

National LGBTI Health Alliance

lesbian, gay, bisexual, transgender, intersex and other
sexuality, sex and gender diverse people and communities
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Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Madam/Sir

The National LGBTI Health Alliance (the Alliance) is pleased to make a submission to the Senate Committee Inquiry into the provision of palliative care in Australia. We recognise, and research has confirmed, that issues connected to palliative care significantly impact on the lesbian, gay, bisexual, trans/transgender, intersex community and on people living with HIV/AIDS and their carers and support networks (Cartwright, 2011; Harrison, 2010).

About the National LGBT Health Alliance

The Alliance is the national peak health organisation for a range of organisations and individuals from across Australia that work together to improve the health and well-being of lesbian, gay, bisexual, trans/transgender, intersex and other sexuality, sex and gender diverse (LGBTI) people and communities. Formed in 2007, the Alliance includes the major providers of services for LGBTI people in Australia, with 67 Member Organisations drawn from each State and Territory. The Alliance provides a representative national voice to: develop policy and advocate on LGBTI health issues; seek increased commitment to services for LGBTI people; develop the capacities of LGBTI organisations; and support evidence-based decision-making through improved data collection covering sexuality, sex and gender identity.

Key areas of work for the Alliance include: ageing and aged care; alcohol, tobacco and other drugs; disabilities; health and human rights; mental health and suicide prevention; monitoring and research; primary care; relationship recognition; sex and gender diversity; sexual health; and violence, homophobia and transphobia. The Alliance's website (www.lgbtihealth.org.au) provides a wide range of resources, including copies of policy submissions, media statements, governance information and LGBTI health information.

LGBTI Health in Australia

Lesbian, gay, bisexual, transgender and intersex (LGBTI) people make up a significant proportion of the Australian population: 9% of adult men and 15% of women report either same sex attraction or some sexual experience with the same sex (Smith et al. 2003), up to 1:1,000 people may be transgender (Department of Health 2008, Olyslager & Conway 2007) and up to 1:200 intersex (Diamond 2004, Blackless 2000).

LGBTI people are part of all population groups, including Australians living in rural and remote areas, indigenous communities, and in culturally and linguistically diverse populations. LGBTI people have demonstrated considerable resilience in looking after themselves and their communities despite adversity. Many LGBTI people lead healthy and fulfilling lives contributing to their families, local communities, workplaces and society as a whole. Nevertheless, the experience of dealing with

marginalisation and stigmatisation often impacts on people's health. For example, we know that LGBTI people have disproportionately negative mental health outcomes in comparison with the rest of the population, including depression and suicide. The use of alcohol, tobacco and other drugs is also higher than the wider population (AIHW, 2011).

Research demonstrates that these negative outcomes are not due to sexual orientation, sex or gender identity as such, but rather are related to the social determinants of health. In particular, these include the experience of discrimination, social exclusion and isolation, and the failure of generic health interventions and prevention strategies to be inclusive of LGBTI people and their needs (Couch et al. 2007, Dyson et al. 2003, Hillier et al. 2005).

LGBTI Ageing and Aged Care

The matters that are significant in relation to LGBTI and aged care generally are also applicable to many of the concerns raised when palliative care and end-of-life issues are considered. The ensuring of equal treatment, recognition of chosen family, rights of same-sex partners, staff trained in LGBTI sensitivity and the presence of legal protections, is essential. LGBTI older people have lived lives of significant persecution and fear of being discriminated against. This has a profound impact on their experience of ageing and their expectations regarding aged care services and end-of-life care.

In October 2011 the Alliance and one of our Member Organisations, ACON, convened Australia's first roundtable to consider the wide range of ageing and aged care issues as they impact on LGBTI populations. The National LGBTI Roundtable on Ageing agreed to the following guiding principles in relation to the agreed need for a national aged care strategic plan:

Guiding Principles for a National LGBTI Aged Care Strategic Plan

1. To make the specific needs and life experiences of older LGBTI Australians visible, in order to promote their health and wellbeing. LGBTI older people are experts on their own needs and situations and need to be at the forefront of the development of solutions.
2. To ensure LGBTI input to all government-related measures that affect the health and well-being of older LGBTI Australians.
3. To ensure LGBTI inclusive service provision in all areas of aged care.
4. To ensure that all aged care workers have the skills and knowledge they need to deliver appropriate person centred care to older LGBTI Australians.
5. To ensure that all government legislation, policies, standards, regulatory mechanisms, documentation and other materials that relate to or impact on the health and well-being of LGBTI older Australians are appropriate to their needs and experiences.
6. To ensure that LGBTI older Australians are treated with respect and are able to engage with the aged care sector and relevant agencies including government as confident consumers and self-advocates.

The Roundtable principles, which can be directly related to situations involving palliative care, arise from a number of key concerns which impact the lives of LGBTI seniors, including:

- LGBTI seniors have endured decades of stigma, discrimination and exclusion by the state and mainstream society;
- LGBTI seniors are almost completely absent from national aged care research, policy, programs and service delivery ;
- LGBTI seniors have less access to carers and/or family support;
- LGBTI seniors risk social isolation from LGBTI communities and within aged care services;
- Aged care services are poorly prepared to meet the needs of LGBTI seniors;
- A significant proportion of aged care provision is by religious based organisations, which have actual or perceived discriminatory policies and practices; and
- Although there have been significant legal reforms in Australia since 2008 affecting the legal status of same-couples, there continues to be considerable resistance to recognizing the legitimate rights and responsibilities of a same-sex partner in health care (including aged care and palliative care) settings (Harrison and Irlam 2010). (For a detailed discussion of these points see www.lgbtihealth.org.au)

Following the roundtable the National LGBTI Health Alliance has empanelled an Ageing and Aged Care Advisory Group to continue the important dialogue of issues faced by seniors within the LGBTI community and aged care sector.

The principles outlined and the key concerns have direct applicability in terms of the “factors influencing access to and choice of appropriate palliative care that meets the needs of the population” (Committee Terms of Reference (a)) for LGBTI Australians. We note however our disappointment that the terms of reference did not specifically include LGBTI populations. In line with our first guiding principle, we encourage the committee to include specific discussion of LGBTI issues within its final report.

Recommendation:

That the Committee specifically consider the needs of LGBTI Australians regarding access and choice in relation to the provision of palliative care, in addition to the other population groups included in the inquiry terms of reference (people living in rural and regional areas, etc).

The Productivity Commission supported such an approach by including a specific section on LGBTI aged care in their final report *Caring for Older Australians*, which is currently under consideration by the Federal government.

With regard to palliative care and end-of-life decision making, some specific points that we recommend be considered include:

- The various forms of social discrimination which take place even when formal legal equality exists. For example the preferences of the person who is ill to have a partner or chosen significant other advocate for them may not be recognised by their biological family. This can be difficult and distressing. This is particularly true where the partner does not live with the palliative care recipient as is likely to be the case.
- LGBTI Seniors are estimated to be twice as likely to be single, compared with their heterosexual peers. This presents unique challenges for palliative care. Specifically “families of choice” may

not be recognized by the Palliative care industry on an equal footing to a person's "biological family". For some LGBTI individuals they may have been rejected by their biological family and substituted this with peers in a "family of choice" and accordingly would wish to ensure their chosen family is included in the palliative care process.

- Legal documents such as Advanced Care Directive, Power of Attorney and Enduring Guardianship documents are vitally important for LGBTI people, above the mainstream population. In situations where partners may choose to be hidden, or where service providers do not recognize the same-sex partner (either inadvertently or deliberately), such legal documents will ensure that LGBTI people are able to assert their rights. While recognizing that different terms and language are used across states and territories, by and large states provide similar avenues to protect legal rights. However these rights are only effective if people are aware of their existence and provided with low-cost, easy to access avenues to enact these legal tools.
- Education of LGBTI cultural awareness within palliative care, addressing specific issues of care networks ("family of choice"), same-sex couples legally equal to different-sex partners in terms of next of kin rights and other related culturally appropriate information, will decrease culturally inappropriate palliative care outcomes.
- Amendments to the Standards for Providing Quality Care to All Australians should include specific reference to LGBTI populations.
- when the person who is seriously ill has died the partner left behind will be bereaved. This is difficult if the relationship was not publicly acknowledged. They may not be able to openly grieve. It is important that same-sex partners are automatically offered the same support that heterosexual partners would receive. (adapted from Care Search, 2012).

We would refer you to the Summary Report from the LGBTI Roundtable on Ageing, listed under publications on our site, www.lgbthealth.org.au, for an overview of relevant matters. We look forward to the opportunity to discuss these matters further as they impact on the provision of culturally appropriate palliative care to the communities represented by our organisation.

Members of the Alliance are available to provide further input as required.

Yours sincerely

Warren Talbot
GENERAL MANAGER

23 March 2012

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