LGBTTQI COMMUNITIES AND HOME CARE IN ONTARIO: PROJECT REPORT

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EXECUTIVE SUMMARY

Home care for Ontario's lesbian, gay, bisexual, trans, queer, and intersex communities (LGBTTQI) was the focus of the LGBTTQI Home Care Access Project. With trends toward community-based care, the topic of home care is timely. Unfortunately, very little is written on home care in general, and specifically with LGBTTQI communities in mind. The LGBTTQI Home Care Access Project (2011-2016) addressed this gap.

THE GOALS OF THE LGBTTQI HOME CARE ACCESS PROJECT WERE TO EXPLORE:

- Experiences of formal and informal home care use by LGBTTQI people
- Home care service providers' access to continuing education opportunities with LGBTTQI content
- How Community Care Access Centres (CCACs) have approached issues of access and equity for LGBTTQI people

COMMUNITY-BASED RESEARCH (CBR)

We took a community-based research approach to this project. From 2011-2016, we consulted with our researcher colleagues, community partners Rainbow Health Ontario (RHO) and the Toronto Central Community Care Access Centre (CCAC), and our advisory committee members at all stages of the project. To gain insight into diverse perspectives on LGBTTQI people and home care, we connected with 4 groups:

- 115 surveys and 38 follow-up interviews with LGBTTQI home care service users
- 379 surveys and 19 interviews (individual or group) with home care service providers (e.g., personal support workers, nurses, social workers)
- 12 interviews with key informant referral sources (those who had experience referring LGBTTQI individuals to home care), and
- 6 interviews with CCAC administrators

KEY FINDINGS

Many LGBTTQI Home Care Service Users Are Under 50, Lower Income & Single

Like other home care users, LGBTTQI clients may experience greater disadvantage such as lower income: almost 50% of the LGBTTQI home care service users who participated reported incomes at or below the poverty line and 1 in 10 had precarious housing. Unique to the experience of LGBTTQI home care users is that they may be more likely to be single, living alone, and isolated from biological family.

Not All Service Users Knew about CCACs

Despite a need for formal home care services, 40% of LGBTTQI service users reported that they had never heard of CCACs. We see this lack of awareness as an opportunity for CCACs to meaningfully engage with LGBTTQI communities.

Service Users Had Fears & Worries Related to Disclosure to Service Providers

LGBTTQI service users reported different fears and worries related to the disclosure of their sexual and gender identities and care in their homes. For example, nearly 1 in 3 service users worried that their providers wouldn't touch them if they knew they were LGBTTQI. Whether or not these fears and worries actually materialized, it's important to remember that the anticipation itself was stressful. In some cases, fears and worries were associated with the complete avoidance of formal home care services.

Trans People Were Less Likely to Use Formal Home Care

Not all LGBTTQI individuals showed the same trends in formal home care use. Both the numbers and the stories we heard told us that trans people avoided using formal home care associated with medical transitioning. We see this as an urgent call to improve CCAC and contract service provider programs and services, LGBTTQI community engagement, and provider and staff education and training.

Very Few Providers Had Received LGBTTQI-Focused Education While in Home Care

90% of home care service providers had never been exposed to LGBTTQI-specific continuing education opportunities while employed in home care. We see this as a critical need to ensure accessible education and training opportunities for CCAC providers and staff. Training on its own is a start; however, the project's findings point to the need for systematic organizational change in CCACs and contracted service provider agencies to foster inclusive and affirming quality care.

The few friends that I have that have used professional home care have had pretty negative experiences. If you happen to be a really homophobic person and you end up being the person that comes to my house, I wouldn't feel safe.

—Gay man, User of Informal Supports
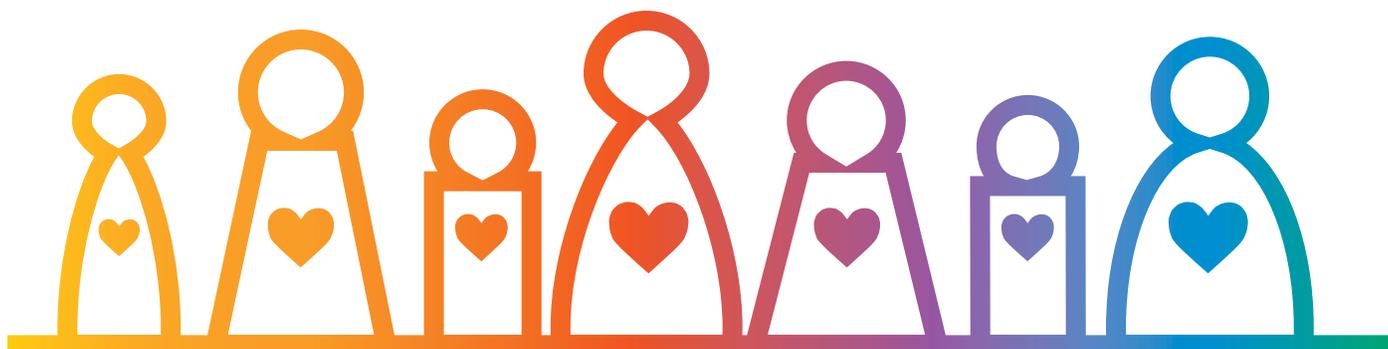
BACKGROUND

This community-based research explored home care for Ontario's lesbian, gay, bisexual, trans, queer, and intersex (LGBTTQI) communities[1], an important focus given an increasing move to community-based care and aging at home. Though most folks prefer to stay in their homes and communities to receive care (Boggs et al., 2014; Brotman et al., 2015; Wright et al., 2014), very little is written on the topic of home care in general, and specifically with LGBTTQI communities in mind.

There is no shortage of studies, however, that point to the significant barriers LGBTTQI people face when attempting to access health care environments free of discrimination in the forms of heterosexism, homophobia, lesbophobia, biphobia, and transphobia (see Institute of Medicine, 2011). In the home care sphere, the limited research that currently exists suggests that there are also unique considerations and concerns for sexual and gender diverse people accessing and receiving care in the home.

Access to high quality and affirmative care, client fears of disclosure of sexual and gender identities, and a lack of provider preparedness to work with LGBTTQI clients in their homes are some of the concerns that have been brought up in the minimal research that currently exists (Daley & MacDonnell, 2015; Grigorovich, 2015a, 2015b, 2015c; MacDonnell & Daley, 2015; Vermette & Godin, 1996).

The LGBTTQI Home Care Access Project is among the first to consider the experiences of LGBTTQI people who are using or could benefit from the use of formal home care delivered through an agency. Because informal caregivers provide invaluable support as well, we considered care by partners, family, friends, and members of queer communities. Finally, we explored issues of access and equity from the perspectives of home care service providers and Community Care Access Centre (CCAC) administrators, those in a position to comment on practice, policy, and procedures that promote equitable and affirmative home care for LGBTTQI people.

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[1] LGBTTQI people and communities are as diverse as the acronym suggests, and the language used to refer to sexual and gender identities differs depending on who you ask. For example, other ways of referring to these communities include 'gender and sexually diverse', 'gender and sexual minorities'. Rainbow Health Ontario (RHO) – a program of Sherbourne Health Centre in Toronto and funded by the Ministry of Health and Long-Term Care – explains how LGBTTQI-related issues and definitions are constantly changing. RHO acknowledges the work of The 519 in Toronto in creating a glossary of terms and definitions that "are not standardized and may be used differently by different people and in different regions."

The glossary can be found here: **http://www.rainbowhealthontario.ca/glossary/** Our study and data collection tools focused on LGBTTQI – lesbian, gay, bisexual, transgender, Two-Spirit, queer and intersex - home care access. Participants included one intersex person and 12 Two-Spirit Peoples. In an effort to represent all participants we use the acronym LGBTTQI in this report.

HOME CARE IN ONTARIO

Publically funded home care is coordinated by 14 CCACs representing different geographic locations across Ontario (Daley & MacDonnell, 2015). In 2013/2014, 699,020 Ontarians received home care services funded by the CCACs, with seniors aged 65+ receiving over 50% of the services, along with approximately 1/3 adults (aged 19-64) and 10% of children (Ontario Home Care Association [OHCA], 2014).

There are no statistics available on the number of LGBTTQI people who use home care services in the province (Daley & MacDonnell, 2015). CCAC care coordinators – nurses, social workers, physiotherapists, and occupational therapists – assess client eligibility for home care, coordinate and evaluate service delivery, and connect clients to community resources and services (Daley & MacDonnell, 2015). Personal support workers and nurses deliver the bulk of the home care in the province, with far fewer social workers, physiotherapists, occupational therapists, speech language pathologists, and dieticians providing services in the home (OHCA, 2014).

While this project is contextualized within the current structure of home care delivery in Ontario, the structure may change in the future. Similarly, home care delivery may be structured differently in other Canadian provinces or international regions. Notwithstanding structural changes or differences in the delivery of home care services, direct care is delivered by a range of health care providers. As such, within the context of differently structured home care delivery we suggest that the project findings presented in this report will be relevant as they reflect the experiences of LGBTTQI service users and home care service providers.

WITH THIS ONTARIO-BASED RESEARCH PROJECT, WE AIMED TO EXPLORE:

- Experiences of formal and informal home care use by LGBTTQI people
- Home care service providers' access to continuing education opportunities with LGBTTQI content
- How CCACs have approached issues of access and equity for LGBTTQI people

APPROACH: COMMUNITY-BASED RESEARCH

Most of my life I've been a closeted lesbian and it's only been in the past few years that I've been able to come out and have freedom. I would like to do anything I can to make people having home care feel the same way. I had home care for my partner in the 70's and we used to have to 'queer-proof' the house. We put everything away that might be indicative of our relationship… So the project's been amazing. I've just learned so much from everybody involved with it and have high hopes for moving forward when it's finished.

–Diane Charter, member of the project's AC

THE TEAM

From 2011-2016, a number of researchers, community partners, and advisory committee (AC) members contributed to the development and implementation of the LGBTTQI Home Care Access Project. The full list of contributors and their biographies can be found on our website (http://yorku.ca/lgtbhome).

As far as we know, this is the most comprehensive research project exploring access and equity for LGBTTQI people on home care in Canada and beyond. This research was firmly rooted in community, and we were grateful to have sustained collaborations with our community partners Rainbow Health Ontario (RHO) and the Toronto Central CCAC, and Community Advisory Committee members (from here on referred to as 'the team') at all stages of the project, from design, to data collection, to interpretation, and finally, the launch of findings.

Rainbow Health Ontario and Toronto Central CCAC played a key role in helping us connect with members of sexual and gender diverse communities and organizations from across the province, and CCACs and their contracted service provider agencies in different regions of Ontario, to ensure good and diverse representation of home care service providers. Hearing from multiple groups provided both similar and different perspectives on relevant issues for LGBTTQI people needing home care in the province. There is much we could write about the extent and value of the involvement of community in this project. All in all, community was engaged and consulted to foster trust between researchers, community members, and service providers, to ensure that the questions we asked addressed issues important to the community, and to discuss ways to meaningfully move project findings forward.

To gain insight into diverse perspectives on LGBTTQI people and home care, we surveyed and/or spoke with 4 groups: LGBTTQI home care service users, home

care service providers, key informant referral sources (those who had experience referring LGBTTQI people to home care), and CCAC administrators.

SURVEY & INTERVIEWS WITH LGBTTQI HOME CARE SERVICE USERS[2]

Because no survey tool existed at the time to tap into LGBTTQI people's experiences with home care, we created one from the ground up. Based on multiple consultations with our team, the survey underwent many revisions, and was piloted with LGBTTQI service users as a final step prior to its launch. Both web-based and paper versions of the survey were available. The accompanying interview guide was an extension of the survey and was meant to help us gain a more detailed understanding of participants' use of and experiences with formal and/or informal home care supports. As with the survey, the interview guide was developed through consultations with the team.

The recruitment period for the survey was October 2012 to July 2013. Our sample of 115 service users was recruited through electronic postings via queer and trans electronic listservs, LGBTTQI- related and broader organizations, the team's professional networks, and word-of-mouth. Additionally, we developed a Facebook page and website to spread the word about the study. Of the service users who completed the survey and at the very end indicated interest in participating in a follow-up interview, we were able to connect with 38. Interviews occurred between February and December 2013.

SURVEY & INTERVIEWS/FOCUS GROUPS WITH HOME CARE SERVICE PROVIDERS

Because no survey tool existed at the time to tap into home care service providers' access to continuing education opportunities with LGBTTQI content, as well as their experiences of working with LGBTTQI clients, we created one from the ground up. Like the

service user edition, this survey underwent extensive revisions based on consultations with the team. Both web-based and paper versions of the survey were available. Service provider membership on the AC helped to ensure that the survey was user-friendly, as brief as possible given the time constraints of service providers, and that it targeted key issues related to the provision of accessible and equitable home care for LGBTTQI people. The accompanying interview/ focus group guide was an extension of the survey. Its purpose was to facilitate discussion about service providers' experiences and/or thoughts related to providing home care to LGBTTQI people. The guide was tailored to engage participants in discussions around their care work with specific populations including: people living with HIV/AIDS; older adults (seniors); people at end of life (palliative); and those living with mental health disabilities. As with the survey, the guide was developed through consultations with the team.

The recruitment period for the survey was October 2013 to August 2014. Our community partner at the Toronto Central CCAC first contacted administrators from 6 CCACs representing geographic diversity across the province, introducing the project and indicating that the researchers would follow-up to provide more information. Our sample of 379 home care service providers was recruited through direct contact with 6 CCACs who facilitated contact between the team and their contracted service provider organizations. Of the service providers who completed the survey and at the very end indicated interest in participating in a follow-up interview or focus group, we were able to connect with 19. Interviews or focus groups occurred between October 2013 and December 2014.

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2 Importantly, both surveys were available in paper versions (mailed to participants), and a French language version was produced, given the population demographics of Francophone Ontarians in three of the six regions. One of the

research team members was able to conduct French language interviews in collaboration with a French-speaking community-based research assistant who was hired for this specific purpose.

KEY INFORMANT REFERRAL SOURCES

To explore barriers to referring LGBTTQI people to home care services, interviews with 12 key informants who had experiences with the referral process generally and with LGBTTQI people specifically were conducted. KIs worked at HIV/AIDS organizations and organizations supporting older people with cognitive impairments; others worked as part of a primary health care provider team. We selected participants based on their having insight into referral facilitators and barriers. Interviews occurred between December 2012 and August 2013. The KI interview findings, while not central to this report, offered important context for home care referral issues across Ontario. For instance, given the limited availability of LGBTTQI-focused organizations outside of many urban areas, individuals seeking home care in rural areas tapped into HIV/AIDS organizations for clues on how to access LGBTTQI affirming care anywhere in the health care system, including home care.

INTERVIEWS WITH CCAC ADMINISTRATORS

In the final phase of data collection, we completed interviews with administrators from 6 of Ontario's 14 CCACs to explore home care access and equity for LGBTTQI people. The 6 CCACs represented geographic diversity in terms of serving urban, rural, and suburban regions of the province. We selected participants based on their having insight into issues of access and equity at their respective CCACs. Key findings from the service user and provider arms suggested gaps in LGBTTQI inclusive care from both CCACS which coordinate home care as well as the contracted service provider agencies that deliver home care. The guide was thus tailored to engage CCAC administrators in discussions around how CCACs have approached issues of access and equity and specifically strategies and resources for leadership and programs and services development in relation to serving LGBTTQI populations who use home care. Interviews occurred between May and June 2015.

THE GROUPS WE HEARD FROM
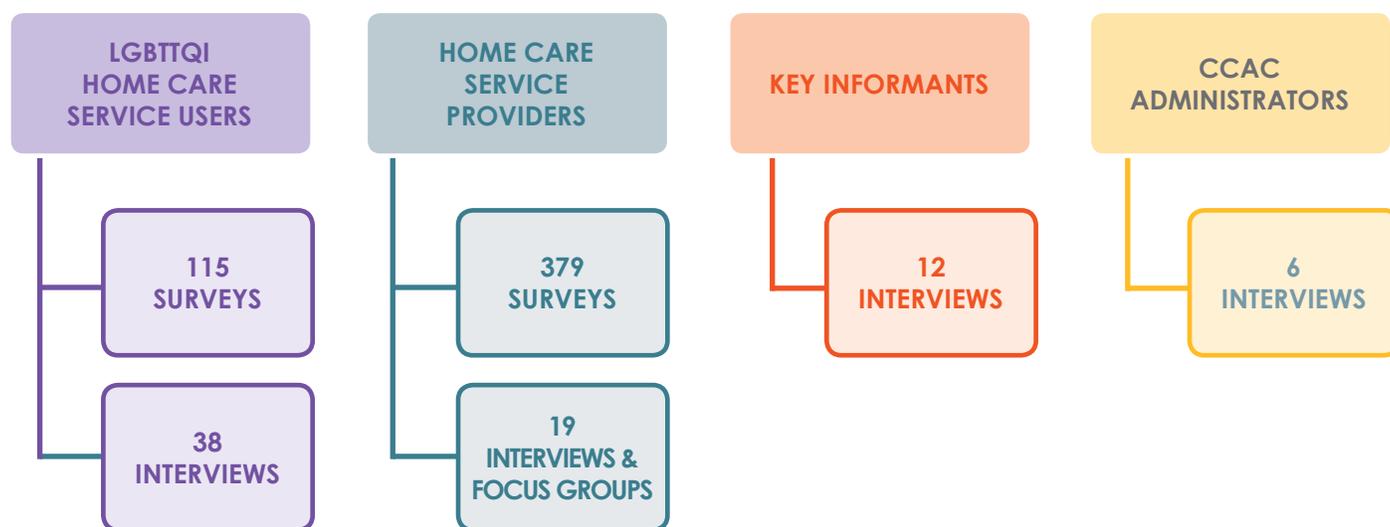
Figure 1: The Groups We Heard From

EXPERIENCES OF LGBTTQI HOME CARE SERVICE USERS

THE LGBTTQI HOME CARE SERVICE USERS WE HEARD FROM

115 surveys were completed by self-identified LGBTTQI formal and/or informal home care users aged 18+ from across Ontario. The demographics of the service users we did follow up interviews with were similar to what is reported here.

- Over 50% were under the age of 50, and the average age was 47
- 37% identified as gay, 30% lesbian, 18% queer, 15% bi, 10% two-spirit
- 46% identified as female, 39% as male, 10% as Two-Spirit
- 20% were trans and/or had a history of transitioning sex/gender[3]

- 27% were perceived or treated as a racialized person or person of colour
- Nearly 50% were single
- Almost 50% reported incomes at or below the poverty line
- 1 in 10 had precarious housing
- 33% lived outside of Toronto or the Greater Toronto Area
- 12% lived in rural communities
- Experienced limitations: 49% physical, 37% mental health, 17% cognitive

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3   Two extra questions were asked to capture current or past trans identity.

Figure 2: Service Users by Age

Age	Percentage
Under 20	2%
20 to 29	18%
30 to 39	17%
40 to 49	18%
50 to 59	24%
60 to 69	15%
70+	7%
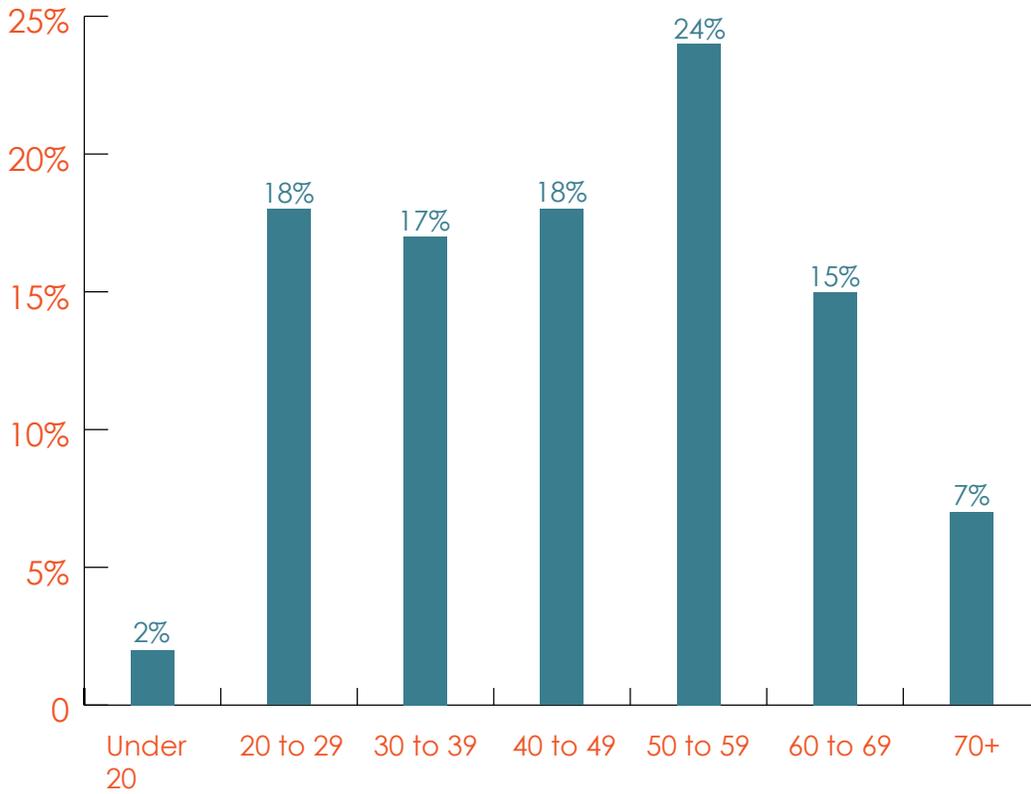
Figure 3: Service Users by Sexual Identity[4]

Sexual Identity	Percentage
Gay	37%
Lesbian	30%
Queer	18%
Bisexual	15%
Two-Spirit	10%
Heterosexual	3%
Unsure	3%
Asexual	2%
Pansexual	2%
Questioning	1%
None of the options (no detail)	1%
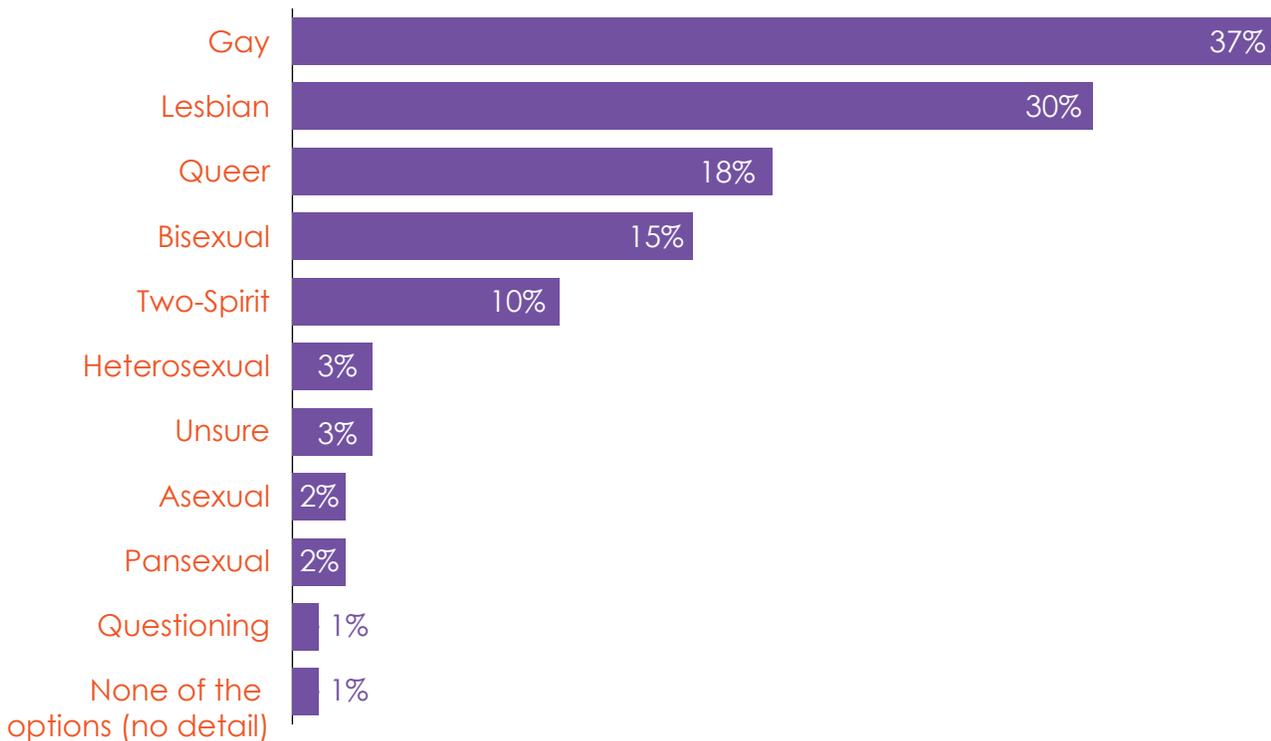
4 For some questions in the survey – especially, identity-related questions – participants could choose more than one option; totals do not add up to 100%.

Figure 4: Service Users by Gender Identity

Gender Identity	Percentage
Female	46%
Male	39%
Two-Spirit	10%
Genderqueer	9%
None of the options(e.g.,femme)	4%
Trans	4%
Transman	3%
Transwoman	1%
Intersex	1%
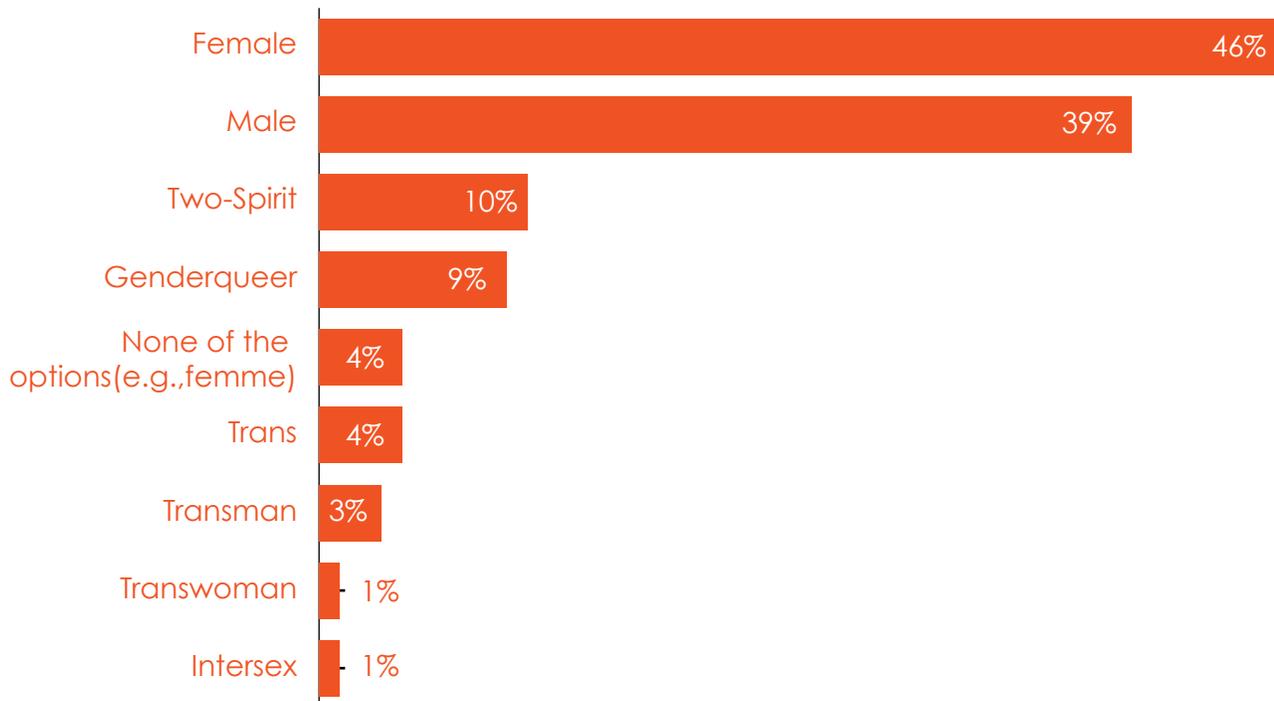
Figure 5: Service Users by Ethno-Racial Indentity

Ethno-Racial Identity	Percentage
White	73%
Aboriginal	15%
None of the options	7%
Black	4%
South Asian	4%
Latin American	3%
Chinese	2%
Japanese	2%
Southeast Asian	1%
Korean	1%
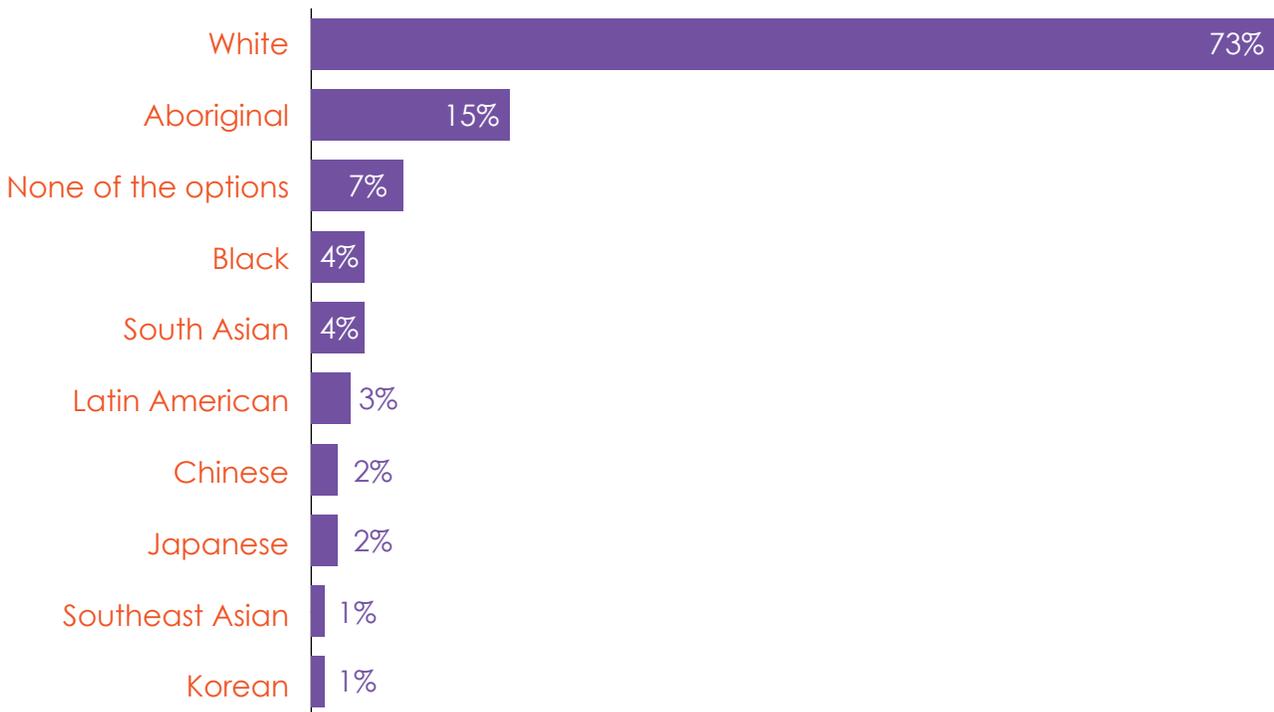
WHY LGBTTQI PEOPLE REPORTED USING HOME CARE

There were many reasons why LGBTTQI people used formal home care services, ranging from short-term needs to support for chronic health conditions. However, despite a need for formal home care, 40% of service users reported that they had never heard of CCACs. 76% of the sample were current and/or past recipients of formal home care. Consistent with who provides the bulk of home care services in Ontario, service users' experiences tended to be with personal support workers, nurses, care coordinators, and social workers.

MAIN REASONS FOR USING FORMAL HOME CARE

- Recovering from illness or surgery (56%)
- Living with ongoing illness or disability (e.g., cancer, HIV) (43%), and/or
- Need for personal care (e.g., bathing; 35%)

OLDER ↑

| MORE LIKELY TO USE FORMAL HOME CARE | LESS LIKELY TO USE FORMAL HOME CARE |

TRANS-IDENTIFIED ↓

Figure 6: Main reasons for using Formal Home Care

Some LGBTTQI people were more likely to use formal home care services than others. Older adults in particular were more likely to report the use of formal home care. In contrast, trans-identified participants were less likely to use formal home care; in other words, trans people were more likely to turn to informal supports.

Most users of formal home care also relied on informal caregiving provided by partners, family, friends, and members of the community (80% of sample).

MAIN REASONS FOR USING INFORMAL SUPPORTS

- Needed more support than given by formal services (40%)
- Wanted more control over when people came into home (30%)
- Concerns about discrimination (20%), and/or
- Weren't comfortable with people they didn't know in the home (16%)

SERVICE USER FEARS AND WORRIES RELATED TO DISCLOSURE TO SERVICE PROVIDERS

Most service users had self-disclosed their sexual and gender identities to at least some of their home care service providers. Very rarely did service users indicate that their providers had asked. Despite being seemingly willing to self-disclose, service users reported fears and worries related to disclosure and care in their homes. Those who identified as female were more likely than those who did not to report some of these. The most common fears and worries are presented below, with excerpts from interviews with service users to give a better sense of what fears and worries look and feel like. The excerpts also show how sometimes, fears and worries came true.

COMMON FEARS AND WORRIES REPORTED BY LGBTTQI HOME CARE USERS

Providers not acknowledging & respecting them (47%)

My health card still had "M" on it. They came in thinking they were dealing with a male. So that was kind of awkward for me.

–Woman with trans history

Providers not acknowledging & respecting partners as family (38%)

He started off by saying, 'How was your mother over the weekend?' And I said, 'She is my partner.' And he said, 'Oh, I just use whatever is more common.' It was clear that he felt uncomfortable once he heard that we were partners.

–Gay woman

Being ignored if providers were told of their identities (35%)

A person who has been raised in a homophobic family, a homophobic society, and a homophobic culture isn't going to change their mentality through taking a 1 or 2-hour long college course. So, I've always been afraid of encountering these types of home care providers. That they would immerse themselves into my life and find out things that I wouldn't want to share. This is one of the reasons why I never called.

Because I would qualify for in-home care through an agency. It would be nice to get some help and respite for my partner, but agencies don't have a history of being gay-friendly.

–Gay man

Providers being fearful of touching them (31%)

She backed up. I was sitting here and she was there and she backed up and, '*Gasp* never heard of that [lesbians]!' And she didn't say a lot in words, but her body language was very judgmental. I was shocked quite frankly at her reaction. She was closed with her hands close to her. She stepped back and sort of put her hands up and then she was very careful not to touch me.

–Lesbian

Seeing pictures, art, etc. that could reveal identities (29%)

I feel like I'm even more in the closet because of people coming to the home. And I don't feel comfortable putting up certain pictures I have that would reveal my sexuality, so they're packed away. It shouldn't be like that, because I'm in my own home.

–Lesbian

MAIN MESSAGE: LGBTTQI HOME CARE SERVICE USERS

The LGBTTQI home care service users who participated in this study represented the full age spectrum, suggesting that not all home care recipients are older. People's identities were complex: up to 15% of LGBTTQI service users identified their sexual, gender, and/or ethno-racial identities in multiple ways.

Like other home care users, LGBTTQI clients may experience greater disadvantage such as lower income and limitations due to physical, mental health, and cognitive challenges. Unique to the experience of LGBTTQI home care users is that they may be more likely to be single, living alone, and isolated from biological family.

LGBTTQI participants required help to support both short-term needs and chronic health conditions. They tended to rely on a combination of both formal and informal caregiving to meet their needs. The exception was trans-identified individuals, who were more likely than others to avoid formal home care. A number of participants had never heard of their local CCAC, whose role includes assessing eligibility and coordinating services.

Service users reported different fears and worries related to the disclosure of their sexual and gender identities and treatment in their homes. Whether or not these fears and worries actually materialized, it's important to remember that the anticipation itself was stressful. In some cases, fears and worries were associated with the complete avoidance of formal home care services.

EXPERIENCES OF HOME CARE SERVICE PROVIDERS

## THE HOME CARE SERVICE PROVIDERS WE HEARD FROM

379 surveys were completed by home care service providers from across Ontario. Follow-up focus group and interview participants were selected based on their background working with specific populations (e.g., HIV clients), and we spoke with a range of service providers (e.g., personal support workers, nurses, care coordinators, social workers) with varying years of experience working in home care.

- 33% were nurses, 24% care coordinators, 23% PSWs
- 72% worked for an agency contracted by a CCAC
- Over 50% had worked for 5 years or less in home care
- Over 70% had also worked in other areas of health care (e.g., hospital)
- 22% worked in South West, 19% Toronto, 16% Central East, 10% Eastern
- 50% worked in both rural and urban settings
- Average age was 40
- 13% were perceived or treated as a racialized person or person of colour
- Almost 90% identified as female
- Almost 90% identified as heterosexual, 10% as LGBQ

Figure 7: Service Providers by Region

- South West (London) — 22%
- Toronto — 19%
- Central East (Durham) — 16%
- Eastern (Ottawa) — 10%
- Northern (Thunder Bay) — 8%
- Central West (Brampton) — 8%
- North Eastern (Sudbury) — 7%
- Hamilton/Niagara — 5%
- Unsure — 3%
- South East (Kingston) — 2%
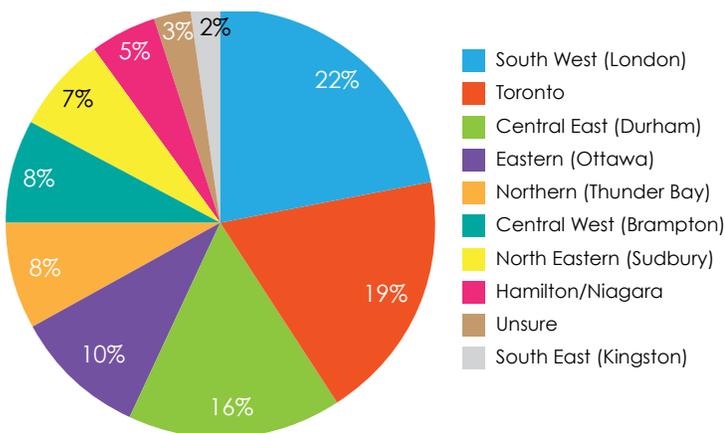
Figure 8: Service Providers by Professional Background

- Nurse — 33%
- Care Coordinator — 24%
- Personal support worker — 23%
- Occupational therapist — 9%
- Social worker — 8%
- Other (e.g., supervisor) — 7%
- Physiotherapist — 6%
- Dietician — 1%
- Speech language pathologist
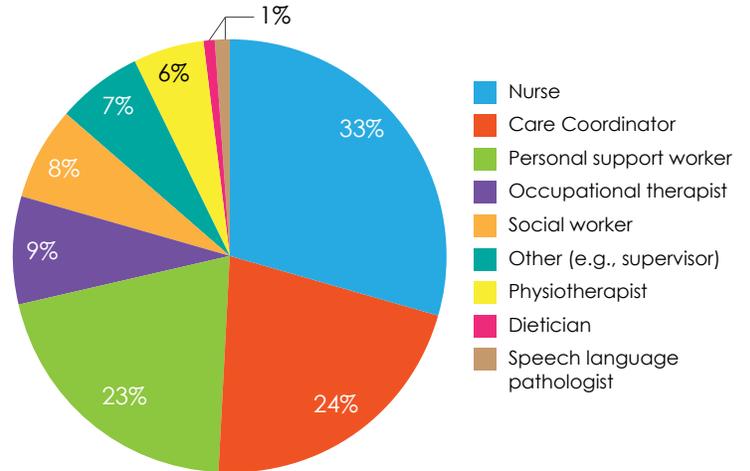
HOME CARE SERVICE PROVIDER AWARENESS OF LGBTTQI CLIENTS

35% of home care service providers indicated that, as far as they knew, they had never worked with an LGBTTQI client. Certain provider groups were more or less likely than others to report that they had never worked with a queer or trans client. A greater number of personal support workers, and fewer social workers and occupational therapists, stated that they had never working with these clients. For those who had worked with a least 1 queer or trans client (65%), we asked how they came to find out about their clients' sexual and gender identities. Similar to what we heard from service users, 85% of service providers indicated that their clients had self-disclosed.

KNOWING ABOUT CLIENT SEXUAL AND GENDER IDENTITIES

During our conversations with both service users and providers, we heard different perspectives on whether knowing about clients sexual and gender identities mattered to quality of care. These two excerpts contrast the perspective of a service user from that of the service provider:

> *They have to know that you are the significant other, you are the partner, you are the wife or husband as it may be and that if anything goes wrong, you are the first person to be called.*
>
> –LGBTTQI service user

> *It's about as relevant as knowing whether or not a person likes to squeeze the toothpaste from the middle or from the bottom.*
>
> –Service provider

ACCESS TO CONTINUING EDUCATION OPPORTUNITIES WITH LGBTTQI CONTENT

An important part of the home care service provider version of our surveys was to inquire about access to continuing education opportunities with LGBTTQI content. Our survey of 379 service providers indicated that, while employed in home care, 33% (121 respondents) had attended at least 1 workshop with *some LGBTTQI content*.

Context of Workshops with Some LGBTTQI Content (n = 121)

- Generally delivered at the workplace (70%)
- Workshop was often but not always required (60%)
- Varied in length, with 60% indicating that workshop lasted 30-60mins
- 40% indicated that workshop lasted 15 minutes or less

We also asked service providers if, while employed in home care, they had ever attended a workshop that focused exclusively on LGBTTQI content (***LGBTTQI-focused***). Only 13% (47 participants) responded in the affirmative.

Context of Workshops with LGBTTQI-Focused Content (n = 47)

- Generally delivered at the workplace (67%) or at a conference (40%)[5]
- Workshop was often but not always required (56%)
- Varied in length, with 50% indicating that workshop lasted half to full day
- About 50% indicated that workshop lasted 1 or 2 hours

> Almost 90% of services providers had never received LGBTTQI-focused education while employed in home care

Content Covered in Workshops with at Least Some LGBTTQI Content (n = 121)

For the limited number of providers who had access to continuing education that considered the experiences of LGBTTQI communities, the content covered was generally basic (e.g., definition of terms), focused on stigma and LGB people and to a much lesser extent, stigma and TTI people, and seemed dedicated to information-sharing rather than the development of practice skills. Despite the fact that over 50% of home care users in Ontario are older, LGBTTQI seniors were given limited attention.

CONTENT MOST LIKELY TO BE COVERED	CONTENT LEAST LIKELY TO BE COVERED
• Basic information (85%) • Mental & physical health (63%) • Heterosexism, homophobia (55%)	• Seniors (29%) • Transphobia (23%) • Other (e.g., safe sex; 2%)

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5   Participants could choose more than one option; totals do not add up to 100%.

LACK OF PROVIDER EDUCATION AND CONSEQUENCES FOR LGBTTQI COMMUNITIES

The theme of home care service providers not having enough background generally on LGBTTQI people and communities, and on specific issues affecting sexual and gender diverse lives, was further highlighted in our conversations with service providers *and* service users. Providers expressed a keen desire to learn, however, as can be seen below:

I really have no knowledge, but I'd like to have some.
–PSW supervisor

We need more in-services or professional development.
–Social worker

More specific issues related to aging, HIV/AIDS, and end of life (palliative care) were discussed by several home care service providers. As the excerpts suggest, these issues aren't usually covered in continuing education for health care professionals:

I think if you look back historically, in the early 80s when the HIV/ AIDS epidemic started, millions of gay men lost friends, partners, and the ones that have survived are left now without supports. And they are now ageing, the men that were highest targets of HIV/ AIDS back in the 80s are now becoming palliative themselves, not necessarily from HIV but just from natural disease processes. But they have been isolated because their friends have died. But also those are the generation where it wasn't acceptable to be gay, and

they have lost family and friends because of that. So not only do they enter into palliative realms without health care society's acceptance still unfortunately, but they are also isolated because they've lost their friends through the HIV/AIDS epidemic, through a myriad of other illnesses as well that are not targeted because LGBT health issues are not identified by health care professions. So they are palliating alone and afraid.
–Nurse practitioner

"I think we need to educate ourselves in how to relate to this group of people so that they don't feel as if they're on the outside looking in."
–PSW

As one provider comments, knowledge on trans people and medical transitioning is especially lacking:

The trans piece would be a knowledge gap for me; supporting the medical side of hormone therapy and all that.
–Nurse

What are the consequences of lack of provider education for trans people? Both the numbers and the stories we heard told us that trans people avoided using formal home care associated with medical transitioning. This excerpt from a key informant explains how informal networks of support are organized to provide extensive care:

I know some folks who've had bottom surgeries, who have had friends and family and partners do all that work even if they've had fistulas or any kind of infections because they're terrified, they don't want CCAC in. So when one of us has surgery like top surgery, and especially if people have precarious housing – many folks do – it's a very marginalized community. So many people are either in shelters or sleeping on somebody's couch or they're in really unsafe housing situations. So we try to set up networks, kind of like the care teams that happen for folks with HIV. We know someone's getting out of hospital so we make sure that there's groceries, there's people who will do on call shifts, change bandages. To make sure that when people come home from surgery that they have support they need, cause many of the folks I work with live alone.

–Key informant who works with trans communities

What are the consequences of lack of provider education for diverse queer people? A common theme from the interviews with service users was a need to educate service providers in response to a lack of learning opportunities. On occasion, service users accepted playing the educator role as part for the course. But over time, these collective experiences added up and became burdensome, as one service user explains:

I'm done at this point of teaching what Black means to me. There's lots of books and the Internet and I can show you some resources, but I'm not going to be the person who's always rehashing these parts of myself for your education.

–Queer woman, service user

MAIN MESSAGES: HOME CARE SERVICE PROVIDERS

Consistent with what we know about who provides the bulk of the home care services in Ontario, we had more nurses, care coordinators, and personal support workers participate in this study than therapists (e.g., physio, speech language).

Having heard from a number of home care workers from across the province, the findings in this report represent geographic diversity with respect to service providers' access to continuing education opportunities with LGBTTQI content.

It is clear that many home care service providers don't know they are working with sexual and gender diverse clients. Providers don't ask about sexual and gender identities, but clients do tell. Certainly this lack of knowledge and discomfort working with LGBTTQI people may be related to lack of comprehensive LGBTTQI-affirmative education and training in home care and in provider curriculum.

Are home care service providers ready to receive their clients' disclosures? Do they know what to do with this information? It's hard to say. While employed in home care, very few providers received LGBTTQI-focused content as part of their continuing education. Those who did learned basic information at the expense of practical skills, like incorporating clients' sexual and gender identities into care plans.

There are real consequences of lack of provider knowledge for diverse queer and trans lives. The burden of responsibility involved in educating

providers, and the avoidance of formal services by trans people, are two examples. We could also speculate that lack of provider knowledge may further contribute to service user fears and worries related to receiving affirming care in their homes.

Finally, the findings suggest that providers may be relying on stereotypes about LGBTTQI people and there was at times sharp disagreement across service providers as to whether knowing about a client's sexual orientation or gender identity is at all relevant to home care practice, for instance when care involves a task such as a dressing change.

EXPERIENCES OF CCACs

KEY FINDINGS FROM CCAC ADMINISTRATORS ON LGBTTQI ACCESS AND EQUITY

Our interviews with administrators from 6 of Ontario's 14 CCACs explored home care access and equity for LGBTTQI people from an organizational perspective. The 6 CCACs were geographically diverse in that they served urban, rural, and suburban regions of the province. To protect their identities given their specific leadership roles, we didn't collect demographic information on the CCAC administrators.

Our key findings suggest a spectrum of LGBTTQI (in)visibility in CCACs. Next, we present 3 scenarios that help illustrate this spectrum.

THE WORST CASE SCENARIO: LGBTTQI INVISIBILITY

In the worst case scenario, LGBTTQI issues are not on the radars of CCACs in terms of leadership, client care, or employee-related indicators. In the worse case scenario, LGBTTQI people are *invisible* in areas such as:

- ☐ Strategic planning
- ☐ Priority populations
- ☐ Orientation and continuing education
- ☐ Client complaints
- ☐ Engagement with communities
- ☐ LGBTTQI employees themselves are invisible

## THE MIDDLE GROUND SCENARIO: LGBTTQI AS VAGUELY VISIBLE

In other CCACs queer and trans people were vaguely visible, where an LGBTTQI-related focus was found in 1 or a few aspects of the organization's programs and policies, or there was some indication of community engagement. In the middle ground scenario, queer and trans people were *vaguely visible*, such that there was:

- ☐ Some focus in orientation and continuing education
- ☐ Some client complaints
- ☐ Some engagement with communities
- ☐ LGBTTQI employees were mostly invisible

THE BEST CASE SCENARIO: LGBTTQI VISIBILITY

In other CCACs, active steps were being taken to address the invisibility of LGBTTQI people. In these CCACs, queer and trans people were recognized as diverse, whether or not they were identified as priority populations. Providers managed to document sexual and gender identities despite the absence of these on intake and assessment forms. Based on client feedback, some in-services were instituted. In the best case scenario, we saw *positive signs of LGBTTQI visibility*, in areas such as:

- ☐ Strategic planning
- ☐ Priority populations

- ☐ Some orientation and continuing education
- ☐ Some focused care discussions
- ☐ Some client complaints
- ☐ Some engagement with communities and
- ☐ LGBTTQI employees themselves were more visible

Even in the best case scenario, efforts were still minimal, one-off initiatives. Our findings suggest that what currently exists is inconsistent, there is very little community engagement, or taking up by leadership and reflected in policy and programming. While this scenario reflects promising practices to build from, there is no evidence that LGBTTQI equity work is woven into the fabric of the CCAC.

> *It takes more than just having a few committed individuals. You really need to formalize that within an organizational structure, so you need to have a policy framework ensuring that you've got components of recognition of diversity built in, not just a singular policy on anti-discrimination but making sure that it's woven through all of the policies, the procedures, sort of, highlighting that, the tools that you use to assess and interact with your clients needs to be built into an educational framework as well, beyond orientation. It needs to be an ongoing discussion. Issues change, opinions change, so it needs to be a framework that's dynamic and responsive to change as well and to new information and research coming in. And it really needs to be informed by the communities.*
>
> *–CCAC administrator*

Figure 9: Spectrum of LGBTTQI (In)visibility in CCACs

INVISIBLE   VAGUELY VISIBLE   VISIBLE

MAIN MESSAGES: EXPERIENCES OF CCACs

From our interviews with CCAC administrators, we sensed that there was a spectrum of LGBTTQI (in)visibility in CCACs, ranging from no visibility, to positive signs that queer and trans communities were being considered through community engagement, for example.

CREATING CHANGE

USING OUR FINDINGS TO MOVE YOUR ORGANIZATION FORWARD: THE LGBTTQI HOME CARE ACCESS & EQUITY FRAMEWORK

The research team focused on creating resources that could be used by providers, LGBTTQI communities and decision-makers to enhance accessible and high quality home care for LGBTTQI people. An integral component of the LGBTTQI Home Care Access Project has been the development of an Access and Equity (A&E) Framework that was explicitly created to address the context of *access to home care* for LGBTTQI people. The Framework was developed as a response to research data from this and other related, preliminary studies, and emerging gaps in research and strategies to address access to high quality home care for LGBTTQI people (Daley & MacDonnell, 2010). See Figure 10: LGBTTQI Home Care Access and Equity Framework.

Figure 10: LGBTTQI Home Care Access & Equity Framework

Two Components:

• Invitational Approach (6P's)
• 6 Access & Equity Elements

Generic framework for home care uses an equity lens which has wide applicability.

Our focus on LGBTTQI and other diversity opens a space for often overlooked sexual & gender minority community access.

(Daley & MacDonnell, 2010)

LEADERSHIP · ENVIRONMENT · PROGRAMS & SERVICES · COMMUNITY ENGAGEMENT · EDUCATION & TRAINING · POLICIES

THE CONTEXT OF HOME CARE

The A&E Framework takes into account the unique dimensions of care provided in the home with attention to the nature and complexity of service provision in CCACs coordinated care that is provided by a range of regulated and unregulated health care providers who work for multiple contracted service provider agencies. The framework considers the unique features of care and care interactions provided in the privacy of the home and points to challenges for ensuring accountability for high quality care on organizational and professional levels (See MacDonnell & Daley, 2015).

SIX INDICATORS OF ACCESS TO HOME CARE

The A&E Framework incorporates 6 indicators of access to care for LGBTTQI people: Leadership, Environment, Programs and Services, Community Engagement, Education and Training, and Policies that are key to enacting a comprehensive and systematic approach to organizational change for high quality and affirming care. As an example, we map 3 of the project's key findings directly onto the A&E Framework. See figure 11: Examples of Indicators of Access to Inclusive and Affirming LGBTTQI Home Care.

Figure 11: Examples of Indicators of Access to Inclusive and Affirming LGBTTQI Home Care

90% of service providers had never been exposed to LGBTTQI-specific education while employed in home care

LEADERSHIP

POLICIES

ENVIRONMENT

EDUCATION & TRAINING

PROGRAMS & SERVICES

COMMUNITY ENGAGEMENT

40% had never heard of CCAC

"We know someone's getting out of hospital so we make sure that there's groceries, there's people who will do on call shifts, change bandages. To make sure that when people come home from surgery that they have support they need, cause many of the folks I work with live alone."
–KI trans community
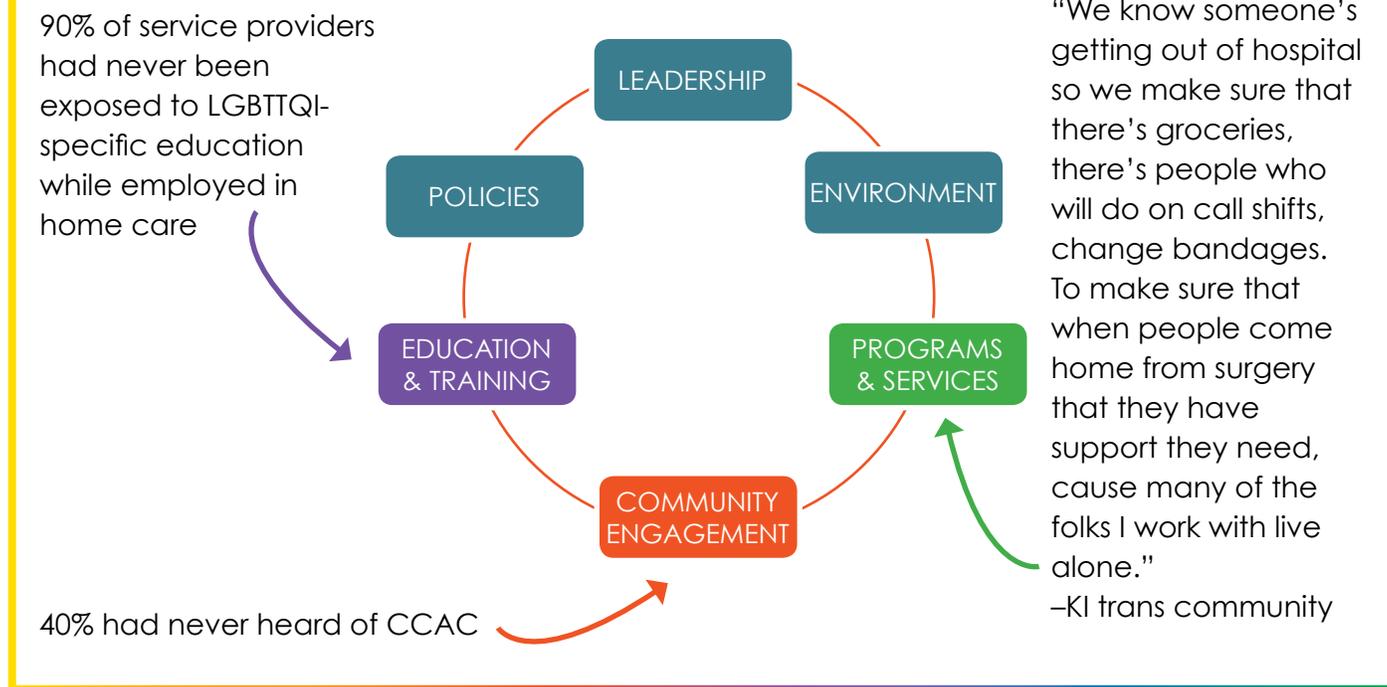
NOT ALL SERVICE USERS KNEW ABOUT CCACs

Despite a need for formal home care services, 40% of LGBTTQI service users reported that they had never heard of CCACs. We see this lack of awareness as an opportunity for CCACs to meaningfully engage with LGBTTQI communities.

TRANS PEOPLE WERE LESS LIKELY TO USE FORMAL HOME CARE

Not all LGBTTQI individuals showed the same trends in formal home care use. Both the numbers and the stories we heard told us that trans people avoided using formal home care associated with medical transitioning. We see this as an urgent call to develop specialized home care programs and services for trans home care service users.

VERY FEW PROVIDERS HAD RECEIVED LGBTTQI-FOCUSED EDUCATION WHILE IN HOME CARE

90% of home care service providers had never been exposed to LGBTTQI-specific continuing education opportunities while employed in home care. We see this as a critical need to ensure accessible education and training opportunities for CCAC provider and staff education and training.

THE INVITATIONAL APPROACH[7]

The A&E framework is underpinned by a theoretical framework called the Invitational Approach (MacDonnell, 2014) which helps to explain how actions on both individual and organizational levels are needed to work toward high quality and accessible care for LGBTTQI people, which is called "intentionally inviting care". This invitational approach is two-pronged:

First, four points on a spectrum reflect how clients perceive and/or anticipate care, as well as factors related to how the provider is situated with respect to interactions with clients. The 4 points are: intentionally inviting, **un**intentionally inviting, **un**intentionally **dis**inviting, and intentionally **dis**inviting environments/care. Concepts such as trust, optimism, respect and intentionality are relevant. Optimal care that is associated with Positive Space and affirming care for LGBTTQI people, is equated with intentionally inviting level of care. At the other end of the spectrum is intentionally **dis**inviting care which prompts client perceptions of care that reflect discriminatory and unwelcoming environments. A one-page rubric (see Table 1: The Invitational Approach for LGBTTQI Inclusive and Affirmative Home Care: Perspectives of Clients and Providers) was created for use by health care providers to address the spectrum of intentionally disinviting, through intentionally inviting care.

It stresses the need to consider both provider and patient/client perspectives, along with a systematic approach using the 6 Ps (see next paragraph) when assessing environments and developing strategies to work toward intentionally inviting health care environments. Clients may perceive that individual providers and/or their service agencies exclude them. They anticipate and may experience hostility, violence; for providers who are aiming to support the LGBTTQI people and communities, this may reflect a "poisoned work environment." The two levels in between are important to consider how providers might be situated to move toward more inclusive and affirming care, showing the need for consistency at the organizational and individual provider levels for high quality care.

Secondly, the Invitational Approach identifies 6 components, known as the 6 P's, that take into account dynamics of power and privilege that can be helpful to consider in relation to organizational assessment and change: people (clients/providers; places (settings); policies; programs; processes; and politics.

Each of the six indicators in the A&E Framework has associated evaluation prompts to assist organizations to consider how each of the 6 P's (e.g., programs, policies and practices) are relevant to providing inclusive, affirming care for LGBTTQI people (Table 2: Access and Equity Framework Prompts for LGBTTQI Affirmative Home Care.

For example, prompts associated with Community Engagement ask whether and how home care organizations engage with LGBTTQI people, and how community engagement strategies ensure the representation of diversity within LGBTTQI communities. Prompts associated with Education and Training ask how diverse LGBTTQI people are reflected and whether education and training occurs onsite or offsite of the agency, and how LGBTTQI people are involved in the development and evaluation of materials.

The use of access and equity indicators and associated prompts holds the potential to create LGBTTQI awareness in the context of home care organizations and open space for LGBTTQI folks to inform home care access and equity strategies (Daley & MacDonnell, 2010).

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6   The term "Invitational Approach" (a modification of the original term "Invitational Theory" (Purkey & Novak, 2008) is used with permission.
     The invitational approach with its 6 Ps is derived from research (MacDonnell, 2014).

Table 1: The Invitational Approach in LGBTTQI Inclusive & Affirmative Care: Perspectives of Clients and Providers

OPTIMAL/INCLUSIVE CARE: POSITIVE SPACE

From Client Perspective:	From the Provider and Agency Perspective:
1. GOAL Intentionally Inviting *Outcome:* Anticipates and experiences welcoming agency care which is: • Respectful • Meaningful • Consistent and thus predictable	GOAL: Welcoming interactions and environments optimal to foster access to equitable care and Positive Space. Requires: • Systematic assessment • Explicit focus on LGBTTQI population • Ongoing evaluation • Individual and institutional components
2. Unintentionally Inviting *Outcome:* Respectful, meaningful care is hit and miss	• Met client needs but it is unclear what worked and why? • Individual providers may be inviting • Institution may be inviting
3. Unintentionally Disinviting *Outcome:* Perceived as having good intentions but not meeting needs • Relevant? Consistent? Respectful?	• Disinviting interactions do not meet client needs • Implications for addressing barriers to access
4. Intentionally Disinviting Care *Outcome:* Care perceived as exclusionary, discriminatory, "poisoned" environment Disinviting interactions have consequences for clients: • Avoidance of care (barriers to access) • Reluctance to disclose • Negative health consequences	• Disinviting interactions do not meet client needs • Implications for addressing barriers to access

6P's for systematic assessment with sample prompts under each of 6 Ps. Possible overlap among Q.

Community Engagement

- ☐ Integrated into agency processes
- ☐ Involved on ad hoc basis
- ☐ Needs assessment
- ☐ Involved in program directions
- ☐ Involved in evaluation
- ☐ Hiring processes
- ☐ Diversity of communities represented

People

Q Are LGBTTQI people engaged with the agency? Which LGBTTQI people are involved in the community engagement process to ensure their diversity is represented?

Places

Q How are LGBTTQI people engaged so that they can see themselves meaningfully represented in the agency and feel a sense of belonging?

Programs

Q How are LGBTTQI people involved in a needs assessment, identifying program/service directions, delivering them and evaluating them?

Processes

Q What processes are in place to ensure consistent and ongoing community engagement (e.g., advisory committee), as well as on ad hoc basis?

Policies

Q How are agency policies developed to ensure hiring of LGBTTQI staff, appropriate data collected about LGBTTQI people in the agency?

Politics

Q How does the agency engage with LGBTTQI people across e.g., age, ethnicity, condition (cancer), to advocate more broadly for resources, support relevant health concerns?

Leadership

- ☐ Shared leadership
- ☐ Board of Directors
- ☐ Senior Management
- ☐ Management
- ☐ Front Line
- ☐ Staff
- ☐ Volunteers & Allies
- ☐ Advocacy
- ☐ Consult with 'out' staff to assist in identifying positive change

People

Q Are people at all levels of the organization involved in leadership opportunities including volunteers and allies associated with the organization?

Places

Q Are openly LGBTTQI people in positions of leadership including 'Out' senior management?

Programs

Q How is shared or distributive leadership implemented across agency programs?

Processes

Q Is leadership on a project distributed across a broad base of employees with each having distinct and different responsibilities that contribute to the overall success of the agency as well as particular service access initiatives?

Q Is decision-making authority spread throughout the agency, creating a "flatter," more representative governance structure?

Policies

Q Are agency policies developed through the participation of staff at all levels of the agency?

Politics

Q Is shared or distributive leadership used across sector-specific agencies/organizations – such as home care service provider organizations – to engage in systems advocacy, for example, in relation to obtaining the resources (e.g., training resources, research) required to address health disparities and access barriers for diverse communities including the LGBTTQI communities?

Environment

- ☐ Staff have understanding of & use language that is inclusive of same-sex relationships
- ☐ Positive images of LGBTTQI people on agency brochures, materials
- ☐ LGBTTQI visual cues on relevant printed material
- ☐ Distribution of LGBTTQI inclusive brochures, policy, client Bill of Rights
- ☐ Advertise positions in LGBTTQI media

People

Q How do staff use language to convey recognition, acceptance and affirmation of LGBTTQI people?

Places

Q Are LGBTTQI people able to see themselves represented in visual cues within the physical environment of the agency? (rainbow/triangle symbols, LGBTTQI representation of available brochures/ posters; LGBTTQI relevant brochures/ posters, promotional materials for agency services and programs are LGBTTQI inclusive)

Programs

Q Do program-specific intake forms include demographic options that convey recognition, acceptance and affirmation of LGBTTQI people? (gender neutral options such as 'domestic partner' or 'same-sex partner' along with options to choose male/ female/trans/trans man/trans woman/gender queer, and gender neutral questions about relationships and sexual behaviour)

Processes

Q What processes are in place to foster the creation of safe space and organizational support of LGBTTQI employees? How does the agency administratively support LGBTTQI employee networks/working groups?

Policies

Q Is there a policy that explicitly states that confidentiality is protected and privacy respected (in response to service users being inhibited about disclosure d/t concerns about confidentiality)?

Politics

Q Does the agency advocate for health equity initiatives to address systemic disparities in access? For example, does the agency advocate for community-based research that will increase their knowledge about the issues in providing LGBTTQI inclusive services and programs?

Policies

- ☐ Comply with human rights
- ☐ Clear harassment policy
- ☐ Non-discrimination policy
- ☐ Discriminatory language policy
- ☐ Anti-homophobia policy
- ☐ Anti-transphobia policy
- ☐ Recruit LGBTTQI for all positions
- ☐ Openly 'out' staff at all levels

People

Q Are there agency policies that address equity for both LGBTTQI clients/service users and employees?

Places & Politics

Q Is there an overarching agency anti-oppression/ diversity policy and/or philosophy that guides policy and program planning and delivery?

Q Is the anti-oppression/diversity polices visible and accessible to clients/service users, employees & the public?

Programs

Q Are policies that address equity for both LGBTTQI clients/service users and employees consistent across all programs?

Processes

Q Do hiring practices include assessing diversity/ LGBTTQI competence? Do staff evaluation practices include assessing diversity/LGBTTQI competency?

Q Have procedures been developed to deal with complaints of discrimination or harassment?

Education & Training

- ☐ Staff
- ☐ Volunteers
- ☐ Students
- ☐ Management
- ☐ Board of Directors
- ☐ Mandatory
- ☐ Volunteer
- ☐ One-off
- ☐ Ongoing
- ☐ Inclusive of LGBTTQI
- ☐ Excludes LGBTTQI
- ☐ Orientation includes reporting processes/ LGBTTQI education
- ☐ Continuing education
- ☐ Specialized education
- ☐ Development of LGBTTQI education (allies/communities)
- ☐ Review of existing training for LGBTTQI inclusivity
- ☐ Training/education for/with partners in care, interprofessional education

People

Q Who receives education and training within the agency?

Q How are diverse LGBTTQI people reflected in education?

Places

Q Where does training occur inside/outside the agency? On site? Online? With partner agencies?

Programs

Q What training opportunities occur? (Orientation, inservices, continuing ed, specialized training to build clinical and human resources capacity?

Q What content is included about antidiscrimination policies/reporting practices?

Processes

Q How are LGBTTQI people involved in education, development of material (e.g., train the trainer)?

Q How is it embedded in the organization-encouraging informal & formal education opportunities?

Policies

Q How is education framed in terms of meeting agency goals for quality (mandatory/elective), accreditation?

Politics

Q How does the agency culture support the notion of a learning organization, allowing for critical questioning?

Q How does the agency advocate for resources for education/training for providers?

Programs & Services

- ☐ Community linkages
- ☐ Monitoring/data collection
- ☐ Intake & assessment forms
- ☐ Visibility of LGBTTQI across services
- ☐ Provision for targeted/specialized services/ supports
- ☐ Hiring/LGBTTQI expertise for programming
- ☐ Congruency of LGBTTQI inclusion in agency mission/vision, strategic plans

People

Q How are LGBTTQI people/staff involved in programming, agency processes (e.g. strategic planning)?

Places

Q How does the agency represent the voice/visibility of LGBTTQI in programs and services?

Q How does the agency support a culture of disclosure for LGBTTQI staff?

Programs

Q How are all programs inclusive of LGBTTQI health (e.g., intake forms)?

Q What unique programs/resources are available?

Processes

Q How are programs developed, delivered, evaluated with LGBTTQI communities?

Policies

Q What reporting processes for clients/staff are in place to respond to discrimination, quality of care/ work environment?

Politics

Q How is the agency involved in research, advocacy for research/programming to meet the needs of LGBTTQI people across e.g., ethnicity, condition, age?

CONCLUDING THOUGHTS

Our research contributes to the growing literature on home care access experiences and realities among LGBTTQI people. While we know that the need for home care services is growing because of the aging population and increasing emphasis on keeping older people at home, little is known about the particular issues facing LGBTTQI people as they negotiate this type of care. Though LGBTTQI community services are beginning to emerge, in the context of Canada, there is little funding for these services in the community, and they are only minimally available in major cities such as Toronto or Vancouver. Most LGBTTQI folks requiring home care must receive it through the mainstream health service sector. This means that pressure must be put on these services to adapt in order to be inclusive and affirming in their care provision. Our project addresses this disjuncture by specifically looking at the design of access and equity as a framework to support LGBTTQI inclusion within home care services in Ontario. A user-friendly tool, the Access and Equity Framework, can assist home care organizations to consider inclusion in a comprehensive and systematic way using specific indicators and prompts that can support inclusion. By building on the indicators to include LGBTTQI people's identities, expressions and realities we can further enhance service provision.

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For further information on this project, see the project website and open access repository of material emerging from the project on York Space (http:// yorkspace.library.yorku.ca/xmlui/) or contact Andrea Daley (adaley@yorku.ca) or Judith MacDonnell (jmacdonn@yorku.ca).