



DisAbled Women's Network of Canada/
Réseau d'action des femmes
handicapées Canada

Parliamentary Brief

Health Issues for LGBTQ2 People with Disabilities

A Brief Prepared for the Standing Committee on Health (HESO) for
their study on LGBTQ2 Health in Canada

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May 2, 2019

Leadership, Partnership & Networking

ABOUT THE DISABLED WOMEN'S NETWORK OF CANADA (DAWN CANADA)

DisAbled Women's Network (DAWN) Canada is a national, feminist, cross-disability organization whose mission is to end the poverty, isolation, discrimination and violence experienced by Canadian women with disabilities and Deaf women. DAWN is an organization that works towards the advancement and inclusion of women and girls with disabilities and Deaf women in Canada. Our overarching strategic theme is one of leadership, partnership and networking to engage all levels of government and the wider disability and women's sectors and other stakeholders in addressing our key issues.

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Health Issues for LGBTQ2 People with Disabilities

Introduction

DAWN Canada recently undertook comprehensive and intersectional research aimed at better understanding the barriers facing girls and women with disabilities in Canada, including issues facing the LGBTQ2 community. This research, which included a review of literature (including grey literature) and some original research, helped to identify key issues and create a call to action in terms of understanding the intersectional issues that women and girls with disabilities face. We are careful to ensure that those who are the most marginalized among our community, including the LGBTQ2 community are centered in our work. Therefore, while we will share insights from our research that is specific to women and girls with disabilities, we will also address more general dynamics as they relate to LGBTQ2 identity and access to health in Canada. Indeed, as research has consistently illustrated a high number of people who have disabilities among the transgender population,¹ making connections between the needs of those who identify as both LGBTQ2 and disabled is a pressing need.

Importance of Intersectionality

Our research indicates that the intersection of multiple identities impacts access, and this can in fact shed light on those among us who experience the most marginalization. These dynamics include gender, race, disability, age, class, Indigenous status, LGBTQ2 identity, geography (and the availability of services), etc. As the population ages, these issues may become more pressing. Indeed, for older LGBTQ2 adults, aging combined with a history of discrimination, may make this population more vulnerable.² Older people who identify as LGBTQ2 remain underserved and may face additional and subtle barriers, including things like staff bias in long term care and retirement facilities.³ Additionally, older adults who identify as having a disability and being LGBTQ2 remain at a higher risk of being housed in long term care facilities, in part because these adults tend to live alone and lack support systems.⁴ The intersections between age and

¹ DREDF (2018) Health Disparities at the Intersection of Disability and Gender Identity: A Framework and Literature Review.

² Fredriksen-Goldsen, K. I., Hoy-Ellis, C. P., Goldsen, J., Emler, C. A., & Hooyman, N. R. (2014). Creating a vision for the future:

² Fredriksen-Goldsen, K. I., Hoy-Ellis, C. P., Goldsen, J., Emler, C. A., & Hooyman, N. R. (2014). Creating a vision for the future: Key competencies and strategies for culturally competent practice with lesbian, gay, bisexual, and transgender (LGBT) older adults in the health and human services. *Journal of gerontological social work*, 57(2-4), 80-107.

Burling, S (2018) Gay and Grey: The retirement housing industry learns how to help LGBT seniors. Toronto Star. Available at: <https://www.thestar.com/life/2018/10/10/gay-and-grey-the-retirement-housing-industry-learns-how-to-help-lgbt-seniors.html>

⁴ Sussman, T., Brotman, S., MacIntosh, H., Chamberland, L., MacDonnell, J., Daley, A., ... & Churchill, M. (2018). Supporting lesbian, gay, bisexual, & transgender inclusivity in long-term care homes: A Canadian perspective. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 37(2), 121-132.

disability are important in this context as 33% of those aged 65 and over report a disability.⁵

Research has tended to treat those who have disabilities and those who are, for example, trans, as separate. Yet there is a need to address those who identify as both and how this shapes their access.⁶ Thus, here we will seek to connect these identities and remind the reader that those with disabilities, including those we support through our research and advocacy, can be and are members of both the disability and LGBTQ2 communities.

General Access & Barriers to Health

For both the disability and the LGBTQ2 communities, the medical model, which tends to treat bodies read as damaged and/or broken as in need of “fixing,” is pervasive and often shapes their access (or lack thereof) to health care. Here both disability and queerness challenge the ‘norm’ in ways that lead to these bodies being perceived as deviant.⁷

Our own research supports this as women with disabilities often have unique interaction with healthcare systems, including the experience of receiving healthcare in ways that are often restricted to issues directly related to their disability.⁸ This is of course problematic as it means their broader health issues are often times ignored as those supporting them tend to focus exclusively on the need to ‘fix’ them. These barriers increase when one also identifies as LGBTQ2. As an example, where the trans community is concerned, access to health care remains a key concern as medical definitions, legislation, and policies tend to view these bodies in binary ways that raise important questions about access to medical and health services.⁹ Research also indicates Deaf patients who identify as LGBTQ2 may feel uncomfortable disclosing gender identity or sexual orientation to their health care provider because of perceived stigma.¹⁰ Since LGBTQ2 communities remain at a higher risk where mental health, suicide, self-harm, and substance use are concerned,¹¹ it is critical that access to safe and respectful health care is ensured.

⁵ Statistics Canada (2017) Canadian Survey on Disability. Available at: <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2015001-eng.htm>

⁶ DREDF (2018) Health Disparities at the Intersection of Disability and Gender Identity: A Framework and Literature Review.

⁷ McRuer, R. (2006). *Crip theory: Cultural signs of queerness and disability*. NYU press.

⁸ BC Centre of Excellence for Women's Health, & Riddell, L. (2003). *We're Women, Too: Identifying Barriers to Gynecologic and Breast Health Care of Women with Disabilities*. Vancouver, BC: British Columbia Centre of Excellence for Women's Health. Available at: http://bccewh.bc.ca/wp-content/uploads/2012/05/2003_Were-Women-Too.pdf

⁹ Krieg, J. (2013). A Social Model of Trans and Crip Theory. *lambda nordica*, 18(3-4), 33-53.

¹⁰ Miller, C. A., Biskupiak, A., & Kushalnagar, P. (2018). Deaf LGBTQ patients' disclosure of sexual orientation and gender identity to health care providers. *Psychology of Sexual Orientation and Gender Diversity*.

¹¹ King, M., Semlyen, J., Tai, S. S., Killaspy, H., Osborn, D., Popelyuk, D., & Nazareth, I. (2008). A systematic review of mental disorder, suicide, and deliberate self harm in lesbian, gay and bisexual people. *BMC psychiatry*, 8(1), 70.

Sexual Health

Where sexual and reproductive rights are concerned, access to health care remains difficult for many. Our own research indicates that the presence of a disability shapes this access in powerful ways. For example, we know that reproductive health has historically tended to exclude bodies who are disabled. Included in this history is a legacy of surgical sterilization.¹² Similarly, the history of transgender and gender-nonconforming bodies tends to be one faced with struggle.¹³ This is an important historical legacy that informs modern practices as for many who are seen as nonconforming bodies, parents, caregivers, and health care providers may still yield power and control that can more broadly influence access to and decisions around reproductive health. This dynamic may be particularly important when looking at the intersections between disability and LGBTQ2 identity, as parents can yield power in ways that prevent access to needed health care based on assumptions about disability and LGBTQ2 identity. Research indicates that both those who are trans and those who have a disability experience disproportionately poor health results.¹⁴

In Canada, women with disabilities continue to face a number of barriers in accessing sexual and reproductive health.¹⁵ As a result, they are more prone to coercion, abortion, and loss of custody.¹⁶ Other social determinants of health also shape access to reproductive health, including stigma, discrimination and poverty, which can all impact sexual confidence and self-esteem.¹⁷ In part many of these barriers are grounded in negative attitudes around sexual and reproductive rights for women with disabilities.¹⁸ Both those who identify as LGBTQ2 and those with disabilities face significant attitudinal barriers that make access to reproductive health difficult. In addition to this, the physical inaccessibility of many health care sites is also a barrier. As an example, those with spinal cord injuries, including possibly those who identify as LGBTQ2, note that a lack of education among health care providers remains a key determinant and barrier with respect to accessing gynaecological care.¹⁹

For those with intellectual disabilities, including those who identify as LGBTQ2, barriers may be unique, especially in adolescents. Parents and guardians may shy away from the topic of sexual health and/or ignore it all together which leads to individuals having very little control over decision-making. There may also be a noticeable lack of sexual

¹² Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Developmental Disabilities Research Reviews*, 12(1), 48-56.

¹³ Beemyn, G. (2014). Transgender history in the United States. *Trans bodies, trans selves: A resource for the transgender community*, 1-49.

¹⁴ DREDF (2018) Health Disparities at the Intersection of Disability and Gender Identity: A Framework and Literature Review.

¹⁵ Boezaarf, T. (2012). Protecting the reproductive rights of children and young adults with disabilities: the roles and responsibilities of the family, the State, and judicial decision-making. *Emory Int'l L. Rev.*, 26, 69.

¹⁶ Kallianes, V., & Rubinfeld, P. (1997). Disabled women and reproductive rights. *Disability & Society*, 12(2), 203-222.

¹⁷ Addlakha, R., Price, J., & Heidari, S. (2017). Disability and sexuality: claiming sexual and reproductive rights.

¹⁸ Rugoho, T., & Maphosa, F. (2017). Challenges faced by women with disabilities in accessing sexual and reproductive health in Zimbabwe: The case of Chitungwiza town. *African journal of disability*, 6(1), 1-8.

¹⁹ Dillaway, H. E., & Lysack, C. L. (2015). "Most of them are amateurs": Women with spinal cord injury experience the lack of education and training among medical providers while seeking gynecological care. *Disability Studies Quarterly*, 35(3).

education that is adapted and accessible to this population.²⁰ These barriers can lead to negative outcomes including a lack of knowledge around sexual health and relationships that may increase risks associated with victimization and unwanted outcomes like unplanned pregnancy and STIs.²¹ Young LGBTQ2 people who also have an intellectual disability have unique and unmet needs where sexual health is concerned.²²

While there are many significant barriers, there are ways to increase access and equity which include: supporting self-advocacy so individuals become partners in their care, and teaching healthcare providers about disability to avoid ignorance and surprise that persons with disabilities are sexually active.²³

Sexuality & Barriers

For persons with disabilities, specifically women with disabilities, sexuality remains an issue that is trapped in misconceptions and myths. As a result the sexuality of women with disabilities is often neglected.²⁴ While there is literature on the subject of sexuality and disability, the voices of persons with disabilities remain largely absent and as with other issues, people with disabilities are often presented as fetishized objects.²⁵ Again, this is an area of shared experience with respect to both disability and LGBTQ2 identities. For persons with disabilities, healthy expressions of sexuality have tended to be viewed as deviant.²⁶ This is also an experience relatable to those who identify as LGBTQ2, so the intersections between heteronormative sexuality and ableism are of particular importance.

Our research around youth, specifically girls with disabilities, also highlights an important dynamic for youth. Some research suggests that notions about dependence and inability have led to situations in which mothers and daughters become interlinked in complex ways, which among other things, can lead to increased protection.²⁷ This sense of 'oneness' has led to situations in which girls with disabilities face barriers in being viewed as independent sexual beings.²⁸ This is an important dynamic to consider as the involvement of parents can influence a range of experiences including how sexuality is expressed, how one develops sexually, and reproductive health.

²⁰ Ramage, K. (2015) Sexual Health Education for Adolescents with Intellectual Disabilities. Saskatchewan Prevention Institute. Available at: <http://skprevention.ca/wp-content/uploads/2017/01/7-527-Sexual-Health-Education-for-Adolescents-with-Intellectual-Disabilities.pdf>

²¹ Ibid.

²² McClelland, A., Flicker, S., Nepveux, D., Nixon, S., Vo, T., Wilson, C., ... & Proudfoot, D. (2012). Seeking safer sexual spaces: queer and trans young people labeled with intellectual disabilities and the paradoxical risks of restriction. *Journal of Homosexuality*, 59(6), 808-819.

²³ Becker, H., Stuijbergen, A., & Tinkle, M. (1997). Reproductive health care experiences of women with physical disabilities: a qualitative study. *Archives of physical medicine and rehabilitation*, 78(12), S26-S33.

²⁴ Basson, R. (1998). Sexual health of women with disabilities. *CMAJ: Canadian Medical Association Journal*, 159(4), 359.

²⁵ Shakespeare, T., Gillespie-Sells, K., & Davies, D. (1996). *The sexual politics of disability: Untold desires*. Burns & Oates.

²⁶ Finger, A (1992) "Forbidden Fruit: Why Shouldn't Disabled People Have sex or become parents?" *New Internationalist*, Issue 233, July

²⁷ Sait, W., Lorenzo, T., Steyn, M., & van Zyl, M. (2009). Nurturing the sexuality of disabled girls: The challenges of parenting for mothers. *The prize and the price shaping sexualities in South Africa*, 192-219.

²⁸ Ibid.

We also know that those who also identify as having a disability are as vulnerable as the general population to things like HIV, yet they are often missing in prevention, care and treatment initiatives. One environmental scan that looked at the intersections between HIV/AIDS Service Organizations (ASOs) and Disability Service Organizations (DSOs) in the Greater Toronto Area found very few instances of accessible services identified within the HIV sector. Similarly, within the disability sector, very few mentions were made of programs or services for people living with HIV.²⁹

For LGBTQ2 persons with disabilities, heterosexism, ableism, and homophobia in health, social services, education, and disability services remain significant barriers. They experience discrimination in the disability movement on one hand, and ableism within the broader LGBTQ2 movement on the other.³⁰ The literature also reveals a bias in terms of heteronormative practices which may further marginalize some. Other barriers include: isolation which impacts access to social contexts where learning can take place, family control, a lack of role models, and internalized notions about around ideal bodies that influence feelings around attractiveness and desirability.³¹ In practice then, gatekeeping remains a significant barrier within disability organizations and among parents in terms of supporting sexual expression among persons with intellectual disabilities.³² For women with intellectual disabilities there may also be barriers related to socialization, sexual expression, partner selection and notions about femininity and sexual restraint.³³ This begins to paint a picture in which those with disabilities are already disadvantaged because of ableism, and thus those who identify as LGBTQ2 may be rendered invisible in similar ways by those supporting them. Indeed, recent research around the dynamic between support workers and adults with intellectual disabilities helps underscore these power dynamics. Findings indicate support workers remain conflicted as they understand people with disabilities have the same rights and needs as others, yet also perceive adults with disabilities as having 'deficits' and frame sexuality as problematic.³⁴

Gender Identity

There are real gaps in the literature connecting disability and transgender studies³⁵ and gender identity studies. One of the difficulties in examining experiences around gender identity among persons with disabilities is that existing research tends to overly pathologize this issue. Here there are similarities with respect to how trans experiences

²⁹ Welsh, K., Porch, W., Murzin, K. (2017) Intersections of Access: HIV/AIDS Service Organizations & Disability Service Organizations (E) Toronto, ON. Conference poster. Canadian Association of HIV Researchers Conference. Montreal.

³⁰ Duke, T. S. (2011). Lesbian, gay, bisexual, and transgender youth with disabilities: A meta-synthesis. *Journal of LGBT Youth*, 8(1), 1-52.

³¹ García, A. G., & Álvarez, C. D. (2014). Sexuality and functional diversity: an analysis from a gender perspective. *Procedia-Social and Behavioral Sciences*, 161, 299-305.

³² Alexander, N., & Taylor Gomez, M. (2017). Pleasure, sex, prohibition, intellectual disability, and dangerous ideas. *Reproductive health matters*, 25(50), 114-120.

³³ Bernert, D. J., & Ogletree, R. J. (2013). Women with intellectual disabilities talk about their perceptions of sex. *Journal of Intellectual Disability Research*, 57(3), 240-249.

³⁴ Ćwirynkało, K., Byra, S., & Żyta, A. (2017). Sexuality of adults with intellectual disabilities as described by support staff workers. *Hrvatska Revija za Rehabilitacijska Istrazivanja*, 53, 77-87.

³⁵ Mog, A., & Swarr, A. L. (2008). Threads of commonality in transgender and disability studies. *Disability Studies Quarterly*, 28(4).

are framed using the medical model, a significant consideration in terms of the power granted to doctors in the lives of trans persons with disabilities.³⁶ The Ontario Human Rights Commission (OHRC) found that individuals expressed concerns with the inclusion of “gender identity disorder” in the Diagnostic and Statistical Manual of Mental Disorders as it assumes individuals who identify as trans have mental health issues.³⁷ Yet there is notable tension here with respect to trans and disability identity as while it is incorrect to assume a link between gender identity and the presence of disability, without disability status those who are trans can lack funding through provincial disability supports to things like hormones.³⁸ This is significant, because for some, aligning their outward and inward identities are important and transitioning may be necessary for some individual’s health, safety, fulfillment, and psychological well-being.³⁹ Yet, many individuals share that with respect to accessing hormones and interaction with the mental health system and hospitalization, they face continued discrimination. This includes not being treated with dignity, not being allowed to transition genders, sexual harassment, and segregation from other patients.⁴⁰ These negative experiences with service providers, coupled with a lack of transition services and limited financial capacity, leads many to seek informal solutions which include hormones from non-medical and or non-prescribed sources.⁴¹

Recommendations

Research: As disability and LGBTQ2 issues are treated as separate in much of the literature, there is a pressing need to support research that explores these intersections. This is especially important in terms of supporting community-based research that promotes and includes lived experience.

Education: As we lead holistic lives, there is an urgent need to educate stakeholders across the board on this issue. This includes health care professionals, partners and caregivers, agencies that support the LGBTQ2 community, and disability support agencies.

Policy: DAWN Canada is working to make the lives of those with disabilities who are most marginalized visible to policy makers. To this end, our recent report, [More than a](#)

³⁶ Withers, A.J. (2015) Disabling Trans: Political Implications and Possibilities of Construction of Trans Disability. Available at: <https://stillmyrevolution.org/2015/08/11/disabling-trans-political-implications-and-possibilities-of-constructions-of-trans-as-a-disability/>

³⁷ Ontario Human Rights Commission. (2012). Minds that Matter: Report on the consultation on human rights, mental health and addictions. *Toronto: Ontario Human Rights Commission*. Available at: <http://www.ohrc.on.ca/en/minds-matter-report-consultation-human-rights-mental-health-and-addictions>

³⁸ Ibid.

³⁹ Rotondi, N. K., Bauer, G. R., Scanlon, K., Kaay, M., Travers, R., & Travers, A. (2013). Nonprescribed hormone use and self-performed surgeries: “do-it-yourself” transitions in transgender communities in Ontario, Canada. *American journal of public health, 103*(10), 1830-1836.

⁴⁰ Ontario Human Rights Commission. (2012). Minds that Matter: Report on the consultation on human rights, mental health and addictions. *Toronto: Ontario Human Rights Commission*. Available at: <http://www.ohrc.on.ca/en/minds-matter-report-consultation-human-rights-mental-health-and-addictions>

⁴¹ Rotondi, N. K., Bauer, G. R., Scanlon, K., Kaay, M., Travers, R., & Travers, A. (2013). Nonprescribed hormone use and self-performed surgeries: “do-it-yourself” transitions in transgender communities in Ontario, Canada. *American journal of public health, 103*(10), 1830-1836.

Footnote, explores many of these intersections. Of note here as well is the name of this report, which intentionally draws attention to the reality that women with disabilities, including those who identify as LGBTQ2 are often only an afterthought to policy makers. The exploration of their lived experiences are treated as footnotes rather than important lived experiences. Given the stated commitment to GBA+, there also needs to be wider and more active work to include intersectionality in informing policy efforts.

Advocacy: We continue to advocate for the inclusion of a disability lens in all aspects of research and policy. To this end, we were disappointed that the stated parameters of this brief did not explicitly name disability as they did with other intersecting identities. This oversight matters to those with disabilities, as this brief outlines the unique and disproportionate barriers they face. As people with disabilities represent a significant amount of Canada's population, an estimated 1 in 5, with even higher rates among women and those who are older,⁴² it is imperative that a disability lens is always employed in these kinds of efforts. To this end, DAWN Canada will continue to work in partnership with other allies to ensure the inclusion of persons with disabilities in all matters of policy and practice.

⁴² Statistics Canada (2018) Canadian Survey on Disability. Available at: <https://www150.statcan.gc.ca/n1/daily-quotidien/181128/dq181128a-eng.htm>