# youth with disabilities needs assessment

external report

planned parenthood toronto may 2020

## **executive summary**

Planned Parenthood Toronto (PPT) adopted a 2015-2020 strategic plan with a major strategic direction to "Expand Our Reach to Youth Who Need Us Most". In pursuit of this strategic direction, PPT undertook a 2015/2016 needs assessment exploring the sexual and reproductive health (SRH) needs of youth in Toronto. This needs assessment identified youth with disabilities as a priority population with high levels of unmet SRH needs. To further "Expand Our Reach to Youth Who Need Us Most", an additional needs assessment was conducted in 2018/2019 to help PPT better understand the barriers and facilitators that affect youth with disabilities' access to SRH information and services.

The Youth With Disabilities project was guided by a Youth Advisory Committee (YAC) consisting of eight youth with a range of disabilities. Input from the YAC included identifying priority populations, improving the accessibility of the research process, and developing outreach strategies. Participants in this needs assessment were 13- to 29-year-old youth with disabilities in Toronto. They were directly engaged through an online survey, focus groups, and individual interviews.

## key findings

#### Accessibility

- Only 56% of survey respondents reported that they have access to all of the SRH information they need, and even fewer (35%) indicated that they have access to all of the SRH services and programs they need.
- 89% of survey respondents agreed that it would be beneficial if SRH service providers asked about their access needs (ie. what they need to be able to fully participate); but only 15% indicated that they have been asked about their access needs.
- The top facilitators to accessing sexual and reproductive health (SRH) programs and services included:
  - Anti-oppressive spaces (83%)
  - Presence of disabled staff and/or volunteers (70%)
  - Convenient location (68%)
  - Programs and services for and by disabled people (66%)
  - Health information specifically for disabled people (64%)
  - Staff knowledgeable about disability and SRH (62%)
  - Non-judgemental staff and volunteers (62%)
  - Staff and/or volunteers who are members of other communities that participants belong to (60%)
- Focus group and interview participants reported seeking and using detailed information about program and service spaces (i.e. seating, lighting, loudness, and visual clutter) to decide if spaces were accessible to them.

#### Financial

• Less than 1/3 of survey respondents (30%) reported that they were able to financially access all of the SRH medication and items that they need.

#### Knowledge/Training

- Focus group and interview participants discussed uncomfortable past experiences with health care providers and drop-in staff that because staff made assumptions about their condition and lacked adequate knowledge surrounding disabilities.
- 53% of survey respondents indicated that staff not being knowledgeable about disability and SRH makes it difficult for them to access SRH programs and services.

#### Making Connections

The majority of focus group participants wanted there to be spaces available specifically
for youth with disabilities, as well as for youth with disabilities who have intersecting
identities such as being Black, Indigenous and People of Colour (BIPOC) or 2SLGBTQ.

#### Programming

- Youth with disabilities currently seek SRH information from online sources, workshops, pamphlets, doctors and friends.
- Neurodiverse youth indicated a lack of information on how to deal with subtle coercion.
- Youth want both more in-person education and access to written information.

#### recommendations for service providers

Recommendations for service providers informed by this needs assessment have been summarized in categories below.

#### Accessibility

- SRH service providers should ask all youth about their access needs (ie. what they need to be able to fully participate in programs and services).
- SRH programs and services should be accessible for youth with mobility devices.
- Program and service spaces should consider accessibility with regard to doors, ramps, elevators, change tables, washrooms and lifts to access exam tables.
- Youth should be provided with details about the program and service spaces including seating, lighting, loudness, and visual clutter, as well as access to pictures and videos of spaces.
- Agencies should clearly communicate their capacity and limitations for meeting accommodation needs.
- Agencies should be aware of mental health-related barriers to access and work to create safe spaces where youth can access SRH services free of stigma and oppression.
- Agencies should consider offering online programming and services to improve access for youth with disabilities.
- Agencies should offer online appointment booking options.

#### Financial

- Agencies should provide lower cost or free SRH items, such as condoms and birth control prescriptions, where possible.
- Food and transit fare should be provided for youth attending programming, including transportation options for youth who cannot use public transit due to disability.

#### Knowledge/Training

- Staff should be trained specifically on SRH and youth with disabilities, including how to
  address common misconceptions about youth with disabilities, and how to make spaces
  more accessible and inclusive of disability as well as intersecting identities such as being
  BIPOC and/or 2SLGBTQ. This should include training on inclusive language and
  inclusive sex education.
- Staff should be trained in trauma-informed care.

#### Making Connections

 Agencies should establish relationships with disability groups to help ensure future programming is more inclusive and representative of disabled communities and interests.

#### **Programming**

- Sexual and reproductive health programming for youth with disabilities should be developed by and for people with disabilities.
- The resources available at agencies and in programming should cover topics including subtle coercion, relationships and include intersectional identities. They should also include more information in ASL, subtitles in videos, plain language, less jargon and resources that are not extremely word heavy.
- Youth with disabilities want more programming and information about communication, healthy relationships, sensation, positioning, basics of anatomy, safe sex, and having sex that doesn't aggravate pain.
- Youth living with disabilities want spaces created for them to specifically talk about disability and sexual health.

## detailed findings

#### who did we hear from?

The Youth With Disabilities needs assessment collected data from a total of 101 youth: 91 survey respondents and 10 additional youth through 2 focus groups and 2 interviews. The 2 focus groups were specific to BIPOC (Black, Indigenous and Person of Colour) youth with disabilities and neurodiverse youth, respectively.

Of the 49 survey participants who responded to the demographic questions (54% of all respondents), 47% identified as non-binary or genderqueer, 37% as women, and 8% as men. Survey participants ranged from age 16 to 29, but of those who completed the demographics questions, most (82%) were 21 or older.

Of the survey participants, 56% identified as white, 8% as Chinese, 8% as mixed race, 6% as Indigenous/Aboriginal, and fewer than 5% each as Asian, Filipinx, Middle Eastern, Person of colour, Ashkenazi Jewish, Roma, and Trinidadian. 12% of survey respondents were not Canadian citizens.

30% of survey participants identified with multi-gender sexual identities including bisexual, pansexual, and polysexual, 30% identified as queer, 13% as straight, and 6% as gay or lesbian.

When asked about life experiences that may affect a person's health or their access to programs and services, the most common life experiences amongst survey participants were and abuse (71%), chronic illness (57%), poverty (33%), unstable housing (33%), drug or alcohol use that has caused problems (25%) and homelessness (22%).

Survey participants reported experiencing a wide range of disabilities, including mental health (86%), learning disabilities (57%), physical disabilities (53%), neurodivergence (41%) being Deaf/hard of hearing (23%), intellectual disabilities (23%) and visual disabilities (22%). Many participants also indicated that they had more than one disability and/or disabilities than affected them in more than one way. Most participants stated that their disability largely impacts their daily life (81%) The majority of participants reported that their disability/ies were not visible (65%).

#### what do youth with disabilities want to know about SRH?

Only 56% of survey respondents reported that they have access to all of the SRH information they need. Among youth surveyed, emotional violence was indicated as the top topic that they wanted to know more about (65%). This was followed closely by LGBTQ issues (63%) which may be due to the large representation of LGBTQ youth in the survey respondents. 59% of participants wanted to learn more communication, including talking about sex and disclosure of STIs, and experiences of violence. 59% of survey participants also indicated wanting to learn more about dealing with pain management during sex. Other topics of interest included healthy relationships (56%), asexuality/aromanticism (52%), fetishization and desirability (52%), health care rights (52%), relationship styles (50%) and sensation & orgasm (50%).

Healthy relationships was an interest reflected in focus groups as well. The BIPOC focus group identified a lack of information about how to deal with mental illness and trauma response during sex. The neurodiverse focus group indicated a lack of information surrounding consent and subtle coercion. This group also noted that school sexual health curriculum is fear-based and does not address important aspects of SRH including consent, different bodies/identities and sex toys.

#### needed programming and services

When asked about unmet SRH needs, the most pressing need identified by youth surveyed was for programs and services that are inclusive to youth with disabilities, including accessible spaces and specifically wheelchair accessible spaces.

Youth were also interested in programming that addressed disability specific topics. This includes programming and services where they could openly talk about disability and sex. In particular, youth want to learn about ways to address barriers related to sex when living with a disability, safe sex, disability and trauma, positioning, disability competent sexual education, and communication.

Lastly, there is a need for trauma informed care identified by both survey respondents and focus group/interview participants.

# how do youth with disabilities want to get SRH information, education, and services?

Only 35% of survey respondents indicated that they have access to all of the SRH services and programs they need.

Increasingly, youth with disabilities want to digital ways to get SRH information, education and services. 66% of survey respondents would like two-way texting services, 47% would like information via social media (Facebook, Twitter, Instagram) and 45% want to access information through live chat online. Receiving information through email and a website dedicated to sexual health was also preferred by 43% of survey respondents. The focus group with neurodiverse youth also identified that these youth appreciate the option to book appointments online.

Youth with disabilities in Toronto still want in-person services to be available as well. 51% of respondents indicated they wanted to receive sexual and reproductive health information, education, and services through disability related appointments, while 51% also indicated that they wanted this through drop-in youth groups. For just under half of respondents, community settings were the preferred location for sexual health clinics and workshops.

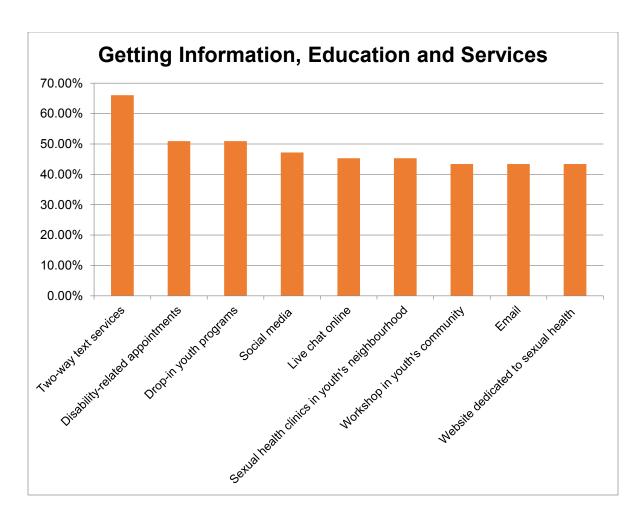


Figure 1: Participants' preferred means of accessing SRH information, education, and services

# what makes it difficult for youth with disabilities to access SRH information, education, and services?

Youth participants in this needs assessment identified a variety of barriers that hinder their access to sexual and reproductive health information, education and services. These barriers fit into the categories of social, knowledge, logistic and economic factors. It is important to note that some of these barriers are structural and difficult to address, but others may be easily mitigated by organizations serving youth with disabilities.

#### Social factors

The most prevalent barrier to access identified by participants was emotional distress, depression or anxiety, cited by almost three quarters of respondents. The next most common barrier was fear of oppression in spaces that offer SRH services. This suggests that these spaces need to do more to help youth with disabilities feel safe accessing them. It is important for staff to work towards building judgment-free and anti-oppressive safe spaces, but they should also seek ongoing feedback from youth with disabilities directly. 89% of survey respondents agreed that it would be beneficial if SRH service providers asked about their

access needs (i.e. what they need to be able to fully participate), but only 15% indicated that they have been asked about their access needs.

Participants in the BIPOC focus group pointed to stigma and stereotyping as a factor influencing their access to SRH information. Some described the sexualization of certain mental health conditions, while others explained that the stigma around sex may lead youth to avoid the topic as a whole to prevent discomfort.

#### Knowledge factors

Lack of staff SRH knowledge specific to disability was a major deterrent for youth with disabilities in accessing SRH services. Relatedly, another barrier was the assumption that youth with disabilities do not need such services. Focus group participants noted that inclusive language is critical in their understanding of SRH information and is often lacking in services that serve them. On the side of youth, a lack of knowledge of the availability of SRH programs and services was a further barrier. Focus group participants also identified a lack of knowledge surrounding how SRH services occurred as a barrier to access (i.e. pap smears).

#### Logistic factors

Some SRH programs and services are difficult for youth with disabilities to access due to their geographic location. Just under half of the youth participants stated that programming being held in inconvenient locations prevented them from accessing it.

Focus group participants noted that calling to make appointments was a barrier and did not allow them to get all the information they needed prior to appointments. Additionally, the policy of allowing only one issue per medical appointment can act as a barrier to youth with more complex needs.

#### Economic factors

For many participants, cost was a major barrier to accessing SRH information, education and services. This may include the costs of services and medications relating to SRH, as well as transportation costs such as subway tokens.

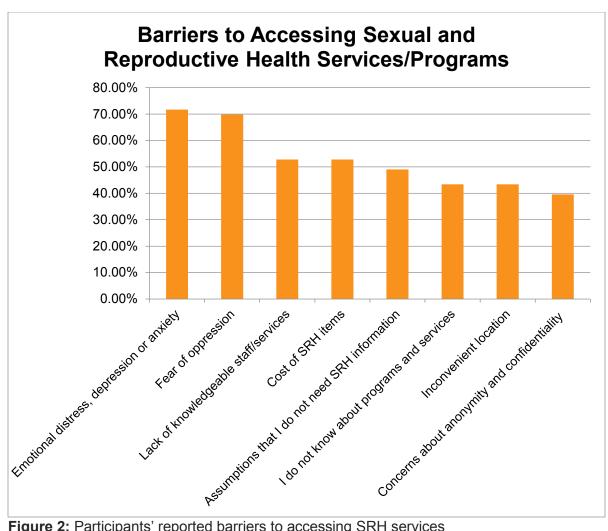


Figure 2: Participants' reported barriers to accessing SRH services

### how can we make it easier for youth with disabilities to access SRH programs and services?

Participants in the Youth With Disabilities needs assessment clarified which factors would help to facilitate their access to SRH information, education and services, summarized into categories below.

#### Meet them where they are at

Participants reported interest in in-person services such as clinics and workshops, but it is crucial that such services take place at a convenient location. Many participants noted a preference for community locations, suggesting a need for more clinics or outreach locations across neighbourhoods in Toronto. Travel to and from service locations should try to minimize walking distance from bus stops and number of bus transfers required if taking public transit. Furthermore, participants noted a need for service locations to be accessible to youth with disabilities. This includes wheelchair accessibility as well as the provision of information

regarding physical elements of the space such as visual clutter, loudness, amount of seating available, etc.

# Foster non-judgmental and anti-oppressive spaces that reflect the youth being served

Participants' feedback demonstrated a strong need for youth with disabilities to feel safe and supported in spaces that provide SRH services. Such spaces should ensure that staff and volunteers are trained in maintaining anti-oppressive spaces, which includes being youth-positive, sex-positive, and sensitive to the diverse forms of oppression that may exist in society (e.g. racism, classism, heterosexism, cissexism, and ageism). Youth with disabilities are also eager to see themselves reflected in the staff and volunteers of organizations that provide SRH. As such, it is important that such organizations are committed to equitable hiring practices that ensure a diverse workforce that represents a range of intersectional identities, including people of varying disability, race, sexual orientation, gender identity, and other factors.

#### Develop programming specific to youth with disabilities

Many youth participants in this needs assessment expressed questions pertaining to their specific experiences in terms of sexual and reproductive health as young people with disabilities. Youth with disabilities would like to see health information and programming specific to their demographic. Furthermore, it is critical that staff and volunteers at organizations that provide SRH to youth with disabilities are knowledgeable about the experience and SRH of these youth. Topics of interest to youth with disabilities were investigated in this needs assessment and could inform the development of resources and programming to help meet this currently unmet need. Organizations should partner with disabled/advocacy groups or work with advisory committees to ensure that programming for youth with disabilities is created by people with disabilities.

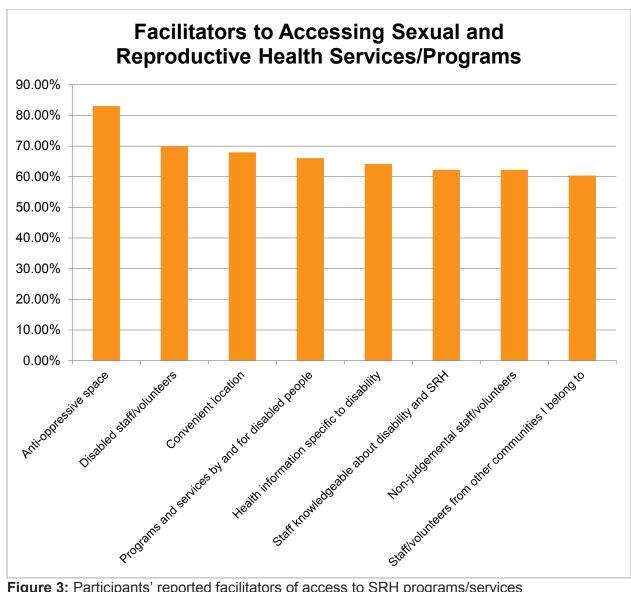


Figure 3: Participants' reported facilitators of access to SRH programs/services