



**ACCEPTANCE &
COMMITMENT to
EMPOWERMENT**

Acceptance and Commitment to Empowerment (ACE) Intervention:

**Reducing HIV Stigma and Promoting Community
Resilience Through Capacity Building**

Phase One:

**Contextual Assessment
Community Report**



Acknowledgements

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- AIDS Committee of Durham
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- Alberta Community Council on HIV
- Community Alliance for Accessible Treatment
- HIV Edmonton
- Regional HIV/AIDS Connection Positive Living Niagara
- SafeLink Alberta



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Executive Summary



The Acceptance and Commitment to Empowerment (ACE) Project is a multi-site Canadian initiative aimed at reducing HIV-related stigma, particularly in racialized and immigrant communities. Through focus groups across six cities (Calgary, Edmonton, the Greater Toronto Area, London, Niagara and Ottawa), the team engaged 97 community members (CMs) and service providers (SPs) to explore local experiences of HIV stigma and the needs for HIV stigma reduction.

Despite major advances in HIV prevention and treatment, HIV-related stigma continues to shape people's lives across Canada. Stigma affects whether people seek testing, access care, disclose their status, and feel safe in their families, workplaces, and communities. These harms are especially pronounced for African, Caribbean, and Black (ACB) communities, immigrants, newcomers, and others facing racism, poverty, gender-based discrimination, or precarious immigration status.

This report presents findings from Phase One of Project Acceptance and Commitment to Empowerment (ACE), a multi-site community-based research initiative focused on understanding local experiences of HIV-related stigma and identifying pathways for meaningful stigma reduction.

Who we heard from

Phase One engaged 97 participants across six Canadian cities (Calgary, Edmonton, the Greater Toronto Area, London, Niagara, and Ottawa) through 11 focus groups. Participants included community members living with or affected by HIV and service providers working in HIV, health, settlement, and social services. In addition, 18 community organizations completed baseline surveys. The study centred lived experience and prioritized voices from racialized, immigrant, and newcomer communities.

Executive Summary



Key Findings

- 1** HIV-related stigma remains widespread and harmful.
- 2** Systems and institutions often reinforce stigma.
- 3** Stigma has serious mental health consequences
- 4** Communities demonstrate strong resilience and care

What Needs to Change

Participants emphasized that HIV-related stigma cannot be addressed by individuals or communities alone. Meaningful change requires coordinated, systemic action across four key areas:

- Dedicated, stable, long-term funding to sustain stigma reduction, education, and community capacity-building
- Widespread, accessible HIV education and training across healthcare, settlement, social services, schools, and the broader public
- Embedded HIV education and services within routine healthcare and everyday community settings to normalize HIV and reduce barriers
- Cross-sector collaboration to prevent people living with HIV from falling through gaps between services

Moving Forward

This report highlights both the persistence of HIV-related stigma and the leadership of people living with and affected by HIV in resisting it. To support this leadership, systems must shift toward equity, cultural safety, and sustained investment. The findings offer a clear roadmap for reducing HIV-related stigma and strengthening community-centred care across Canada.

About Project ACE

Project Acceptance and Commitment to Empowerment (ACE) is a community-centred action research, which examines the facilitators and barriers to taking up an evidence-based intervention on stigma reduction in real-world settings. The project was based on over a decade of research on stigma reduction with African, Caribbean and Black (ACB), Asian, and Latinx communities in Canada and with university students in China.

Project ACE consists of three phases:

Phase One: Conduct contextual assessments on the local needs and experiences of HIV stigma using a (i) baseline survey with local service organizations serving immigrants/refugees; and (ii) focus groups with service providers (SPs), and community members (CMs).

Phase Two: Engage SPs and community leaders in the ACE intervention and the Train-the-trainer program that enable them to become ACE facilitators.

Phase Three: Engage CMs living with or affected by HIV stigma in the ACE intervention to enable them to become HIV community champions.

Phases two and three focus on implementing the ACE intervention

which has integrated two evidence-based training: Acceptance and Commitment Therapy (ACT) that promotes psychological flexibility through mindfulness-based exercises and experiential activities; and Social Justice Capacity Building (SJCB), an empowerment education that promotes a critical understanding of stigma as power relations, and collective action to reduce stigma at the personal, interpersonal, organizational and community levels.



Contexts Matter

Project ACE engages PLHIV, and communities affected by HIV stigma in six cities (Calgary, Edmonton, the Greater Toronto Area, London, Niagara and Ottawa), chosen based on HIV trends and needs identified by community partners and interest holders in these cities.

(A) HIV in Ontario: Trends and Inequities



Historically, most HIV cases have been in larger cities, especially Toronto. While Toronto still has many cases, its rate of new diagnoses went down in 2022, and rates in smaller cities (e.g., Ottawa, London, Niagara) and suburban areas have gone up [1]. HIV affects different populations differently. People who experience social and economic inequities (e.g., racism, sexism, homophobia, transphobia, poverty, stigma, etc.) are more vulnerable to HIV [2,3,4].

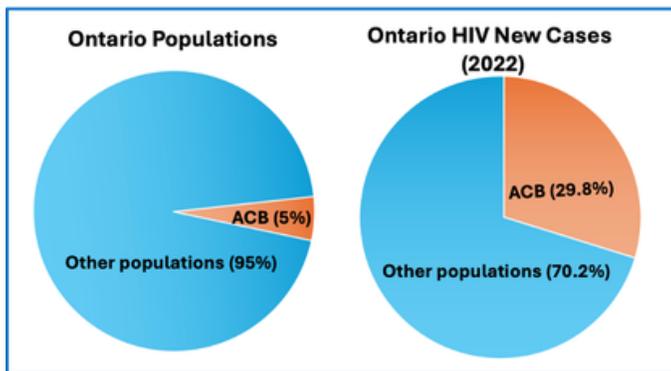


Figure 1.

An example of HIV disparities in Ontario

- **African, Caribbean, and Black (ACB) people** make up less than 5% of Ontario's population and yet account for a large share (29.8%) of new HIV cases in 2022.
- **Indigenous peoples** make up 2.9 % of Ontario's population and account for 4.6% of new HIV cases [5,6].
- **Gay, Bisexual, and Men Who Have Sex with Men (gbMSM)** continue to have the highest number of new HIV diagnoses; they made up half (about 57%) of new cases where the cause was known.
- **Women:** About one in four (nearly 27%) new HIV diagnoses in 2022 were among women. This number has been slowly going up over the last decade.
- Around 10.6% of new HIV cases were among **People who Inject Drugs**.

It is important to note that social determinants such as inequitable access to income, employment and healthcare, systemic racism and other marginalization can significantly increase the risk of HIV in ACB communities. For example, unemployed ACB individuals had a much higher rate of HIV (10.9%) compared to those with full-time jobs (3.1%). Immigrants in this community also had higher rates [2,4]. Housing instability and stigma are also common barriers to HIV prevention, testing, care, and treatment adherence. This is particularly true for structurally marginalized populations. [3]



(1) Greater Toronto Area (GTA)



The GTA is comprised of the City of Toronto and the neighbouring regional municipalities of Peel, Halton, Durham, and York. In the early 1980s, local activism and organizing in response to AIDS-related illness and deaths had led to the establishment of ASOs such as AIDS Committee of Toronto (ACT) and People of AIDS Foundation (PWA) in the city of Toronto.

In the 1990s, ethno-specific AIDS service organizations (ASOs) were established in Toronto to address systemic racism and cultural-linguistic barriers faced by racialized and immigrant PLHIV and affected communities. They included Africans in Partnership Against AIDS (APAA), Alliance for South Asian AIDS Prevention (ASAAP), Asian Community AIDS Services (ACAS) and Black Coalition for AIDS Prevention (BlackCAP). The changing demographics of HIV/AIDS and immigration-settlement patterns led to increased needs for ASO resources in the GTA. In response, many organizations started providing specific HIV related programs and services. In 2007/2008, the Toronto HIV / AIDS Network was established to facilitate HIV/AIDS planning, collaboration, engagement and access based on the principles of GIPA-MEPA principle, inclusion, harm reduction and a social justice and anti-oppression approaches.

(2) Niagara Region

Niagara region comprises 12 municipalities with a mixture of urban (e.g., the cities of St. Catharines and Niagara Falls) and rural areas. Between 2016 and 2021, residents who identified as Black had increased by about 40%, making up 2.89% of the Niagara population [7]. Positive Living Niagara (former AIDS Niagara) is the only HIV/AIDS service organization (ASO) and is highly recognized. Since its inception in 1990, they have been creating a supportive community to those affected by HIV, HCV, STIBBs, and substance use by providing a range of proactive and innovative services including harm reduction, community outreach and education. Aligned with the Ontario HIV/AIDS Strategy, Positive Living Niagara provides services to women faced with complex structural and systemic challenges, gbMSM, African, Caribbean and Black (ACB) communities, Indigenous communities, migrant agricultural workers, and individuals who use drugs. They provide HIV testing, HIV support programs including case management, in-home support, and counselling, as well as Niagara's Pre-Exposure Prophylaxis (PrEP) clinic in partnership with two Community Health Centres in two major Cities: St. Catharines and Niagara Falls.

(3) London

The Middlesex-London region, which includes London, has a higher average rate of first-time HIV diagnoses than the provincial average in Ontario (7.7 per 100,000) between 2017 and 2021. In recent years, the changing demographics of HIV was also observed in London, affecting not only GBMSM but also Indigenous peoples, ACB people (particularly women), people who inject drugs, new immigrants, and people from HIV-endemic countries.

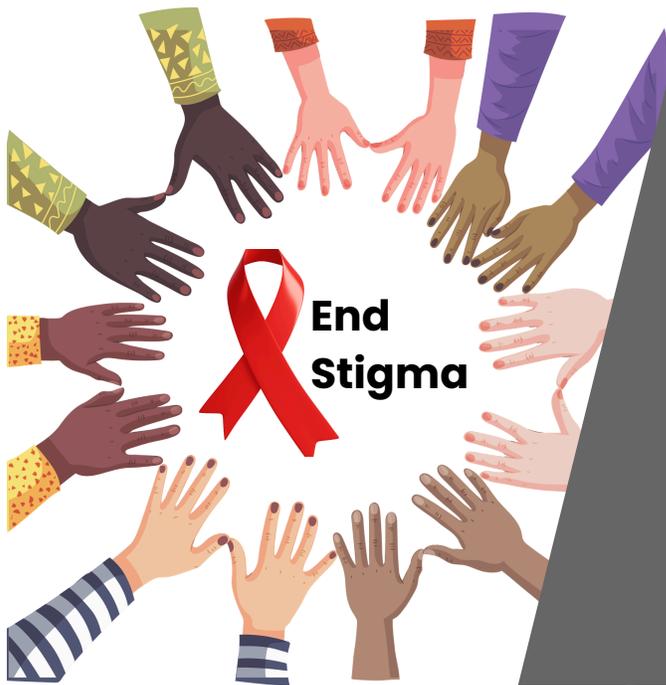
Local community-based research (e.g., the BLACCH study, weSpeak, and the A/C study), has provided critical insights into the impact of HIV on affected populations in London. Regional HIV/AIDS Connection (RHAC) is the leading ASO for London and surrounding areas, providing a comprehensive suite of free and confidential services, including HIV/HCV testing, counselling, support and referrals. RHAC also provides harm reduction programs and collaborates with other organizations such as the Middlesex Health Unit, the London Intercommunity Health Centre, the Cross-Cultural Learners Centre, Francophone Community Centre, University of Western Ontario (UWO), faith leaders and other local community leaders to enhance access to services.



(4) Ottawa

HIV/AIDS continues to be a pressing public health issue in both Ottawa. Between 2019 and 2021, first time HIV diagnosis rates in Ottawa decreased by 23-25%. But, in 2022, the rate had gone up by 27%-40%. [5,6]. The AIDS Committee of Ottawa (ACO) has played a crucial role in community outreach and education to dispel misconceptions about HIV, reduce stigma, and promote understanding of HIV as a manageable chronic condition. ACT also provides counselling to GBMSM, women, PLHIV and affected groups, and comprehensive support to PLHIV (e.g., foodbank, social connections). In addition, Ottawa Public Health has been proactive in implementing harm reduction strategies and providing accessible testing and treatment options. Their initiatives have focused on increasing awareness of HIV transmission and prevention methods, particularly among highly vulnerable populations, thereby fostering a more informed community. These organizations not only provided essential services but also created safe spaces for dialogue, allowing individuals to share their experiences and challenges related to living with HIV.

(B) HIV in Alberta: Contexts and Trends



In Alberta, HIV has been monitored by public health since 1998. HIV rates have remained relatively stable. In recent years, there were significant increases in new HIV cases. In 2023, new HIV cases in Alberta rose by 73% from 2022 [8]. Most of these new cases were linked to people who were exposed to HIV outside of Canada. More people now have access to HIV testing, like rapid testing, self-testing [9,10]. Migration to Alberta from other Canadian provinces and internationally has increased. But, access to HIV related care and support has not kept pace with this rise in cases.



In addition, many social and political changes have affected PLHIV in Alberta. In the early 2000s, the Alberta Community Council on HIV (ACCH), the Government of Alberta, and the Government of Canada worked within a formalized partnership through the Alberta Community HIV Fund (ACHF) to equitably distribute public funding to ASOs based on public health data. Over the years, funding allocations and focus on HIV work in the community has decreased due to fiscal restraints, and changing trends in HIV/AIDS, Hepatitis C, and other STBBIs in Alberta. The ACHF program and Consortium ended when funding approaches to HIV in Canada shifted. The number of ASOs offering psychosocial support for PLHIV have dropped significantly since 2001. The ACHF partnership that once existed among the community, PLHIV, the provincial and federal government has also ended.

(5) Calgary and (6) Edmonton

The loss of partnerships, reduced funding, and weakened service coordination have made it increasingly difficult to deliver comprehensive, accessible care for PLHIV and affected communities. The systemic gaps are further compounded by Alberta's centralized care structure. Currently, there are only two HIV clinics in the province – one located in Calgary (supports southern Alberta) and the other in Edmonton (serving central and northern Alberta). This centralized model has resulted in significant service gaps for those living outside the two cities and has contributed to fragmented communication between regions and service providers (SPs). Currently, SafeLink Alberta is the key ASO serving Calgary, and HIV Edmonton is the key ASO serving Edmonton. These structural limitations directly shape the lived experiences of PLHIV and affected individuals and communities, impacting their access to prevention, testing, continuity of treatment and care, and experiences of stigma. Recognizing these challenges is crucial to developing effective, community-based responses. Given the role that Calgary and Edmonton play as regional service hubs, these cities were selected as our research sites.

Phase One: Contextual Assessment



Objective

The overall objective of Phase One was to engage collaborators, community stakeholders, and target populations to identify local contexts of HIV stigma, and factors that determine the how acceptable, feasible, and easy it is to adopt the ACE intervention in the local communities. Phase One results were used to refine the ACE intervention to be implemented in Phases Two and Three. This report captures insights and findings from Phase One in which focus groups were conducted with CMs living with or affected by HIV and SPs working with racialized immigrants in health, settlement, and social service sectors.

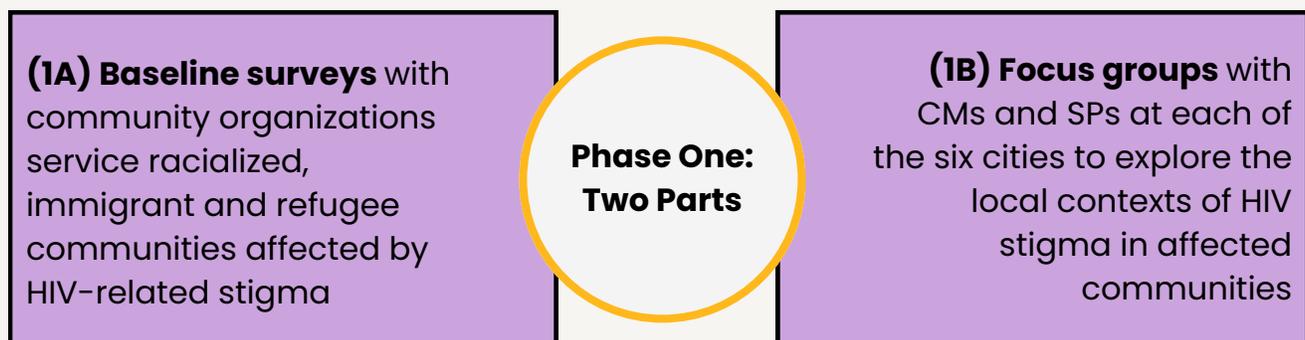


Research Methods

Project ACE is guided by the principles of **equity, access and social justice**, which are essential components of critical health promotion [11]. Throughout all phases of the project, we use approaches of **meaningful engagement, capacity building, and collective empowerment** [12,13,14] to achieve our objectives. We also applied a theoretical framework that integrates critical race-feminist perspectives with intersectionality to illuminate the impact of unequal power relations on HIV stigma. Phase One consisted of two components (see Figure 2).

Figure 2.

Phase One - Parts A and B



Phase 1A Organization Surveys

Phase 1A surveyed community organizations that serve racialized, immigrant, and refugee communities affected by HIV-related stigma. The survey consists of questions on types of service, populations served, internal policies, staff training, and programs on stigma reduction.

Purpose To establish a baseline on the types and extent of HIV stigma reduction efforts at each local site. Results will be used for comparison of efforts at the end of the project.

Figure 3. Phase 1A Participation by City

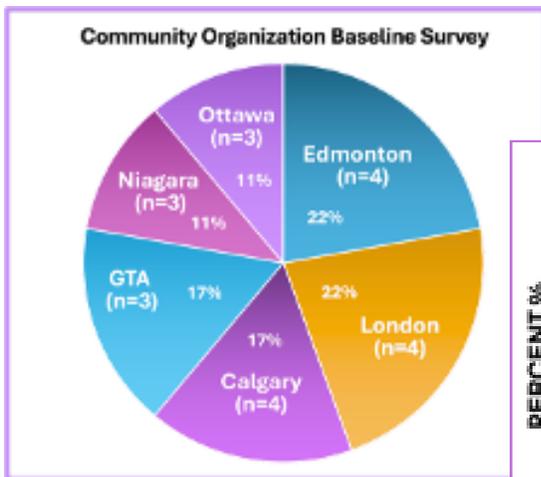
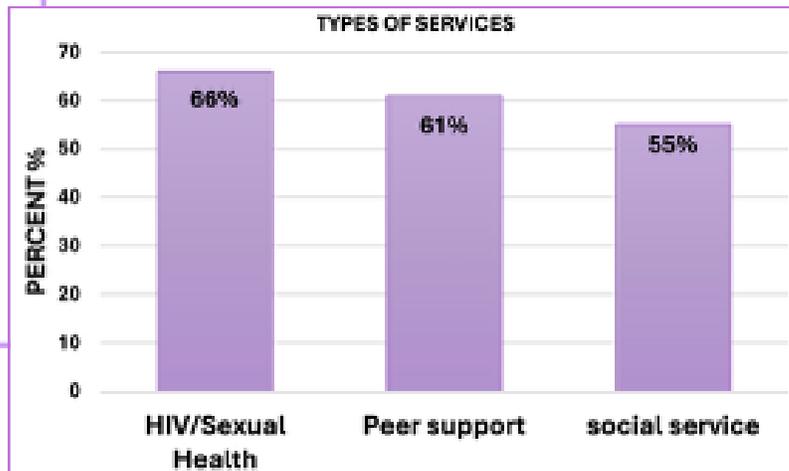


Figure 4. Types of Services



18

community organizations

The annual number of service users at these organizations:

- <1,000 (44%)
- 1,001-5,000 (22%)
- 5,001-20,000 (17%),
- 20,001+ (17%)

Most organizations reported the following service user populations in the prior 3 months:

- racialized immigrants and/or refugees (94%)
- people living with HIV (55%),
- people living with addiction or substance use (67%),
- people living with mental illness (72%), and
- someone engaging in sex work (55%)

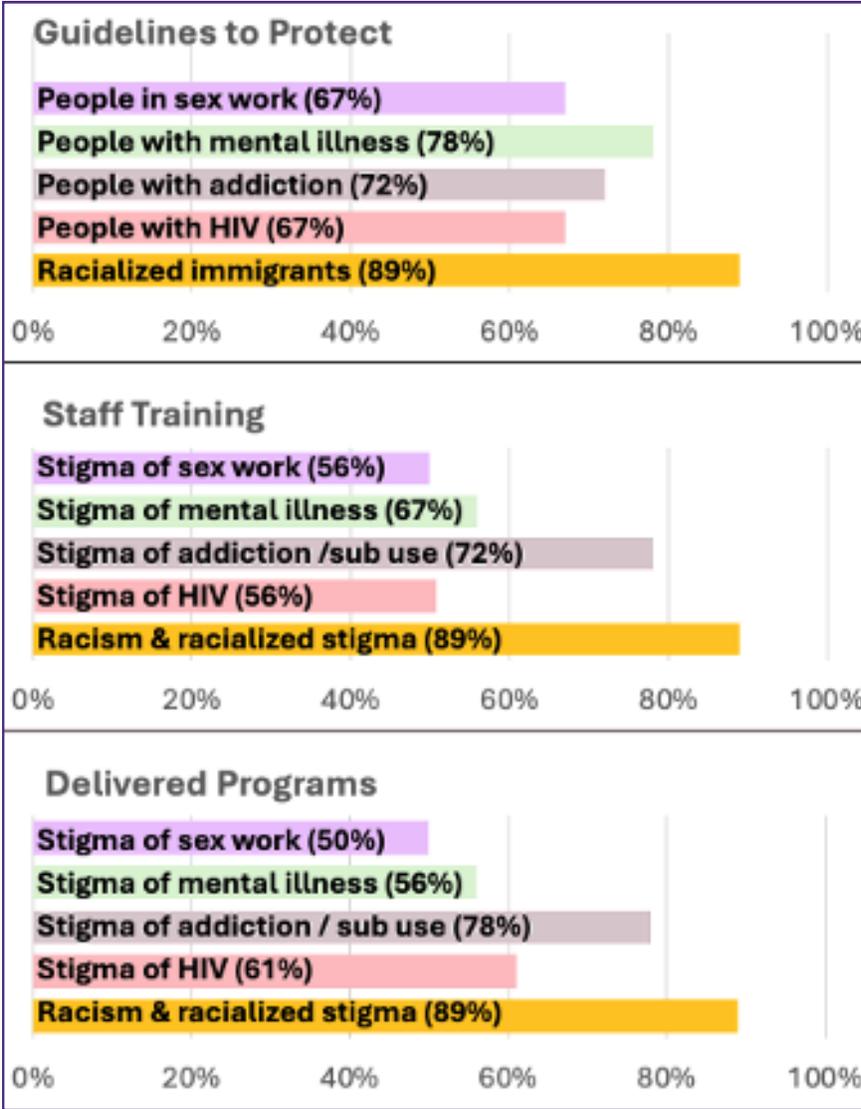


When asked

about **organizational policies/guidelines** that protect the rights of different service user groups, **staff training** on different stigmas, and **programs** that address stigmas, the responses showed that at least half (50%) of the organizations had attended to these policy and practice issues in the 3 months prior to the survey. But, it can also be noted that these policy and practice issues specific to **PLHIV and HIV related stigma** were carried out by fewer organizations, even though 66% of the participating organizations were providing HIV and sexual health services. These results indicated that HIV related advocacy and stigma reduction are critically needed.

Figure 5.

Organizational guidelines, staff training and program delivery



Phase 1B Service Provider and Community Member Focus Groups

Phase 1B conducted online focus groups (FGs) with CMs to explore their experiences and or perspectives on HIV stigma, their resistance and resilience strategies, and access to relevant support. We also conducted focus groups with SPs to explore their perspectives on HIV stigma reduction needs in their organization and in communities, challenges and enablers of stigma reduction, available resources, and critical aspects of stigma reduction interventions.

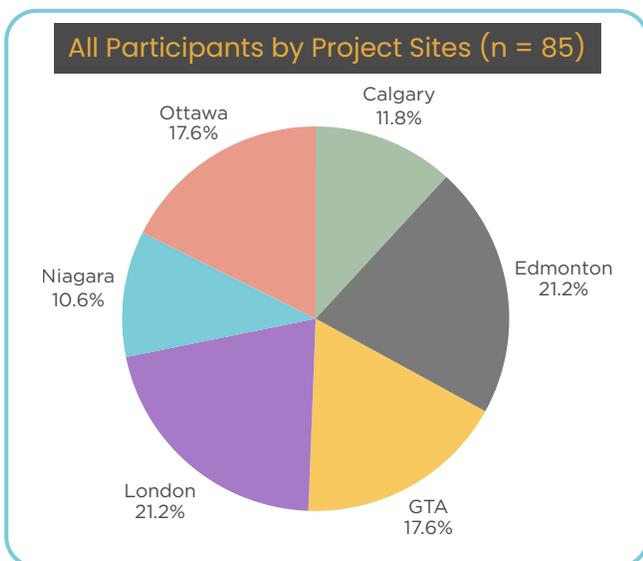


- 11** focus groups
- Ethics
- Consent

GTA/Niagara (2 CM focus groups, 1 SP focus group)
 London/Ottawa (1 CM focus group, 2 SP focus groups)
 Edmonton/Calgary (2 CM focus groups, 2 SP focus groups)
 All-sites (1 CM focus group)

Figure 6.

Phase 1B Participant at six sites

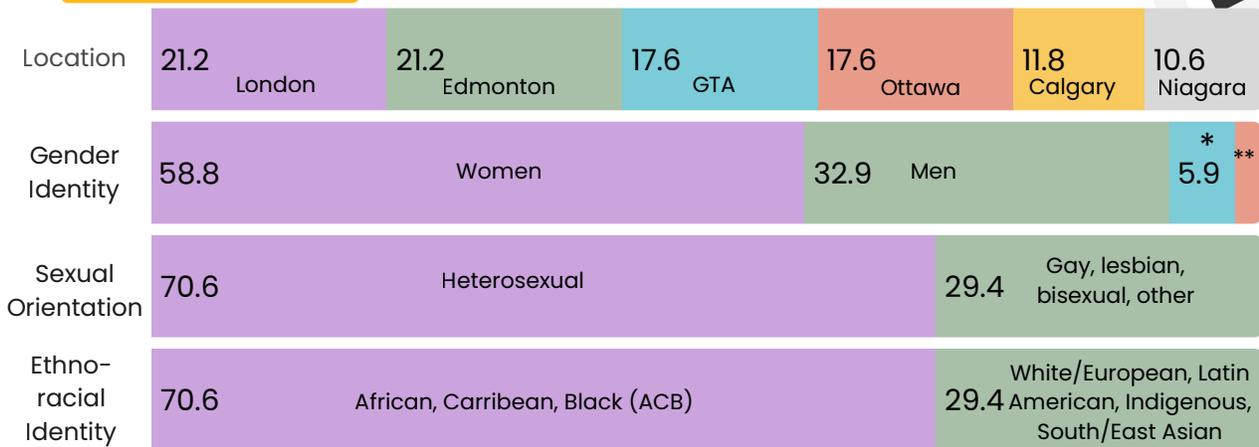


As presented in Figure 6, Phase 1B study participants were from six cities: GTA, Niagara, London, Ottawa, Calgary and Edmonton. These focus groups were intentionally grouped into 3 clusters to enhance outreach and recruitment, as well as participation access by providing more scheduling options. Participants were recruited by local site coordinators with support from Project ACE community partners and networks. Communication channels included social media, e-flyers, word-of-mouth, emails and phone calls.

A **total of 97 participants** took part in 11 focus groups. Of those, **85 (88%) completed a sociodemographic survey**. Thus, the following figures represent only the information of 85 participants.



Figure 7. Participants Characteristics (%)



* Non-binary

** Option was not listed 1.1% (n=1) or provided no response 1.1% (n=1).

As shown in Figure 7, most of the participants identified as women (58.8%), African, Caribbean and Black (ACB) (70.6%), and as heterosexual (70.6%). Participation from the SP and CM populations varied across the six cities (see Figure 8), with a large proportion of SPs from London and relatively small proportions from Calgary and Edmonton. This finding is reflective of the local contexts of HIV/AIDS services and affected communities (see the Contexts Matter section). Similarly, the proportions of CM participants in Niagara region and London were comparatively smaller, likely related to community stigma and barriers to participate, especially among agricultural workers.

Figure 8. Participation of SPs and CMs across project sites

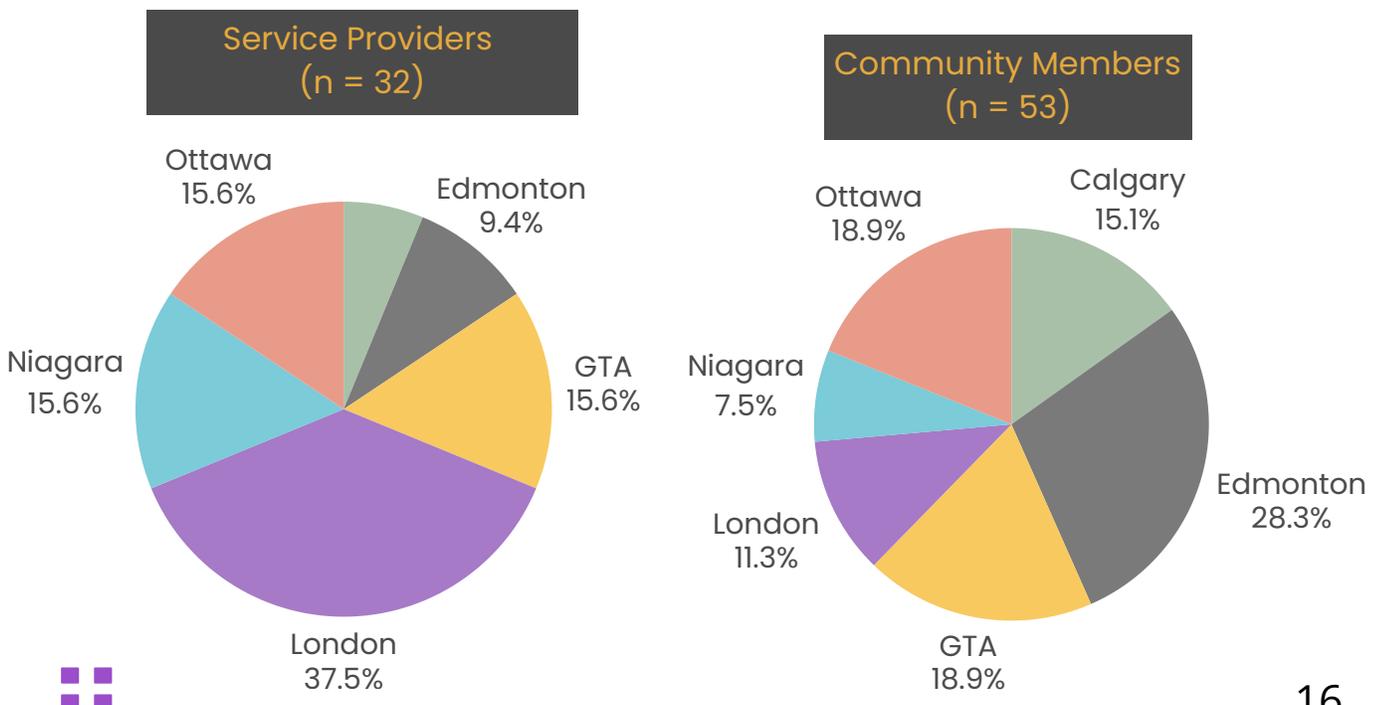
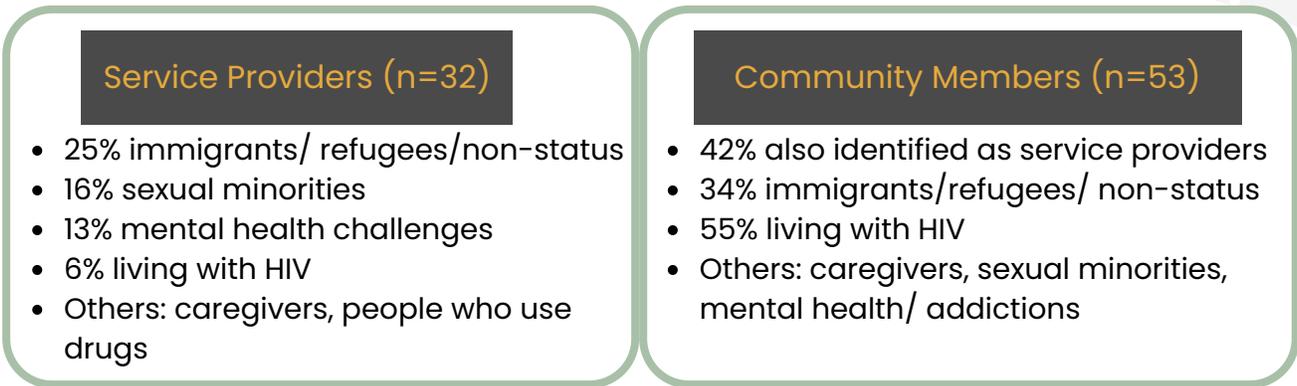


Figure 9.

Participant lived experiences and affiliations



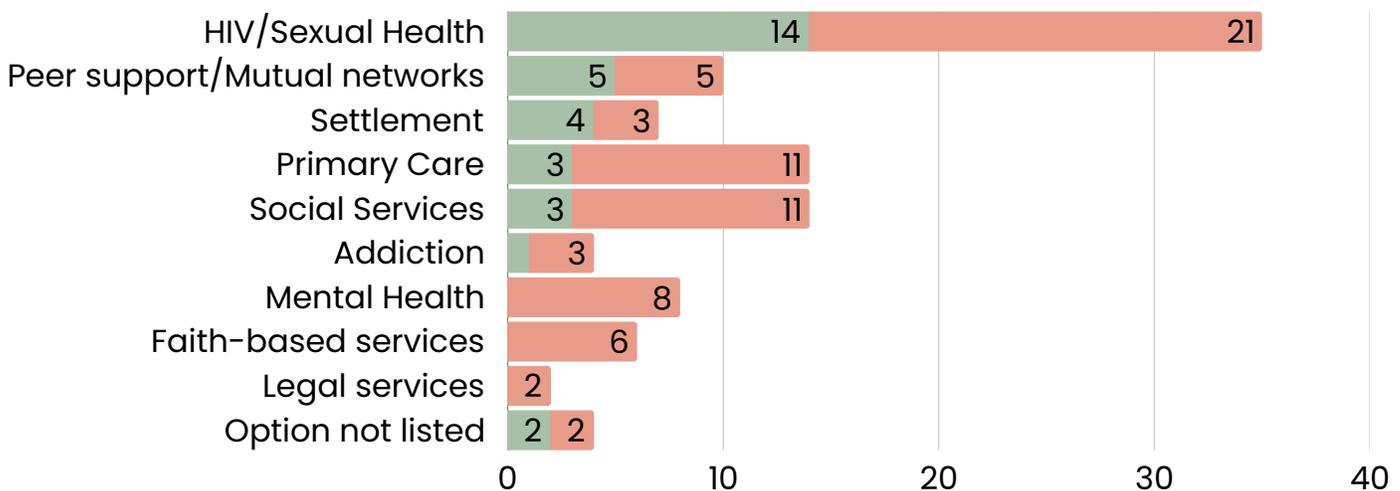
In term of age, a majority (57%) of CMs were between 26 and 45 years old. As indicated in Figure 9, about one-quarter of SPs and one-third of CMs identified as immigrants, refugees, or people with precarious immigration status. Over one-third (36%) of CMs had been in Canada for 10 years or more, and 58% spoke English as a first language. Whereas a small percentage of SPs identified as living with HIV, **more than half (55%) of the CM identified as living with HIV.**

It is important to note that although CM participants chose to join the CM focus groups, **42% also identify as service providers**, with the most common roles in peer support (27%), HIV/sexual health (27%), and primary care (23%). These results suggest that the roles, identities and experiences of SPs and CMs in the HIV service sector are complex and cannot be understood in silos.

Figure 10.

Service provision and usage

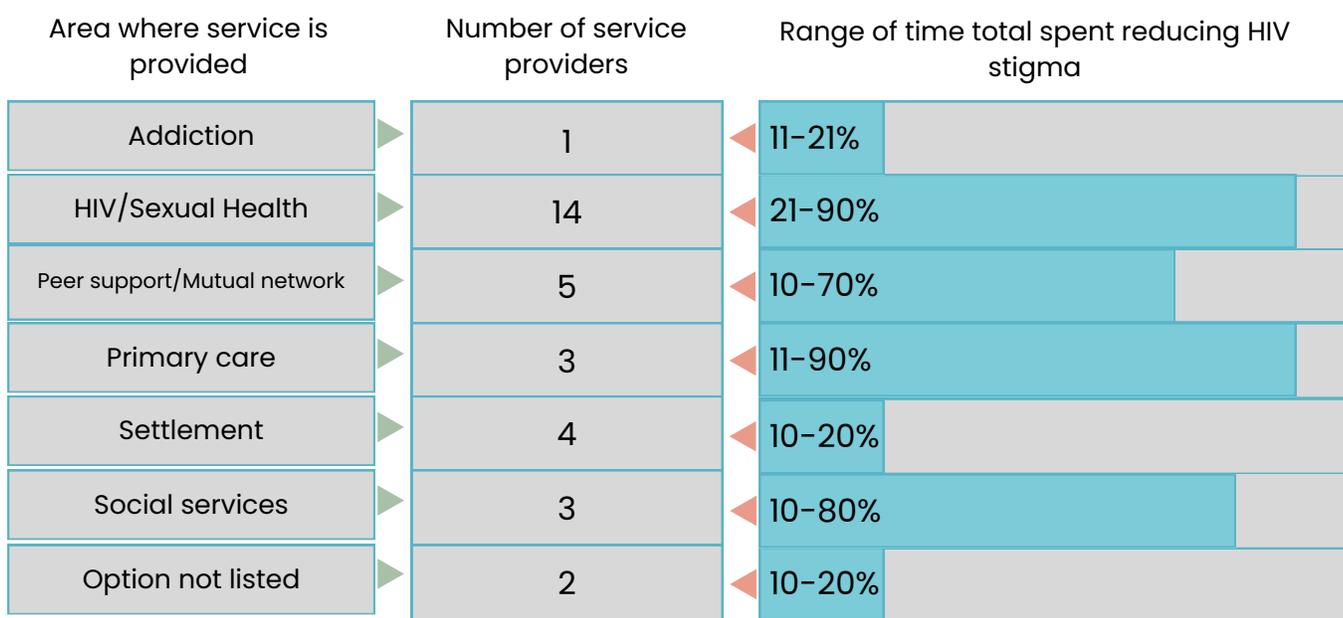
● SP role ● Service Used by CM



In addition, the majority (72%) of CMs indicated that they used services. As shown in Figure 10, the top services they used were: HIV/sexual health (55%), settlement services, primary care, and social services (29%). Among SPs, a significant number (21.9%) also reported that they accessed services.

Figure 11.

Percentage of time spent reducing HIV stigma by Service Providers



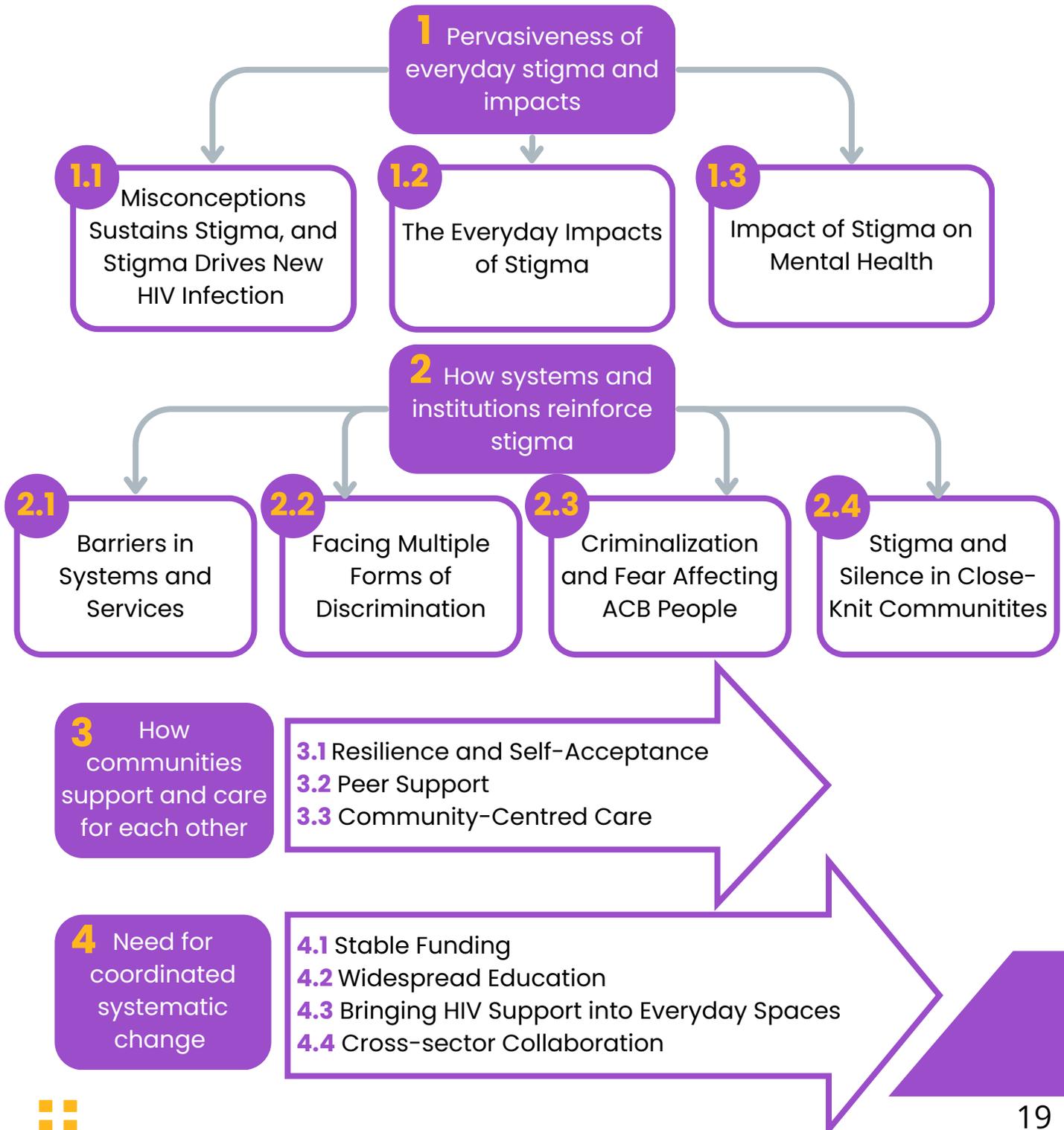
A key finding was the wide variation in how much time service providers spent on HIV stigma reduction in their roles (see Figure 11). While some (18.8%) reported spending most of their time (91–100%) on stigma reduction, a substantial portion (28.1%) reported dedicating only 0–10% of their time. This suggests a gap between service roles and focused anti-stigma work, and points to the need for more targeted resources, training, and institutional support.

SPs from addiction and settlement service areas reported the lowest range. Plausible explanations include the priority to address stigma specific to the service area (e.g., addiction), deliverables determined by funding requirements (e.g., settlements), or perceived inadequate expertise to address HIV stigma, as reflected in the narratives of some focus groups participants.



Findings

We identified four key themes from the focus group discussions. These themes are based on participants' sharing and discussion, and examples will be shared using pseudonyms to protect the identity of participants. Many aspects in these themes were echoed across all project sites.



1. Pervasiveness of everyday stigma

Despite decades of medical progress and public education, HIV-related stigma remains a pervasive and harmful force in many communities across Canada.

1.1

Misconceptions Sustains Stigma, and Stigma Drives New HIV Infection

Stigma continues to shape public attitudes, healthcare interactions, and everyday social experiences for PLHIV:

- Misconception (wrong ideas or beliefs) fuels stigma (e.g., HIV is still a death sentence).
- Stigma is driven by moral judgements toward sex, drug use, or sex work, and PLHIV are blamed for their status.
- PLHIV also experience stigma related to their racial, sexual, gender and immigration identities.
- Silence about sexual health, especially within family and with younger people, reinforces stigma and wrong information (e.g., HIV is a gay disease).

A lot of people assume that if you have HIV, you're either gay or a drug user. ... Everything right now around HIV is still focusing on that 90s AIDS crisis [thinking] not the actual [situation] in 2023, which is very different.

(Dylan, GTA/Niagara)

SP

They don't think about different ways of contracting HIV. They just relate it to [... having] sex in the wrong way or choosing the wrong partner. It's like you did the wrong thing and those are the consequences.

(Marie, London)

SP

I've noticed [a] reluctance to talk about [sexual health, HIV, and stigma with] younger [people ...] And the longer younger people go without knowing these things [they're] either misinformed or not informed at all.

(Marie, London)

SP



1.2

The Everyday Impacts of Stigma

PLHIV experience stigma in many aspects of their life, at home, with friends, at work, within health and social care, and in the community. Stigma affects daily life in many ways:

- Many PLHIV avoid sharing their status to protect themselves from rejection and discrimination.
- Stigma prevents people from accessing HIV prevention, testing, treatment, and support.
- Some PLHIV feel powerless and engage in negative coping (e.g., substance use, addiction, unprotected sex).
- PLHIV often experience compounding social isolation from family, friends, peers, SPs and communities.



I've not been able to settle down because no woman is willing to accept me.

(Paul, GTA/Niagara)

CM

Some folks avoid testing because of slut shaming.

(Lucas, Ottawa)

SP

[A CM with a newborn] had people come from her community [to] congratulate [them.] Her husband did not want [anyone] to assume [she had] HIV, so, he forced her to continue breastfeeding her child. The baby got HIV.

(Christina, Calgary/Edmonton)

SP

1.3

Impact of Stigma on Mental Health

Stigma is not limited to how PLHIV are treated by others (external stigma). It also affects how PLHIV view and treat themselves (self-stigma). Both forms of stigma increase mental health stress and reduce people's ability to care for themselves.

- When PLHIV feel powerless, they may develop self-stigma (e.g., shame, guilt, self-blame), become isolated, and avoid care and support.
- PLHIV who experience external and self-stigma often report anxiety, depression, and loneliness, and even thoughts of self-harm.



I was mentally derailed to the point that I wasn't myself. HIV may not have killed me, but depression might have.

(Simon, GTA / Niagara)

CM

We know how people talk [...] 'so and so used to do this, he used to sleep around, they used to do this.' [...] If there's anyone who did disclose and you know how they were treated, you're now scared of that same treatment coming to you.

(The Rock, Calgary /
Edmonton)

CM

2. How systems and institutions reinforce stigma

HIV-related stigma doesn't happen on its own. Systems and institutions reinforce HIV-related stigma, especially when people also face racism, sexism, homophobia, transphobia, poverty, or precarious immigration status. ■ ■ ■ ■

2.1

Barriers in Systems and Services

Many people living with HIV feel judged, unsafe, or ignored when trying to access healthcare, immigration services, housing, jobs, or even faith-based spaces. These systems often reinforce stigma instead of offering protection and support. places where stigma is reinforced

- Language barriers make it hard for newcomers to explain their health concerns or understand their options
- Fear of losing their job or immigration opportunities discourages people from seeking care
- Some healthcare providers dismiss symptoms, show bias, or treat people unfairly
- A lack of privacy and culturally safe spaces make it risky to ask for help

Some CMs don't speak English but most of the SPs are English speakers. Expressing their emotions and health problems around their status is problematic [given the language barrier].

(Marie, London)

SP

"My symptoms or my needs or my feelings are often invalidated in those spaces" [where she was dismissed as] an angry Black woman, [or] overreacting and [making assumptions re: drug abuse, mental health, or upbringing.]

(Kiki, GTA/Niagara)

CM

The government has made its face scary and produced legislation that is discriminatory, which perpetuates stigma.

(Rotie, London/Ottawa)

CM



2.2

Facing Multiple Forms of Discrimination

HIV stigma often becomes stronger when combined with racism, gender inequality, sexuality-based discrimination, and newcomer status. These layers of stigma compound each other and make everyday life more difficult.

- PLHIV are also judged for being poor, racialized, LGBTQ+, or newcomers, in addition to living with HIV
- Dominant norms based on false ideas can restrict open conversations about sexual health
- Families, schools, and newcomer settings often avoid talking about sexual health altogether
- Some women and trans participants also linked stigma to a higher risk of partner or family violence



Sometimes people feel the stigma ... not just because of HIV status, but because maybe they are poor, and they are thinking about their HIV status and many other issues. They do not have housing, enough food, and they're just feeling frustrated.

(Star, GTA/Niagara)

SP

Stigma impacts ACB communities. People are afraid of running into people from their community when accessing services.

(Mimi, Ottawa)

SP

Your partner might beat you up because you're HIV positive. You did the right thing [to disclose], yet you're facing isolation from the one you call your partner. It's painful.

(Fabiola, GTA/Niagara)

CM

2.3

Criminalization and Fear affecting ACB People



Fear of the law, police, and the criminalization of those living with HIV has created deep mistrust within ACB communities. This fear makes many people afraid to share their HIV status, seek care, or feel safe when accessing services.

- Black and gay men have been unfairly targeted and over-policed, as also reflected in existing evidence [15-16]
- The history of criminal charges related to HIV have created lasting fear across communities
- Public prosecutions reinforce harmful stereotypes about who is “responsible” for HIV



A big thing... especially in Canada, was that Black people were selectively picked when it comes to HIV. Most men in the early 2000s until 2010 were Black men who were either charged by police or the judge, saying you go to prison for this long because you did one, two, three and so forth. There was no information, there was no education. It was just criminalizing, criminalizing, criminalizing, seeing Black face after Black face. That's why people ended up thinking HIV / AIDS was for Black people ... especially Black people and gay people as the ones [driving] HIV. And maybe that's why people feel scared to share their status.

(Gary, London)

SP



2.4

Stigma and Silence in Close Knit Cultural Communities

In close-knit communities, HIV-related stigma can be especially intense. Social pressure, fear of gossip, and fear of being “outed” make many people afraid to speak openly about HIV or seek support. Participants shared that stigma within their own communities often feels more painful and dangerous than stigma from outside.

- Participants described how when PLHIV witness HIV-related abuse and negative treatment of others, their own fears also deepen.
- Some communities deny that HIV exists among them, while other communities have limited awareness about HIV



[PLHIV] are not open and comfortable telling other members of their community because they know the backlash from within their own culture and community is worse than that of living with HIV.

(Ash, Calgary/Edmonton)

SP

Where I come from, being HIV positive and also being queer [is] very hard to deal with because being queer is [...] a crime where you get arrested and jailed [...] coupled with the fact that you are also HIV positive, the level of stigmatization [is] high.

(Martina, Calgary/Edmonton)

CM

I was in [town in Alberta] one of the biggest communities there is east African, and they were not receptive to SPs to begin with. One CM said: 'I know everybody in this community, and no one is living with HIV' [...] Do you think anyone will disclose to you with this kind of attitude?

(Louise, Calgary/Edmonton)

SP

3. How communities support and care for each other

Despite facing persistent stigma and discrimination, PLHIV and their supporters have described strong personal resilience, meaningful peer support, and the importance of community-centred care. Participants shared how self-acceptance, safe spaces, and community connection help with coping, healing, and resisting stigma together.



3.1

Resilience and Self-Acceptance

For many community members living with HIV, resilience began with learning to accept themselves and their diagnosis. Self-acceptance helped them move from surviving in fear and shame, towards confidence, strength, and hope.

- Reclaim identity and control, and rebuild self-image without self-blame
- Reframe that HIV is manageable and letting go of shame and fear
- Managing mental health and emotional stress to reject stigma towards themselves
- Exercise the choice for when and to whom to disclose
- Feel stronger, more confident, and more focused on their goals, even while stigma remained.



I choose who I feel comfortable disclosing my HIV status to. It's not necessary to disclose to everyone. It is my personal decision.

(Jenny, London/Ottawa)

CM

I admit to myself that this is what I am – this is part of me, so I cannot hate myself for it. I have to love myself.

(Fisher E, GTA/Niagara)

CM

Au début lorsqu'on m'a dit que je vis avec le virus, je me suis demandée: est-ce que je vais vivre ou bien je vais mourir aujourd'hui? Mais au fil du temps, je commence les médicaments, les traitements, etc., et aujourd'hui, je vie bien mieux plus que d'autres personnes. Alors, quel est mon conseil Il faut s'assumer et il faut s'accepter. [1]

(Rotie, London/Ottawa)

[1] English Translation: *At first, when I was told I was living with the virus, I wondered: am I going to live or am I going to die today? But as time went on, I started taking medications, treatments, etc., and today I'm living much better than other people. So, what is my advice? You have to take responsibility and accept yourself.*



3.2

Peer Support

Peer support plays a powerful role in reducing isolation, increasing hope, and helping PLHIV feel seen, supported, and understood. Local ASOs were seen as champions in creating these spaces, but participants advocated for even more spaces for PLHIV and their supporters.

- Safe spaces for to talk openly without judgement were fundamental for social connection and learning
- Humanizes the HIV experience, and encourages building trust and mutual understanding
- Encourages individuals to access care without the burden of shame
- Increases visible, unified efforts that demand respect and support in solidarity within and beyond the community



It automatically creates a catalyst [...] for [...] comfort and sharing and knowledge exchange [...] among people who are all in the same boat.

(Ash, Calgary/Edmonton)

SP

We have to find a common ground and stand together to fight stigma and let people know that what we have is like any other disease.

Luc, Ottawa

CM

You start to see people use their courage to open up and share intimate details of their lives to support other people and make them feel less alone when they are new with the diagnosis. So, I point out the resiliency that I am always honored to witness [...] I've noticed some powerful moments between people doing peer support for no reason other than not wanting someone to feel as alone as they did.

(Barbara, Ottawa)

SP

3.3

Community-centred Care

Community-based organizations, especially ASOs, were described as lifelines for many participants. These spaces offer not only practical help, but also safety, belonging, and dignity. ■ ■

- Stigma reduction must be community-driven, not imposed. There is no one-size-fits-all way to address HIV-related stigma in different communities. Leadership must be grounded in diverse lived experiences
- While PLHIV and their supporters are essential to support each other, they should not be expected to compensate for gaps in formal systems of care.
- Women and trans participants noted education, training, and community engagement opportunities that fostered collective empowerment. In contrast, men were noticeably less vocal about accessing community resources, suggesting a gender gap in accessing community-based care.

“ The community support makes me feel people still love me. I'm not alone. They guarantee that if I face anything difficult, I can call their number anytime, even at midnight.

(Jeremy, GTA/Niagara)

CM

It's something I want to see [...] moving forward; we should always have fair representation of different communities [to] hear different experiences and [...] how to tackle issues from different perspectives.

(Martina, Calgary/Edmonton)

CM

I'm seeing a lot of community partnerships. I'm seeing a lot of unity. I'm currently working on a winter clothing drive for these folks, and I'm not the only one doing that in my region. There are quite a few coordinated efforts to feed, house, and support those newcomers who are currently without stable housing. It's beautiful to see.

(Jamie, GTA/Niagara)

SP

4. Need for Coordinated and Systematic Change

Participants emphasized that stigma surrounding HIV cannot be addressed by individuals or communities alone. It is reinforced by underfunding, limited education, fragmented services, and a lack of culturally appropriate support. ■■

4.1

Stable Funding

Limited and unstable funding undermines HIV-related services and stigma reduction efforts. Without adequate resources, organizations struggle to meet growing community needs, and important services remain out of reach.

- Currently, programs providing HIV-related support are reduced or shut down, limiting access from PLHIV
- PLHIV and their supporters have seen positive outcomes from investing in people for community capacity-building, for example, staff and allyship support during clinical visits to ensure respectful treatment
- Stable, long-term funding is the foundational cornerstone that enables everything else. Without funding, the next three strategies become near impossible, and stigma will persist.

Some of our offices are in stigmatizing locations. We need funds to have a workshop or dialogue in a neutral space. That requires money.

(Louise, Calgary/Edmonton)

SP

The lack of funding not only strips away services, but also enforces the view that people don't need or deserve that support.

(Jenn, Calgary/Edmonton)

SP

We went in together and I would look to my client to [...] encourage them to ask their question. Now the doctor has two people in the room. They cannot get around being rude or dismissive to my [client.] To put it in context, my role at that time [included the] capacity to support them at their individual appointments. I shuddered to think what would have happened if they [hadn't had] a support person with them in that moment.

(Louise, Calgary/Edmonton)

SP



4.2

Widespread Education

Many people lack basic knowledge about HIV transmission and treatment. Widespread, accessible education is needed to address outdated beliefs and misinformation about HIV. Education efforts must extend beyond ASOs and reach youth, families, healthcare providers, community workers, and the general public.

- Education must use person-centred language, be culturally relevant and easy to understand
- U = U and treatment knowledge must be widely shared
- Public messaging should normalize HIV like other chronic conditions such as mental health, addiction, suicide, cancer, dementia, and asthma
- Stronger HIV training for healthcare providers
- Settlement and social service workers need the right vocabulary and know-how to refer clients to local ASOs and other relevant care
- Sharing lived experience and wisdom across generations to foster empowerment and reduce misinformation

HIV can be managed, and it is preventable. More training and education for medical practitioners is needed, because new research and new ways of managing the disease have been [developed]

(Charlotte, GTA/Niagara)

CM

Policy and the procedures have to be part of the education at all levels: for healthcare providers, for us who are SPs, for newcomers, and for community leaders.

(Marie, London)

SP

We know how to correct stigma. [...] U = U is a big one when we're doing outreach. I tell people that it's safer for me to have sex with someone who has HIV and is undetectable than it is with someone who doesn't know their status. That opens people's eyes.

(Dylan, GTA/Niagara)

SP

4.3

Bringing HIV Support into Everyday Spaces

Stigma discourages people from seeking out HIV-specific programs. Embedding HIV-related education and services into everyday settings and trusted community spaces was seen as a way to normalize conversations about HIV and reduce barriers.

- Offer information and invite conversation about HIV in familiar, informal, and non-stigmatizing spaces such as barbershops and community events that are not specific to HIV
- Include HIV testing as a part of routine STBBI testing to normalize testing and decrease the chance of missing diagnoses



A program in which people were invited to share recipes while casually engaging in conversation about HIV and health in general

(Fortune, London)

SP

HIV testing has not been part of routine STBBI testing. You have to request it separately [...] how would you know? [...] It is, limiting and stigmatizing by not including it in routine checkups.

(Asia, Calgary/Edmonton)

SP

We need to [...] embed it in [...] existing programs and services. If we have a parenting group, let's provide that information in the form of a conversation. If we are going to reduce stigma, it has to be in an environment that is safe, with a provider that people already know [in that context, rather than] a [separate] workshop.

(Louise, Calgary/Edmonton)

SP





4.4

Cross-Sector Collaboration

Healthcare, settlement, housing, and social services often work in silos, which makes it harder for PLHIV to navigate care. PLHIV may have complex and overlapping needs and are subject to fall through the cracks between services without adequate support.

- Participants from non-ASO sectors (e.g., settlement services, outreach for migrant workers, and general social services) highlighted the need for stronger partnership and collaboration between sectors
- Non-HIV organizations may feel unprepared to address HIV-related needs, which may result in sidelining HIV-related issues to prioritize other urgent needs
- Access to care for PLHIV varies widely depending on location
- Cross-organizational partnerships have helped to meet growing community needs, especially between local organizations, healthcare providers, and community leaders
- Building bridges between sectors can help underserved populations and communities reach timely education and support related to HIV



People working with homeless and newcomers aren't having conversations about sex, sexual health, HIV, and STBBI prevention. It gets pushed to the side compared to material needs. If housing is not stable, we're not focused on HIV.

(Jamie, GTA/Niagara)

SP

I've been able to access resources that I know are in the community, [...] but I'm in [major city.] I'm not living outside the city. [...] What I know is what I know here. [...] I can [...] only support folks here.

(Ash, Calgary/Edmonton)

SP

Conclusions

As described in this report, the research study highlights the fact that HIV-related stigma continues to harm individuals across Canada, especially within African, Caribbean, and Black (ACB) and immigrant communities. Stigma is reinforced by misinformation, assumptions, cultural taboos, systemic inequities, and a lack of inclusive, informed care and support systems. It deeply affects the lives of PLHIV and their communities and affects everyday decisions – whether to get tested, access care, or disclose status. PLHIV face emotional and social consequences of being stigmatized, including internalized shame, fear, isolation, rejection, avoidance of support, and related mental health challenges.

Structural and intersectional barriers – including racism, xenophobia, and inadequate services – exacerbate stigma and limit access to care. People living with and affected by HIV and AIDS experience overlapping stigma and discrimination – layers of vulnerability and disadvantage – making their everyday lives much more difficult than is necessary.

Despite their challenges and vulnerabilities, PLHIV demonstrate resilience through self-acceptance, peer support, and engagement with community-based services. CMs are developing coping strategies rooted in compassion, self-acceptance, and solidarity. ASOs and other grassroots community groups are offering safe, affirming spaces and resources, while working with limited funding and increasing demand. SPs are also recognizing the need for intersectional, trauma-informed, and culturally responsive approaches to care.

The findings point towards moving forward on a path centred on the insight and lived experiences of PLHIV who have the insight and experience needed to shape better systems and processes. PLHIV are not waiting for permission to lead – they are already leading. To fully support their leadership stable funding will development of the other strategies from the finding.

Ultimately reducing stigma is not the responsibility of individuals, it requires coordinated and systemic change. This research brought to light four strategies for affecting this change: widespread education, embedded HIV services, and cross-sector collaboration, enabled by stable and sustained funding.





Recommendations

1 Dedicated, Stable, Long-Term Funding

Stable funding is the foundation that enables all the other recommendations:

Facilitate broad-based education and training, including investment in people for community capacity-building

Make it possible to advocate for embedding HIV support into existing services

Provide resources (people) to allow cross-sector collaboration

Enable the development of safe neutral spaces for service delivery

2 Widespread, Broad-Based HIV Education and Training

Consistent, culturally appropriate, inclusive of the insights of PLHIV, and aligned with the latest medical advances

Public-facing education, similar in approach to other chronic health issues, targeting everyone (youth, seniors, families, citizens, newcomers, and migrant workers), delivered in schools, community groups, faith spaces, workplaces, healthcare settings

Training for professionals across all health and wellness sectors, focused on capacity-building, delivering appropriate language and information on accessing services and support

Recommendations

3

HIV-Related Education & Services Embedded in Everyday Programs

Integrated into existing community programs and broader activities (casual, social, familiar spaces) to reorient service provision, extend reach and remove barriers

Include HIV testing in routine check-ups and STBBI testing

4

Cross-Sector Collaboration



Settlement services

Migrant worker outreach

Public health

General social and community services (e.g., homelessness, substance use, mental health)

Promote consistency and ongoing alignment

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