



Productivity Commission Inquiry: Carer Leave Submission from LGBTIQ+ Health Australia

About LGBTIQ+ Health Australia

LGBTIQ+ Health Australia (LHA) is the national peak organisation working to promote the health and wellbeing of LGBTIQ+ people and communities.

LHA is uniquely placed with a diverse membership that spans across states and territories, and includes LGBTIQ+ community-controlled health organisations, LGBTIQ+ community groups and state and territory peak bodies, service providers, researchers, and individuals. LHA is strategically positioned to provide a national focus to improving the health and wellbeing of LGBTIQ+ people through policy, advocacy, representation, research evidence, and capacity building across all health portfolios of significance to our communities. We recognise that people's genders, bodies, relationships, and sexualities affect their health and wellbeing in every domain of their life.

Silver Rainbow is LHA's ageing and aged care programme. It provides national coordination and support activities promoting the well-being of LGBTI elders. This is achieved through providing policy and program advice to government and the ageing and aged care sector, delivery of LGBTI awareness training to the sector, and partnering with LGBTI organisations and individuals across Australia and internationally. Silver Rainbow works towards achieving the best possible health outcomes for LGBTI elders by ensuring aged care services are inclusive and accessible.

Executive Summary

In LHA's consultations to inform its submissions to the Royal Commission into Aged Care Quality and Safety (Royal Commission)¹, many participants called for the development and delivery of initiatives to better support diverse family and friend carers. However, increased support for informal carers must not be a substitute for adequate, quality formal home and residential aged care.

Within the terms of reference of the Productivity Commission's current review, LHA supports:

- an entitlement for extended unpaid leave for carers of older Australians.
- recognition of the diverse 'family of choice' that provides care to LGBTI older Australians.
- mechanisms that protect privacy and prevent discrimination.
- coordination of leave entitlements with improved supports for informal carers.

¹ <https://www.lgbtiqhealth.org.au/rc>



Understanding diversity within diversity

The term 'LGBTI' (lesbian, gay, bisexual, transgender and gender diverse, and intersex) includes distinct and overlapping population groups that have a range of commonalities as well as diverse needs and characteristics.

The term needs to be used with care to ensure it does not obscure an issue that is important for a particular population but not for others. The need for and impacts of caregiving can vary significantly across each of these groups as well as for specific for individuals. The carer, the older person or both may be part of an LGBTI population, raising different issues for consideration.

Older LGBTI people are likely to have experienced a history of exclusion, stigma, trauma and criminalisation or pathologisation of their sexuality, gender identity and/or sex characteristics during their lifetime. 'Queer' has historically been solely a term of abuse for many older LGBTI Australians and LHA currently does not include 'Q' when referring to older people in our communities.

Many LGBTI community members also experience intersecting discrimination in relation to other factors such as being Aboriginal and/or Torres Strait Islander, disability, age, ethnicity, gender, HIV status, disability, drug use, as well as the stigma of living with poor mental health.

LGBTI populations and informal (unpaid) care

LHA recognises the essential role of people who provide informal (unpaid) care and support for older people. This includes a continuum of care, including being a sole carer, providing informal care with others, and in conjunction with formal (paid) care providers.

We endorse the conclusion of the Royal Commission that the aged care system does not adequately support informal carers. We also reiterate concerns that the aged care system has not provided adequate care for Australia's LGBTI populations—**informal care must not be a substitute for systemic reform to ensure LGBTI older people can access culturally safe and appropriate formal care.**

Within LGBTI populations, informal carers can provide more culturally safe care and help maintain essential social and community connections. Many LGBTI older people experience isolation, especially throughout the COVID pandemic, and fear loss of contact with community members who will instinctively understand them without the need for continual explanation or education.

Many LGBTI older people prefer to receive informal care or have a significant need for informal care from friends or family due to anticipated and actual experiences of discrimination within formal care settings. During LHA's consultations for the Royal Commission, LGBTI people spoke about the lack of knowledge and awareness by residential and in-home aged care providers. They spoke of their fear of accessing formal care due to their past experiences of discrimination and the reports of others about prejudice within formal care settings.



Many LGBTI older people fear letting unknown people into their own home. When receiving home care, some older lesbians and gay men remove all signs of their sexuality, including photographs of partners and friends, for fear of what reaction they might receive. Many trans or intersex people receiving personal care do not have that option and need to repeatedly explain or educate care staff.

Being open is fraught with fear of discrimination. Even when nothing is said, paid caring staff can make it clear they do not accept LGBTI people. When something occurs in the home, the home becomes an unsafe space. Often the home is the only safe space for LGBTI elders and older people.

Prejudice and stigma aimed at LGBTI people often extends beyond older people themselves to their partners, family, friends and carers, even when the carer is not themselves part of an LGBTI population group.

In the context of formal care, LGBTI people report that they feel the need to 'straighten up' whenever they visit facilities. They report feeling uncomfortable talking about their LGBTI family members or friends with other residents or staff, and often find they do not receive the same levels of interest and concern about their family members as the other residents.

Gay men and lesbians report that they are often the child in the family that is relied upon to take on the caring role due to a stereotypical perspective that they have greater capacity and fewer family commitments.

LGBTI people can often be the main or sole carer for a parent but may also have a history of rejection and/or abuse from that parent. Similarly, many LGBTI older people rely on family members who can take advantage of this dependency to control the expression of their gender, body, sexuality or relationships. There is very limited understanding of, support for, or resourcing of services for LGBTI people in this type of caring relationship.

Family of choice

Informal systems of care for older LGBTI people can be limited and significantly different to the broader population. Many older LGBTI people have not had biological children or are alienated from their families of origin, who may have been the instigators of violence and trauma.

In the absence of family defined by biology or formal frameworks, many older LGBTI people have intimate connections to a network of others, characterised by shared values, common beliefs, collective histories, mutual support and respect. These **families of choice** may include ex-partners, long-term friends, fellow activists, household members and non-biological children.

These families of choice may not be recognised or understood by others when considering who is providing care for the older LGBTI person and can be denied information, left out of decision making and ignored in their role as next of kin.



LGBTI carers report having to explain their home situation or relationship repeatedly because they are dealing with many different people in the aged care system. This can be particularly difficult in conservative regional and rural areas if they are not 'out' to their community.

The aged care sector needs to be trained so that they can support diverse care networks of LGBTI older people, including partners, family of choice and friends, and deliver services in a way that is responsive to and respectful of this diversity.

Workplace context

LGBTI community-controlled organisations that participated in our consultation for this submission expressed clear support for an entitlement for extended unpaid leave for carers of older Australians.

Those organisations indicated that they could provide extended unpaid leave under existing employment policies subject to the constraints of the role, such as time-limited funding for positions.

Many LGBTIQ+ people face the risk of prejudice and discrimination within their workplaces and requests for extended unpaid leave could result in pressure to work part time or to resign. In our consultation for the Royal Commission, some people expressed concern about being put into financial and mortgage stress due to their caring role.

There is a clear need to ensure that any leave entitlement includes protections against inappropriate and unnecessary disclosure of sexual orientation, gender identity or intersex status.

LGBTIQ+ data on informal (unpaid) care

Many questions posed by the Productivity Commission in its *Carers Leave Issues Paper* rely on the collection and analysis of reliable data about the demography of those involved with informal care.

There is a lack of data on the sexual orientation, gender identity and variations in sex characteristics of the Australian population. Base data does not exist for LGBTI people and the government has not included relevant questions in the National Census. There is no reliable and indicative data about the demography of LGBTI people who need formal or informal care support. We rely on research and estimates to determine the number of LGBTI people in the Australian population.

As there is little or no data on LGBTI populations, they are often excluded from policy creation, program implementation and evaluation. When data collection is attempted, questions are often inappropriate and use language that is harmful or marginalising.

In early 2021, the Australian Bureau of Statistics (ABS) released an updated Standard for Sex, Gender, Variation of Sex Characteristics and Sexual Orientation Variables, 2020 ('2020 Standard'). Where the Standard is implemented, the collection and dissemination of relevant data will become consistent and provide valuable information about LGBTIQ+ people.



Health and wellbeing for lesbian, gay, bisexual, trans, intersex, queer [LGBTIQ+] people and sexuality, genders, and bodily diverse people and communities throughout Australia.

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LHA is seeking full implementation of the ABS 2020 Standard in all government surveys, minimum data sets, suicide death data records, research surveys and the next national Census in 2026. LHA has recommended the establishment of a national aged care minimum data set that includes data relevant to older LGBTI people.

Information in this submission is based on recent consultation with LHA full member community controlled organisations and previous extensive consultation undertaken to develop comprehensive submissions for the Royal Commission, including with LGBTIQ+ older people, their families, friends and carers and LGBTI aged care workers.

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