

MOVING THE DIAL ON YOUTH WELLBEING

A YouthREX Research to Practice Report



Supporting Youth Living With and Affected by HIV in Ontario





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Abstract

The conditions that drive vulnerability to HIV infection for young people in Ontario also limit access to resources and result in poorer health outcomes for youth living with and affected by HIV. Synthesized literature that addresses the ways in which the social determinants of health intersect and influence the experiences of youth living with and affected by HIV is limited. This Research to Practice report contextualizes the current demographics and experiences of young people in Ontario, and highlights critical frameworks, interventions, and program features to support working with youth living with and affected by HIV. Furthermore, it recommends evidence-based best practices and strategies, using a critical, anti-oppressive lens, for youth workers, youth-serving organizations, and frontline staff across Ontario's youth sector to improve wellbeing for youth living with and affected by HIV.

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Research to Practice Reports

Moving the Dial on Youth Wellbeing is a series of multi-source plain language Research to Practice reports that selectively review, synthesize and translate practice-relevant research, evaluation and experiential evidence applicable to the work of youth sector stakeholders across Ontario.

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Foreword

IN ONTARIO TODAY, youth living with and affected by HIV (LWAH) need better supports. They navigate adolescence, while living with a misunderstood and highly stigmatized chronic health condition. In addition to typical teenage concerns (such as getting through high school, making career or post-secondary school decisions, navigating romantic relationships and friendships, and seeking independence from parents/caregivers), they also juggle the additional stress of dependence on daily medication, navigating fear of ostracization or rejection, and searching for support and understanding.

Supporting Youth Living With and Affected By HIV in Ontario is an essential best practices resource for service providers working with these young people.

The Teresa Group aims to advance the dignity and wellbeing of children and families affected by HIV. Our team of social workers interact daily with youth living with HIV – hearing from them about their experiences navigating health services and the barriers they confront in relation to social and economic determinants of health and living life with HIV. Due to society’s discriminatory view of HIV and general lack of understanding about the condition, many of the youth we work with learn to carry their HIV status as a deep secret from a young age. This is why The Teresa Group focuses much of its time and energy on programs such as mutual support therapy groups, peer navigation, summer camp, and other immersive experiences.

We are thrilled that YouthREX’s Research to Practice report provides evidence-based information to support youth living with HIV. The research on this topic has been limited to date. By better understanding the social and economic determinants of health affecting youth LWAH, we can work towards educating service providers to work with youth and ensure that their interactions are rooted in anti-oppressive practice. We must continue to update our knowledge of evidence-based interventions and find ways to incorporate new approaches based on the needs of youth and changing political landscapes.

We will know we are on the right track when youth living with HIV access supports and report that their autonomy, dignity, confidentiality, and unique needs are respected. Once they feel safe and secure, we will see more well-supported youth meaningfully engaged in programming and living fulfilling lives.

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Introduction

YOUTH IN COMMUNITIES that are underserved and disadvantaged experience social, political, and economic challenges – including racism, sexism, and poverty – that negatively impact their health. The Public Health Agency of Canada describes how the social determinants of health – “the range of social, economic, environmental, and personal factors that influence the health status of individuals and populations”¹ – contribute to vulnerability for HIV infection. Social and economic marginalization can further drive the prevalence² of HIV. The experiences of young people living with and affected by HIV can be compounded by these determinants, as well as by stigma and discrimination. Understanding these forces, using social determinants of health and health equity frameworks, brings systemic barriers and oppressive power relations to the surface. It also draws attention to strategies for supportive and equitable interventions that improve youth wellbeing.

As resource navigators and connectors to services and programs, youth workers play an important role in the wellbeing of youth;³ they are uniquely positioned to support young people living with and affected by HIV. They can also play an important role in breaking down stigma. As such, youth workers must integrate a critical approach when engaging young people, understanding not only the facts about HIV transmission and treatment, but also the social drivers that contribute to, and result in, increased vulnerability of young people living with or affected by HIV.

This report is designed for practitioners working with young people living with and affected by HIV in Ontario. It offers recommendations for best practices at the individual, interpersonal, organizational, and community levels.

1.1. Understanding the Terminology

Intersectionality

A critical and insightful theoretical approach in understanding the prejudices and inequities experienced by individuals by analyzing the interconnectedness of social identities such as race, gender, sexual orientation, identity, and class.⁴ With this framework, the lived experiences of individuals are centered.

Social Determinants of Health

The social, economic, political, environmental, and personal factors that contribute to vulnerability and create or enforce health disparities.⁵ The conditions in which someone lives, grows, and works shape their health outcomes.⁶ In the context of youth living with and affected by HIV, this includes addressing the institutional and intersectional factors that contribute to higher rates of HIV among youth who are Indigenous, Black, racialized, homeless, and LGBT2SIQ, and youth who use substances.

Anti-Oppressive Framework

This means working from a strength-based approach to critically examine power imbalances embedded in organizational structures.⁷ This approach aims to understand the experiences of marginalized populations and encourage the use of inclusive best practices when working with youth living with and affected by HIV. This includes identifying the most vulnerable populations of young people who face challenges in accessing health and social support services, and prioritizing recommendations to eliminate these challenges. Additionally, this approach encompasses an anti-stigma framework that addresses and tackles manifestations of stigma and discrimination directed towards people living with and affected by HIV.⁸

Health Inequity

Strongly tied to the social determinants of health, health inequity refers to the unfair and avoidable differences in health statuses among different populations.⁹ In the context of this report, health inequity is a result of the systemic factors – such as policies, practices or procedures – that create barriers in accessibility to services and ultimately shape the experiences of youth living with and affected by HIV.

1.2. Purpose and Scope of this Report

Adolescence, defined in this report as being between the ages of 13-19, is an important life stage and a significant period of transition and change.¹⁰ Young people experience physical, emotional, and psychological changes as they transition from childhood to adulthood. This life stage is also marked by shifts in health needs. Addressing the unique needs of young people is a way of reducing vulnerability and minimizing risks linked to poor health outcomes.

Young people at risk of contracting HIV require prevention services, whereas young people living with HIV diagnoses require support in navigating health and social support services, as they can experience immense barriers to accessing treatment and care, and face unique societal attitudes fueled by ignorance and misinformation. Understanding the social conditions and circumstances that shape and influence the experiences of youth living with and affected by HIV is critical to understanding support strategies and best practices required to facilitate a supportive transition into adulthood.

The questions guiding this report are:

What are the systemic factors that influence barriers to accessing support services for this demographic?

In what capacity are youth living with and affected by HIV in Ontario currently being supported?

What approaches are critical in providing well-rounded supports for youth living with and affected by HIV, and how can youth-serving organizations adopt these best practices?

1.3. Methodology

The literature selected for this report includes a diverse range of sources, comprising evidence from research, practice, and lived experience.

The initial literature search was conducted using academic databases and grey literature sources. This preliminary search determined the availability of resources pertaining to young people living with HIV in Ontario; although there was a surplus of research addressing HIV interventions for the general population in Canada, there were limited results when searching for evidence that connected the social determinants of health to HIV among vulnerable youth populations in Ontario. Therefore, to further narrow the results, additional keywords were included: “social determinants of health”, “HIV”, “youth”, “health”, and “Canada”. Sources were also expanded to include public health agencies, coalitions, research and knowledge exchange institutions, and community-based councils and organizations.

Evidence used to guide the development of this report was given priority on the basis of the following criteria: (a) the resource outlined research that conceptualized influencing factors for HIV risk and best practices for support and education for vulnerable youth living with and affected by HIV; (b) the study population included vulnerable populations in the context of Canada or Ontario; (c) the resource was written after the year 2007; (d) the resource was written in English.

1.4. Organization of this Report

This report is organized into three main sections. The first sets the context, highlighting the demographics of youth living with HIV in Canada, and specifically in Ontario, and the intersecting factors that contribute to the vulnerability of youth living with and affected by HIV, through a social determinants of health lens. The next section details frameworks, evidence-based interventions, and program features that support youth living with and affected by HIV. The final section outlines recommendations for best practices and strategies that can be adopted by youth workers and youth-serving organizations.

Setting the Context: A Critical Review

THE POPULATION of people impacted by HIV in Ontario includes young people. In recent years there have been renewed efforts to increase support services and resources to the most vulnerable youth.

We're approaching the fourth decade since the first cases of what would become known as HIV & AIDS were initially diagnosed. In that time, tremendous gains have been made. We now better understand how HIV works, and the ways in which the disease impacts individuals and transforms communities. We can't cure HIV yet, but we can prevent it and treat it.

2.1. HIV Timeline

1981

First cases of what would become known as AIDS are reported. The disease is initially thought to only affect gay men. By the end of the year, cases have been reported in other populations.

1982

Term 'AIDS' is coined.

Canada reports its first case of AIDS.

1983

Major virus transmission routes for HIV (the virus causing AIDS) are identified.

1984

Studies reveal epidemics in Africa are being driven by heterosexual sex.

AIDS Committee of Toronto initiates the first AIDS Awareness Week.

1985

Canadian Red Cross begins testing all blood products for HIV.

1986

First commercial blood test for HIV is licensed by the US Food and Drug Administration (FDA).

1987

FDA approves the first anti-retroviral drug (HIV treatment), called AZT.

First global strategy on AIDS is developed by the World Health Organization (WHO).

1988

First World AIDS Day is held on December 1.

1989

Government of Canada announces compensation for people who contracted HIV through tainted blood products.

1991

Red Ribbon becomes the international symbol of AIDS awareness.

1992

First successful combination of drugs to treat AIDS are approved by the FDA.

1994

Greater Involvement of People Living with HIV (GIPA) Principle is established.

1996

Highly Active Anti-Retroviral Therapy (HAART) becomes the standard treatment for HIV. HAART will go on to transform HIV treatment.

1997

Joint United Nations Programme on HIV/AIDS (UNAIDS) estimates that approximately 30 million people are living with HIV worldwide. For the first time since its emergence, the number of AIDS-related deaths drops.

1998

Post-Exposure Prophylaxis (PEP) introduced. See page 12 for more details.

1999

Progress is made in finding treatment solutions to prevent mother-to-child transmission of HIV.

2001

Globally, over 40 million people are living with HIV/AIDS; 24.8 million have died. Women make up half of those living with HIV/AIDS.

2002

HIV becomes the leading cause of death worldwide in 15-59-year-olds.

2005

Health Canada approves the rapid HIV point-of-care test.

2011

HIV 'Treatment as Prevention' gains momentum. See page 12 for more details.

2012

Pre-Exposure Prophylaxis (PrEP) use gains momentum. See page 12 for more details.

Supreme Court of Canada issues monumental ruling on HIV non-disclosure and criminalization, which was widely criticized by people living with HIV, activists & advocates.

2013

WHO introduces new HIV treatment guidelines, based on a public health approach.

2014

United Nations introduces ambitious 90-90-90 targets:

- 90% of people living with HIV diagnosed;
- 90% treated; and
- 90% viral suppression in those in treatment, by 2020.

2016

Health Canada approves PrEP. See page 12 for more details.

2017

Canada's chief Medical Officers of Health release a statement supporting U=U (Undetectable = Untransmittable) prevention campaign. See page 12 for more details.

On World AIDS Day, Ontario government announces that Crown prosecutors will no longer proceed with criminal prosecutions for non-disclosure of HIV status in cases where the accused has suppressed viral loads for six months before the incident.

2018

36.9 million people are living with HIV globally.

21.7 million people are accessing anti-retroviral therapy.

35.4 million people have died from AIDS-related illnesses.

Risk of acquiring HIV is:

- 27 times higher among men who have sex with men.
- 23 times higher among people who inject drugs.
- 13 times higher for female sex workers.
- 12 times higher for transgender women.

On World AIDS Day, federal government announces that Crown attorneys will no longer prosecute non-disclosure of HIV status in cases in which an individual's viral load was suppressed.

2.2. HIV by the Numbers

36.9 million people worldwide were living with HIV at the end of 2017; an estimated 21.7 million were on HIV treatment.¹¹

Highly-effective medications mean that someone diagnosed with HIV today can effectively manage the illness and expect a better quality of life. Additionally, fewer people worldwide are prematurely dying of AIDS-related causes. In the meantime, researchers continue to work on developing a widely useable cure.

Despite these gains, HIV is still an issue to be concerned about. In Canada, as in other parts of the world, HIV overwhelmingly affects already marginalized groups and communities, such as men who have sex with men, people who inject drugs, and racialized populations, including Indigenous people. In Ontario, like the rest of Canada, the story of HIV draws attention to existing fractures and structural inequalities.

The HIV epidemic in Ontario is concentrated in priority populations:



01.
Gay, bisexual, and other men who have sex with men (GBMSM)

02.
Black communities

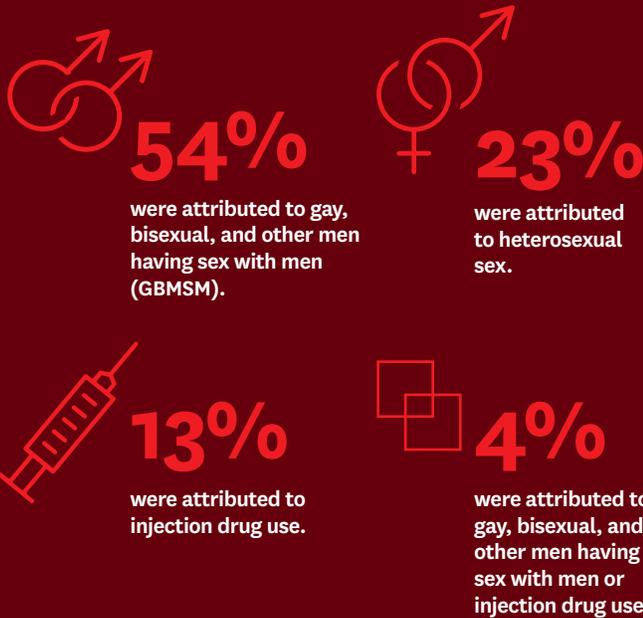
03.
Indigenous communities

04.
People who inject drugs (PWID)

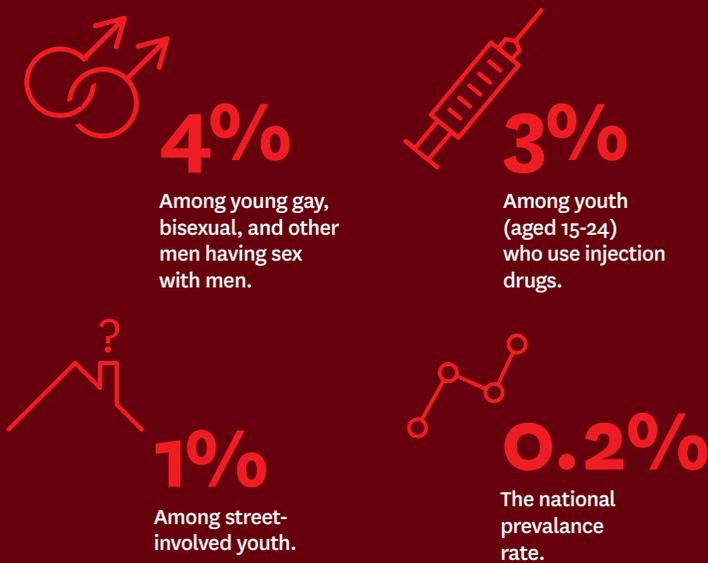
05.
At-risk women, in particular trans women

All data from 2016.	CANADA	ONTARIO
 Estimated number of people living with HIV	63,110	31,200
 Percentage of people living with HIV who didn't know their status	14%	21%
 Number of people newly diagnosed with HIV	2,165	881
 Number of young people (aged 15-29) newly diagnosed with HIV	574	235

To provide well-rounded and effective services to youth living with and affected by HIV, it is important that service providers understand how youth come into contact with HIV. Among new youth diagnoses in 2016:



As of 2014, HIV prevalence among certain youth populations was higher than the national rate.



The number of new HIV diagnoses among youth increased by 13% from 2012 to 2016.

75% of new diagnoses among youth were in males.

DATA SOURCES

- A <https://www.catie.ca/en/fact-sheets/epidemiology/epidemiology-hiv-canada>
- B <https://www.canada.ca/en/public-health/services/reports-publications/canada-communicable-disease-report-ccdr/monthly-issue/2017-43/ccdr-volume-43-12-december-7-2017/hiv-2016-supplementary-tables.html>
- C <https://www.catie.ca/en/fact-sheets/epidemiology/epidemiology-hiv-youth>
- D <http://www.ohtn.on.ca/research-portals/priority-populations/people-living-with-hiv/>

2.3. Understanding HIV

What is HIV?

Human Immunodeficiency Virus or HIV is a virus that attacks the body's immune system. It weakens the body's defenses, making it harder to fight off illness and infection.

What is AIDS?

Acquired Immunodeficiency Syndrome or AIDS is late-stage HIV. Someone living with AIDS has a severely compromised immune system and serious health complications.

How is HIV passed?

HIV is not passed or transmitted by everyday (casual) contact like hugs, shaking hands or sharing washroom facilities. HIV is passed when body fluids carrying significant levels of the virus from someone who is HIV-positive get into the bloodstream of a person who is HIV-negative. For HIV to be passed, there has to be an opening, such as a cut, for the virus to pass from one person to the next. HIV can only be passed through five body fluids:

- Blood
- Breast Milk
- Vaginal Fluids
- Semen
- Anal Fluids

HIV can't be passed through body fluids such as sweat, urine, tears or saliva.

What is HIV status?

This term describes whether someone is living with HIV (HIV-positive) or not (HIV-negative). The only way to know your HIV status is to get tested. Someone can have HIV even if they don't have symptoms or feel ill. Testing with same-day results is available in most parts of Ontario.

How can HIV be treated?

There is no cure for HIV yet, but treatment exists. It's taken daily, and it manages the effects of HIV on the body. When taken, HIV treatment (also called combination antiretroviral treatment, or cART) reduces the amount of virus in the body, making it harder to pass the virus onto others.

How can HIV be prevented?

It is possible to reduce the chances of getting or passing HIV by limiting exposure to risk factors. There are several tools and strategies that can be used to prevent HIV, such as using condoms to prevent passing the virus on through sex, or using harm-reduction strategies, such as using new materials every time when injecting drugs.

Other prevention tools include:

POST-EXPOSURE PROPHYLAXIS (PEP)

This is a method of preventing passing HIV by taking a short-course of HIV medications after exposure to HIV. PEP blocks HIV from establishing itself in the body after exposure.

PRE-EXPOSURE PROPHYLAXIS (PREP)

This is a prevention strategy used by an HIV-negative person who might be at higher risk of HIV infection. PrEP is taken before exposure to HIV. It blocks the virus from establishing itself in the body if the person taking it is exposed to the virus. PrEP is very effective when used correctly and consistently.

UNDETECTABLE = UNTRANSMITTABLE (U=U)

An HIV-positive person taking treatment daily can reduce the virus in their body to such low amounts that it can't be passed on sexually (untransmittable). This is called being undetectable.

Treatment as Prevention (TasP)

TasP is a population-level (rather than individual-level) strategy in which treatment is made accessible to people living with HIV, with the goal of reducing HIV viral loads and reducing HIV transmission risk. TasP strategies include improving access to HIV testing and improving access to services to help people stay connected to treatment. In Ontario, treatment guidelines have changed in recent years. Today, someone diagnosed with HIV can begin taking treatment right away, instead of waiting until their health declines as the illness progresses.

2.4. Social Determinants of Health

Understanding the interplay of the social determinants of health and the lived experiences of youth who are LWAH in Ontario is a key part of providing effective support services. Determinants of health influence how people navigate their own health and wellbeing, as well as how they access health services. Bringing a health determinants lens to the analysis of HIV in Ontario helps us to better understand factors that drive marginalization, health inequity, and poor health outcomes among youth LWAH. These determinants are interlocking and overlap; below are a few that are of specific concern in working with young people LWAH:

Socioeconomic Status

This determinant includes an individual's education, income, and employment status.^{13, 14} Socioeconomic status can be understood as existing within a hierarchy, measuring a person, family or group's position relative to others. For example, in Ontario, having higher education and income levels is associated with having access to more resources and opportunities. Evidence shows there are strong links between a person's socioeconomic status and their health outcomes,^{15, 16, 17} such that people with higher socioeconomic status have better health outcomes.

For young people LWAH, socioeconomic status determines vulnerability to poor health outcomes linked to HIV.

For example, employment and income provide access to financial resources, which are important determining factors in accessing services and treatment (e.g. prescription drug treatments and preventative materials, such as condoms and PrEP). Socioeconomic status also influences whether youth have the social supports they need to stay connected to care and to take treatment as prescribed (this is called adherence). Youth who are experiencing homelessness or living in poverty are among the most vulnerable, as they are faced with limited access to support systems and programs.¹⁸ In fact, socioeconomic status is a significant barrier in seeking supports more broadly; the number of young

HIV Disclosure

HIV disclosure means sharing information about HIV status. Young people living with HIV consider a few things when it comes to HIV disclosure. Like anyone else, they have a right to privacy about their health information. However, sometimes it's necessary to share information about their health and status.

It's important for young people to consider how disclosure will impact their lives. In Ontario, there are circumstances where people living with HIV are legally obligated to disclose their status. Service providers can support young people in learning about their rights and obligations as far as HIV disclosure is concerned. Service providers can also help young people to prepare for conversations in which they will be disclosing their status, and process how disclosure might impact their lives.

Disclosing HIV status can be empowering and affirming, but young people may also experience negative outcomes after disclosure. For example, they may experience stigma, discrimination, and harassment. Service providers can assist young people in processing negative or unexpected outcomes. To learn more, see the Canadian HIV/AIDS Legal Network's privacy and disclosure guide for youth.¹²

HIV Criminalization

One of the most pressing issues facing people living with HIV in Canada is the over-criminalization of HIV non-disclosure. Laws governing prosecution for HIV non-disclosure lag behind current science and knowledge of HIV. These regressive approaches have discouraged people from testing for HIV and accessing treatment. They also increase stigma and discrimination faced by people living with HIV.

On World AIDS Day 2018, the federal government announced that federal crown attorneys would no longer prosecute cases in which an individual's viral load was suppressed ("undetectable"). As of this writing, similar guidelines have not been implemented in Ontario. Service providers working with young people can support youth in accessing services from experts leading this work, such as the **HIV/AIDS Legal Clinic Ontario (HALCO)**.

people who seek services is much higher among those who have a higher socioeconomic status.¹⁹

Social Conditions

Inequities in social conditions produce noticeable disparities in health outcomes, particularly for racialized youth. For example, socioeconomic status, institutional systems, and structural policies strongly affect Indigenous people and put Indigenous youth affected by HIV at a significant disadvantage.²⁰

Indigenous youth living in northern and remote communities often have limited access to equitable services and supports, resulting in increased vulnerability to HIV.

In Ontario, HIV prevalence among Indigenous people is 1.7 times that of non-Indigenous populations. At a national level, this grows to 3.6 times.^{21, 22} Additionally, social and economic disparities limit wellbeing and increase exposure to risk factors.

A study outlining the inequalities in the determinants of health among Indigenous people living with HIV in Ontario found that Indigenous people living with HIV receive inadequate care and limited access to health and social services that contribute to poorer health outcomes.²³ Furthermore, this study found that compared to White people living with HIV, Indigenous people live in poorer conditions, mostly in rural and remote communities within Northern Ontario.²⁴

Physical Environments

The physical environments in which youth live, including geographic location and housing, determine accessibility to social and health services.^{25, 26} Youth living in rural and remote communities have less access to resources (including those related to HIV prevention and harm reduction), compared to their counterparts in urban settings. Increased access can serve as a protective factor for positive health outcomes. Additionally, access to stable and affordable housing impacts health behaviours and outcomes.

Precarious housing and homelessness are in themselves sources of stigma and increase vulnerability to risks linked to HIV.²⁷

For example, street involvement or homelessness may result in increased behaviour classified as “high risk,” such as survival sex work and sharing materials used for injection drug use. These factors increase risk of exposure to HIV.²⁸ A 2014 study found that HIV prevalence in street-involved youth was higher than the national prevalence rate – 1% compared to 0.2%.²⁹ These statistics highlight the need for services that address the social, economic, and political underpinnings that create inequities in services for vulnerable youth populations.

Race

Race is a prominent health determinant for youth LWAH.^{30, 31} In Ontario, as in other parts of Canada, race is closely linked to socioeconomic status. Racialized populations are disproportionately represented in lower socioeconomic categories.³² These dynamics are tied to long histories of colonization, racism, structural inequality, and social exclusion. Their outcome is a reduction in protective factors and greater risk of poor outcomes. For example, Black youth make up a notable proportion of youth living with HIV in the province.^{33, 34, 35, 36}

In addition to being hard-hit by HIV, Black youth experience other factors that complicate health outcomes, such as racism, unemployment, and immigration concerns.^{37, 38, 39, 40}

The intersections of these experiences inhibit access to social and health services.^{41, 42}

Similarly, studies have found that Indigenous youth are at increased risk of homelessness, and that street-involved Indigenous youth have higher HIV prevalence rates compared to their non-Indigenous counterparts.⁴³

Cultural norms and misinformation on sexual identity and its correlation with HIV can lead to bias and inadequate prevention practices.

Acknowledging the lived experiences of LGBT2SIQ youth and providing culturally-appropriate, sensitive, and tailored services is essential in closing the gap in accessibility to services.

These disparate outcomes are driven by multi-generational legacies of racism and colonization, which exacerbate vulnerabilities. In a similar vein, racialized newcomer youth LWAH face barriers to settlement in Ontario, such as delayed access to health services, language barriers, limited resources to address mental health challenges, and unemployment. These barriers further complicate the means of accessing services that are tailored to their unique needs.^{44, 45}

Gender & Sexual Orientation

LGBT2SIQ youth LWAH in Ontario experience higher rates of stigma and discrimination compared to their non-LGBT2SIQ peers.^{46, 47} As a result, HIV-positive LGBT2SIQ youth experience worse physical, mental, emotional, and sexual health than their counterparts.⁴⁸ In particular, men who have sex with men (MSM) are over-represented in both the overall population of people living with HIV in Ontario and in new infections. Racialized MSM deal with limited access to resources, and a lack of literature and holistic programs to support and meet their needs in preventing HIV and managing existing diagnoses.^{49, 50}

Additionally, stigma and discrimination generally faced by LGBT2SIQ young people deters them from accessing health services.^{51, 52, 53} For example, transphobia and other forms of discrimination experienced by transgender and gender non-conforming youth results in increased stress, reduced access to important services, and poor health outcomes. Furthermore, cultural norms and misinformation on sexual identity and its correlation with HIV can lead to bias and inadequate prevention practices.^{54, 55} Acknowledging the lived experiences of LGBT2SIQ youth and providing culturally-appropriate, sensitive, and tailored services is essential in closing the gap in accessibility to services.

Exploring the intersections of the aforementioned social identities and experiences is critical to providing well-rounded and holistic support services to vulnerable youth LWAH in Ontario. This includes addressing the structural systems that further perpetuate stigma and discrimination through practice that ultimately affects the health of vulnerable youth.

The findings from the literature review highlight the need for specialized interventions that address multiple broader and intersecting social determinants of health in order to meet the needs of vulnerable youth LWAH in Ontario. The review also demonstrates the lack of data exploring the intersecting experiences of youth LWAH in this province, which is crucial for designing structural interventions that are tailored to their unique needs.

Acknowledging Stigma

In addition to the social determinants of health, it is important to take into account how stigma and discrimination create barriers to services for young people LWAH.⁵⁶

At its core, stigma is about power. It leads to labeling, stereotyping, and separation within groups, and to the exclusion of specific individuals. Stigma is driven by misperceived notions.⁵⁷ The implications of stigma for young people LWAH are profound. Stigma can lead to experiences of isolation, ostracization, and shunning by peers, family, and others in community.^{58, 59}

Stigma does not affect specific groups of youth in isolation, as it is deeply rooted in systemic practices in health care.^{60, 61, 62} HIV stigma prevents youth from disclosing their HIV status, accessing support services, and developing social connections, all of which undermines their health.⁶³

2.5. CASE STUDY 01

Providing Well-Rounded Supports Through an Intersectional Lens

Sarah is 17 years old and a newcomer who has been living in Windsor for the past two years.

Living with HIV, Sarah has had a difficult time finding programs and services that are tailored to her settlement and health needs, and that are offered in a welcoming and safe space. Her settlement worker has referred her to group programs, but Sarah would only attend one session and not return.

She has yet to meet another young person who shares her cultural background or experience, and she remains concerned about identifying publicly as HIV-positive; her community is very close-knit, and Sarah does not want her HIV status disclosed or discovered, as she is afraid of being ostracized.

Most recently, Sarah was referred to a youth program that provides peer mentoring support for newcomer youth living with and affected by HIV. The youth program is run by Jackie, a frontline worker who provides support services.

A week prior to the intake meeting, Jackie:

- **Asks Sarah** if she requires any accessibility accommodations, and if she would like to meet and have a tour of the youth centre.
- **Provides the option** of Sarah bringing her settlement worker, a family member, or even a friend.
- **Asks if Sarah** requires services to be provided in a language other than English, and if she would be more comfortable working with someone who shares the same language or lived experience.

During Jackie and Sarah's initial meeting, Jackie:

- **Asks Sarah** about school and what she enjoys doing in her spare time.
- **Ensures their conversation** takes place in a confidential space, and listens attentively to Sarah, asking non-judgemental questions to learn more about Sarah, her family, and her community.

After they meet, Jackie:

- **Gives Sarah a tour** of the youth centre so that she can see some of the programs in action, and provides Sarah with some brochures that outline the various youth support groups.
- **Lets Sarah know** that youth are provided with bus tokens to attend the session, and that snacks are provided.
- **Shares that the location** of the program is only provided to the youth who are invited by facilitators to attend.

Sarah's interest is peaked by the "Wellness Conversation Circle" that is led by newcomer youth on topics related to sexual health and resources.

Jackie took many essential steps to ensure that Sarah's experiences and perspectives were taken into account to build rapport and foster trust, and to understand and meet Sarah's needs.

Critical Frameworks and Evidence-Based Interventions

3.1. Critical Frameworks

Intersectionality

Intersectionality is an essential framework that addresses the social determinants of health, structural factors in the discourse, and experiences of young people LWAH. Intersectionality refers to understanding the prejudices and inequities experienced by individuals and exploring the interconnectedness of social identities such as race, gender, and class.⁶⁴

This term was first coined by Kimberle Crenshaw in 1991, when she explored the intersections of race and gender and how they influence health outcomes for women.⁶⁵ Her research on addressing violence against women through an intersectional approach paved the way for many studies to apply this critical and insightful theoretical framework to a variety of health and social phenomena.

When providing support services to young people LWAH, an intersectional approach would account for their lived experiences. It would also allow for an examination of the interactions between social identities and young people's experiences of reduced accessibility to support services.⁶⁶ Using this approach, the focus is on addressing the structural and macro-level factors that are beyond an individual's control:⁶⁷ the social, political, economic, and environmental factors that influence and perpetuate HIV disparities.⁶⁸ Furthermore, intersectionality can address issues resulting from systemic barriers that perpetuate stigma, discrimination, and barriers to support services.⁶⁹

Anti-Oppressive Approaches

An essential component of ensuring an intersectional lens is applied when supporting youth LWAH is the use of an anti-oppressive framework. This includes working from a strength-based approach to critically examine the power imbalances that are embedded in organizational structures,⁷⁰ and to understand the experiences of marginalized populations in the development of inclusive best practices.

This approach requires identifying the most vulnerable youth populations affected by HIV and who experience barriers to support services, and prioritizing recommendations to remove these barriers. With the application of an anti-oppressive framework and an intersectional approach, programs will be able to acknowledge the lived experiences of young people LWAH, and simultaneously address the systemic barriers that prevent them from accessing services.

Anti-Stigma

An anti-stigma approach is mindful of stereotypes, prejudices, discriminations, and microaggressions (those comments or actions that subtly and often unconsciously or unintentionally express a prejudiced attitude toward a member of a marginalized group). In this way, experiences of stigma are addressed and validated, and there is space for young people and their families to feel seen, heard, and valued.

3.2. Evidence-Based Interventions

Current strategies and interventions in Ontario to support youth LWAH aim to foster supportive relationships and increase accessibility to services. These programs address the need for structural interventions that critically address the social determinants of health. A report on the barriers experienced by youth LWAH outlines the significance of structural interventions to highlight these experiences in order to change the social, political, and environmental factors that have a significant impact on the resilience and vulnerability of youth LWAH.^{71,72}

Within Ontario, there are various strategies applied within community groups and organizations that aim to positively impact the resilience of youth LWAH. One such approach is the group therapy model. A prime example of how this model has been implemented effectively is through programming offered by The Teresa Group. This organization provides an eight-week psychosocial support intervention twice a year for children and youth LWAH; program facilitators and counsellors use activity-based group therapy, and separate groups based on the disclosure status and age of youth.⁷³ The findings suggest that this approach provided opportunities for youth to connect with their peers in a safe environment and to discuss dimensions of living with HIV, including their fears, experiences of stigma, and interpersonal relationships.⁷⁴

An evaluation of this program indicated that the approach was successful and provided valuable lessons in effective programming for youth LWAH.⁷⁵ The benefits of using a strength-based approach in group programming have been proven highly effective in fostering resilience and improving access to support.⁷⁶

Other strategies to support young people LWAH in Ontario include working with peer leaders and mentors living with HIV to facilitate conversations and programming.

Peer-based models have been effective in challenging stereotypes and reducing stigma in HIV knowledge among people LWAH and service providers.⁷⁷

A systematic review of peer-led interventions as prevention strategies highlighted the effectiveness of youth peer leaders across low-income communities in various countries; 24 interventions that used peer educators and mentors to connect with youth at-risk of HIV were selected, and, among all of the interventions, 11 that were specifically tailored to address HIV stigma and cultural norms reported success in shifting the norms and knowledge of HIV in their communities.⁷⁸ Peer leadership and mentor group models have been increasingly adopted by various youth-serving organizations in Ontario.⁷⁹ Through the use of peer leaders, youth can be provided with a holistic approach in the provision of support services, such as community learning series, resources, referrals, and weekly social supports.⁸⁰

The strategies discussed above provide insight on how to best support youth LWAH through the incorporation of age-specific programming, group models, and peer mentoring. Implementing concepts from these programs into the practices of youth-serving organizations will be beneficial to youth LWAH in Ontario.

3.3. CASE STUDY 02

Safe Spaces for Youth Living with HIV

Jared recently turned 18. For the last two years, he's been attending an arts-based drop-in program offered by a youth organization in his neighbourhood.

Shamir is a youth worker in the community-based organization and the lead facilitator of the programs Jared attends. He's noticed that, lately, Jared seems to be struggling with something. He seems troubled and disengaged. In the past Jared has been one of the most active and outgoing participants in program; lately he seems withdrawn and worried, although he still attends programs at least twice a week.

After one of the weekly drop-in sessions, Shamir:

- **Checks in with Jared** and asks him if he's doing okay. Jared hesitates at first, but eventually says he's doing okay.
- **Doesn't want to** make him feel uncomfortable so he doesn't press the issue, however he offers a gentle reminder that the workers at the program are trained and can help Jared work through an issue or link him to someone else who can, if he needs it. Jared thanks him and leaves.

The following week Jared stops in to see Shamir. Over the course of their conversation, he discloses that he's lived with HIV his whole life. He was diagnosed as a baby, he's been on treatment since. Jared also discloses that when he turned 18 he transitioned out of paediatric HIV care to adult care. Since then he's been feeling disconnected, struggling to connect with other youth similar in age to him who are also living with HIV. Jared is gay and he's also been struggling with connecting with other LGBT2SIQ youth living with HIV who will understand his experience. Jared feels isolated and scared. He's not sure who he can talk to about HIV disclosure and he's been worried

about asking Shamir to connect him to services because he's been afraid of being judged or 'outed' to other youth accessing services at the centre.

Shamir listens attentively and respectfully as Jared speaks. When he is finished, Shamir:

- **Thanks Jared** for sharing this information with him.
- **Acknowledges that** he doesn't know very much about HIV, but he knows a few organizations that work with youth living with HIV.
- **Affirms that he** will maintain Jared's confidentiality and won't disclose his status to other workers at the program or youth attending the program.
- **Asks Jared if** he can come back to see him later that week, at which point Shamir will have gathered some information on organizations working with youth living with HIV.

Over the next few days, Shamir:

- **Gathers information** for Jared; he finds resources for youth living with HIV (e.g. online disclosure guides) and identifies organizations offering specialized services to LGBT2SIQ youth living with HIV.
- **Presents these options** during their follow-up meetings and offers to connect Jared with outreach workers in these programs.
- **Affirms once again** that Jared's information will remain private and thanks Jared for courageously sharing with him.

Jared thanks Shamir for his help, he takes the resources Shamir has gathered for him, and gives Shamir permission to reach out to a youth outreach worker at a local HIV organization on his behalf.

3.4. Program Features to Support Youth LWAH

There has been an increase in efforts to promote and center the lived experiences of youth LWAH. ^{81, 82, 83}

Programs that have been effective in supporting diverse youth populations LWAH vary in the approaches taken, and each have successfully shown an increase in resiliency, self-awareness, and increased uptake of support services. Although many of the interventions reviewed take place in different geographic contexts, there remain similarities in the marginalization experienced by youth, in addition to the intersecting factors that contribute to their vulnerability.

The following program features were identified as being highly effective in working with youth LWAH.

01

Group Therapy Models

Psychosocial support interventions through the use of activities, play therapy, and conversations on experiences of living with HIV.

02

Age-Specific Programming

Strength-based support groups that are tailored to different age demographics to encourage relatability and trust.

03

Peer-Led Conversations & Mentorship

Workshops and discussions facilitated by youth leaders in the community living with HIV.

04

Mutual & Supportive Relationships

The inclusion of peers, family, friends, and other individuals who demonstrate support and concern for youth LWAH.

05

Conversations to Reduce Stigma & Discrimination, Promote Inclusiveness

Increased participation of youth LWHA, in addition to peers, family, friends, and other members of support networks, in conversations about living with HIV.

06

Inclusion of Parents, Schools, Community Leaders in Knowledge Exchange

Promoting and incorporating opportunities for education and knowledge sharing at levels of the family and community.

07

Intersectional Frameworks

Highlighting the intersections of identities and the social determinants of health that influence vulnerability for youth LWAH.

Best Practices to Support Youth LWAH

Programs can adopt a range of evidence-informed practices to support young people living with and affected by HIV.

Although each of the eight recommendations is critical in and of themselves, the inclusion of multiple recommendations will strengthen programs and services, and holistic approaches to supporting young people LWAH.

01. Understand youth's lived experiences

- **Ensure staff listen** and understand each young person's lived experience and the services they may need.
- **Understand youth** in terms of their strengths, assets, and excellence.
- **Recognize the different barriers** facing youth in accessing support services, and how these barriers are linked to the social determinants of health.
- **Acknowledge the role** that health literacy plays in accessing services. Health literacy refers to a young person's capacity to understand and obtain basic health information, and is dependent on social conditions.⁸⁴ Ensure that toolkits and other resources for youth LWAH are accessible and youth-friendly; for example, present information in different languages and use visual aids.

02. Create leadership roles and opportunities

- **Train youth LWAH** to lead workshops or to serve as one-to-one peer mentors for other youth LWAH, on topics like mental health, disclosure, navigating support services, stigma, etc.
- **Integrate peer leadership** and mentorship opportunities for youth with lived experience.
- **Be flexible and adaptable** to ensure that youth leaders are able to direct conversations and programming.

03. Prioritize youth voice

- **Engage youth** in all aspects of programming, including program design, development, and evaluation.
- **Position youth** at the forefront of addressing their barriers to frame attainable and acceptable program and support service objectives. This process can be implemented in multiple aspects of programming (for example, from grant writing to the facilitation of workshops).

04. Implement group programming

- **Implement strength-based** support groups that are focused on the lived experiences of youth LWAH.
- **Ensure group programs** are age-specific and based on disclosure status to foster inclusion and trust between staff and peers, and to create a safe environment to learn about support services and to host conversations about living with HIV.

05. Remove barriers to services and programming

- **Reduce and eliminate** barriers experienced by youth LWAH; consider the hours of programming, location of services, transportation options and costs, and the availability of peer leaders, mentors, and frontline service providers who understand living with HIV from a critical and anti-oppressive lens.
- **Ensure an intersectional approach** is used when planning programs and support services by being mindful of the various social determinants of health.

06. Provide a safe and supportive environment

- **Promote mutual and supportive** relationships – within the physical space, among staff, and across the culture of the organization.
- **During group programming**, ensure the presence of peers, family, friends, and other members of young people’s networks to demonstrate and encourage support (when appropriate).

07. Provide holistic support

- **Integrate other support services** (for example, mental health services) into HIV care and support programs, and facilitate a seamless transition and referral process.
- **Ensure that programming** is provided on an individual level, and support youth in navigating health and social systems to build rapport and trust.
- **Strengthen relationships** with other service providers to improve the referral process for medical and social services, in addition to other organizations that support parents, youth, and families LWAH.

08. Provide anti-oppressive practice training for frontline staff

- **Develop training opportunities** for youth workers in anti-oppressive practice and address the social determinants of health when providing support or care to youth LWAH.
- **Use appropriate terms** and be mindful of language (i.e. living with HIV rather than HIV-infected, experiencing substance use rather than drug user).
- **Ensure that the staff** of your organization are representative of the populations you serve and work alongside; young people may feel more connected or able to build rapport more easily with professionals and peers who have similar lived experiences.

HIV Disclosure: Respecting Confidentiality

Practitioners who work alongside youth LWAH must respect each young person’s needs and wants regarding privacy and confidentiality about their HIV status and personal health information.

- Never disclose a person’s status unless you have their express permission for each circumstance.
- Even when someone discloses in a small, closed group of peers, do not assume that they are comfortable with disclosure in other settings.
- Never identify a program or group publicly as being for youth LWAH.
- Understand your legal and ethical responsibilities, including the standards of practice for your profession and the policies of your organization.

To learn more about HIV disclosure, revisit the [Canadian HIV/AIDS Legal Network’s privacy and disclosure guide for youth](#).⁸⁵

We will know we are on the right track when youth living with HIV access supports and report that their autonomy, dignity, confidentiality, and unique needs are respected.

Once they feel safe and secure, we will see more well-supported youth meaningfully engaged in programming and living fulfilling lives.

Conclusion

THIS REPORT CONTEXTUALIZES the experiences of youth living with and affected by HIV from a social determinants of health lens, and outlines frameworks, interventions, program features, and best practices for youth workers and youth-serving organizations.

The implementation of recommendations in this report will result in increased accessibility to support services for youth LWAH. As the strategies are centred around the lived experiences of disempowered youth, who most often have little to no opportunities to have their voices and experiences shape programming and policies, the opportunity to engage in programs that effectively do so will result in greater empowerment and the opportunity to build capacity and strengthen social support networks.

In fact, these recommendations address the intersecting needs of a variety of marginalized youth, as marginalization increases vulnerability for youth LWAH, who also face stigma and discrimination. Programming that is inclusive, safe, holistic, and prioritizes the voices and experiences of young people can mitigate the barriers they face and create pathways to support and opportunity.

Learn More

1. Canadian HIV/AIDS Legal Network

<http://www.aidslaw.ca>

One of the world's leading organizations tackling the legal and human rights issues related to HIV, and advocating at both the policy and community levels.

Toolkit

Privacy and Disclosure for Youth Living With HIV or Hep C

<https://exchange.youthrex.com/toolkit/privacy-and-disclosure-youth-living-hiv-or-hep-c-questions-answers>

2. CATIE

(Canadian AIDS Treatment Information Exchange)

<https://www.catie.ca>

Canada's official knowledge broker for HIV and hepatitis C. CATIE strengthens Canada's response to HIV and hepatitis C by bridging research and practice, connecting healthcare and community-based service providers with the latest science, and promoting good practices for prevention and treatment programs.

3. HIV & AIDS Legal Clinic Ontario (HALCO)

<https://www.halco.org>

Community-based legal clinic that provides free legal services for people living with HIV/AIDS in Ontario.

4. Ontario AIDS Network (OAN)

<https://oan.red>

A coalition of AIDS Service Organizations and AIDS Service Programs that work collectively to provide a just, effective response to HIV and AIDS, improve life for people infected with and affected by HIV and AIDS, and prevent the spread of the virus.

5. Ontario HIV Treatment Network

<http://www.ohtn.on.ca>

A non-profit network funded by the AIDS Bureau of the Ontario Ministry of Health & Long-Term Care.

6. The Teresa Group

<https://www.teresagroup.ca>

Canada's oldest community-based charitable organization specifically serving children and youth affected by HIV and AIDS and their families.

Toolkit

How Do I Tell My Kids? A Booklet about HIV Disclosure in the Family

<https://exchange.youthrex.com/toolkit/how-do-i-tell-my-kids-booklet-about-hiv-disclosure-family>

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