal morbidity, and neonatal intensive care unit [NICU] admission; Brown et al., 2022).

Health inequities due to barriers to education, employment, and accessible health care services contribute to poorer preconception health among disabled people, which can predispose disabled people to future adverse perinatal outcomes (Shah et al., 2024; Tarasoff, Ravindran et al., 2020). Further, inadequate and inaccessible perinatal and postpartum care can leave disabled people without appropriate and necessary supports (Tarasoff, Saeed et al., 2023).

Another important component of reproductive justice is the voluntary choice to terminate a pregnancy legally and safely (Action Canada for Sexual Health & Rights, 2017; World Health Organizations, 2023). However, ableist assumptions about the capacity of disabled people to have children can contribute to disabled people who become pregnant to be unwillingly pushed towards, or even coerced into, getting an abortion due the belief that they are not fit to become parents (Hassan et al., 2023; Nguyen 2020). 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).

Summary point:

Disabled people are more likely than non-disabled people to experience abuse and violence. Care-related forms of abuse are particularly concerning among disabled youth, as individuals who are supposed to support disabled people are often the perpetrators of abuse. Prevailing stigma and the social devaluation of disabled people not only increase disabled people's vulnerability to abuse, but also decrease their access to safe and reliable sexuality-related supports and services.

Disabled people are more likely than non-disabled people to have negative sexual health outcomes, including higher rates of STIs, unintended pregnancies, cervical cancer, and adverse perinatal outcomes. Barriers to accessing sexual health education and services for disabled people can limit disabled youths' knowledge of and access to appropriate and safe sexual and reproductive health services.

Reducing vulnerability and mitigating negative outcomes for disabled youth requires addressing stigma, providing disabled people with sexual health education tailored to their needs and desires, ensuring equitable access to sexual health services, addressing knowledge and training gaps among service providers, and making communities and health care facilities more physically accessible.

SECTION 2: BARRIERS TO SEXUAL HEALTH PROMOTION FOR DISABLED YOUTH

This section draws on the Socio-Ecological Model (SEM) to outline barriers to sexual health promotion for disabled youth at the individual, interpersonal, community, and societal levels.

Key definitions

Medical model of disability	The medical model of disability perceives the disadvantages disabled people experience to be primarily due to their impairments (i.e., conditions affecting their body structure and/or function; Goering, 2015).
Social model of disability	The social model of disability perceives the disadvantages that disabled people experience to be primarily due to barriers in the individual's social and physical environments (Oliver, 1995).
Sexual ableism	Sexual ableism refers to society's lowered sexual expectations for disabled people, which can manifest itself through negative attitudes and false assumptions about the sexuality of disabled people, as well as exclusionary policies and inaccessible spaces that restrict the sexual rights of disabled people (Mintz, 2022).
Sexual esteem	Sexual esteem refers to one's perception of themselves as a sexual being, including the degree to which an individual feels sexually appealing and sexually competent, which can impact one's sense of self-worth (Hassouneh-Phillips & McNeff, 2005).

Applying the Socio-Ecological Model to sexual health promotion with disabled youth

According to the Socio-Ecological Model (SEM), an individual's experience is a product of a complex interplay between individual, relationship, community, and societal factors (Bronfenbrenner & Morris, 1998). The use of this model allows for a more nuanced understanding of the interrelated factors at different levels of society that contribute to fostering or hindering sexual health and well-being for disabled youth and highlights the importance of implementing solutions across different levels of society to improve sexual health promotion for disabled youth.

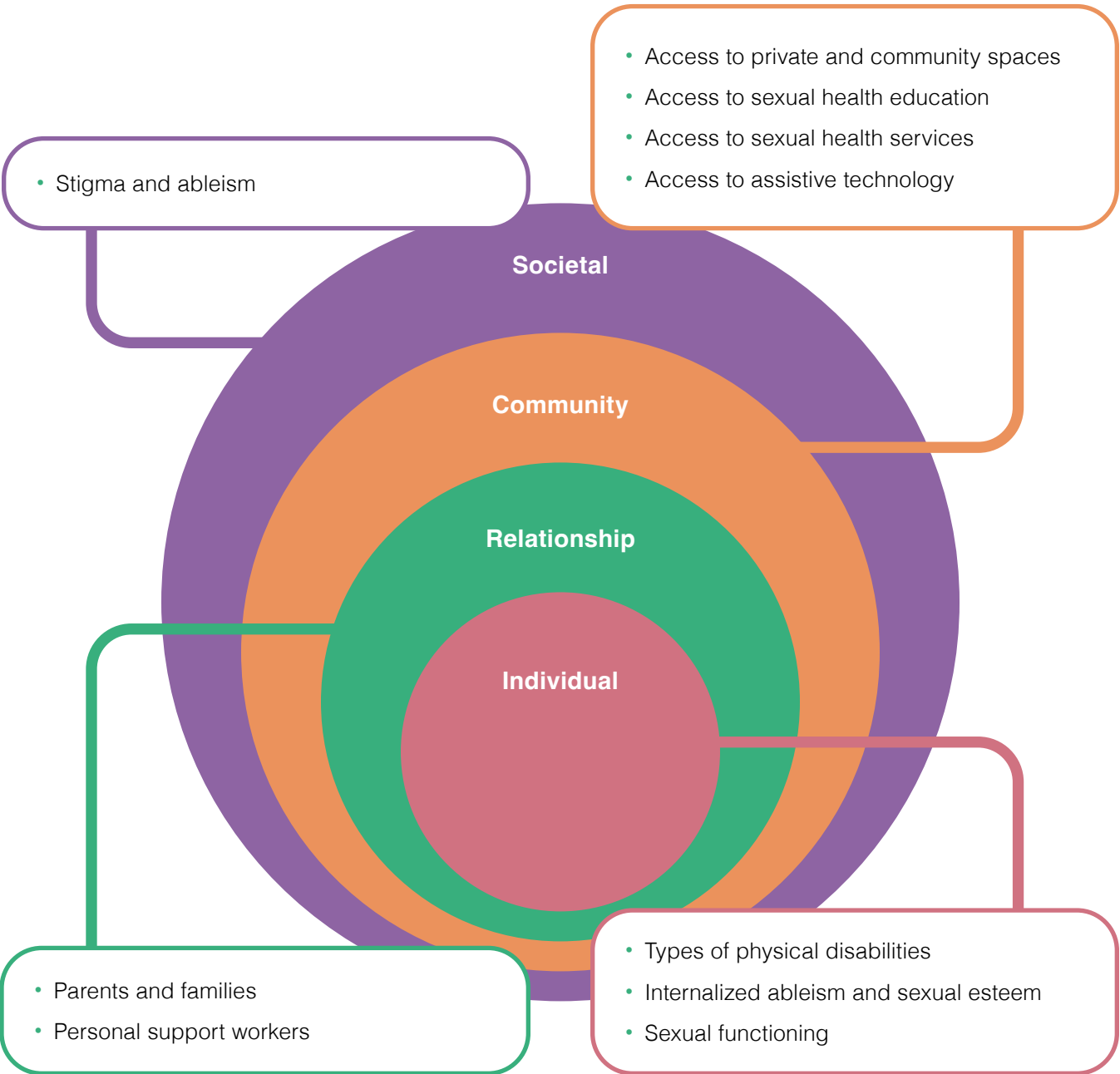


Figure 2: The Socio-Ecological Model of factors that impact sexual health promotion for disabled youth

Societal factors

Stigma and ableism

Ableism refers to a belief system rooted in negative beliefs (e.g., false assumptions and stereotypes about disabled people) and feelings (e.g., discomfort in interacting with disabled people) about disabled people, which can be conscious or unconscious (Ontario Human Rights Commission, 2016). Ableism can manifest itself through acts of discrimination, social exclusion, and limited opportunities for disabled people to fully participate in society.

To better understand how ableist assumptions and stereotypes have come about, it is helpful to consider the ways in which disability has been conceptualized. The medical model of disability has traditionally been the dominant lens through which disability has been understood. While a medical model of disability has contributed to important advancements in medical research that have benefited disabled people (e.g., increased life expectancy, reduced pain, improved functioning), this perspective largely views disabled bodies/minds as deficient and in need of fixing (Crow, 2010; Goering, 2015). From this perspective, the disadvantages that disabled people experience (e.g., activity limitation, participation restriction) can only be rectified through medical treatments and cures (e.g., medical, rehabilitation, therapeutic interventions; Cameron, 2007; Crow, 2010).

However, the medical model overlooks the ways in which society disadvantages and creates barriers to the full participation of disabled people in their communities (e.g., negative social attitudes, exclusionary policies, inaccessible infrastructure; Cameron, 2007; Goering, 2015; Petasis, 2019). Further, viewing disabled bodies/minds as deficient contributes to the stigmatization and devaluation of disabled bodies/minds and ways of being.

In the context of sexual health, the medical model contributes to false beliefs (e.g., disabled people not having sexual desires; disabled people not being capable of having romantic relationships) and negative attitudes (e.g., disabled people not being

viewed as a potential romantic/sexual partner) about the sexuality of disabled people (Shah, 2017).

“...and it’ll get to the point where even my able-bodied friends will be like, wait but how do you do this [have sex], I didn’t know you could do this.”

- Focus group participant: Disabled youth

Sexual ableism refers to society’s lowered sexual expectations for disabled people, which can manifest itself through negative attitudes and false assumptions about the sexuality of disabled people, as well as exclusionary policies and inaccessible spaces that restrict the sexual rights of disabled people (Mintz, 2022).

Sexual ableism contributes to the development of negative sexual esteem among disabled people and restricts opportunities for disabled people to have safe and meaningful relationships and sexual experiences (Dune, 2014a).

“...many folks think disabled people do not have feelings/thoughts of being loved.”

- Focus group participant: Disabled youth

How opportunities for sexual expression and sexual health are restricted for disabled people:
Limited access to sexual health information (e.g., service providers and parents not proactively talking to disabled people about sexual health; school-based sexual health education not being offered to disabled people)
Limited access to sexual health services (e.g., health service providers not offering STI tests and Pap tests to disabled people because they are believed to be unnecessary; limited access to adaptive equipment to administer STI/Pap tests safely)
Restricted opportunities for sexual expression (e.g., disabled people not being pursued romantically/sexually; physical barriers to going on dates; restricted access to private spaces)
Overemphasis on the prevention of negative outcomes and a lack of emphasis on the promotion of positive aspects of sexuality (e.g., sexual pleasure not being encouraged for disabled people)
Bahner (2012); Benoit et al. (2022); Chan et al. (2022); East & Orchard (2014); Tepper (2000)

The social model of disability emerged as a response to the harmful impact and limitations of the medical model and shifts the focus away from problematizing disabled bodies towards addressing the social and environmental barriers that create disadvantages for disabled people (Oliver, 1995). From this perspective, the focus of sexual health promotion becomes about addressing the physical and social barriers that contribute to sexual health inequities for disabled people and promoting more equitable access to sexual health education, services, and opportunities for sexual expression

(Dune, 2014b; Sakellariou, 2006; Shah, 2017). Further, the social model of disability allows for the broadening of conceptualizations of sexuality to be more inclusive of disabled bodies and experiences so that disabled youth can fully embrace the diverse ways they may experience and express their sexuality (Bahner, 2012; Dune, 2014a; Esmail, Darry, et al., 2010; Osborne et al., 2023).

Community factors

Access to private and community spaces

Dating and having romantic or sexual experiences require having access to private space (e.g., for intimacy) and community spaces (e.g., for socializing and going on dates). However, disabled people often experience barriers to accessing both private and community spaces (Santinele Martino, 2020; Santinele Martino & Kinitz, 2022).

Access to private spaces can be limited when disabled youth live with parents or in a group home or receive care support from a personal support worker (Appel, 2010; Bahner, 2012; Dewson et al., 2018; Wiegerink et al., 2011).

Disabled people in Canada also experience many barriers to affordable, quality, and adequate housing (Alzheimer Society of Canada et al., 2017; Government of Canada, 2022). Disabled people are often subjected to housing discrimination, live in poverty, or lack access to suitable supported housing options, which can, in turn, limit their autonomy and privacy.

Access to community spaces can be restricted for disabled youth due to physical and financial barriers, which can limit their opportunities to meet potential sexual and romantic partners or to engage in dating/relationship activities (Dune, 2014a; Shakespeare, 2000). For instance, common locations where people socialize or meet potential partners (e.g., restaurants, bars, nightclubs, workplace) may not always be physically accessible to disabled people (Dune,

2014a). In addition, access to 2SLGBTQINA+⁵ spaces such as Pride and other similar events may be less accessible to disabled people.

Disabled people in Canada are also less likely to be employed and more likely to live in poverty than non-disabled people (Morris et al., 2018). Lack of financial security can limit disabled youths' ability to go on dates and engage in various activities with a romantic/intimate partner (Bahner, 2012; Sakellariou, 2006).

Taking a Universal Design approach is imperative to creating more inclusive community spaces. Universal Design refers to the design of environments (e.g., spaces, products, or services) so that “it can be accessed, understood, and used to the greatest extent possible by all people” (National Disability Authority, 2020). This approach requires considering the needs of disabled people in design processes so that spaces, products, and services can be used by disabled people who wish use to them.

Finally, addressing systemic factors (e.g., physical inaccessibility of public spaces, housing, transportation, financial security) that contribute to the social exclusion of disabled youth is critical to fostering more opportunities for disabled youth to meet potential partners and to engage in dating activities with partners.

Access to sexual health education

Comprehensive sexual health education has an important role to play in enhancing sexual health and well-being by equipping youth with the necessary knowledge and skills to make informed decisions about their sexual health and relationships (SIECCAN, 2019; 2020a). However, sexual health

education for disabled youth in both formal (e.g., schools) and informal (e.g., at home) educational settings is often inadequate in meeting the needs of disabled youth (East & Orchard, 2014; Giles et al., 2023; SIECCAN, 2023c).

“But a lot of the time we aren’t given access to that information. No matter who we go to, who we ask, we don’t have a supportive family member to ask. Or [...] doctors don’t listen. It’s not as if we’re going to actually need that advice. So, I think it’s a major problem in that system that we actually aren’t getting that help. And it creates a problem in areas of consent, in areas of understanding our sexuality...”

- Focus group participant: Disabled youth

Educators often feel uncomfortable or ill-equipped to discuss issues of sexuality with disabled youth and may not be supported by the health/social/educational systems, their workplace, or parents to provide sexual health education to disabled youth (Bonder et al., 2021; Esmail, Krupa, et al., 2010; SIECCAN, 2023a; Taylor & Abernathy, 2022).

Many disabled youths have reported being excluded from school-based sexual health education altogether (Berman et al., 1999; SIECCAN, 2023b). Further, sexual health education for disabled youth is often provided reactively (i.e., in response to a particular incident) as opposed to proactively (i.e., ensuring that disabled youth are well-informed about their sexual health prior to making sexuality-related decisions; East & Orchard, 2014; Giles et al., 2023).

5 2SLGBTQINA+ is an acronym for Two-Spirit, lesbian, gay, bisexual, transgender, queer, intersex, nonbinary, and asexual people, and other emerging identities.

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

- Focus group participant: Disabled youth

Reluctance to provide disabled youth with sexual health education can stem from a desire to protect disabled youth, who are often perceived to be more vulnerable to negative experiences (Giles et al., 2023). As a result, disabled youth with more complex supports needs or those who are non-speaking may be more likely to be left out (East & Orchard, 2014).

Limiting disabled youths’ access to necessary and relevant sexual health information limits their capacity to make informed decisions about their sexual health, which, in turn, contributes to making disabled youth more vulnerable to exploitation and being taken advantage of (Giles et al., 2023; Hollomotz, 2011; Taylor & Abernathy, 2022).

When disabled youth do receive sexual health education, the information tends to focus on preventing abuse or pregnancy, and lacks discussion on intimacy, healthy relationships, sexual exploration, pleasure, and gender and sexual orientation diversity (Berman et al., 1999; East & Orchard, 2014; Taylor & Abernathy, 2022).

Disability-specific information, in particular, is inadequately included within existing sexual health education programs (Giles et al., 2023; Heller et al., 2016; Taylor & Abernathy, 2022).

“I feel sexual education in schools doesn’t talk about emotion and doesn’t include disability.”

- Focus group participant: Disabled youth

In a SIECCAN survey of youth (ages 16 – 24) in Canada, only 48% of disabled youth⁶ indicated that the sexual health education they received met their needs and only 45% indicated that it was inclusive of their disability (SIECCAN, 2023c). When asked to rate how well the topic of sexuality and disability was covered within sexual health education, only 34% indicated that it was well covered, while 44% indicated that it was not covered at all.

“I hate it when some answers isn’t really what I’m looking for. Disability isn’t in the inclusion. I just try to tailor it to my disability.”

- Focus group participant: Disabled youth

Sexual health education needs to be disability-inclusive and should promote autonomy and self-determination, respect for oneself and for others, positive identity formation, pleasure, and safety (Bonder et al., 2021; Dune 2014a; Taylor & Abernathy, 2022).

Ensuring disabled youth have access to sexual health education enables disabled youth to build self-confidence, feel empowered, develop positive identities, make more informed decisions, protect themselves, and fulfill their needs and desires in ways that are safe (Bonder et al., 2021; Esmail, Krupa, et al., 2010; Murphy & Elias, 2006; Taylor & Abernathy, 2022).

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

Access to sexual health services

Disabled people encounter many barriers to accessing sexual health services that meet their needs. In a survey of 341 disabled people, 67% indicated that they wanted professional support with sexuality-related concerns, but only 34% of these individuals actually connected with a health service provider about their concerns (Kedde et al., 2012). Of the disabled people who connected with a health service provider, only 32% described their experiences as positive.

Gender

Disabled men with acquired disabilities are more likely than disabled women with acquired disabilities to receive sexual health counselling (Myburgh et al., 2010; Pascual et al., 2021). Disabled women with spinal cord injuries have expressed that the sexual health information they received during their rehabilitation process largely focused on issues such as erectile difficulties that were not relevant to their needs and experiences (Leibowitz, 2005; Thrussell et al., 2018). There is a need for more research to better understand the sexual health needs of disabled women, as well as gender diverse people.

Training

Professional programs for health service providers do not consistently include training regarding sexuality or disability, and very rarely about both sexuality and disability (SIECCAN, 2023a; Solursh et al., 2003; Tarasoff, Lunskey et al., 2023; Valvano et al., 2014). Consequently, health service providers may hold negative attitudes and ableist assumptions about the sexuality of disabled people and feel ill-equipped to support the sexual health of disabled people (Cooper & Yoshida, 2007; Ramjan, 2016; Malouf et al., 2017; SIECCAN 2023b). This contributes to limited access to quality sexual health services for disabled people (Sweeney, 2019; Shah et al., 2024). Health service providers require training to address

internalized ableism and to better understand how they can support the sexual health of disabled youth (Giles et al., 2023).

“...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

Support

Health service providers need to be better supported to effectively provide sexual health services to disabled people. Currently, workplace barriers such as not having sufficient time during appointments to address sexual health with disabled people, being worried about potential negative reactions from parents, and not having colleagues' support can prevent health service providers from effectively delivering sexual health services to disabled people (Giles et al., 2023; Murphy & Elias, 2006; Neufeld et al., 2002; SIECCAN, 2023a).

Facilities

The physical inaccessibility of health service facilities is a significant barrier to accessing sexual health services for disabled people (Chan et al., 2022; Iezzoni et al., 2015; Lagu et al., 2013). According to a study in the United States, many physicians are not able to accommodate disabled people in their practice because of inaccessible buildings and/or examination rooms (Lagu et al., 2013). Gynecologists' offices were identified as being the least accessible to disabled people.

Transportation

Obtaining and arranging suitable transportation to get to health care facilities can be challenging and cumbersome (e.g., limited availability of suitable transportation options, transportation not arriving on time, delays at the health care facility contributing to disabled people missing their transportation home), which also limits disabled people's access to sexual health services (Angus et al., 2012; Chan et al., 2022; Ramjan et al., 2016).

Improving the physical accessibility of health care facilities and strengthening health service providers' knowledge and skills to effectively support the sexual health of disabled youth will not only improve access to necessary information and supports but will also encourage disabled youth to proactively seek out sexual health advice and services when needed.

Access to assistive technology

Assistive technology refers to products, equipment, and systems that can enhance disabled people's capacity to learn, work, and engage in other daily activities (Assistive Technology Industry Association, 2023).

Examples of assistive technology for sexual health enhancement:

Mobility aids can enable disabled youth to access community spaces to go on dates.

Augmentative and alternative communication (AAC) systems can be used to enhance communication in relationships.

Mechanical lifts and height-adjustable examination tables can assist disabled youth in getting onto examination tables at a health clinic.

Examples of assistive technology for sexual health enhancement:

Sex toys and other equipment (e.g., slings, ramps, pillows) can enhance individual and partnered sexual activity, particularly for individuals experiencing challenges with sexual functioning, mobility, and chronic pain.

Gregory (2021); Morales et al. (2018); O'Keefe et al. (2007); Pritchard et al. (2014)

Barriers to using assistive technology include:

Physical environments that are not designed to meet the needs of those who use assistive technology

Limited societal awareness and understanding about the importance of assistive technology and how to support people who use assistive technology

Limited options of assistive technology for enhancing sexual health

Lack of formal avenues to receive information and support to use assistive technology for enhancing sexual health

High costs of assistive technology

Assistive technology for sexual health enhancement not typically covered within government disability funding programs

Lagu et al. (2013); Moorcroft et al. (2019); Ministry of Children, Community and Social Services (2023); Morales et al. (2020)

Service providers can play an important role in providing disabled people with information about assistive technology for enhancing sexual health (Bonder et al., 2021). Research and innovation are also needed to expand the availability of assistive technology to meet the diverse needs of disabled

youth. Finally, consideration needs to be given to the financial accessibility of assistive technology (Gregory, 2021).

In addition to improving access to assistive technology, taking a Universal Design approach to designing sexual health services, sexual health enhancement products, and community spaces that account for the needs of disabled youth is also necessary to minimize the need for assistive technology, which may not always be available or accessible.

Relationship factors

Parents and families

Parents and families have an important role to play in facilitating disabled youths' access to sexual health information and education. However, parents/families often feel uncomfortable or ill-equipped to engage in discussions about sexuality with disabled youth (East & Orchard, 2014; Esmail, Krupa, et al., 2010; Giles et al., 2023). In a SIECCAN survey of parents in Canada, only 26% of those with a disabled child indicated that they encouraged their child to ask questions about sexual health (SIECCAN, 2020b). However, parents were supportive of their child receiving sexual health education, with 90% indicating that they wanted sexual health education to be taught in schools.

Widespread societal stigma and misconceptions about the sexuality of disabled people can become internalized by parents/families, which may impact the degree to which parents/families are comfortable and willing to facilitate sexual health education for disabled youth, and which sexual health topics get addressed (or not) with disabled youth (e.g., focus on preventing negative outcomes and overlooking the positive aspects of sexuality; Esmail, Krupa, et al., 2010; Giles et al., 2023). Being concerned with other aspects of disabled youths' health and well-being may also lead parents/families to overlook their child's sexual health-related needs (East & Orchard, 2014). Further, limited resources and support available to parents/families may

leave parents/families feeling unsure about how to effectively provide sexual health information to disabled youth (Esmail, Krupa, et al., 2010; Taylor & Abernathy, 2022).

Parents also have an important role to play in promoting the self-determination of disabled youth, by providing disabled youth with opportunities and support to make personal choices in their everyday lives (Taub & Werner, 2023). Higher capacities for self-determination among disabled youth tend to be associated with greater opportunities for self-determination and autonomous decision-making at home (Taub & Werner, 2023).

Self-determination is essential to the sexual health and well-being of disabled youth as it enables disabled youth to make choices about their bodies, provide informed consent, as well as set and maintain boundaries in romantic and sexual relationships (Dune, 2014b). Being able to act in a self-determined manner can also improve the self-esteem of disabled youth (Campbell-Whatley, 2008).

Parents and families require more resources and support to address sexual health with disabled youth in ways that are disability-affirming and to cultivate the self-determination of disabled youth. Greater collaboration between service providers, parents/families, and disabled youth is imperative so that all stakeholders are working towards a shared goal (Giles et al., 2023).

Personal support workers

Personal support workers refer to individuals who support disabled people with daily activities (e.g., getting around, personal care, running errands, attending appointments, managing household activities) in their personal homes, hospitals, or long-term care facilities (triOS College, 2021). Other terms may be used to refer to personal support workers such as personal care attendant, caregiver, aide, and attendant.

While personal support workers are tasked with supporting disabled people with their physical and psychosocial needs (triOS College, 2021), it is not always clear what their role is in supporting disabled people with their sexual needs (Bahner, 2016; Hall, 2018). Some disabled people may require support to be able to engage in sexual activity (e.g., getting undressed, body positioning, meeting a romantic/sexual partner, accessing private spaces; Bahner, 2016; Gutiérrez-Bermejo & Jenaro, 2022). However, personal support workers may be reluctant or afraid to support disabled youth with these needs without adequate education and training, as well as clear guidance regarding how they should provide support and what legal boundaries may exist (Santinele Martino & Perrault-Laird, 2019).

Existing policies/guidelines regarding the role of personal support workers in supporting the sexual health of disabled people tend to be either ambiguous or restrictive (e.g., emphasize supervision, prevent disabled people from engaging in sexual behaviours; Grigorovich & Kontos, 2020; Saxe & Flanagan, 2016; Santinele Martino & Perrault-Laird, 2019). A lack of clear guidance often leaves the sexuality of disabled youth unaddressed.

According to the World Health Organization, sexuality is a central aspect of personhood and therefore, sexuality-related needs are “basic needs” that disabled youth should be supported with (World Health Organization, 2002). Clear policies and guidelines, as well as adequate training, are needed so that personal support workers know their role in supporting the sexual rights and dignity of disabled youth.

Individual factors

Types of physical disabilities

There are many different types of physical disabilities, each of which can have unique implications for sexual health and well-being.

Common categorizations of physical disabilities include:	
Congenital and acquired disabilities	Congenital disabilities (e.g., muscular dystrophy, spina bifida) refer to disabilities that an individual is born with, while acquired disabilities (e.g., amputation, spinal cord injury) refer to disabilities that are developed later in life (Carehome.co.uk, 2023).
Visible⁷ and invisible disabilities	The terms <i>visible/apparent/noticeable</i> (e.g., cerebral palsy, spinal cord injury) and <i>invisible/non-apparent/hidden</i> (e.g., fibromyalgia, multiple sclerosis) have often been used to distinguish between disabilities that are immediately obvious to others and those that are not (Dakessian, 2022; Esmail, Darry, et al., 2010; Porter et al., 2017).
Episodic disabilities	Episodic disabilities (e.g., arthritis, multiple sclerosis) refer to disabilities that are lifelong, but have unpredictable episodes of impairment (Morris et al., 2019). These episodes can vary in intensity and duration and are often followed by periods of no impairment.

7 We have chosen to use the terms *visible disabilities* and *invisible disabilities*, but we acknowledge that there is no consensus regarding the most appropriate terminology to use.

These distinctions are made here to highlight a few ways in which the sexual health and well-being experiences can differ across different types of physical disabilities.

For instance, sexual ableism can manifest itself in different ways for those with visible and invisible disabilities. Disabled people with invisible disabilities may avoid some of the overt forms of discrimination that disabled people with visible disabilities regularly experience (Dakessian, 2022). In the context of dating, disabled people with visible disabilities may experience immediate rejection from potential partners who are uncomfortable with disabilities and/or lack understanding (Turner, 2022), or may be fetishized for their disability (SIECCAN, 2023b). Disabled people with invisible disabilities may not experience the same forms of immediate rejection based on their disability but face tough choices about disclosing their disability in fear of eventual rejection (Heller et al., 2016; O'Dea, 2019).

For individuals with invisible and/or episodic disabilities, the legitimacy of their disability is often called into question (Dakessian, 2022; Lightman et al., 2009). Individuals with invisible and/or episodic disabilities often find themselves having to “prove” that they are disabled and require accommodations. In the context of dating, this may make it more challenging for those with invisible and/or episodic disabilities to have their needs validated and respected, which can lead to unsafe or uncomfortable experiences (O'Dea, 2019).

The process of developing positive sexual esteem may be experienced differently for those with chronic disabilities compared to those with acquired disabilities. Disabled people may develop more positive feelings about their sexuality over time, suggesting that there may be a period of adjustment where individuals explore new sexual scripts and learn to embrace their sexuality (McCabe & Taleporos, 2003; Thrussell et al., 2018).

It is important to consider these differences when promoting sexual health with diverse disabled youth.

Internalized ableism and sexual esteem

Sexual esteem refers to one's perception of themselves as a sexual being, including the degree to which an individual feels sexually appealing and sexually competent, which can impact one's sense of self-worth and dating behaviours (e.g., whether a person initiates romantic/sexual relationships; Hassouneh-Phillips & McNeff, 2005; Wiegerink, 2010). Unfortunately, disabled people often believe that they are less sexually desirable than non-disabled people (Taleporos, 2001; Taleporos & McCabe, 2001).

“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

Negative sexual esteem is often due to prevailing societal stigma about the sexuality of disabled people (e.g., negative discourse around the sexuality of disabled people, experiences of discrimination), which become internalized, leading many disabled people to believe that they are not able to have or are not worthy of positive sexual experiences (Connell et al., 2014; Dune, 2014b; Tepper et al., 2001).

“I actually opened up to a person once and she thought I was just trying to joke around.”

- Focus group participant: Disabled youth

Negative sexual esteem can make disabled people more reluctant to set boundaries or to assert their needs in relationships to avoid upsetting their partner (Dune, 2014b). Not being able to express one's needs and boundaries can lead to negative romantic/sexual experiences and places disabled people at greater risk of being manipulated or taken advantage of (Dune, 2014b; Hassouneh-Phillips & McNeff, 2005).

Ensuring that disabled people have access to positive and empowering disability representation from a young age can help disabled youth internalize positive views about their own sexual potential. Access to peer support can also enable disabled youth to develop positive self-esteem (Thrussell et al., 2018). Finally, addressing ableism, which contributes to the devaluation and desexualization of disabled people, is imperative to enhancing the sexual esteem of disabled youth.

Sexual functioning

Sexual functioning refers to a person's ability to engage in sexual behaviours and to experience sexual pleasure and satisfaction in individual and/or partnered sexual behaviours (Fielder, 2013). Disabled people may experience various challenges with sexual functioning such as fatigue, pain, numbness, weakness, spasticity, decreased genital sensation and lubrication, reduced libido and arousal, movement limitations, stiffness of joints and muscles, and challenges achieving orgasm (Kedde et al., 2010; Morozowski & Roughley, 2020; Thrussell et al., 2018; Wiegerink et al., 2011). The use of certain medications can also affect sexual functioning. Health service providers should consider and inform disabled people of the sexual health implications of these medications prior to prescribing them (Hough et al., 2020; Thrussell et al., 2018).

Urinary and fecal incontinence during sexual activity is often a major concern for disabled people, which can be experienced as embarrassing or frustrating (Heller et al., 2016; Streur et al., 2021; Thrussell et al., 2018). Many disabled people adopt strategies for reducing incontinence. However, even when incontinence is managed, some disabled people may feel that having to self-catheterize or plan for sexual activity may take away from the excitement or spontaneity of sexual activity (Thrussell et al., 2018). This underscores the importance of rethinking and challenging dominant sexual scripts, which are often based on non-disabled norms and experiences.

Disabled youth have indicated wanting more information on sexual functioning related to their disability (Heller et al., 2016; Osborne et al., 2023). Many disabled people wish to discuss their sexuality-related concerns or questions with a health service provider, but often do not feel comfortable initiating these discussions, fearing that health service providers may hold negative attitudes regarding the sexuality of disabled people (Kedde et al., 2012; Ricciardi et al., 2007).

Ensuring that comprehensive sexual health education is inclusive of the needs of disabled people can enable disabled youth to acquire more knowledge about how their disability can impact sexual functioning and develop strategies for adapting sexual activity to meet their needs. Improving health service providers' ability to better respond to the sexual health needs of disabled people can enable disabled people to receive the support they need. Finally, fostering more diverse and inclusive narratives of sexuality can allow disabled youth to explore and express their sexuality more freely.

Summary point:

Disabled people experience many barriers to sexual health and well-being. The Socio-Ecological Model (SEM) is a useful way to highlight key interrelated factors at the societal, community, relationship, and individual levels that impact the sexual health and well-being of disabled youth.

These factors include:

- **Societal:** Stigma and ableism;
- **Community:** Access to private and community spaces, sexual health education and services, and assistive technology;
- **Relationship:** Parents/families, and personal support workers; and
- **Individual:** Types of physical disabilities, sexual esteem, and sexual functioning.

Addressing barriers at each level of society is necessary to effectively promote the sexual health of disabled youth.

SECTION 3: CORE PRINCIPLES FOR THE EFFECTIVE SEXUAL HEALTH PROMOTION OF DISABLED YOUTH

This section outlines core principles for the effective sexual health promotion of disabled youth. Sexual health promotion with disabled youth should be guided by the nine core principles for sexual health education, drawn from the *Canadian Guidelines for Sexual Health Education* (https://www.sieccan.org/files/ugd/1332d5_e3ee36e39d944009956af5b86f0a5ed6.pdf), as well as the ten core principles of disability justice.

Applying the core principles of comprehensive sexual health education to sexual health promotion with disabled youth

The *Canadian Guidelines for Sexual Health Education* outlines nine core principles of comprehensive sexual health education, which should inform, and be respected, in the planning and teaching of sexual health education in Canada (SIECCAN, 2019). These core principles should also be adapted and applied to sexual health promotion for disabled youth.

Accordingly, sexual health promotion with disabled youth:

1. Is accessible to all people inclusive of age, race, sex, gender identity, sexual orientation, STI status, geographic location, socio-economic status, cultural or religious background, ability, or housing status (e.g., those who are incarcerated, homeless, or living in care facilities)
2. Promotes human rights including autonomous decision-making and respect for the rights of others
3. Is scientifically accurate and uses evidence-based teaching methods
4. Is broadly-based in scope and depth and addresses a range of topics relevant to sexual health and well-being
5. Is inclusive of the identities and lived experiences of Two-Spirit, lesbian, gay, bisexual, transgender, queer, intersex, nonbinary, and asexual people, and other emerging identities (2SLGBTQINA+)
6. Promotes gender equality and the prevention of sexual and gender-based violence
7. Incorporates a balanced approach to sexual health promotion that includes the positive aspects of sexuality and relationships, as well as the prevention of outcomes that can have a negative impact on sexual health and well-being
8. Is responsive to and incorporates emerging issues related to sexual health and well-being
9. Is provided by service providers who have the knowledge and skills to promote sexual health and who receive administrative support to undertake this work

Applying the core principles of disability justice to sexual health promotion with disabled youth

Disability justice is a cross-disability framework that values individual differences and that works to address the collective experience of disadvantage of marginalized groups to promote a society where all bodies and minds are valued (Ortiz, 2012; Sins Invalid, 2015). A disability justice framework should be applied to the sexual health promotion of disabled youth.

Accordingly, sexual health promotion with disabled youth:

- 10. Considers intersectionality** (i.e., understanding how multiple social identities, such as race, gender identity, and sexual orientation, intersect to create unique experiences of advantage/disadvantage for diverse disabled youth)
- 11. Promotes the leadership of those who are most impacted** (i.e., valuing and prioritizing the perspectives of those who have been the most disadvantaged by societal systems and who understand the systems best through their lived experiences)
- 12. Works to challenge ableist social norms, which do not account for the needs and experiences of disabled people**
- 13. Is committed to cross-movement organizing** (i.e., working with other marginalized groups to address shared experiences of systemic disadvantages that contribute to sexual health inequities)
- 14. Recognizes wholeness** (i.e., recognizing the many dimensions of a person, such as their experiences, strengths, and identities, as well as the inherent worth of all individuals)
- 15. Encourages each individual to honour their bodies, needs, and abilities**
- 16. Is committed to cross-disability solidarity** (i.e., working to address the collective experience of disadvantage that contributes to the sexual health inequities experienced by all members of the disability community)
- 17. Promotes interdependence** (i.e., recognizing the value of reciprocal relationships and community support)
- 18. Promotes collective access** (i.e., working to create spaces and systems where everyone's accessibility needs are considered and addressed)
- 19. Leaves no one behind** (i.e., working to ensure that sexual health promotion accounts for and addresses the needs of all disabled people)

SECTION 4: GUIDELINES FOR SEXUAL HEALTH PROMOTION WITH DISABLED YOUTH

This section outlines seven guidelines for effective sexual health promotion with disabled youth for policy and program decision-makers to consider and implement. Key priorities for the sexual health promotion of disabled youth were identified through the service provider consultation survey and focus groups with disabled youth, as well as through discussions with working group members. Existing research and policy documents were then reviewed to identify recommendations and promising practices for the development of education, services, and policies that meet the sexual health needs of disabled youth.

Guidelines

1. Promote disability acceptance by improving public knowledge about and attitudes towards the sexuality of disabled people

Social stigma and misconceptions about the sexuality of disabled people contribute to restricting disabled youths' access to sexual health education and services, as well as opportunities for sexual expression (East & Orchard, 2014; McRee et al., 2010; Shah, 2017). Further, negative societal attitudes can become internalized by disabled youth, resulting in negative sexual esteem (Dune, 2014b). Improving public knowledge about and attitudes towards the sexuality of disabled people are, therefore, imperative to fostering enabling environments that support the sexual health and well-being of disabled youth.

Recommendations for improving public knowledge about and attitudes towards the sexuality of disabled people:

Adopt a disability-affirming approach to sexual health promotion

Adopting a disability-affirming approach to sexual health promotion involves:

- Recognizing that disabled youth have sexual rights;
- Recognizing disability as a dimension of difference that should be accepted and embraced;
- Reflecting, questioning, and challenging existing assumptions about the sexuality of disabled people and seeking opportunities to learn from disabled people;
- Recognizing the social and environmental barriers that hinder sexual health and well-being for disabled youth, and working to address these barriers;
- Supporting disabled youth to have positive sexual and relationship experiences (e.g., positive identity formation, healthy interpersonal relationships, safe sexual exploration) along with preventing negative outcomes (e.g., sexually transmitted infections, unintended pregnancies, sexual abuse, feelings of sexual/relationship distress or worry);
- Validating and accepting diverse ways of expressing and experiencing sexuality as opposed to pushing disabled people to fit non-disabled norms; and
- Broadening conceptualizations of sex and sexuality to be more inclusive of diverse experiences, including that of disabled people (Bahner, 2012; Eglseder & Webb, 2017; Eisenberg et al., 2015; Rich, 2014).

Implement policies to improve public attitudes regarding the sexuality of disabled people

Policies that are effective in addressing disability-related stigma can also be used to improve public attitudes about the sexuality of disabled people (Fisher & Purcal, 2017). These policies can include:

- Public campaigns and awareness trainings that provide the public with accurate information about the sexuality of disabled people;
- Promoting direct and positive social contact between disabled and non-disabled people, that is accompanied by additional information that challenge misconceptions about the sexuality of disabled people and promote equity; and
- Positive and diverse portrayals of the sexuality of disabled people in the media.

Policies involving disabled people in their design and implementation are more likely to contribute to positive and beneficial change (Fisher & Purcal, 2017). Further, implementing policies that target stigma at multiple levels of society (e.g., individual, organizational, and governmental) are needed to effectively create societal level change.

Recommendations for improving public knowledge about and attitudes towards the sexuality of disabled people:

Deliver disability awareness and acceptance initiatives in schools to foster inclusion

Disability awareness and acceptance initiatives within school settings can enable non-disabled students to better understand and be more accepting of their disabled peers (Fisher & Purcal, 2017; Lindsay & Edwards, 2013). Greater understanding and acceptance can, in turn, lead to a greater sense of belonging and inclusion for disabled youth (Renwick et al., 2019), and enable disabled youth to develop a positive sense of self (Tepper, 2000). Whole-school based approaches that involve school boards, the broader community, teachers, parents/families, and students can further facilitate school and community inclusion.

Disability awareness and acceptance initiatives for school-aged children are more effective when they:

- Facilitate direct and positive interactions between disabled and non-disabled youth within a supportive environment;
- Raise awareness about the systemic barriers that disabled people experience (e.g., inaccessible spaces, negative attitudes about disability);
- Use diverse teaching methods such as multi-media, stories, class activities, discussions, and interactive activities (e.g., having non-disabled people navigate spaces designed for disabled people);
- Are delivered across multiple sessions over a long period of time;
- Are delivered to students starting at a young age; and
- Adapt to local contexts (e.g., local educational policies, customs; Lindsay & Edwards, 2013; Watkins et al., 2020)

Include disability within sexual health education for non-disabled youth

To address misconceptions about the sexuality of disabled youth, comprehensive school-based sexual health education delivered to both disabled and non-disabled students should include information about sexuality and disability (East & Orchard, 2014).

This education should:

- Center the perspectives and expertise of a broad spectrum of disabled people and avoid having the experience of a few disabled people represent the experiences of all disabled people;
- Ensure that disabled people are meaningfully participating in sexual health education, particularly when the sexual health needs and experiences of disabled people are being discussed;
- Dispel myths and misconceptions about the sexuality of disabled people;
- Include positive representations of the sexuality of disabled people;
- Broaden conceptualizations of sexuality and sexual health to be more inclusive of the experiences of disabled people; and
- Encourage all youth to define how they want to express and experience their sexuality (Dune, 2014b; East & Orchard, 2014; Neufeld et al., 2002; Parker & Yau, 2012; Watkins et al., 2020).

Recommendations for improving public knowledge about and attitudes towards the sexuality of disabled people:

Provide service providers with education and training about adopting a disability-affirming approach in their practice

Service providers need to be routinely trained on taking a disability-affirming approach to the provision of sexual health education and services that is regularly updated based on emerging knowledge and promising practices (East & Orchard, 2014; Valvano et al., 2014).

This training should:

- Be designed with disabled people, including service users and service providers, and integrate the diverse perspectives and needs of disabled people;
- Provide strategies for fostering positive interactions with disabled service users and disabled colleagues;
- Encourage service providers to recognize the disabled people they support as experts on their lived experiences;
- Provide practical strategies for implementing Inclusive Design for Learning (See Guideline 3)
- Address ableism (e.g., what it is and how it harms disabled people) and dispel misconceptions related to the sexuality of disabled people;
- Emphasize taking a rights-based approach to supporting the sexual health of disabled people;
- Promote more inclusive discourse about the diverse ways sexuality can be experienced; and
- Address the intersectionality of disability with other dimensions of difference (e.g., culture, ethnicity, gender identity, and sexual orientation), which can impact experiences of sexual health and well-being (Hough et al., 2020; Watkins et al., 2020).

2. Deliver sexual health services and supports that are accessible to and address the needs of disabled youth

Disabled youth experience many barriers to accessing sexual health services that meet their needs (Chan et al., 2022; Shah et al., 2024). Misconceptions about the sexuality of disabled youth often result in necessary sexual health services not being offered to disabled youth (Ramjan et al., 2016). Further, the physical inaccessibility of health care facilities can make sexual health services difficult to access and can dissuade disabled youth from seeking these services. Making sexual health services accessible to disabled youth is critical to promoting the sexual health of disabled youth.

Recommendations for health service providers for the delivery of sexual health services and supports that are accessible to and address the needs of disabled youth:

Initiate conversations about sexual health with disabled youth

Health service providers are often regarded as a preferred and trusted source of sexual health information (SIECCAN, 2019). Many disabled youth want to discuss sexual health with health service providers, but may not feel comfortable bringing up this topic, fearing that health service providers may hold stigmatizing views about the sexuality of disabled youth (Dune, 2014b; East & Orchard, 2014; Thrussell et al., 2018). Further, given that disabled youth experience barriers to accessing sexual health information and often have limited opportunities to exercise self-determination, disabled youth may not be aware of important sexual health services they could be accessing nor have the skills or confidence to advocate for their needs (Chan et al., 2022; Giles et al., 2023).

Health service providers need to proactively initiate discussions about sexual health with disabled youth (Giles et al., 2023; Morozowski & Roughley, 2020; Wiegerink et al., 2011). Health service providers should also encourage and build the confidence of youth to have sexual health-related discussions with their health service providers. This requires health service providers to recognize disabled youth as sexual beings, and sexual health as an important aspect of overall health and well-being. By initiating conversations about sexual health, health service providers can also help to validate the sexuality of disabled youth and foster an environment where youth feel safe talking about sexuality (Bonder et al., 2021; East & Orchard, 2014; Thrussell et al., 2018).

Sexual health-related questions that are inclusive of the needs of disabled youth can be incorporated into standard health questionnaires (e.g., when taking initial assessments or health histories; Rowen et al., 2015). These questions should seek to understand youths' sexual health-related concerns (Hough et al., 2020) and factors that impact their sexual health and well-being (Rowen et al., 2015). Appropriate supports and referrals should also be offered to address the concerns and challenges expressed by disabled youth. The status of disabled youths' sexual health and well-being should be periodically reassessed as their situation can change over time (Rowen et al., 2015; Tellier & Calleja, 2017). Finally, sexual health services (e.g., Pap test, STI test, HPV vaccine) that are regularly offered to non-disabled people should also be offered to disabled people.

Recommendations for health service providers for the delivery of sexual health services and supports that are accessible to and address the needs of disabled youth:

Work to build trust and rapport with disabled youth

Recognizing that many disabled youth have had past negative experiences with health service providers, it is critical that health service providers work to build trust and rapport (Cooper & Yoshida, 2007).

To foster a positive and trusting relationship with disabled youth, health service providers need to demonstrate a commitment to challenging ableism and a willingness to listen, validate, and work with disabled youth to address their needs. This can be done by:

- Adopting a disability-affirming approach (see Guideline 1);
- Learning from the experiences and professional work of diverse disabled people;
- Connecting disabled youth with disabled peers who can serve as role models or offer informal support;
- Getting to know the disabled youth as each individual's needs and experiences are different;
- Recognizing lived experience as a form of expertise and listening to the perspectives of disabled youth;
- Working with disabled youth to identify appropriate solutions to addressing their needs;
- Communicating directly to disabled youth, even when they are accompanied by a support person;
- Remaining flexible and willing to adapt and make accommodations to meet the needs of disabled youth;
- Protecting the confidentiality and privacy of disabled youth;
- Adjusting language used according to youths' needs;
- Allocating sufficient time for appointments; and
- Ensuring the physical accessibility of office/building spaces (East & Orchard, 2014; Hough et al., 2020; Magoon & Meadows-Oliver, 2011; Tylee et al., 2007; Zacharin, 2009).

Provide counselling about fertility, contraception, pregnancy, parenthood, and family planning

Ensuring that disabled youth have equitable access to reproductive health services is critical to protecting their reproductive rights. All disabled youth should receive preconception counselling so that they can make informed decisions about having children or not, and if so, when and how (Shah et al., 2024; Visconti et al., 2012; Tarasoff, Lunskey et al., 2020). This includes information about how their disability may impact fertility, contraceptive use, and/or pregnancy. While the choice to get pregnant or not is ultimately that of the person who can get pregnant, partners should be informed about how they can respect and support that decision.

Disabled youth who want to get pregnant should be informed of any potential complications or risks that may occur during pregnancy and receive support to manage these risks (Stoffel et al., 2018). For certain disabilities, preparing to get pregnant may necessitate changes to existing medical treatments and therapies (Krysko et al., 2020; Warmbrodt, 2022). Managing urinary tract infections (UTIs) during pregnancy may also be particularly critical for disabled youth as they may be more likely to develop UTIs and may be more susceptible to adverse consequences (Krysko et al., 2020; Stoffel et al., 2018; Visconti et al., 2012). Health service providers should also discuss labour and delivery plans with disabled youth and their partners early on during pregnancy (Stoffel et al., 2018).

Recommendations for health service providers for the delivery of sexual health services and supports that are accessible to and address the needs of disabled youth:

Make health care facilities and services physically accessible

Canada has stated its commitment to reducing barriers and increasing opportunities for disabled people to fully participate in Canadian society (Accessibility for Ontarians with Disabilities Act, 2005; Accessibility Services Canada, 2023; Government of Canada, 2018). Reducing barriers includes ensuring that health care facilities and services are physically accessible to disabled youth.

Some important considerations include:

- Parking (e.g., having a parking lot; having accessible parking spots located close to the building);
- Transportation (e.g., improving the quality of adapted transportation services; improving the accessibility of public transportation services; improving the financial accessibility of taxis/rideshare services);
- Buildings (e.g., automatic door openers; doors that are wide enough to accommodate wheelchairs or scooters; elevators; ramps; smooth floor surfaces; continuous handrails);
- Examination rooms (e.g., rooms large enough to accommodate wheelchairs and scooters; examination tables that are height-adjustable; examination table located near a wall; ceiling and/or mechanical lift; railing or straps to support individuals with getting onto an examination table; portable examination equipment; accessible weighing scales);
- Staff who are knowledgeable about using adapted equipment and able to assist with positioning and transferring disabled youth onto examination tables;
- Accessible washroom facilities (e.g., sufficient space for wheelchairs or scooters; grab bars; emergency call bells; sinks, mirrors, soap, and paper towel dispensers at a wheelchair-accessible height); and
- Clear and simple signs (e.g., use of contrasting colours, graphics, and Braille) to indicate the location of buildings, offices, rooms, elevators, washrooms, and emergency exits (Chan et al., 2022; Iezzoni et al., 2015; Pritchard et al., 2014).

Health care procedures may also need to be adapted for some disabled youth so that the procedures can be carried out successfully and safely. For instance, Pap tests, which require the use of a speculum, can be challenging to carry out for some disabled youth (Nguyen et al., 2018; Sweeney, 2019). Using a smaller speculum can make the Pap test more comfortable (Cleveland Clinic, 2023). HPV testing may be an alternative option for cervical cancer screening that is more accessible for some disabled youth (Clark & Horton, 2021). Further, introducing HPV self-sampling, which allows individuals to collect their own samples in the comfort of their own homes, within cervical cancer screening programs can offer another option for disabled youth to access cervical cancer screening.

3. Deliver comprehensive sexual health education that is accessible and inclusive of the needs and experiences of disabled youth

Comprehensive sexual health education can enable disabled youth to make informed decisions about their sexual health and well-being (Bonder et al., 2021; Esmail, Krupa, et al., 2010; Murphy & Elias, 2006; Taylor & Abernathy, 2022). However, sexual health education is often either inaccessible to disabled youth, based on misconceptions about the sexuality of disabled youth, or inadequate in meeting the needs of disabled youth. Sexual health education needs to be accessible and inclusive of the needs of disabled youth.

Recommendations for improving both the content and delivery of comprehensive sexual health education for disabled youth:

Provide disabled youth with information about their sexual rights

The United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD) stipulates that disabled youth are entitled to the full range of human rights and fundamental freedoms on an equal basis with others (United Nations General Assembly, 2006). Disabled youth need to be taught about their sexual rights and should be provided with the knowledge, tools, and supports to advocate for themselves should their sexual rights be violated or denied.

The sexual rights that disabled youth should be aware of include, but are not limited to, their right to:

- Access sexual health information and services;
- Make decisions about their sexual lives, including choices about being sexually active, using contraceptives, and having children;
- Define their own sexuality and identity;
- Express their sexuality;
- Choose their own sexual partners;
- Safe and pleasurable sexual experiences;
- Be free from sexual violence;
- Privacy; and
- Marriage equality.

Recommendations for improving both the content and delivery of comprehensive sexual health education for disabled youth:

All sexual health topics that are important to teach non-disabled youth should also be taught to disabled youth

The delivery of sexual health education to disabled youth should follow the *Canadian Guidelines for Sexual Health Education* and aim to increase disabled youths' capacity for sexual health enhancement (e.g., sexual pleasure, intimacy, healthy relationships, sexual esteem) and for preventing outcomes that can have a negative impact (e.g., abuse, sexually transmitted infections, unintended pregnancies; SIECCAN 2019).

Sexual health education should be taught to disabled youth, beginning at a young age, and take a foundational, 'building block' approach that considers youths' age and developmental level (Dockerty et al., 2015; Esmail, Krupa, et al., 2010; SIECCAN, 2023d). The information provided should also be inclusive of the needs and experiences of disabled people and 2SLGBTQINA+ people (Tarasoff, 2021).

Sexual health education should:

- Inform disabled youth that sexuality is an important subject to discuss;
- Enable disabled youth to ask sexuality-related questions to adults they trust and have their questions answered in an open and honest manner; and
- Provide disabled youth with the vocabulary to communicate about a variety of sexual health topics.

Recommendations for improving both the content and delivery of comprehensive sexual health education for disabled youth:

Provide disabled youth with information about adapting sexual activity

Disabled people have expressed a desire for more practical information about sexual activity (e.g., sexual positioning, sensations, sexual functioning; Bryant et al., 2022). Disabled youth should be informed about the benefits of engaging in self-exploration (e.g., genital and non-genital touching, trying different positions, and the use of equipment/sex toys) prior to partnered sexual activity so that they can better understand their bodies and needs, including sensations that they find pleasurable and ways of engaging in sexual activity that work for them (Consortium for Spinal Cord Medicine, 2010; Esmail, Huang, et al., 2010; Rowen et al., 2015).

Some strategies for enhancing individual or partnered sexual activity include:

- The use of props and devices (e.g., pillows and cushions) to assist with positioning, balance, and comfort;
- The use of sex toys;
- Having a partner assist with putting on a condom;
- The use of lubricants;
- Planning for sexual activity (e.g., based on energy level, spasms, pain);
- Asking for support (e.g., from a partner, care provider) to prepare for sexual activity; and
- Challenging existing sexual scripts and exploring new ones (Rowen et al., 2015; Thrussell et al., 2018).

Strategies for reducing fecal incontinence (e.g., evacuating stool before sexual activity, developing bowel management skills), urinary incontinence (e.g., catheterization before sex, reducing fluid intake before sexual activity), and urinary tract infections (e.g., washing and catheterizing immediately after sex) can also improve sexual experiences (Streuer et al., 2021; Thrussell et al., 2018).

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 (Heller et al., 2016). 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.

Recommendations for improving both the content and delivery of comprehensive sexual health education for disabled youth:

Provide disabled youth with information related to the prevention of abuse

To improve the safety of disabled youth, sexual health education should include information about what behaviours constitute abuse and how to identify potentially harmful situations, including forms of abuse that specifically target disabled people (e.g., the forced removal of disabled people's mobility devices; intentionally withholding necessary supports; deliberately imposing physical barriers; Plummer & Findley, 2012).

Sexual health education should also provide guidance on distinguishing between appropriate and inappropriate touch in the context of receiving personal care support, and building disabled youths' consent capacity so that disabled youth are able to set boundaries with their care providers (e.g., personal support workers, family members, partners) and advocate for themselves if they perceive a behaviour to be inappropriate (Public Health Agency of Canada, 2013).

All disabled youth, including those who use sign language or augmentative and alternative communication (AAC), need to have the vocabulary (e.g., words, symbols, signs) to communicate about abuse (Shah, 2017; SIECCAN, 2023e). Finally, sexual health education should equip disabled youth with knowledge about accessing abuse-related supports (Rajan, 2011).

Recommendations for improving both the content and delivery of comprehensive sexual health education for disabled youth:

Applying Inclusive Design for Learning to the delivery of sexual health education

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 and works to develop individualized teaching approaches within an integrated learning environment so that the diversity of learning needs is met (Watkins et al., 2020).

Inclusive Design for Learning is different, but complementary, to the principles of Universal Design for Learning (i.e., principles for setting up learning environments so that they meet the needs of diverse learners) and the concept of accessibility (i.e., providing learning supports and making accommodations to meet the needs of disabled people specifically). Inclusive Design for Learning is an ongoing process, rather than a set of principles, that engages with individuals whose needs are not met by standardized approaches to teaching to co-create solutions that meet diverse learning needs so that everyone can benefit.

Inclusive approaches to teaching sexual health education can include:

- Obtaining feedback from learners, particularly those whose needs are not met within standardized learning environments, about how they are doing and challenges they may be experiencing, and remaining flexible and responsive to that feedback;
- Ensuring that learners whose identities have traditionally been underrepresented and/or marginalized are being reflected within sexual health education;
- Promoting the self-determination of learners by offering choices (e.g., having materials in multiple formats, providing options for how students demonstrate their learning);
- Creating a learning environment that encourages learners to try new and different approaches to learning to determine what works for them;
- Developing strategies to foster a supportive learning environment so that all learners can thrive; and
- Being transparent about one's limitations and the limitations of the learning environment (e.g., due to existing policies, access to resources).

4. Promote and amplify the voices of disabled youth in the delivery and implementation of sexual health promotion initiatives for disabled youth

There is growing recognition that lived experience expertise is imperative to the planning, development, and delivery of health promotion initiatives (Bryant, 2002). Engaging with disabled youth at every level of decision-making is key to providing services that are responsive to the needs of disabled youth. To date, disabled people have often been excluded from decision-making processes that affect their lives (Dockerty et al., 2015; Giles et al., 2023). “Nothing about us without us” reflects the notion that disabled youth should be meaningfully involved in initiatives that are meant to benefit them (Charlton, 2000).

Recommendations for promoting disabled youths’ involvement and leadership in the development and delivery of sexual health promotion initiatives:

Support disabled youth in developing self-determination skills

Disabled youth should be taught about and given opportunities to exercise their right to self-determination (Angell et al., 2010; Wehmeyer & Palmer, 2000). Given that opportunities for self-determination have often been restricted for disabled youth, explicit training to develop self-determination skills (e.g., goal-setting, developing an action plan to reach goals, engaging in self-reflection and self-assessment) is required (Angell et al., 2010; Giles et al., 2023). Further, disabled youth require opportunities to practice self-determined behaviours through exploration, taking risks, and making decisions about their goals and desires (Angell et al., 2010; Wehmeyer & Palmer, 2000).

Parents/families and service providers need to recognize the importance of integrating opportunities for self-determination into all aspects of disabled youths’ lives. At home, parents/families should be intentional about providing regular opportunities for disabled youth to make their own choices (Wehmeyer & Palmer, 2000). Service providers, including educators and health service providers, should seek to promote the self-determination of disabled youth by encouraging youth to set their own goals and identify the supports they need to achieve those goals (Angell et al., 2010). Parents/families and service providers should also support disabled youth in acquiring the knowledge they need to make informed decisions about their own sexual health and well-being (Giles et al., 2023).

It is important to note that self-determination is a separate concept from “independence.” Self-determination is about ensuring that disabled youth are given opportunities to make their own decisions about their lives and that decisions are not made for them by other people. In cases where disabled youth require assistance, supported decision-making models should be adopted rather than substitute decision-making (see Guideline 5).

Recommendations for promoting disabled youths' involvement and leadership in the development and delivery of sexual health promotion initiatives:

Consult with diverse disabled youth

It is critical that the perspectives of diverse disabled youth (e.g., 2SLGBTQINA+ disabled youth, Black, Indigenous, and disabled youth of colour, disabled youth from different cultural backgrounds, disabled youth with complex support needs, disabled youth with different types of physical disabilities) are informing the development of sexual health education, services, and policies that are intended to benefit disabled youth (Dockerty et al., 2015; Giles et al., 2023). Having the voices of diverse disabled youth inform sexual health promotion initiatives increases the likelihood that these initiatives will accurately respond to their diverse needs and experiences.

Create opportunities for disabled youth to hold positions of leadership in the development and delivery of sexual health promotion initiatives

Disabled youth should be encouraged to assume leadership positions in the development and delivery of sexual health promotion initiatives and be compensated fairly for their contributions. Organizations and institutions should consider how their funding and organizational activities can foster leadership opportunities for disabled youth (e.g., allocate funding to compensate disabled youth for their work, offer accessibility accommodations, offer leadership training and mentorship for disabled youth).

Fostering peer support and mentorship opportunities can enable disabled youth to learn from one another's experiences and to share information for mutual support and learning (Byrant et al., 2022; Esmail, Krupa et al., 2010). Disabled people have expressed a desire to learn from other disabled people and a preference for receiving sexual health education and services from someone with similar lived experiences. Having positive role models can also encourage disabled youth to develop positive sexual esteem (Retznik et al., 2017). Finally, creating dedicated spaces for disabled youth to connect with one another (e.g., online communities) can enable community-building and facilitate peer support (Benoit et al., 2022).

5. Build the capacity of service providers and parents/families to have the knowledge and confidence to effectively promote sexual health with disabled youth

Service providers and parents/families have an important role to play in supporting the sexual health of disabled youth, but many feel ill-equipped to effectively do so (East & Orchard, 2014; Esmail, Krupa, et al., 2010). Currently, a lack of training and organizational policies/guidelines for service providers leave many unsure about their role in supporting the sexual health of disabled youth, how best to support disabled youth and their families, and what kind of support is appropriate and legal (Bahner, 2016; Saxe & Flanagan, 2016). Service providers and parents/families need more guidance and resources to effectively promote sexual health with disabled youth.

Recommendations for improving the knowledge and confidence of service providers and parents/families in promoting sexual health with disabled youth:

Develop and implement organizational/institutional policies and guidelines that support the sexual rights of disabled youth

Comprehensive policies/guidelines for the role of service providers in supporting the sexual rights of disabled youth are needed to clarify what is expected of service providers and to ensure the prioritization and sustainability of sexual health promotion efforts for disabled youth within different organizations (Vancouver Coastal Health Authority, 2009).

Policies/guidelines should take a rights-based approach (e.g., promote youths' right to self-determination and bodily autonomy, to privacy, to express their sexuality; Samowitz, 2010) and outline the specific roles of service providers in supporting the sexuality of disabled youth given existing legal boundaries. Policies/guidelines should also address issues of consent and privacy (Browne & Russell, 2005; Samowitz, 2010). Service providers should receive training about these policies/guidelines (Saxe & Flanagan, 2016).

The *Guidelines for Supporting Sexual Health and Intimacy in Care Facilities* developed by the Vancouver Coastal Health Authority offers an example of a set of guidelines that can be helpful for promoting the sexual health of adults living in long-term care facilities (Vancouver Coastal Health Authority, 2009). The document discusses the rights of residents, facilities' responsibilities, and the role of staff given existing laws, as well as addresses issues of consent and privacy. Future policies/guidelines should seek to outline the role of different service providers (e.g., health service providers, educators, personal support workers) in supporting disabled people across all ages, in a variety of settings (e.g., at home, in the community), and across jurisdictions.

Recommendations for improving the knowledge and confidence of service providers and parents/families in promoting sexual health with disabled youth:

Develop policies and guidelines that promote supported decision-making, including for sexuality-related decisions

There is a need to develop policies and guidelines across Canadian provinces and territories that promote and enforce supported decision-making. As outlined in Article 12 of the CRPD, supported decision-making refers to providing disabled people with the support they need so that they can exercise their legal capacity (United Nations General Assembly, 2006). However, Canada currently lacks basic legislative frameworks for supported decision-making and, consequently, guardianship and substitute decision-making practices continue to dominate (Stainton, 2016).

Some examples of promising supported decision-making models include:

- The Planned Lifetime Advocacy Network, which focuses on building strong support networks around an individual that can be maintained once parents are no longer around to provide support;
- Forming microboards, which are small (micro) groups of family and friends who, together, form a non-profit society (board) to support an individual with planning, decision-making, advocacy, and forming community connections; and
- The Nidus Personal Planning Resource Centre and Registry, which provides an individual with resources and training to set up Representation Agreements and other personal planning tools.

Key elements for effective supported decision-making policies include an enforceable and easily accessible legal framework, appropriate funding allocation, and building community capacity to sustain support networks. A monitoring system is also necessary to ensure that supported decision-making does not inadvertently revert to substitute decision-making.

Recommendations for improving the knowledge and confidence of service providers and parents/families in promoting sexual health with disabled youth:

Provide service providers with pre-service and in-service training about sexual health promotion with disabled youth

There is a need to establish standards of education for addressing the sexual health of disabled youth across professional disciplines (e.g., nursing, medicine, rehabilitation, mental health, social services, personal care support; Eglseder & Webb, 2017). The amount of education that health professional students receive on the topic of sexuality can improve their attitudes about the sexuality of disabled people (Valvano et al., 2014).

Including training about sexuality and disability within educational programs for different service providers ensures that service providers:

- Recognize the importance of sexual health to disabled youths' overall health and well-being;
- Understand their role in supporting the sexual health of disabled youth; and
- Have the knowledge base and confidence to address sexuality with disabled youth (East & Orchard, 2014).

Training should include information about the diverse sexual health needs and experiences of disabled youth, such as the impact disability can have on sexual functioning, sexual activity, contraceptive use, and pregnancy, and how disabled youth can be supported across these experiences (Neufeld et al., 2002; Shah et al., 2020; 2024). Service providers should also be knowledgeable about ways they can adapt their care and make their support more accessible to diverse disabled youth.

Conversation scripts can support service providers to initiate conversations about sexuality with disabled youth (Heller et al., 2016). The Disability and Sexuality Resource Hub offers examples of conversation guides and other resources that can be helpful to service providers (<https://hollandbloorview.ca/disability-sexuality-resource-hub/sexuality-guides>).

Interdisciplinary and multidisciplinary training programs for service providers may be particularly beneficial in increasing service providers' comfort and knowledge to provide sexual health support to disabled youth (Fronek et al., 2009; Gianotten et al., 2006). An interdisciplinary/multidisciplinary approach to training can enable service providers to develop a better understanding of the division of tasks and responsibilities across different disciplines and enable service providers across different disciplines to, collectively, better respond to disabled people's sexual health needs (Eglseder & Webb, 2017).

Recommendations for improving the knowledge and confidence of service providers and parents/families in promoting sexual health with disabled youth:

Provide parents/families with resources and support for addressing sexual health with disabled youth

There is a need for more accessible and relevant resources and supports for parents/families about the sexual health of disabled youth (East & Orchard, 2014). Research on sexual health education programs for parents of children with intellectual disabilities indicate that parents who take part in these programs develop a better understanding of the importance of providing sexual health education to youth with intellectual disabilities and how they can better support youth (Kok & Akyuz, 2015; Rooks-Ellis et al., 2020; Yildiz & Cavkaytar, 2017).

Similar to service providers, parents/families can benefit from education and training on addressing internalized ableism, as internalized ableism can impact how parents/families support the sexual health of disabled youth. Parents/families should also receive support on promoting the self-determination of disabled youth (e.g., teaching disabled youth to set goals and boundaries, creating opportunities for disabled youth to make their own choices, building disabled youths' capacity for consent; Dune, 2014b; Neubauer et al., 2021; Taub & Werner, 2023; Vasquez et al., 2016).

The Disability & Sexuality Lab offers some helpful resources for parents/families to address different sexual health topics with disabled youth (www.disabilitysexualitylab.com). Service providers can also play an important role in supporting parents/families by addressing their concerns and questions related to the sexuality of disabled youth using a disability-affirming approach (i.e., strengths-based and sexual health enhancement approach; East & Orchard, 2014; Eisenberg et al., 2015).

Foster collaboration between service providers, parents/families, and disabled youth

Service providers should seek to collaborate with parents/families and disabled youth themselves so that all stakeholders are working towards a common goal (Giles et al., 2023). The involvement of disabled youth in decision-making processes about their own sexual health is critical to cultivating the self-determination of disabled youth.

Multidisciplinary collaboration between service providers across professional disciplines can help to strengthen service providers' knowledge and confidence to promote sexual health with disabled youth. Multidisciplinary collaboration can also allow for:

- More diverse sexual health topics to be addressed with disabled youth;
- The sexuality of disabled youth to be addressed from multiple perspectives;
- Service providers to gain a better understanding of the roles of other professional disciplines so that they can provide referrals when necessary; and
- Greater sharing of information, resources, and best practices between service providers and across sectors (e.g., education, health, social, disability services; Ballan & Freyer, 2017; Bonder et al., 2021; Dockerty et al., 2015; Hough et al., 2020)

6. Improve abuse prevention and response for disabled youth

Disabled people are more likely than non-disabled people to be targets of violence (Hughes et al., 2012). In many instances, perpetrators of abuse are individuals that disabled people rely on for their personal care needs (Dockerty et al., 2015; Hassouneh-Phillips, 2005; Plummer & Findley, 2012; Rajan, 2011). Strengthening abuse prevention and response for disabled youth is imperative to promoting the sexual health and well-being of disabled youth and ensuring their safety.

Recommendations for preventing disabled youth from being abused and supporting those who have experienced abuse:

Address systemic issues that make disabled youth more likely to be targets of abuse

Poverty is a risk factor for abuse (Barrett et al., 2009; Ellsberg et al., 2015). As such, promoting equitable access to employment opportunities for disabled youth (i.e., non-discriminatory hiring practices, workplaces that are physically accessible) and ensuring that disabled youth have financial security are critical to reducing incidences of abuse and enabling disabled youth to leave abusive situations (Dockerty et al., 2015; Rajan, 2011).

Service agencies need to have policies and procedures in place to protect disabled people from being abused (Dubé, 2016). Policies also need to be enforced so that those who commit abuse are held accountable. Regular safety audits of health and social services are needed to ensure that disabled youth are being appropriately supported and not experiencing abuse within these systems (Rajan, 2011).

Support services also need to be made accessible to disabled youth. 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 support programs and services for those who have been abused (Disability Rights Wisconsin, 2004).

Adopt a trauma-informed approach to sexual health promotion with disabled youth

A trauma-informed approach begins with a recognition that youth accessing services and supports may have experienced distressing life events in the past that continue to affect their lives, including their interactions with service providers (Ghandour et al., 2015; Reeves, 2015). Adopting a trauma-informed approach requires an understanding of the complex interplay of individual and societal factors that contribute to experiences of trauma, as well as how individuals may cope differently with trauma (Quiros & Berger, 2015). Further, a trauma-informed approach involves taking the necessary precautions to avoid inadvertently causing additional trauma when providing supports to an individual (Reeves, 2015).

Some important elements of a trauma-informed approach include building trust, promoting safety, fostering choice and self-agency, and improving emotional self-regulation (Berger et al., 2021). Empowering individuals to make their own choices (e.g., choice about service providers, choice about their goals and the supports they need to meet those goals) is particularly important as it contributes to restoring a sense of power in individuals who have had choices removed from them through their traumatic experiences (Ballan & Freyer, 2017).

Recommendations for preventing disabled youth from being abused and supporting those who have experienced abuse:

Conduct a risk assessment and develop a safety plan with disabled youth who are currently experiencing or have previously experienced abuse

Service providers supporting disabled youth who have experienced abuse should work with disabled youth to assess risk of future abuse and develop a safety plan accordingly (Ballan & Freyer, 2017; Dockerty et al., 2015; Rajan, 2011). The goal of safety planning may not necessarily be about leaving an abusive situation, as this may not always be possible or preferred by those experiencing abuse (Bader et al., 2019). Instead, safety planning aims to support people who experience abuse to develop strategies to reduce immediate risk of violence.

The following resources can help to guide risk assessments and safety planning:

- The Canadian Domestic Homicide Prevention Initiative's *Creating Safety Plans with Vulnerable Populations to Reduce the Risk of Repeated Violence and Domestic Homicide* outlines strategies, promising practices, and other resources to support women who have experienced domestic abuse and those close to them (Bader et al., 2019).
- Safe and Equal, a family violence organization in Australia, has outlined specific considerations for conducting risk assessments and developing safety plans with disabled people (e.g., ensure access to mobility devices, have care needs met, accessibility of support services; Safe and Equal, n.d.).
- The *Model Protocol: Safety Planning for Domestic Violence Victims with Disabilities*, developed by the Washington State Coalition Against Domestic Violence in the United States, provides recommendations for domestic violence agencies on supporting disabled people with safety planning in ways that promote their self-determination and consider environmental and social barriers that disabled people may encounter (Hoog, 2010).
- The *Safety Planning with LGBTQ Sexual Assault Survivors: A Guide for Advocates and Attorneys*, developed by the Victim Rights Law Center in the United States, offers recommendations for advocates and attorneys for supporting LGBTQ survivors of non-intimate partner sexual assault to assess risks and develop safety plans (Victim Rights Law Center, 2017).

Recommendations for preventing disabled youth from being abused and supporting those who have experienced abuse:

Training service providers to better support disabled youth who have experienced abuse

There is a need to increase the number of skilled, disability-affirming, and empathic service providers who can support disabled youth who have experienced or are experiencing abuse (Dockerty et al., 2015; Rajan, 2011).

Service providers need to be knowledgeable about:

- Higher incidences of abuse experienced by disabled people and be aware that abuse is often perpetrated by care providers;
- Fostering a safe/non-judgemental environment so that disabled youth feel comfortable disclosing experiences of abuse;
- The social and environmental factors that make disabled youth more vulnerable to experiencing abuse (e.g., stigma, low socioeconomic status, limited access to health services, barriers to community participation, lack of sexual health education);
- Barriers disabled youth experience to leaving abusive situations (e.g., not being believed when disclosing incidents of abuse, fear of losing access to care support, lack of financial security);
- The impact that abuse can have on disabled youth;
- Providing disabled youth with the vocabulary to communicate about abuse;
- Different ways disabled youth may communicate and be able to accommodate for different communication methods;
- Conducting risk assessments and working with disabled youth to develop a safety plan;
- Local services and supports (e.g., crisis centres, mental health support) that they can refer disabled youth;
- Adopting anti-oppression frameworks and intersectionality; and
- Adopting a trauma-informed approach in their practice (Dockerty et al., 2015; Ghandour et al., 2015; Rajan, 2011).

7. Advance research on the sexual health and well-being of disabled youth

Future research to advance the knowledge base on the sexual health and well-being of disabled youth should adopt a disability-affirming approach and focus on addressing the self-identified sexual health needs of disabled youth. Participatory and action-oriented research, which involves researchers collaborating with community members (e.g., disabled youth, families) as equal partners in research design and decision-making, can enable the greater involvement of disabled youth in research that is intended to benefit them (Balcazar et al., 1998). This requires being intentional about meaningfully engaging diverse community members in the research process, accommodating for diverse accessibility needs, and distributing power equally among members of the research team (Greenwood et al., 2016). Further, building the capacity of disabled researchers

(e.g., training, funding opportunities) can strengthen and expand the disability research base as disabled researchers bring both research and lived experience expertise to the field.

Recommended areas for future research:
<p>Sexual health needs of diverse disabled youth:</p> <ul style="list-style-type: none">• Sexual behaviours and dating/relationship experiences of diverse disabled youth (e.g., 2SLGBTQINA+ disabled youth, Black, Indigenous, and disabled youth of colour, disabled youth from different cultural backgrounds, disabled youth with complex support needs, disabled youth with different types of physical disabilities);• The psychological, social, and environmental barriers and facilitators to the development of positive sexual esteem for disabled youth;• Strategies for adapting sexual activity for diverse disabled youth; and• Innovative sex toy designs that meet the accessibility needs of diverse disabled youth.
<p>Training and guidelines for service providers and service agencies:</p> <ul style="list-style-type: none">• Environmental scans of service agencies and other institutions to determine how effectively they implement Inclusive Design and disability justice and ways they can improve;• Policies/guidelines for service agencies that effectively promote the sexual rights of disabled youth, while respecting existing laws and ensuring the safety of both service providers and disabled youth;• Effective service provider training programs/educational curricula for different professionals for addressing the sexual health needs of disabled youth; and• Strategies for meaningfully involving disabled youth in the development and implementation of training programs/educational curricula for service providers about disability and sexuality.
<p>Sexual health education needs of disabled youth</p> <ul style="list-style-type: none">• Identifying sexual health content that is applicable to disabled youth;• Developing and evaluating sexual health education programs that are inclusive of the needs of disabled youth; and• Approaches to teaching about sexuality to disabled youth across the lifespan (e.g., the building blocks that children should learn earlier to prepare them for later sexual relationships).
<p>Approaches to improving sexual health promotion with disabled youth</p> <ul style="list-style-type: none">• Effective initiatives for reducing incidences of abuse among disabled youth and improving the safety of disabled youth in their communities;• The use of innovative and equitable approaches (e.g., arts-based, digital story-telling, Indigenous research methodologies) to addressing stigma and promoting more diverse narratives about sexuality that are inclusive of the experiences of disabled youth; and• Developing approaches to perinatal care, including obstetric care guidelines, that meet the needs of disabled youth.

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