



LGBTQ COMMUNITIES AND HOME CARE

Findings From Ontario-Based Research

WHY THIS RESEARCH?

“It’s very different when you’re going outside of your home to the emergency room and receiving care versus people coming into your personal space, your private life, where you have what you have going on and you may not be out about it.” —**LGBTQ Service User**

- This research explored home care for Ontario’s lesbian, gay, bisexual, trans, and queer (LGBTQ) communities, an important focus given the increasing move to community-based care, yet almost no research addresses LGBTQ people in this context. As the service user above explains, receiving care in the home is different, especially for LGBTQ people. We aimed to bring attention to LGBTQ folks within this sector, to address both opportunities and gaps in service delivery.
- From 2011–2015 the project incorporated a variety of perspectives, including LGBTQ home care service users, referral sources (e.g., those referring clients to home care services), home care service providers (e.g., personal support workers, nurses, and social workers), and Community Care Access Centre (CCAC) administrators. Surveys, individual interviews, and focus groups were conducted.
- Led by Andrea Daley and Judith MacDonnell from York University and Post-Doctoral Visitor Melissa St. Pierre, in partnership with: Toronto Central CCAC, Rainbow Health Ontario, McMaster University, McGill University, the project’s community advisory committees, and collaborator, the Senior Pride Network at The 519 Community Centre. Funded by the Canadian Institutes of Health Research, Institute of Gender and Health.



UNDER 50



SINGLE



BELOW
POVERTY LINE



RACIALIZED



RURAL

MANY LGBTQ HOME CARE SERVICE USERS ARE UNDER 50, LOWER INCOME, AND SINGLE

- 115 self-identified LGBTQ adults aged 18+ from across the province completed a survey on their experiences of relying on, for most, a combination of informal and formal home care for both acute (e.g., post-operative care for trans clients) and chronic care (e.g., cancer, HIV, etc.) reasons.
- They identified with a range of sexual (e.g., lesbian, gay, queer, poly) and gender (e.g., male, female, trans, genderqueer) identities.
- These home care service users represented the full age spectrum, with over 50% under the age of 50. Nearly 50% were single, almost 50% reported an annual income at or below the poverty line, and many lived with a range of disabilities. Almost 30% felt that they were perceived or treated as a racialized person. 12% of participants lived in rural parts of Ontario. Participants lived in various parts of the province, with approximately 1/3 receiving home care outside of Toronto and the Greater Toronto Area.
- Like other home care users, LGBTQ clients may experience greater disadvantage such as lower income and limitations due to impairments. Unique to the experience of LGBTQ home care users is that they may be more likely to live alone and be isolated from the support of biological family.

40%

40% OF LGBTQ SERVICE USERS HAD NEVER HEARD OF COMMUNITY CARE ACCESS CENTRES

- For those with fewer informal supports, an awareness of home care services would be incredibly important. However, a number of service users had never heard of their local CCAC, whose role is to first help people access home and community supports and later to coordinate these services. In particular, those who self-identified as bisexual, trans, Aboriginal, those who were perceived and/or treated as racialized, and those with lower incomes were least likely to know about the CCAC.

“I didn’t know about the system.” —LGBTQ Service User

LGBTQ SERVICE USERS HAVE FEARS RELATED TO DISCLOSURE AND TREATMENT IN THEIR HOMES

- For some LGBTQ folks, especially trans people, home care through CCAC or an agency was avoided, despite a clear need for services. This participant talks about the reasons they turned to friends and family instead:

“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.” —LGBTQ User of Informal Supports

- LGBTQ service users who did have experience with formal home care reported a range of fears related to disclosure of their sexual and/or gender identities and treatment in the context of their private homes.



50%

LOSE
RESPECT

1/3

USERS
FEAR OF
BEING TOUCHED

- Almost 50% of service users feared that they would lose the respect of their service providers should they come out.
- Approximately 1 out of 3 service users feared that their home care provider wouldn't touch them if they knew they were LGBTQ.
- This service user describes their home care provider's reaction to knowing about their sexual orientation, showing how some fears actually come true:

"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 judgemental. She stepped back and sort of put her hands up and then she was very careful not to touch me."

—LGBTQ Service User

MANY HOME CARE SERVICE PROVIDERS DON'T KNOW THEY'RE WORKING WITH LGBTQ CLIENTS

- 1 out of 3 home care providers reported that as far as they knew, they had never worked with an LGBTQ client.
- Rarely did service providers inquire about their clients' sexual and gender identities. Generally speaking, when service users did come out, they self-disclosed to their home care providers.
- Participants differed on whether they believed knowing about a client's sexual and/or gender identity mattered to quality of care. These two quotations contrast the perspective of a service user and that of a home care 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."

—LGBTQ 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."

—Home Care Service Provider



90%

90% OF CARE PROVIDERS HAVE NEVER RECEIVED LGBTQ-FOCUSED EDUCATION WHILE EMPLOYED IN HOME CARE

- In a survey completed by 379 home care service providers from across the province and a range of professional backgrounds, including personal support workers, nurses, social workers, and care coordinators, almost 90% of participants indicated that they had never received continuing education with focus on LGBTQ communities while employed in home care.

A home care service provider articulates a keen desire to learn, however, which was a common sentiment expressed by participants:

“I really have no knowledge, but I'd like to have some.” —Home Care Service Provider

- A common theme from the interviews with LGBTQ 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 par for the course. But over time, these collective experiences added up and became burdensome:

“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.” —LGBTQ Service User

WHAT IS LGBTQ-AFFIRMING HOME CARE?

- Not all LGBTQ participants reported negative experiences with their home care providers. In fact, a number of people provided examples of affirming care. As this participant illustrates, affirming home care for LGBTQ people is based on safety and respect:

“My PSW of 5 years was very supportive and accepting of me. I was able to speak freely about my friends and my life. Support and acceptance helped me to feel less stressed overall and increased my levels of safety and trust.” —LGBTQ Service User



FOR MORE INFORMATION ABOUT THE
LGBTQ HOME CARE ACCESS PROJECT,
VISIT: <http://yorku.ca/lgbthome>

*Andrea Daley, School of Social Work, York University, adaley@yorku.ca and
Judith MacDonnell, School of Nursing, York University, jmacdonn@yorku.ca.*



This project was supported by the Canadian Institutes of Health Research — Institute of Gender and Health.