

Canadian Guidelines for Sexual Health Promotion with Autistic Youth



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Consultation

SIECCAN conducted an online consultation survey with service providers, between August and October 2022, to inform the development of the capacity-building toolkit resources focused on the needs of Autistic youth. SIECCAN also worked with Wisdom2Action to conduct focus groups and interviews with Autistic and/or neurodivergent youth in September of 2022. SIECCAN would like to thank the Autistic and neurodivergent youth, as well as service providers, from across Canada, who participated in the consultation.

Working group

To develop the capacity-building toolkit focused on the needs of Autistic youth, SIECCAN put together a working group of individuals with diverse lived experience and professional expertise, including Autistic 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 the content and the presentation of information in the capacity-building toolkit to best meet the needs of both service providers working in this area and the Autistic 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 is developing two capacity-building toolkits for service providers focused on the sexual health needs of Autistic youth and disabled youth with physical disabilities, respectively.

The following Canadian Guidelines for Sexual Health Promotion with Autistic Youth is one component of the capacity-building toolkit focused on the needs of Autistic youth, which also includes a guide for services providers and resources for Autistic youth. The Canadian Guidelines for Sexual Health Promotion with Autistic Youth aims to inform policy and program decision-makers about the importance of promoting sexual health with Autistic youth. Further, this document provides recommendations to help guide policy and program decision-makers in taking action to enhance sexual health promotion with Autistic youth.

Explanation of language choices

There is currently no consensus regarding preferred language to talk about autism either among people with lived experience (i.e., Autistic 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., Autistic youth), which views autism as a core aspect of an individual's identity that cannot be separated from the individual, is often preferred among those with lived experience (Botha, 2021; Bury et al., 2020). This contrasts person-first language (i.e., youth with autism), which views autism as an attribute of a person rather than defining feature of who they are. As such, we have chosen to use identity-first language for this project, but we recognize this is not preferred by all. It is also important to note that while some Autistic people identify as being disabled, not all Autistic people identify this way. Therefore, any reference to disabled people in this project will not include Autistic people. This document will specifically mention Autistic people when referring to this population.

Developing the Canadian Guidelines for Sexual Health Promotion with Autistic Youth

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

A total of 127 service providers participated in the survey. Participants included educators, social workers, public health professionals, community organization staff, psychologists/counsellors, nurses, caregivers/personal support workers, behavioural therapists, occupational therapists, physicians, life skills coaches, employment support providers, executive functioning coaches, and group home staff.

The Findings from the Service Provider Consultation Survey: Focus on Autistic Youth (https://www.sieccan.org/ady-autisticyouth) provides a complete summary of findings from the consultation survey (SIECCAN, 2022a). Overall, feelings of apprehension by parents and family members remain an important barrier to sexual health education and services for Autistic youth. Further, service providers reported requiring more support in understanding Autistic experiences of sexuality (e.g., sensory and communication differences between Autistic and non-autistic youth) and how to tailor their support to better address topics such as gender identity and expression, communication within relationships, sexual decision-making, and sexual behaviours with Autistic youth.

In September 2022, two focus groups (in English) and two interviews (in French) were also conducted with Autistic and/or neurodivergent¹ youth (17 – 23 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 Autistic and/or neurodivergent youth between the ages of 16 and 24 (open session), while the other was specifically for those who identify as Black, Indigenous, or People of Colour (BIPOC session). A total of 10 Autistic and/or neurodivergent youth participated: six in the open session, two in the BIPOC session, and two in the interviews.

The Findings from Focus Groups and Interviews with Autistic and Neurodivergent Youth (https:// www.sieccan.org/ady-autisticyouth) report provides a complete summary of findings from the focus groups and interviews (SIECCAN, 2022b). Overall, Autistic and neurodivergent youth indicated encountering many challenges to dating, forming and maintaining relationships, and to having enjoyable sexual experiences. Underpinning many of these challenges was prevailing stigma about Autistic and neurodivergent people, which contributed to misconceptions. negative experiences, and barriers to accessing sexual health information and services. These challenges were further compounded for Autistic and neurodivergent youth who identified as Black, Indigenous, People of Colour, or 2SLGBTQINA+.

In December 2022, once the consultation survey, focus groups, and interviews were completed, SIECCAN met with working group members to review key findings and identify priorities for the Canadian Guidelines for Sexual Health Promotion with Autistic 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.

Neurodivergence includes a range of neurological differences, including autism, dyslexia, attention deficit hyperactivity disorder, fetal alcohol spectrum disorder, obsessive-compulsive disorder, Tourette syndrome, and others. While this project focuses on the needs of Autistic youth, the focus groups and interviews were also open to those with other neurological differences due to the likelihood of shared experiences. Participants were not asked to specify their diagnoses or identities.

Defining autism

Autism is a lifelong neurodevelopmental condition that is characterized by how some people process information, make sense of the world around them, and interact and relate with others differently than non-autistic people (Milton, 2012a).

Some areas of differences may include hypersensitivity and hyposensitivity to certain stimuli (e.g., sound, light, smell, touch), having highly focused interests, as well as differences in self-regulation and communication (Bettin, 2019; Canadian Academy of Health Sciences, 2022; Milton, 2012a). It is important to note that there are wide variations in how autism presents itself from one life domain to another, from one life stage to another, and from one person to another, which is why Autistic people are often described as falling along a spectrum.

The way autism is understood and defined is continuously evolving. Earlier understandings of autism have largely been based on a biomedical lens, focused on identifying and managing what have been commonly referred to as symptoms of autism (Canadian Academy of Health Sciences, 2022). While this perspective has contributed to an understanding of the unique characteristics of autism, it largely positions these characteristics as problems or deficits that need to be prevented or modified and overlooks the ways in which society is not set up to meet the needs of Autistic people.

Portraying autism as a deficit can be harmful to the self-esteem of Autistic people and has contributed to the stigma Autistic people experience. In response to stigma, many Autistic people have adopted masking as a way to cope (Pearson & Rose, 2021). Masking refers to the act of hiding one's natural Autistic characteristics and/or behaviours and adopting those that are more socially accepted, which has been shown to have negative implications for Autistic people's mental health.

Increasingly, autism is being viewed from a neurodiversity lens, which considers autism as a dimension of difference that is a natural part of neurological variation and that should be respected (Silberman, 2017).

From this perspective, the capacities and strengths of Autistic people are also recognized (Dwyer, 2022). Further, the focus shifts towards leveraging the strengths of Autistic people, providing effective supports and accommodations to address areas of needs, promoting dignity and human rights, and addressing social and environmental barriers, as opposed to "fixing" the person.

Defining sexual health promotion

The World Health Organization defines sexual health as "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 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).

Priorities for sexual health promotion with Autistic youth

Even though the sexual rights of Autistic youth are enshrined in the United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD), the sexuality and sexual well-being of Autistic youth have largely been overlooked and neglected in Canada. Autistic youth often do not receive the sexual health education and services they need.

Prevailing stigma and misconceptions about Autistic people largely underpin the lack of available, accessible, and appropriate supports for this population. This lack of education and services places an already disadvantaged population at an increased risk of victimization. Further, it strips Autistic youth of their fundamental right to sexual expression and fulfillment.

Delivering sexual health education and services to Autistic youth that is inclusive of their particular needs can enable Autistic youth to make informed decisions to enhance their sexual health and well-being.

As the guideline statements in this document stipulate, improving sexual health promotion for Autistic youth should be an important public health priority and requires:

- 1. Promoting Autistic acceptance, including dispelling myths and misconceptions about the sexuality of Autistic youth;
- 2. Delivering comprehensive sexual health education that is accessible and addresses the specific needs and experiences of Autistic youth and that goes beyond reducing risk and harm to including healthy relationships and sexual pleasure;
- Promoting and amplifying the voices of Autistic youth in the development and implementation of sexual health education and services for Autistic youth;
- 4. Building the capacity of service providers (e.g., educators and health professionals) and families to have the knowledge and confidence to effectively promote sexual health with Autistic youth; and
- **5.** Advancing research on the sexual health and well-being of Autistic youth.

Structure of the document

The Canadian Guidelines for Sexual Health Promotion with Autistic Youth has four sections. Sections 1 and 2 draw attention to the importance of and key barriers to sexual health promotion with Autistic youth. Section 3 describes core principles to consider when developing sexual health promotion initiatives for Autistic youth, while section 4 outlines guidelines and recommendations for effective sexual health promotion with Autistic youth. Quotes from the focus groups and interviews with Autistic and neurodivergent 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 AUTISTIC YOUTH

This section outlines the sexual rights of Autistic 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 Autistic youths' vulnerability to victimization and in promoting Autistic youths' overall health and well-being.

Sexual rights of Autistic 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 right 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;
- · Information and education; and
- The highest attainable standard of health.

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

Specifically, the CRPD outlines the rights of Autistic people and 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); and

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

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

At the core of sexual rights is the right to bodily autonomy and self-determination (National Partnership for Women & Families & Autistic Self Advocacy Network, 2021; Sexual Rights Initiative, 2018). Self-determination refers to the ability of making things happen in one's own life and being able to pursue freely chosen goals (Wehmeyer, 2015). Self-determination is related to the concept of autonomy (i.e., having the capacity to make one's own decisions based on one's own values, interests, and an understanding of the consequences of one's decisions; Späth &

Jongsma, 2020) and agency (i.e., having control over one's actions; Moore, 2016). The capacity of Autistic people to exercise self-determination has often been questioned and restricted, with many decisions being made for them by others (Sexual Rights Initiative, 2018; Webster et al., 2022).

Denying Autistic people and disabled people their right to exercise legal capacity has, in the past, led to the forced and coerced sterilisation of Autistic people and 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). While these practices may be condemned today, much of the thinking that led to the systemic violation of Autistic people and disabled people's sexual rights in the past remain prevalent today and contribute to their ongoing exclusion from accessing important and necessary sexual health information, services, and opportunities (Joyal et al., 2021).

As such, promoting the sexual rights of Autistic youth requires:

Addressing stigma and misconceptions that prevent Autistic youth from sexual expression and fulfillment:

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

Strengthening laws and policies that promote the self-determination of Autistic youth.

Sexual Rights Initiative, 2018

Promoting overall health and wellbeing and improving quality of life

According to the *Canadian Guidelines for Sexual Health Education*, sexual well-being contributes to a better quality of life and overall health and well-being (SIECCAN, 2019).

Sexual well-being requires promoting positive experiences (e.g., sexual and interpersonal relationship satisfaction, self-acceptance, feelings of belonging/inclusion) and mitigating negative experiences (e.g., sexually transmitted infections, unintended pregnancies, sexual abuse, feelings of sexual/relationship distress or worry;

Pearlman-Avnion et al., 2017; SIECCAN, 2019).

Sexual well-being can be experienced individually or in relationships with others and is determined by how an individual perceives a wide range of physical, mental, emotional, and social experiences (World Health Organization, 2002).

Despite the importance of sexuality to Autistic people's self-identity and overall quality of life, Autistic people tend to experience a lower sense of sexual well-being than non-autistic people (Byers & Nichols, 2014; Pecora et al., 2016). Autistic people are at an increased risk of experiencing abuse and sexual victimization, which contribute to poorer sexual well-being (see *Reducing Vulnerability and Mitigating Negative Outcomes*). Further, research indicates that Autistic people are just as likely to want to be in romantic relationships as non-autistic people (Hancock et al., 2020; Strunz et al., 2017), but are much less likely to be in a relationship (Yew et al., 2021).

Project focus group and interview participants indicated that stigma, including misconceptions about autism and negative attitudes towards Autistic youth, is an important barrier to positive relationship experiences for Autistic youth (SIECCAN, 2022b). Further, research indicates that while social connections and feelings of belonging are predictors of romantic relationship initiation, Autistic people tend to have fewer social connections and are more likely to experience reduced feelings of belonging (Pearlman-Avnion et al., 2017).

While factors that contribute to positive sexual wellbeing for Autistic people are not well understood, some research indicates that Autistic people who have an Autistic partner report greater satisfaction with their relationships than Autistic people with non-autistic partners (Strunz et al., 2017). This may be due to greater acceptance and understanding of Autistic ways of being, as well as shared experiences and mutual understanding between partners (Bertilsdotter Rosqvist, 2014).

Fostering Autistic acceptance and understanding among non-autistic youth is, therefore, critical for improving relationship satisfaction for Autistic youth with non-autistic partners.

Research also indicates that some Autistic people who are not in relationships are not distressed about being single (Strunz et al., 2017) and that for some single Autistic people, their sexual satisfaction may increase as their sexual involvement decreases (Pearlman-Avnion et al., 2017).

These findings indicate that, similar to nonautistic people, sexual satisfaction can be experienced in many different ways by Autistic people and that being in an intimate or sexual relationship is not necessary to experience sexual well-being, satisfaction, and personal fulfilment (Park et al., 2021;

Pearlman-Avnion et al., 2017; Træen & Kvalem, 2022).

Being asexual, which refers to not having any or having reduced feelings of sexual attraction or interest in sexual experiences, may be more common among Autistic people (George & Stokes, 2018). Research on how asexuality is experienced among different Autistic youth is limited and requires further investigation (Ronis et al., 2021).

It is also possible that challenges experienced by Autistic people within partnered relationships (e.g., communication differences, sensory sensitivities not addressed) may contribute to relationship and/or sexual dissatisfaction for Autistic people (Bush, 2019; Yew et al., 2021), which may lead to a preference for being single.

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

Focus group/interview participant:
 Autistic/neurodivergent youth

Supporting Autistic youth in identifying and communicating their needs and boundaries to their partners, as well as improving non-autistic youths' responsiveness to their Autistic partner's needs are some ways to promote more positive relationship experiences for Autistic youth (Yew et al., 2021).

Future research is needed to better understand factors that contribute to sexual well-being from the perspective of Autistic youth.

Reducing vulnerability and mitigating negative outcomes

Autistic people are at an increased risk of experiencing abuse and sexual violence

(Dike et al., 2022; Weiss & Fardella, 2018).

Autistic children are more likely to experience physical, psychological/emotional, and sexual abuse compared to non-autistic children (Weiss & Fardella, 2018). Autistic college students are more likely to

report being subjected to unwanted sexual contact than non-autistic students (K. R. Brown et al., 2017), while Autistic adults are two to three times more likely to report having experienced some form of sexual victimization, including sexual assault, compared to non-autistic adults (Brown-Lavoie et al., 2014).

At a societal level, stigma and ableism (i.e., negative attitudes and feelings towards
Autistic youth) contribute to negative
behaviours enacted towards Autistic youth,
including bullying, exclusion, neglect, and
abuse (Canadian Academy of Health Sciences, 2022).

Stigma, lack of community supports for families, and high financial costs associated with supporting an Autistic child can contribute to family/parental stress and isolation, which can create environments where maltreatment may be more likely to occur (Canadian Academy of Health Sciences, 2022; Carey et al., 2020; Chan & Lam, 2016; Tucker & Rodriguez, 2014).

More broadly, Autistic youth may require greater support from caregivers, which can increase their vulnerability to being abused as the perpetrators of maltreatment are often the caregivers themselves (Collier et al., 2006; Martinello, 2014; McDonnell et al., 2019) and maltreatment is more likely to occur when a caregiver or guardian has absolute power over the individual they are caring for (Demer, 2018).

At an individual level, challenges in understanding and recognizing more subtle forms of manipulation and coercion can lead to the misinterpretation of others' behavioural intentions, which may contribute to Autistic youths' vulnerability to being victimized (Cridland et al., 2014; Gibbs et al., 2021; Pecora et al., 2016; SIECCAN, 2022b). Project focus group and interview participants mentioned finding themselves in dangerous situations because they missed "red flags" when interacting with strangers (SIECCAN, 2022b).

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

Focus group/interview participant:
 Autistic/neurodivergent youth

Cisgender Autistic women and girls and Autistic youth who are gender diverse may be particularly vulnerable to sexual victimization. Research indicates that Autistic women and girls are more likely to have engaged in a sexual behaviour or experience that they later regretted and to have experienced unwanted sexual advances compared to both non-autistic women and Autistic men (Dike et al., 2022; Pecora et al., 2016).

It is estimated that nine out of 10 Autistic women have experienced sexual violence (Cazalis et al., 2022).

Autistic women may be more prone to masking (i.e., hiding their natural Autistic characteristics and/or behaviours and adopting those that are more socially accepted), which may increase their vulnerability to unwanted sexual experiences due to feeling pressured into engaging in behaviours they may believe are expected of them (Bargiela et al., 2016). Nonbinary Autistic youth have also been found to be at greater risk of experiencing unwanted sexual contact (K. R. Brown et al., 2017).

Autistic people with more sexual health knowledge are less likely to experience victimization (Brown-Lavoie et al., 2014).

Providing Autistic youth with sexual health education that addresses personal boundaries, consent, personal safety, optimal decision-making, and risk management can increase their capacity to make more informed decisions related to their sexual health (Gerhardt & Lainer, 2011; Mackin et al., 2016).

Further, reducing Autistic youths' risk of victimization requires:

Addressing the structural and systemic factors that contribute to violence (e.g., addressing stigma and discrimination; Gibbs et al., 2021);

Providing parents and families with greater support to reduce family stress (Carey et al., 2020; McDonnell et al., 2019); and

Putting safeguards in place within communities to protect Autistic youth (e.g., regular monitoring and auditing of service agencies; Dubé, 2016).

Finally, safe housing and support services, along with training and resources for service agencies and service providers, are needed so that survivors can access appropriate care, support, and protection (Dubé, 2016).

SECTION 2: BARRIERS TO SEXUAL HEALTH PROMOTION FOR AUTISTIC YOUTH

This section describes barriers to sexual health promotion for Autistic youth, including the impact of prevailing stigma and ableism, the intersectionality of autism with other dimensions of identity, as well as factors that contribute to limited sexual health education for Autistic youth.

Stigma and ableism

Ableism refers to a belief system rooted in negative beliefs (e.g., false assumptions and stereotypes) and feelings (e.g., discomfort) towards Autistic people and disabled people, which can be both conscious and unconscious

(Ontario Human Rights Commission, 2016).

Ableism can manifest itself through acts of discrimination, social exclusion, and limited opportunities for Autistic people and disabled people to fully participate in society (Cremin et al., 2021; Engel & Sheppard, 2020; Ontario Human Rights Commission, 2016).

To better understand how ableist assumptions and stereotypes have come about, it is helpful to consider how autism has been conceptualized. Autism has traditionally been described through a deficit lens, which assumes that non-autistic ways of being are ideal and that deviations from these "ideals" (e.g., Autistic differences) are problems requiring prevention or modification (Bottema-Beutel et al., 2021). This perspective of autism is reflected in the pathologizing language used to talk about autism (e.g., Autistic people as having social/communication deficits and problem behaviours), which, in turn, impacts how Autistic people are treated within society (e.g., being taught to adopt non-autistic behaviours rather than being accepted for who they are).

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

> - Focus group/interview participant: Autistic/neurodivergent youth

In the context of sexual health, the deficit lens of autism assumes that Autistic people are not interested in and/or capable of having safe, fulfilling, and healthy relationships and/or sexual experiences (Brooks, 2018; Joyal et al., 2021). Autistic people are often assumed to lack self-awareness and insight into their own sexuality (Sala, Hooley, et al., 2020). Differences in how Autistic people communicate or interact with others are assumed to be communication deficits and a reflection of their alleged lack of empathy, precluding them from forming meaningful relationships (Brooks, 2018). Requiring any level of support for daily activities is often interpreted as being too dependent and immature to be able to make decisions about romantic and sexual relationships (Brooks, 2018).

Consequently, Autistic people are often excluded from sexual health education, services, and opportunities, which are assumed to be irrelevant to them (Joyal et al., 2021; Sala, Hooley, et al., 2020). The de-sexualization of Autistic and neurodivergent youth was a recurring theme in the

focus group discussions and interviews. Autistic and neurodivergent youth noted that health and social service providers often assumed they were uninterested in engaging in sexual activity and that peers rarely saw them as potential romantic or sexual partners (SIECCAN, 2022b). Further, there is a general lack of acceptance of Autistic ways of experiencing and/or expressing sexuality. Common discourse around the sexuality of Autistic people typically compares Autistic experiences to non-autistic ideals, positioning Autistic experiences of sexuality as either problematic when they differ from non-autistic experiences or acceptable when they align (Bertilsdotter Rosqvist, 2014).

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

- Focus group/interview participant: Autistic/neurodivergent youth

Recently, there has been growing support for the Autistic-led neurodiversity conceptualization of autism, which frames autism as a dimension of difference, representing an important aspect of an individual's sense of self, that should be respected (Orsini, 2012). From this perspective, Autistic people are recognized as full persons, with unique strengths and areas of support needs, as well as with rights that should be upheld.

The neurodiversity perspective acknowledges the role that society plays in creating barriers and limitations to the full societal participation of Autistic people (Botha & Gillespie-Lynch, 2022; Dwyer, 2022). As such, the focus shifts away from changing the Autistic person to fit their environment towards accepting Autistic people as they are and providing Autistic people with the supports, services, and accommodations they need to navigate environments that may not have been designed with their needs in mind (Canadian Academy of Health Sciences, 2022;

Orsini, 2012). Further, this perspective calls for societal level change (e.g., addressing stigma, changing the built environment) to better meet the needs of Autistic people (Botha & Gillespie-Lynch, 2022).

Adopting a neurodiversity perspective within sexual health promotion initiatives involves approaching autism through a lens of acceptance and supporting Autistic youth to achieve sexual well-being in ways that work for them.

A neurodiversity-affirming approach that validates and affirms Autistic identities can contribute to greater societal acceptance of autism and enable Autistic youth to develop a more positive self-image. Further, a neurodiversity perspective shifts the focus away from problematizing Autistic ways of experiencing sexuality and towards identifying ways society can remove existing barriers to sexual health education, services, supports, and opportunities for Autistic youth.

At a broader community level, incorporating a neurodiversity-affirming approach to sexual health can allow for a beneficial expansion of conceptualizations of sexual and relationship well-being that is inclusive of the needs and rights of all people.

Stigma and the intersectionality of autism

Intersectionality refers to the many social identities that an individual can have, which interact with one another in complex ways to create unique experiences of advantage or disadvantage (Crenshaw, 1989).

In recognizing the impact that stigma can have on access to sexual health education, services, and opportunities for Autistic youth, it is important to also consider how ableism intersects with other forms of stigma and systemic disadvantage to create additional barriers to sexual health and wellbeing for particular groups of Autistic youth.

Intersecting identities that need to be considered include, but are not limited to, the following:

Black Autistic youth

Black Autistic youth are subjected to both ableism and systemic racism, which contribute to sexual health inequities. Systemic racism refers to the ways in which systems (e.g., political, legal, health care, education, economic) are set up to advantage certain groups of people and disadvantage others on the basis of race (Anti-Racism Directorate, 2022; Braveman et al., 2022). These systems, in turn, create harm, as well as barriers to accessing opportunities, for racialized groups in ways that are unjust. These systems are rooted in historical and ongoing negative beliefs and attitudes about racialized groups, and contribute to further perpetuating these harmful ways of thinking, as well as maintaining racial inequities.

Systemic racism, and specifically anti-Black racism (i.e., negative attitudes and beliefs, stereotypes, and acts of discrimination enacted towards Black people, Anti-Racism Directorate, 2022), directly affects access to quality supports and services for Black Autistic people (Straiton & Sridhar, 2022).

Black Autistic people are less likely to access specialized health services compared to white Autistic people (Smith et al., 2020). Families of Black Autistic people report experiencing racist

interactions with service providers when receiving health care services (e.g., having their concerns dismissed due to racial bias, lack of cultural sensitivity among service providers), which contribute to lower quality of care for Black Autistic people (Jones & Mandell, 2020; Stahmer et al., 2019).

Black Autistic youth are also more likely to be subjected to abuse and maltreatment. For instance, due to racial profiling and a misinterpretation of Autistic behaviours, Black Autistic youth may be at heightened risk of being targeted by, and to having negative interactions with, law enforcement (Davenport et al., 2021).

Indigenous Autistic youth

Canada's colonial history, within which Indigenous people were forcibly removed from their families, traditional lands, and cultures, and were physically and sexually abused within residential school systems, has produced immense trauma with ongoing ramifications for creating and maintaining sexual health inequities (Hackett et al., 2021; Matheson et al., 2022; Negin et al., 2015).

For instance, Negin and colleagues (2015) noted that factors that contribute to higher HIV risk among Indigenous people (e.g., substance use, childhood abuse, domestic violence, and a mistrust of the health care system) are rooted in colonialism.

Indigenous people experience many barriers to accessing health services including limited availability of local services, having to travel long distances to access services, and a lack of culturally responsive services (e.g., services that account for cultural and language differences; Nguyen et al., 2020). Further, Indigenous people often experience racial stereotyping by health care providers, which contribute to poorer quality of care (Turpel-Lafond, 2020). Similar barriers are experienced by families of Indigenous Autistic youth when seeking autism-related services (Gerlach et al.,

2022). As a result, many Indigenous Autistic youth are not able to access the services they need, including sexual health services.

Opportunities to learn about sexual health may also be limited for Indigenous Autistic people. Residential schools destroyed many traditional means of passing down culturally safe sexual health knowledge from generation to generation and instead, stigmatized sexuality and sexual health as children were taught to view sex as taboo (Hackett et al., 2021). These negative teachings about sexuality, along with experiences of sexual abuse within residential schools, have made it difficult for parents to initiate positive conversations about sexual health with their children (Henderson et al., 2018). Further, remote reserves often have limited access to reliable and affordable broadband Internet, which limits access to online sexual health information and virtual services (Collier, 2021; Nguyen et al., 2020).

Culturally diverse Autistic youth from immigrant families

According to the 2021 Canadian Census, about 25% of Canadians were a landed immigrant or permanent resident in Canada, with the majority of immigrants (62%) coming from Asia (including the Middle East; Statistics Canada, 2022). Further, 31.5% of Canadian youth under the age of 15 are second-generation Canadians (i.e., children of immigrant parents).

Accessing services in a new country can pose many challenges for immigrant families, who have to learn and navigate new and complex systems of services (Khanlou et al., 2017).

Language barriers, lack of culturally sensitive services, and experiences of discrimination limit access to quality services for Autistic youth from immigrant families (Khanlou et al., 2017; Shanmugarajah et al., 2022).

These barriers also create challenges for youth from immigrant families to access sexual health education and services (Louie-Poon et al., 2021; Maheen et al., 2021).

Talking about sexuality may also be taboo in some cultures, which may make it difficult for Autistic youth from immigrant families to turn to their families for sexual health related guidance and support (Louie-Poon et al., 2021; SIECCAN, 2022b; Wong et al., 2017).

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

Focus group/interview participant:
 Autistic/neurodivergent youth

Two-Spirit, lesbian, gay, bisexual, transgender, queer, intersex, nonbinary, and asexual (2SLGBTQINA+) Autistic youth

Autistic people are more likely to identify with a gender different from sex assigned at birth and a sexual orientation other than heterosexuality compared to non-autistic people (Strang et al., 2018; Weir et al., 2021).

Ableist assumptions that Autistic people lack self-awareness about their sexuality often result in 2SLGBTQINA+ Autistic people having their gender identity or sexual orientation dismissed or invalidated (Hillier et al., 2020; Khudiakova & Chasteen, 2022; Lewis et al., 2021). These ableist assumptions create additional barriers for 2SLGBTQINA+ Autistic youth to access needed supports and services, including access to gender-affirming care for trans Autistic youth (Strauss et al., 2021).

2SLGBTQINA+ Autistic youth often experience ableism within 2SLGBTQINA+ communities, as well as a lack of acceptance of their 2SLGBTQINA+ identity within their families and peer groups, which can create additional challenges to finding a community where 2SLGBTQINA+ Autistic youth feel safe and accepted (Hillier et al., 2020; Khudiakova & Chasteen, 2022; Lewis et al., 2021).

2SLGBTQINA+ Autistic youth often have to make tough choices around disclosing their gender identity and/or sexual orientation, as well as disclosing their Autistic identity (Lewis et al., 2021).

Asexual Autistic youth also experience unique challenges. Stereotypes about Autistic people as necessarily being asexual may cause Autistic people to deliberately distance themselves from the "asexual" label, which can, in turn, create additional stigma towards asexual Autistic youth (The Ace and Aro Advocacy Project, 2022). Further, as with many Autistic people, asexual Autistic youth can engage in masking (i.e., hiding their natural Autistic characteristics and/or behaviours and adopting those that are more socially accepted) within their relationships, which can lead to unwanted sexual experiences in an effort to please their partner, as well as increase their vulnerability to abuse (SIECCAN, 2022b).

"Sometimes he asks 'do you even want to have sex?' and I'll be like 'well yeah.' I don't have the drive for it at all, I'm asexual, that's just how it is, but I'm like he does and I enjoy being with him so let's do that."

Focus group/interview participant:
 Autistic/neurodivergent youth

These intersecting forms of stigma contribute to challenges with self-acceptance, mental health, social isolation, and abuse for 2SLGBTQINA+ Autistic youth, which can negatively impact their sexual health (Hillier et al., 2020; Lewis et al., 2021).

Autistic youth who have an intellectual disability

Intellectual disabilities refer to impairments in both intellectual and adaptive functioning that begin in childhood (American Psychiatric Association, 2013). It is estimated that 30-40% of Autistic children have a co-occurring intellectual disability (Shenouda et al., 2023).

People with intellectual disabilities experience many of the same barriers to accessing sexual health education, services, and opportunities as Autistic people. These barriers include stigma, obstacles to exercising self-determination, lack of sexual health education that is accessible and relevant, and limited knowledge and training among service providers to address the sexual health needs of people with intellectual disabilities. (M. Brown & Mccann, 2018; Schaafsma et al., 2017; Thompson et al., 2014).

These issues may be further compounded for Autistic youth with a co-occurring intellectual disability, resulting in additional gaps in sexual health education (e.g., lack of information addressing communication and sensory differences that is offered in plain language; Sala et al., 2019), additional barriers to self-determination (Chou et al., 2017), and greater vulnerability to abuse (McDonnell et al., 2019).

Autistic youth who are non-speaking

Autistic youth who are non-speaking experience communication barriers due to a lack of social acceptance of alternative forms of communication. Augmentative and alternative communication (AAC) are text-based or symbol-based communication systems that can range from basic pen and paper or picture exchange communication systems (PECS) to more complex text-to-speech generating devices and smartphone/tablet applications (van Grunsven & Roeser, 2022).

AAC systems can facilitate communication and enable the inclusion of many non-speaking or partially speaking Autistic youth. However, a lack of public acceptance of AAC and the privileging of verbal forms of communication can serve as a barrier to non-speaking Autistic youth having access to AAC systems, as well as using AAC systems in their everyday lives (Moorcroft et al., 2019). These barriers contribute to the exclusion of non-speaking Autistic youth from opportunities to socialize, date, work, and participate in community life.

Further, many AAC systems do not offer sufficient vocabulary related to sexual health, including words and symbols to communicate about relationships, consent, abuse, gender identities, and sexual orientations (AssistiveWare, 2023; Collier et al., 2006; Denome, 2020; Sellwood et al., 2022). While these words can be added or programmed into AAC systems, doing so may require the assistance of service providers or family members, who may not always be open to providing Autistic youth with sexual health vocabulary due to prevailing stigma about the sexuality of Autistic youth.

Not having the means to communicate about sexual health can make AAC users more likely to be targeted by abusers, can limit opportunities for AAC users to have fulfilling relationships and to explore their identity, as well as prevent AAC users from communicating consent (Collier et al., 2006; Denome, 2020).

Limited sexual health education for Autistic youth

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, 2020). For Autistic people, evidence indicates that sexual health education can increase their knowledge of a variety of sexual health topics (Visser et al., 2017) and reduce their vulnerability to sexual violence (Brown-Lavoie et al., 2014).

Most schools in Canada offer some form of sexual health education curriculum. However, Autistic youth often do not have access to school-based sexual health education (Davies et al., 2022).

For instance, many Autistic students are placed in special education environments where sexual health education is not provided (Barnett & Maticka-Tyndale, 2015). Even when sexual health education is offered to Autistic youth, most programs are not designed to meet their needs (Davies et al., 2022; Strnadová et al., 2021).

At home, parents and family members can play an important role in providing sexual health information to Autistic youth. However, as with parents of non-autistic youth, many experience discomfort talking about sexuality with their children (André et al., 2020). Parents often have limited support and resources to effectively engage in conversations about sexual health with their children (Mackin et al., 2016).

Research indicates that the topics parents are more likely to cover with their Autistic children include privacy of body parts, types of physical contact, personal hygiene, and puberty (André et al., 2020; Graham Holmes et al., 2019). Topics such as dating, sexual intercourse, sexually transmitted infections, pregnancy, and preventative care (e.g., Pap tests) are less likely to be discussed, possibly due to discomfort discussing these topics or the assumption

that these topics are not relevant to Autistic youth (André et al., 2020; Graham Holmes et al., 2019). Parents with more positive romantic expectations for their children tend to discuss a wider range of sexual health topics with their children (André et al., 2020).

Without access to formal and reliable avenues for sexual health information, Autistic youth may be more likely to turn to unmonitored sources to learn about sexual health, such as television/radio, sexually explicit media (e.g., pornography), and the Internet (Brown-Lavoie et al., 2014). The majority of project focus group and interview participants indicated that the Internet was their main source of sexual health information (SIECCAN, 2022b). However, Autistic and neurodivergent youth noted that they were not always able to find the answers they were looking for on the Internet and that they sometimes consumed misinformation. Further, some participants mentioned finding themselves in dangerous situations when interacting with strangers due to challenges recognizing more subtle forms of manipulation or coercion.

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

Focus group/interview participant:
 Autistic/neurodivergent youth

It is imperative to improve sexual health education for Autistic youth - both in terms of content and accessibility.

Autistic youth have indicated a need to gain more knowledge and skills related to forming and maintaining romantic relationships, as well as more specific information about different sexual behaviours (Cheak-Zamora et al., 2019). Sexual health education for Autistic youth should consider how particular aspects of autism, such as sensory sensitivities, having highly focused interests, and communication differences, can influence different aspects of sexuality and sexual health (Dewinter et al., 2015). Further, sexual health education should cover both the promotion of positive experiences and the prevention of negative experiences (SIECCAN, 2019, 2022b).

"We need to teach more about prioritizing pleasure, being able to define sex in various ways, deconstructing virginity/purity culture and publicizing info on intimacy that isn't inherently sexual."

Focus group/interview participant:
 Autistic/neurodivergent youth

Finally, addressing self-respect and self-esteem may be particularly important for Autistic youth as prevailing stigma about the sexuality of Autistic youth can hinder positive self-identity formation (Cooper et al., 2017; Joyal et al., 2021).

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

This section outlines core principles for effective sexual health promotion with Autistic youth. Nine core principles are drawn from the *Canadian Guidelines for Sexual Health Education* (SIECCAN, 2019), and five new core principles are recommended to specifically address the sexual health needs of Autistic youth.

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

The Canadian Guidelines for Sexual Health Education (https://www.sieccan.org/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 with Autistic youth.

Accordingly, sexual health promotion with Autistic 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 (2SLGBTQINA+), and other emerging identities;
- 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; and
- 9. Is provided by service providers who have the knowledge and skills to deliver sexual health education and who receive administrative support to undertake this work.

Additional core principles for effective sexual health promotion with Autistic youth

To complement the core principles of comprehensive sexual health education, the following five additional core principles are recommended to ensure that sexual health promotion with Autistic youth prioritizes the perspectives of Autistic youth, affirms and validates Autistic identities, is tailored to individual needs and experiences, and mitigates the reproduction of past harms.

Accordingly, sexual health promotion with Autistic youth:

10. Is neurodiversity-affirming by accepting and validating Autistic ways of being:

Neurodiversity-affirming practices are approaches to supporting Autistic youth that accept and validate Autistic ways of being and interacting with the world (Dallman et al., 2022). Supports and services for Autistic youth should be rooted in promoting their dignity, identity, and human rights as opposed to changing the core of who Autistic youth are (Dwyer, 2022). Goals of supports should be determined in collaboration with Autistic youth and prioritize health and well-being over "fitting in" or meeting non-autistic ideals. Diverse ways of communicating, including the use of AAC devices, should also be offered and respected.

11. Considers how multiple social identities intersect to create unique experiences of advantage/ disadvantage for Autistic youth:

Intersectionality refers to the many social identities (e.g., race, gender identity, sexual orientation) that an individual can have, which interact with one another in complex ways to create unique experiences of advantage or disadvantage (Crenshaw, 1989). This perspective recognizes that some Autistic youth may experience greater disadvantage related to sexual health and well-being due to having multiple marginalized identities, which needs to be considered within sexual health promotion initiatives.

Accordingly, sexual health promotion with Autistic youth:

12. Is person-directed in that Autistic youth play a leading role in identifying their sexual health goals and the supports they need to meet these goals:

Person-directed planning is an approach to supporting Autistic youth whereby Autistic youth play a leading role in defining their own goals and the supports they need to achieve those goals (Martin et al., 2016; Ministry of Community and Social Services, 2013). Person-directed planning is similar to person-centred approach in that supports are personalized to account for each Autistic youth's unique needs and circumstances but takes it a step further by transferring decision-making power away from service providers to Autistic youth.

To facilitate person-directed planning, it is important to have a support team who is chosen by the Autistic youth, who values and respects decisions made by Autistic youth, and who provides ongoing support over the long term. The use of inclusive approaches (e.g., using diverse communication methods, making accommodations to address accessibility needs, providing Autistic youth with enough time to make decisions) can facilitate the meaningful participation of Autistic youth in decision-making processes (Luke et al., 2012; Maye et al., 2021; Nicolaidis et al., 2011; Satkoske et al., 2020). Some Autistic youth may require support in making important sexuality and sexual health decisions and communicating these decisions to others. In these cases, supported decision-making should be made available to the full extent possible instead of guardianship or substitute decision-making (Stainton, 2016).

13. Is strengths-based by leveraging each Autistic youth's unique abilities:

A strengths-based approach to supporting Autistic youth begins with a recognition of the strengths and capabilities that the individual already possesses and explores ways these strengths can be leveraged to achieve a particular goal (Lee et al., 2020). This approach avoids pathologizing Autistic ways of being and, instead, empowers Autistic youth to recognize their owns strengths and to value the contributions they make to improving their own lives.

14. Is trauma-informed by considering how past traumas can continue to impact the lives of Autistic 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 (Reeves, 2015). Autistic youth may be at an increased risk of experiencing stressful and traumatic life events compared to non-autistic youth and thus, adopting a trauma-informed approach is particularly important when supporting Autistic youth (Allely & Faccini, 2020).

Some important elements of trauma-informed approaches include building trust, promoting safety, fostering choice and self-agency, and improving emotional self-regulation (Berger et al., 2021). Adopting a trauma-informed approach also requires taking the necessary precautions to avoid inadvertently causing additional trauma when providing supports to an individual (Reeves, 2015).

SECTION 4: GUIDELINES FOR SEXUAL HEALTH PROMOTION WITH AUTISTIC YOUTH

This section outlines five guidelines for effective sexual health promotion with Autistic youth for policy and program decision-makers to consider and implement. Key priorities for sexual health promotion with Autistic youth were identified through SIECCAN's service provider consultation survey and focus groups and interviews with Autistic and neurodivergent 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 and delivery of sexual health education and services for Autistic youth.

Guidelines

1. Promote Autistic acceptance, including dispelling myths and misconceptions about the sexuality of Autistic youth.

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

Focus group/interview participant:
 Autistic/neurodivergent youth

Social stigma and misconceptions about Autistic youth create barriers to accessing sexual health education, services, and opportunities (Joyal et al., 2021). Promoting Autistic awareness and acceptance is, therefore, imperative to improving sexual health promotion for Autistic youth.

Recommendations for fostering greater understanding and acceptance of Autistic ways of being:

Approach autism through a neurodiversity-affirming lens

Autistic awareness and acceptance initiatives (e.g., public campaigns, educational and training programs) should reflect a neurodiversity perspective and emphasize Autistic acceptance (Kim, 2020). Showcasing the diversity that exists among Autistic youth can help to challenge existing myths and stereotypes about autism and foster greater recognition of the diversity that exists (Brooks, 2018). Any initiative about Autistic youth should be done in collaboration with Autistic youth to avoid perpetuating harmful stereotypes (Bertilsdotter Rosqvist, 2014; Brooks, 2018).

Deliver public campaigns aimed at improving public attitudes

Public campaigns have the potential to improve public attitudes and challenge misconceptions about the sexuality of Autistic youth. Effective public campaigns are well-funded, adopt a neurodiversity perspective, include Autistic people in their design and implementation, use multiple communication strategies, and are carried out for an extended period of time (Canadian Academy of Health Sciences, 2022; Kras, 2010; Milton, 2012a).

Provide service providers with education and training about neurodiversity

Provide training and professional development opportunities to service providers that emphasize the use of neurodiversity-affirming approaches that respect and validate Autistic perspectives and ways of being (Chun & Fisher, 2014; Kapp, 2019), as well as the adoption of trauma-informed approaches that acknowledge Autistic youths' experiences of trauma, including trauma related to stigma and ableism (Benevides et al., 2020).

Provide non-autistic youth with education about autism

Peer-focused programs can improve knowledge, attitudes, and behaviours of non-autistic youth towards their Autistic peers, which can, in turn, help foster school and community inclusion (Cremin et al., 2021). A combination of the following factors can improve effectiveness of peer-focused programs: having multiple sessions, using smaller groups, facilitating social contact between Autistic and non-autistic youth, using both descriptive and explanatory information, and using structured in-person teaching and/or multimedia (Cremin et al., 2021; Lindsay & Edwards, 2013).

Foster opportunities for non-autistic youth to interact with Autistic youth

Create and facilitate direct and positive interactions between Autistic and non-autistic youth within a supportive environment (Anthony et al., 2020; Fisher & Purcal, 2017; Huskin et al., 2018; Kuzminski et al., 2019). These interactions should also be accompanied by additional information that challenge misconceptions and promote equity (Fisher & Purcal, 2017; Huskin et al., 2018).

Recommendations for fostering greater understanding and acceptance of Autistic ways of being:

Include autism within sexual health education for non-autistic youth

To address misconceptions about the sexuality of Autistic youth and to foster greater understanding and acceptance of autism, sexual health education delivered to non-autistic youth should include information about Autistic ways of experiencing sexuality, depicted from a neurodiversity perspective (Joyal et al., 2021; Sala, Hooley, et al., 2020). Greater understanding and acceptance of autism can, in turn, lead to a greater sense of belonging and inclusion for Autistic youth (Renwick et al., 2019) and encourage Autistic youth to develop a positive sense of self (Adams & Liang, 2020; Dwyer, 2022).

2. Deliver comprehensive sexual health education that is accessible and addresses the specific needs and experiences of Autistic youth.

Comprehensive sexual health education can enable Autistic youth to make informed decisions about their sexual health and well-being (Brown-Lavoie et al., 2014; SIECCAN, 2019). However, sexual health education is often either inaccessible to Autistic youth, based on misconceptions about the sexuality of Autistic youth, or does not adequately meet the needs of Autistic youth.

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

Improve the accessibility of comprehensive sexual health education for Autistic youth

Given that Autistic youth are less likely to receive credible sexual health education from sources such as peers, romantic partners, and parents/caregivers, formal means of learning about sexual health are particularly important for Autistic youth (Brown-Lavoie et al., 2014). Applying the principles of Universal Design for Learning to the content and delivery of sexual health education can make this information more accessible to Autistic youth (Carrington et al., 2020).

For instance, it is recommended that sexual health education for Autistic youth is highly structured, communicates information explicitly and in detail, includes concrete examples, provides opportunities for Autistic youth to practice and review their learning, and uses video or other visual materials (Austin & Peña, 2017; Barnett & Maticka-Tyndale, 2015; Davies et al., 2022). Service providers are also encouraged to monitor the emotional well-being of Autistic youth, recognize potential triggers for anxiety, and offer breaks when necessary (Gobbo & Shmulsky, 2014). Sexual health education should also be offered throughout the lifespan to allow for ongoing learning (Barnett & Maticka-Tyndale, 2015).

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

Provide Autistic youth with information about their sexual rights

The United Nations' *Convention on the Rights of Persons with Disabilities* (CRPD) stipulates that Autistic youth are entitled to the full range of human rights and fundamental freedoms on an equal basis with others (UN General Assembly, 2006). Autistic 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 Autistic youth should be aware of include, but are not limited to, their right to:

- Access sexual health information and services;
- Make decisions about their own lives;
- · Define their own sexuality and identity;
- Express their sexuality;
- · Decide if they want to be sexually active or not;
- · Choose their own sexual partners;
- · Safe and pleasurable sexual experiences;
- Be free from sexual violence;
- Privacy;
- Marriage equality; and
- Have children

Chin et al., 2018; Illinois Guardianship and Advocacy Commission, 2020

Provide Autistic youth with information related to the prevention of abuse

To improve the safety of Autistic youth, it is recommended that sexual health education addresses what constitutes abuse (Sala et al., 2019), how to recognize potentially harmful or dangerous situations (Brown-Lavoie et al., 2014), self-protection and assertiveness (Weiss & Fardella, 2018), and empowered decision-making (Sala et al., 2019). Ensuring Autistic youth, including AAC users, have the vocabulary to communicate consent and to report abuse is imperative to promoting the safety of Autistic youth (Collier et al., 2006).

Sexual health education should also provide guidance on understanding the intentions of others (Hannah & Stagg, 2016) and discerning between appropriate and inappropriate behaviours (Brown-Lavoie et al., 2014; Sala, Hooley, et al., 2020), including providing examples of more subtle forms of abuse, exploitation, manipulation, and coercion (Barnett & Maticka-Tyndale, 2015). Finally, education about consent, including refusing unwanted touch or interactions, may be particularly important for Autistic youth, whose ability to exercise self-determination has often been restricted (Martinello, 2014).

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

Foster understanding and improving communication between Autistic and non-autistic youth

Autistic and non-autistic youth have different communication preferences. For instance, Autistic youth tend to prefer more direct communication when dating, while non-autistic youth often rely on subtle, implicit, and indirect forms of communication (Sala, Hooley, et al., 2020; SIECCAN, 2022b). Autistic people have often been described as having communication deficits and as lacking empathy (Milton, 2012b). However, the theory of the double empathy problem suggests that the social challenges Autistic people experience may be due to misunderstandings between Autistic and non-autistic people, who think and interact with the world differently, rather than an inherent deficit within the Autistic person (Milton, 2012b).

As such, educating both Autistic and non-autistic youth about different communication styles, understanding verbal and non-verbal communication, effective listening, and strategies for accommodating different preferences and needs can improve understanding and communication between Autistic and non-autistic youth (Joyal et al., 2021; Weir et al., 2021; Yew et al., 2021).

Provide Autistic youth with strategies to navigate a predominantly non-autistic world, while affirming Autistic ways of being

Providing Autistic youth with information about non-autistic ways of dating and engaging in intimate/ sexual relationships can enable Autistic youth to better understand non-autistic people (SIECCAN, 2022b). However, it is also important to emphasize that non-autistic ways of being are not ideals to strive for (Rothman et al., 2022). Information about the unique and diverse ways Autistic youth may experience relationships and sexuality (e.g., sensory sensitivities, communication differences) should also be presented as valid ways of being (Barnett & Maticka-Tyndale, 2015; Gray et al., 2021; Rothman et al., 2022).

Further, in relationships involving Autistic and non-autistic youth, both Autistic and non-autistic youth should be encouraged to listen, understand, and accommodate the needs of the other person, as opposed to placing the responsibility of accommodating solely on the Autistic youth (Sala, Hooley, et al., 2020). Ultimately, sexual health education should be neurodiversity-affirming and enable Autistic youth to develop positive self-esteem and pride in their Autistic identity (Adams & Liang, 2020; Joyal et al., 2021).

3. Promote and amplify the voices of Autistic youth in the development and implementation of sexual health education and services for Autistic youth.

There is growing recognition that lived experience expertise is imperative to the planning, development, and delivery of health promotion initiatives (Bryant, 2002). However, initiatives that are intended to benefit Autistic youth have predominantly been carried out by non-autistic people, without the meaningful input of Autistic youth (Milton, 2014; Petri et al., 2021; Renwick et al., 2019).

The lack of meaningful Autistic representation in research and decision-making processes has contributed to a misrepresentation of autism (e.g., from a deficit lens) and health promotion initiatives that have missed the mark on addressing the self-defined needs of Autistic youth (van den Bosch et al., 2019). "Nothing about us without us" reflects the notion that Autistic youth should be meaningfully involved in initiatives that are meant to benefit Autistic youth (van den Bosch et al., 2019).

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

Support Autistic youth in developing leadership skills

Given that the self-determination of Autistic youth has historically been restricted, many have not had opportunities to develop these important life skills (Gillespie-Lynch et al., 2017; Webster et al., 2022). As such, self-advocacy training, along with mentorship and coaching, can enable Autistic youth to develop leadership and decision-making skills, have greater control over their lives, and take on greater leadership roles (Bertilsdotter Rosqvist et al., 2015; Gillespie-Lynch et al., 2017; Waltz et al., 2015).

Consult with diverse Autistic youth

It is critical that diverse Autistic voices are informing the development of sexual health education and services, including 2SLGBTQINA+ Autistic youth, Black, Indigenous, and Autistic youth of colour, Autistic youth from immigrant families, Autistic youth who are non-speaking, Autistic youth who have an intellectual disability, and Autistic youth with complex support needs. Having the voices of diverse Autistic youth inform sexual health promotion initiatives increases the likelihood that these initiatives will accurately respond to the diverse needs and experiences of Autistic youth (Botha & Gillespie-Lynch, 2022; Cheak-Zamora et al., 2019; Maye et al., 2021; Strnadová et al., 2021).

Create opportunities for Autistic youth to hold positions of leadership and to be meaningfully involved in the development and delivery of sexual health promotion initiatives

Autistic youth should be co-leading and co-producing sexual health education/training and research initiatives (Rothman et al., 2022; Strnadová et al., 2021). Evidence indicates that autism-related educational and training programs tend to be more impactful when delivered by an Autistic person (Cremin et al., 2021). Organizations and institutions should consider how their funding and organizational activities can foster leadership opportunities for Autistic youth (e.g., allocate funding to provide appropriate compensation for Autistic youths' contributions, support diverse communication methods and other accessibility considerations, offer leadership training and mentorship for Autistic youth; Petri et al., 2021; Waltz et al., 2015).

Strategies for meaningfully engaging with Autistic youth include using inclusive decision-making strategies (e.g., see five-finger method in Nicolaidis et al., 2011), addressing the unequal distribution of power between Autistic and non-autistic people, using diverse communication methods (e.g., verbal, written, augmentative and alternative communication (AAC), American Sign Language), providing people with enough time and information to make informed decisions, removing potential distractions, and fostering a safe environment (e.g., adopting a trauma-informed approach; Luke et al., 2012; Maye et al., 2021; Nicolaidis et al., 2011; Satkoske et al., 2020).

4. Build the capacity of service providers and families to have the knowledge and confidence to effectively promote sexual health with Autistic youth.

Service providers and family members have an important role to play in supporting the sexual health of Autistic youth, but many feel ill-equipped to effectively do so (André et al., 2020; Pecora et al., 2016; Strnadová et al., 2021).

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

Provide service providers with training and education

Service providers require pre- and in-service training and education on autism/disability and sexuality. Training should emphasize Autistic acceptance (e.g., neurodiversity-affirming approach, addressing misconceptions), safety (e.g., trauma-informed approach), and accessibility (e.g., principles of Universal Design for Learning; Strnadová et al., 2021; Weir et al., 2021). Further, training should focus on both the promotion of positive experiences (e.g., healthy relationships, making informed choices if or when Autistic youth engage in sexual activity, pregnancy, and parenthood), as well as the prevention of negative outcomes (e.g., sexually transmitted infections, unintended pregnancies, sexual abuse, feelings of sexual/relationship distress or worry).

Ongoing training opportunities, such as professional development courses, webinars, and conferences, can reinforce knowledge and enable service providers to update their learning based on emerging research and promising practices (Davies et al., 2022).

Improving abuse prevention and response within service agencies

Service agencies that support Autistic youth should have clear and transparent abuse prevention and reporting policies and procedures that are developed with Autistic youth and made available in accessible formats (Collier et al., 2006). Service providers require training on what constitutes abuse, recognizing risk factors and signs of abuse, how to engage in discussions about abuse with Autistic youth, proactively screening for abuse, and referring Autistic youth to appropriate supports (Bowman et al., 2010; Sala, Pecora, et al., 2020; Weir et al., 2021).

Role of service providers in supporting parents/families

Service providers can support parents and families by engaging in ongoing discussions about sexual health education content, creating opportunities and safe environments for open and honest conversations that are led by a knowledgeable facilitator, developing resources for parents to use at home (e.g., a list of frequently asked questions, list of useful terminology, scripts), and directing parents and families to helpful resources (e.g., articles written by Autistic people, books, and online support groups; Davies et al., 2022; Mackin et al., 2016; Sala, Pecora, et al., 2020).

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

Collaboration between service providers, families, and Autistic youth

Effective sexual health promotion with Autistic youth requires collaboration and shared decision-making between service providers, parents/families, and Autistic youth themselves so that all stakeholders are working towards a common goal (Travers & Tincani, 2010). Collaborating with parents/families and Autistic youth in the planning, development, and implementation of sexual health promotion initiatives is critical so that unique cultural and contextual factors are accounted for. The involvement of parents/families enables supports to be provided across multiples settings (e.g., at home, at school, and in the community), while the involvement of Autistic youth ensures that their needs and goals are prioritized (Davies et al., 2022; Travers & Tincani, 2010; Weir et al., 2021).

Greater sharing of information, resources, and best practices between service providers across different sectors (e.g., education, health, and autism services) can also help to strengthen service providers' knowledge, skills, and confidence in supporting Autistic youth (Canadian Academy of Health Sciences, 2022).

5. Advance research on the sexual health and well-being of Autistic youth.

The sexuality and sexual well-being of Autistic youth have received limited attention in research and therefore, remain poorly understood (Pecora et al., 2016). Further, research that has been carried out in this area has often adopted a deficit-based lens, depicting Autistic ways of being as deficient in comparison to non-autistic ideals (Bertilsdotter Rosqvist & Jackson-Perry, 2021).

Future research should adopt a neurodiversity-affirming approach and focus on addressing the self-identified sexual health needs of Autistic youth (Dwyer, 2022). Participatory and action-oriented research, which involves researchers collaborating with community members (e.g., Autistic youth, families) as equal partners in research design and decision-making, can enable the greater involvement of Autistic youth in research that is intended to benefit them (Maye et al., 2021). This requires being intentional about meaningfully engaging diverse community members in the research process, including accommodating for diverse accessibility needs (Canadian Academy of Health Sciences, 2022). Further, building the capacity of Autistic researchers (e.g., training, funding opportunities) can strengthen and expand the autism research base as Autistic researchers bring both research and lived experience expertise to the field.

Recommended areas for future research:

Define sexual well-being and healthy relationships from the perspective of Autistic youth;

Identify factors that contribute to sexual well-being for diverse Autistic youth, including those who identify as asexual;

Understand the sexual health experiences and needs of diverse Autistic youth, including 2SLGBTQINA+ Autistic youth, Black, Indigenous, and Autistic youth of colour, Autistic youth from immigrant families, Autistic youth who are non-speaking, Autistic youth who have an intellectual disability, and Autistic youth with complex support needs;

Understand the sensory experiences of Autistic youth and their implications for sexual health;

Understand and address challenges Autistic youth experience with forming and maintaining romantic/intimate relationships; and

Understand and address factors that contribute to risk of victimization, particularly for Autistic women and girls and Autistic youth who are gender diverse.

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