

**Submission  
No 77**

## **INQUIRY INTO PREVALENCE, CAUSES AND IMPACTS OF LONELINESS IN NEW SOUTH WALES**

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# **ACON SUBMISSION TO THE INQUIRY INTO THE PREVALENCE, CAUSES AND IMPACTS OF LONELINESS IN NSW**

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## About ACON



ACON is NSW's leading health organisation specialising in community health, inclusion and HIV responses for people of diverse sexualities and genders. Established in 1985, ACON works to create opportunities for people in our communities to live their healthiest lives.

We are a fiercely proud community organisation, unique in our connection to our LGBTQ+ communities and in our role as an authentic and respected voice.

Members of Australia's sexuality and gender diverse communities experience health disparities when compared to health and wellbeing outcomes experienced by the total population.

We recognise that members of our communities also share their sexuality and gender diversity with other intersecting identities and experiences, and we strive to ensure this is reflected in our work. These may include LGBTQ+ people who are Aboriginal and Torres Strait Islander; from culturally, linguistically and ethnically diverse migrant or refugee backgrounds; people who use drugs; mature aged people; young adults; and people with disability.

## Contact

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*ACON acknowledges the Traditional Owners of the lands on which we work. We pay respect to Aboriginal Elders past and present.*

## Introduction

ACON welcomes the opportunity to provide input to the Standing Committee's inquiry into the prevalence, causes and impacts of loneliness in New South Wales.

ACON makes the following recommendations to the Inquiry:

1. That the NSW Government develops a statewide NSW Strategy to address loneliness as a public health issue with involvement from both NSW Health and the Department of Communities and Justice.
2. That the NSW Government work in partnership with community organisations to strengthen long-term funding arrangements for community based programs for vulnerable populations.
3. That the NSW Ministry of Health strengthens and expands existing commitments that address social stigma towards people living with HIV as a fundamental driver of social exclusion, isolation and loneliness in our communities.
4. That the NSW Government expedites the NSW Law Reform Commission's review of the *Anti-Discrimination Act 1977*, and uses that review as an opportunity to remove exemptions that allow for discrimination in faith-based services, especially schools, health and social services.
5. That the NSW Police Force, in partnership with local councils, develops best practice guidelines for hosting LGBTQ+ community events, including developing effective strategies to respond to threats of violence from hate groups.
6. That the NSW Ministry of Health, in partnership with the mental health sector and LGBTQ+ community organisations, develop standardised assessment tools to better describe the impact of responses to loneliness and social isolation.

ACON is NSW's leading health organisation specialising in community health, inclusion, and HIV responses for people of diverse sexualities and genders. We provide a range of services to trans and gender diverse people and have been building a rapidly growing suite of programs to improve their health and wellbeing.

ACON knows that fostering social connection, a sense of belonging, and inclusion are crucial to achieving better health outcomes for LGBTQ+ communities in NSW.

ACON delivers programs and services targeted to increase social inclusion and community connection for LGBTQ+ people. Fostering a sense of belonging among LGBTQ+ people living in NSW helps ACON to better engage our communities with targeted sexual health messaging around prevention, testing and treatment interventions. It also helps mitigate some of the negative mental health impacts of loneliness known to affect LGBTQ+ people disproportionately.

## LGBTQ+ People's Experiences of Social Isolation and the Value of Peer Support and Social Support Services in Combating Loneliness



ACON is aware that among LGBTQ+ communities, experiences of loneliness caused by social exclusion, disconnection, and isolation are more frequently reported among adolescents and young adults, among those who are ageing, and particularly among those also living with HIV.<sup>1,2,3,4</sup> Loneliness and isolation within our communities are linked to increased rates of mental ill health, depression, suicidal ideation, substance use, and engagement in high-risk sexual behaviours.<sup>5</sup>

We know that LGBTQ+ people living with disability are particularly susceptible to experiencing loneliness, especially when that disability limits mobility, as are those living in regional or rural areas who may have limited social networks or encounter more difficulty accessing appropriate services and support than their urban counterparts.

Financial distress and housing insecurity are known to increase the likelihood of social isolation and feelings of loneliness, especially for older LGBTQ+ people who frequently express concern about a lack of secure, affordable housing options and inclusive aged care services free from discrimination.<sup>6</sup>

Many community-based organisations have considerable expertise in the delivery of services and programs that reduce and mitigate the impact of loneliness. These programs often also work toward other outcomes such as health improvement, skills acquisition and healthy ageing. They work best when integrated with other offerings such as financial assistance and primary health care.

In most cases, the impact of this on health and skills outcomes are more highly valued than the impact on reducing isolation and loneliness. This means that programs that impact loneliness tend not to operate at scale, have uncertain funding and offered as time limited or sporadic responses.

Prejudice and discrimination towards sexuality and gender diversity, as well as stigma around HIV status, are major contributors to social exclusion and loneliness among LGBTQ+ people and people living with HIV. A legal environment that promotes inclusion and gives protection against discrimination can assist in reducing isolation by making it more likely that people will feel safe making connections.

### **People living with HIV**

ACON recognises that despite advancements in HIV treatment allowing individuals to lead healthy lives, stigma around HIV persists, leading to social isolation and loneliness. Newly diagnosed individuals often withdraw from connections due to fear of discrimination and rejection.<sup>7 8</sup> For some, social disconnection and isolation can mean they end up struggling with adherence to treatment regimens and possibly becoming lost to care.

ACON is aware that of the 816 participants in the HIV Futures 10 survey – a national survey of people living with HIV – 36.6% reported experiencing HIV-related stigma in the past 12 months, and 29.8% reported being treated differently by a healthcare worker due to their HIV status. 22.1 % of participants also reported having a clinical diagnosis of anxiety, 21.4 % reported having a clinical diagnosis of depression, and 23.3% reported having attempted suicide in their lifetime.<sup>9</sup>

We know that people living with HIV in Australia value community support, with around a quarter accessing peer worker assistance.<sup>10</sup> The ACON Lunch Club is an important example of a service that

provides social support, connection and free meals, delivering 1,595 meals to people living with HIV in the 2023-24 financial year.

Additionally, ACON has operated a Community Support Network (CSN) for over 40 years, assisting older LGBTQ+ individuals living with HIV. In 2023-24, the CSN team provided 770 instances of support, including grocery shopping, household chores, gardening, meal preparation and wellbeing check-ins using telehealth support to older people living with HIV.

**Case study:**

*A 51-year-old gay man with multiple comorbidities living in Sydney was paired with a CSN volunteer. He lives in a housing commission unit on the second floor of a building with no lift. Because of his severe mobility issues, he only left his apartment to attend essential medical appointments, and his health condition and isolation left him with severe anxiety.*

*This client commented that he would not survive without his ACON peer support volunteer, and that when once he would feel intense anxiety at the thought of having someone visit him in his apartment, he now very much looked forward to visits from his ACON volunteer, explaining that he would not survive without their bi-weekly support and that he would be lost without ACON as an organisation.*

Peer support programs provide people living with HIV and other LGBTQ+ communities, who often face isolation and loneliness, with meaningful connections to individuals who share similar experiences. This shared lived experience between community peer support workers and those affected by HIV allows organisations like ACON to offer effective programs and initiatives that enhance social connections. The trust built within these peer support programs gives them unique significance and value among communities impacted by HIV. For some people, these programs are their only social connections.

Despite these initiatives considerable benefits in fostering social connections and support, many peer support services rely on volunteer labour. Compensating peer support workers for their contributions would lead to better retention of those with valuable lived experiences. It would also create more opportunities for skill development and improve the overall outcomes of peer support programs.<sup>11</sup>

**LGBTQ+ older adults**

ACON recognises that loneliness impacts people at all life stages, with older adults being particularly vulnerable. Research shows a strong link between social disconnection and increased risks of heart disease, stroke, and dementia.<sup>12,13</sup> Age-related health issues can limit mobility and social engagement, which is often compounded by the loss of partners and friends or isolation in aged care settings.<sup>14</sup>

We know older LGBTQ+ adults face additional challenges, including lifelong stigma, discrimination, and strained family relationships. They often experience heightened social anxiety linked to housing insecurity and financial stress, leading to increased loneliness. Many have weaker social networks, especially in rural areas with limited LGBTQ+ support, and have lost many friends during the HIV epidemic.<sup>15</sup>

We know that if older LGBTQ+ adults do have a significant long-term partner, it is common for older LGBTQ+ adults to become isolated at the time their partner passes away.

**Case study:**

*A senior lesbian who moved into residential aged care after her partner of 40 years passed away. At the time she sought out peer support through the ACVVS program she had been residing in aged care for 3 years and hadn't disclosed her identity as a lesbian to anyone in the facility for fear of experiencing discrimination.*

*However, after connecting with ACON's peer support volunteer who was a woman that shared many aspects of the client's own life experience, she found the confidence to disclose her identity to other residents and to staff. She described the enormous relief she felt after being supported to find the confidence to come out and now openly acknowledges the picture of her partner as her late significant other. The experience, she said, helped her find the confidence and support to be herself which had a huge impact on her mental wellbeing and her sense of belonging at the aged care facility.*

**Case study:**

*A volunteer peer support worker recounted the story of a gay man living with HIV who, upon entering aged care, was informed by the facility he would incur additional charges for them to "manage his HIV". When his partner wanted to join him in the facility, they were denied access to a shared room that would normally be given to cohabitant couples. The facility reasoned that this was because of the cost differential attributed to the HIV management. The couple were forced to accept the significant additional cost of living in two separate rooms.*

ACON offers The LOVE Project (Living Older, Visibly and Engaged) to reduce social isolation and promote community connection for older LGBTQ+ people. Participants appreciate the welcoming environment, and many reconnect with lost friends or find new significant partners.

The LOVE Project delivers educational workshops on maintaining mental and physical health, navigating aged care services, planning for palliative care, and end-of-life legal advice and decision-making strategies. Unfortunately, funding for these services is often limited and short-term.

Most people attending these services are not aged care recipients. Attendees do experience isolation but don't yet have the level of support needs to be approved for aged care. While similar services could be provided through the aged care system, many existing clients would not be eligible.

Older LGBTQ+ people face prejudice and discrimination in aged care, forcing them to hide their identities, especially in faith-based facilities, leading to increased loneliness and depression. This highlights the critical need for inclusive care options for older LGBTQ+ individuals.

As outlined in ACON's recent submission to the NSW Law Reform Commission's review of the *Anti-Discrimination Act 1977*, there must be no exemptions for faith-based organisations to discriminate against those accessing their services or their employees. The current exemptions in NSW discrimination law are the broadest in the country and do not foster an inclusive environment in services provided by faith-based organisations, including aged care services.

## Trans and gender diverse people

ACON knows that trans and gender diverse people experience prejudice, discrimination and social exclusion at particularly high levels and international research shows loneliness among trans and gender diverse people at rates as high as 83%.<sup>16</sup>

ACON's clients often report high levels of social disconnection and isolation due to internalised shame, rejection from family, and lack of access to gender affirming care. Many of our clients report using alcohol and other drugs to cope with their feelings of social disconnection, isolation and loneliness, while others create a controlled circle of trusted friends and family to foster a sense of safety and belonging. Across all LGBTQ+ communities creating a "chosen family" of peers and allies is common to foster a sense of safety and belonging.

ACON is aware that online spaces are able to create a greater sense of connection. Online spaces to provide high quality information for trans and gender diverse people lack funding stability that would allow them to reach more trans and gender diverse people.

Many trans people also find connection through positive engagement in community advocacy, finding connection through community-based activities, and advocacy for gender diverse communities.

## Measuring and recording experiences of loneliness among LGBTQ+ communities

At ACON, social isolation and loneliness data are gathered through various peer support programs using tools like the K10 and pre- and post-service evaluations. Staff record these experiences in client records, noting a common theme among participants.

Validated tools such as PozQoL, a tool used across the HIV sector to measure the various factors that contribute to the quality of life for people living with HIV, including social connection and sense of belonging.<sup>17</sup>

To better address social isolation and loneliness across the LGBTQ+ communities, a standardised statewide approach for data collection is needed to create comparable datasets. This would help peer support programs across NSW to better tailor interventions for vulnerable individuals and strengthen advocacy efforts.



## References

- <sup>1</sup> Garcia, J., Vargas, N., Clark, J. L., Magaña Álvarez, M., Nelons, D. A., & Parker, R. G. (2020). Social isolation and connectedness as determinants of well-being: Global evidence mapping focused on LGBTQ youth. *Global Public Health*, 15(4), 497–519.
- <sup>2</sup> Mendonca, C. J., Newton-John, T. R. O., Alperstein, D. M., Begley, K., Hennessy, R. M., & Bulsara, S. M. (2023). Quality of Life of People Living with HIV in Australia: The Role of Stigma, Social Disconnection and Mental Health. *AIDS and Behavior*, 27(2), 545–557.
- <sup>3</sup> Fekete, E., Williams, S., & Skinta, M. (2018). Internalised HIV-stigma, loneliness, depressive symptoms and sleep quality in people living with HIV. *Psychology & Health*, 33(3), 398–415.
- <sup>4</sup> Eres, R., Postolovski, N., Thielking, M., & Lim, M. H. (2021). Loneliness, mental health, and social health indicators in LGBTQIA+ Australians. *American Journal of Orthopsychiatry*, 91(3), 358–366.
- <sup>5</sup> Garcia et al (2020).
- <sup>6</sup> ACON. (2013). The LOVE Project Consultation Report: Service Needs and Preferences of Older Lesbian, Gay, Bisexual and Transgender People in NSW.  
[https://d3n8a8pro7vhmx.cloudfront.net/acon/pages/8533/attachments/original/1590453794/Living\\_Older\\_Visibly\\_and\\_Engaged.pdf?1590453794](https://d3n8a8pro7vhmx.cloudfront.net/acon/pages/8533/attachments/original/1590453794/Living_Older_Visibly_and_Engaged.pdf?1590453794)
- <sup>7</sup> Ninnoni, J. P., Agyemang, S. O., Bennin, L., Agyare, E., Gyimah, L., Senya, K., Baddoo, N. A., Annor, F., & Obiri-Yeboah, D. (2023). Coping with loneliness and stigma associated with HIV in a resource-limited setting, making a case for mental health interventions; a sequential mixed methods study. *BMC Psychiatry*, 23(1).
- <sup>8</sup> Rueda S, Mitra S, Chen S, et al Examining the associations between HIV-related stigma and health outcomes in people living with HIV/AIDS: a series of meta-analyses *BMJ Open* 2016; 6: e011453.
- <sup>9</sup> Norman et al (2022).
- <sup>10</sup> Norman et al (2022).
- <sup>11</sup> Molyneux, A., Delhomme, F., Mackie, B. (2021) It's Who We Are: Exploring the Role, Impact and Value of Peers.
- <sup>12</sup> Sutin, A.R., Stephan, Y., Luchetti, M., & Terracciano, A. (2020). Loneliness and risk of dementia. *Journals of Gerontology: Psychological Sciences*, Vol. 75(7), 1414–1422.
- <sup>13</sup> Holt-Lunstad J, & Smith, T.B. (2016). Loneliness and social isolation as risk factors for CVD: implications for evidence-based patient care and scientific inquiry. *Heart*, Vol. 102(13), pp. 987-989.
- <sup>14</sup> Brooker, R. (2023). GRAI Quality of Life Survey Report: LGBT+ and 50+ Loneliness and quality of life under the rainbow.
- <sup>15</sup> Brooker, R. (2023).
- <sup>16</sup> Hajek, A., König, H. H., Blessmann, M., & Grupp, K. (2023). Loneliness and Social Isolation among Transgender and Gender Diverse People. *Healthcare (Switzerland)*, 11(10).
- <sup>17</sup> Australian Research Centre in Sex, Health and Society. PozQol: Valuing quality of life among people with HIV. Retrieved October 10, 2024, from [www.pozqol.org](http://www.pozqol.org)