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21 March 2012

Submission to the Committee's Inquiry on Palliative Care in Australia

Dear Sir/Madam

Thank you for the opportunity to have input to the Inquiry into Palliative Care in Australia being conducted by the Senate Community Affairs Committee.

1. About GRAI

The GLTBI Retirement Association Inc (GRAI) is a Western Australian not-for-profit, community-based organisation. We aim to identify and address the needs of older people of diverse sexualities and gender identities and work to create an inclusive mature age environment to support a good quality of life for GLBTI[1] elders. Nationally, GRAI is the only organisation focusing exclusively on the needs of GLBTI elders.

In offering submissions to inquiries such as this one, we find that the first, most common point of concern is, invariably, the omission of GLBTI people from the terms of reference and, following this, a need to explain the relevance of an inclusive approach for this cohort.

Although this submission addresses GLBTI elders, many of the points apply equally to GLBTI people of all ages.

2. The importance of an inclusive approach for GLBTI Elders

2.1 Consequences of historical discrimination

GLBTI elders have grown up in an era when homosexuality was criminalised or regarded as a mental illness. Consequently, GLBTI elders tend to have deeply internalised fears of homophobia, be

[1] GLBTI (gay, lesbian, bisexual, transgendered, transsexual and intersex) is used throughout this document. There is much debate on terminology for this group and other terms are also used, including: LGBTI (lesbian, gay, bisexual, trans, intersex), sexual minority groups, and sexual and gender diverse. GLBTI is used here as a general term to include people who are not exclusively heterosexual in identity, attraction and/or behaviour.

profoundly concerned about exposure and are often very adept at identity concealment. The ramifications of these patterns are an increased incidence of stress, depression and social isolation. Of special relevance to this inquiry is that GLBTI elders are also less likely to access health care and other services as a result of their fears regarding institutions.[2] Research confirms that GLBTI identity is a significant social determinant of health, with issues including higher rates of substance abuse, suicidal behaviours and obesity,[3] and a reluctance to access screening programs impacting adversely on diagnostics and timely treatments.[4]

2.2 GLBTI not a 'cultural diversity'

It is emphatically not sufficient to conflate the needs of GLBTI elders under a 'cultural diversity' heading. Historically, religious institutions and the State have sanctioned spiritual, legal and medical discrimination against this cohort – and some inequities still remain. This has created unique sensitivities that need addressing in their own right, and the need to 'name' the issue is a critical first step in raising awareness within the aged care industry and in the community.

2.3 Identity

GLBTI elders may not necessarily be sexually 'active', however one still retains one's sexual identity regardless of its expression. This is a core understanding which the aged care sector (among others) is yet to appreciate: sexuality is a key facet of our identity and is unrelated to sexual activity. As noted above (2.1), 'pretending' to be heterosexual comes at enormous cost, emotionally and physically. Not feeling safe to express their authentic selves denies GLBTI elders the ability to be open about their lives or to tell their histories. A critical consequence can be the exclusion of friends or even a lifelong partner from care-giving and decision-making, particularly if the GLBTI person finds themselves in an unsafe or non-inclusive environment.

2.4 Invisibility of the 'largest minority'

A key concern confirmed by GRAI's and other GLBTI gerontology research is the invisibility of GLBTI elders.[5] There is a vicious 3-part cycle which perpetuates this invisibility: care providers remain pervasively heteronormative and largely unaware of GLBTI elders' existence; these clients go to great lengths to conceal their sexuality identity; and national and state laws and regulations fail to recognise them or offer legal protection.

GRAI's study of residential aged care services in Western Australia[6] revealed that 86 percent of survey respondents were unaware of any GLBTI residents within their facility. Indeed, a typical

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[2] Gay and Lesbian Medical Association, 2001, *Guidelines for care for LGBT patients: Gay and Lesbian Medical Association (GMLA),* www.gmla,org ; Barrett, C. 2008, *My People*, *A project exploring the experiences of gay, lesbian, bisexual, transgender and intersex seniors in aged-care services,* Victoria, www.also.org.au; Brotman, S. B. Ryan and R. Cormier, 2003, 'The Health and Social Service Needs of Gay and Lesbian Elders and their Families in Canada', *The Gerontologist,* 43 (2).

[3] Gay and Lesbian Medical Association (2001), *Healthy People 2010: The companion document for Lesbian, Gay, Bisexual and Transgender (GLBT) Health*, in Rawlings D and Tieman J, *Sexual and gender diversity: Implications for palliative care,* www.caresearch.com.au

[4] Van Dam M, Koh A, and Dibble S., 2001, Lesbian Disclosure to Health Care providers and Delay of Care, *Journal of the Gay and Lesbian Medical Association* , 5 (1), pp. 11-15.

[5] eg Harrison, J., 2002, 'What are you really afraid of? Gay, lesbian, bisexual, transgender and intersex ageing, ageism and activism', *Word is Out e-journal,* www.arts.usyd.edu.au/publications/wordisout/archive/02harri.pdf

[6] GRAI and Curtin Health Innovation Research Institute, 2010, *We don't have any of those people here*, Curtin University, Bentley, WA.

response was: 'We don't have any of those people here'. This is of great concern as it can be estimated that between 8 to 10 percent of seniors will have non-heterosexual identities, making them the largest minority group in aged care.[7] This lack of recognition provides an unequivocal indication that GLBTI elders' emotional and social needs remain unmet in these care settings.

The implications of GLBTI individuals' 'invisibility' within aged care, (and by extension, palliative care) are profoundly disturbing. This submission offers some suggestions of ways to address this problem, particularly through education and law reform.

3. GLTBI Elders and Palliative Care

The following discussion responds directly to the Committee's terms of reference for this Inquiry.

3.1 Factors influencing access to and choice of appropriate palliative care

GLBTI elders needing access to palliative care can feel unsafe in exposing their hitherto private living arrangements to strangers who may well harbour uncertainties or negative attitudes towards GLBTI people. At this most vulnerable time, when client-affirming support is essential, such added insecurity is frankly tragic.

While it is acknowledged that some care providers are to be congratulated because they have made positive steps to address GLBTI issues, the majority have failed to do so. This reflects the heteronormative environment of care environments where everyone is assumed to be heterosexual and heterosexuality is privileged. A lack of acknowledgement of GLBTI clients is not necessarily the result of deliberate acts but is more likely to arise due to the invisibility and ignorance of the issue.

A palliative care service can implement some simple measures to alleviate these fears, not only for the client, but also for their friends, families, 'families of choice' and care networks. GRAI's earlier work with residential aged care providers resulted in the development of Best Practice Guidelines which clearly articulated five practices for GLBTI inclusive and safe practice[8]. These are:

3.1.1 A safe and inclusive environment

A safe and inclusive environment can be demonstrated by a number of means, including: displaying posters and symbols such as the rainbow flag; using diverse images on promotional material showing same-sex couples and intergenerational images; and including explicit references to non-discriminatory policies regarding GLBTI people on organisational advertising. Symbolic gestures are only a start: also needed are measures to safeguard GLBTI people from discrimination and prejudice, by staff and (if in a residential care setting) other residents and/or their visitors. A GLBTI-positive environment will affirm their identity, value their relationships and encourage social interaction with the GLBTI community.

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[7] Around 900,000 older Australians currently receive government subsidised aged care services (DoHA 2009 in Productivity Commission, 2010, *Caring For Older Australians*). Therefore the GLBTI cohort receiving these services could be up to 90,000 people. (GRAI and Curtin Health Innovation Research Institute, 2010, *We don't have any of those people here*, Curtin University, Bentley, WA).

[8] A full copy of GRAI's *'Best Practice Guidelines'*, which formed part of a research project funded by Lotteries West in 2010 – GRAI and Curtin Health Innovation Research Institute, 2010, *We don't have any of those people here*, Curtin University, Bentley, WA.
http://wachpr.curtin.edu.au/local/docs/reports/Report_Retirement_Bestpracticeguidelines.pdf.

3.1.2 Open communication

Open and inclusive communication can be achieved by using appropriate language which avoids assuming that everyone is heterosexual. Measures include: staff training in the use of gender-neutral and non-discriminatory language; recognition of families of choice rather than blood relatives; and the inclusion of same-sex partners in care planning and personal activities. Fundamental acknowledgment of a GLBTI client's identity is signalled by being comfortable in speaking openly and sensitively about GLBTI issues.

3.1.3 GLBTI-sensitive practices

GLBTI-sensitive practices are based on an understanding of the impacts of past experiences on an individual, and how these may affect their interactions with health professionals and others. Palliative care services should have access to a list of GLBTI-friendly practitioners and develop a referral processes where appropriate. Intake and assessment practices can inform the service's responses (eg admission forms providing an opportunity for disclosure of sexual orientation and/or gender identity). Although many GLBTI elders will not self-disclose in this way, these forms signal an organisation's welcoming stance. Additionally, maintaining a list of GLBTI organisations, support groups and networks can provide valuable social resources for the palliative care team. An identified GLBTI liaison officer within agencies may also assist in this process.

3.1.4. Staff education and training

Aged care and palliative care staff need to be provided with education and training to equip them with the skills and knowledge required to support and work with GLBTI people, so they are better able to understand the specific needs of this group. This point is developed further under 3.2.

3.1.5 GLBTI-inclusive organisational policies and procedures

A palliative care service's commitment to GLBTI inclusivity should be embedded in the organisation's policies and procedures. These policies should be clearly communicated to staff and prominently displayed. A written complaints mechanism should be in place as well as a clearly nominated, well-trained 'go to' person for GLBTI clients. This ensures that there is management support for work which protects GLBTI clients and also encourages staff to provide GLBTI inclusive practices.

3.2 Composition of the palliative care workforce

As has been well-documented elsewhere,[9] the aged care workforce is notoriously poorly paid and often transitory. This increases the challenges of introducing additional training to staff. However, both despite and because of these difficulties, GRAI strongly advocates for the inclusion of mandatory GLBTI sensitivity and awareness training for all aged care and palliative care services.

The aged care sector is also a major employee of recent migrants to Australia, some of whom have come from countries where homosexuality is still regarded as a criminal offense. This heightens the urgency for frequent and good quality training within the sector regarding GLBTI issues.

This training should be directed to both management and staff, as on-going in-service training of existing care workers and health professionals, as well as introduced as a module in initial qualifications. Staff competency should be regularly monitored and demonstrated competency should be a prerequisite for ongoing funding of the service.

[9] Including in the Productivity Commission's inquiry, *Caring for Older Australians*, 2011.

GRAI, in collaboration with the National LGBTI Health Alliance, is aiming to develop a GLBTI accredited national training package for the Vocational Education and Training (VET) sector. Both GRAI and the LGBTI National Health Alliance would welcome the opportunity to provide input on training within the palliative care workforce, and assist with particular challenges that may be faced in this area.

3.3 Adequacy of standards

3.3.1 The Residential Aged Care Accreditation and Community Aged Care Standards

The Residential Aged Care Accreditation standards should be amended to make specific inclusion of GLBTI people. This is critical, as its inclusion will drive the awareness training regime, as VET competencies comply with the Standards. Similarly, specific inclusion of GLBTI people in the Community Care Common Standards is also essential.

All government funded aged care providers should be required to develop policies and organisational processes to combat discrimination and promote inclusion of GLBTI people. These standards should be mandatory; show evidence of implementation; require annual reporting; include a complaints process and carry enforceable penalties (eg be tied to funding). These steps support other diversity inclusive work that has already been undertaken to various degrees by the health workforce. The inclusion of GLBTI cultural competency in all palliative care environments also supports a diversity agenda which has included, but is not limited to, areas such as ethnic diversity.

3.3.2 Law reform

Nationally, there are a number of studies detailing instances of discrimination suffered by GLBTI elders, both overt and covert.[10] At present, Australian laws are silent on the needs of this vulnerable minority, failing to offer recognition or legal protection. The two main pieces of Federal legislation governing Aged Care services and programs, the *Aged Care Act (1997)* and the *Home and Community Care Act (1985),* both fail to recognise GLBTI people as a 'special needs' group. This is an unfortunate omission, as 'special needs' status draws attention to the need to offer substantive equality measures to ensure the safety and well being of the identified group.

The *Australian Government's Code of Ethics and Guide to Ethical Conduct for Residential Aged Care* excludes discrimination based on sexuality, only providing for an optional approach to discrimination on the grounds of sexuality, sexual preference and expression.[11] This has serious implications for GLBTI clients, particularly as over one third of residential care services are provided by faith-based organisations (in Western Australia, 36.7 percent),[12] some of whom have publicly stated positions against homosexuality.

To achieve a safe and inclusive environment for GLBTI elders, GRAI calls for the following law reforms:

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[10] eg Harrison, J. 1999, 'A Lavender Pink Grey Power: Gay and Lesbian Gerontology in Australia', *Australian Journal on Ageing,* 18 (1), 32-37, Wiley Interscience, http://dx.doi.org/10.1111/j.1741-6621.1999.tb00086.x; Birch, H. 2004, *About Time! GLBT seniors ALSO matter*, ALSO Foundation, South Yarra, www.dialog.unimelb.edu.au/Lesbian/pdf/About%20time%20ALSO%20GLTB%20Ageing%20Strategy%202004.pdf

[11] Harrison, J. 2002, 'What are you really afraid of? Gay, lesbian, bisexual, transgender and intersex ageing, ageism and activism', *Word is Out e-journal,* www.arts.usyd.edu.au/publications/wordisout/archive/02harri.pdf

[12] GRAI and Curtin Health Innovation Research Institute, 2010, *We don't have any of those people here*, Curtin University, Bentley, WA (p. 18).

- The *Aged Care Act (1997)* and the *Home and Community Care Act (1985),* be amended to include GLBTI people as a 'special needs' group.
- The *Australian Government's Code of Ethics and Guide to Ethical Conduct for Residential Aged Care* be amended to outlaw discrimination on the grounds of sexuality.
- Religious exemptions be withdrawn from all anti-discrimination legislations. If institutions receive public subsidies for services, they should be bound by mainstream laws and provide non discriminatory and inclusive service to all Australians including GLBTI people.
- The Government be called upon to pass these law reform measures.
- The Human Rights Commission be called upon to examine how current gaps in the law impact on GLTBI elders and make recommendations to remedy inequities.

The Human Rights Commission website acknowledges: 'Elderly LGB people... face difficulty accessing aged care and receiving equal treatment in the provision of aged care services'. We would add that until actions are taken to alleviate the situation, the human rights of GLTBI elders will continue to be compromised.

3.4 Advance care planning

Australian research scoping the experiences of GLBT people around end-of-life care (Leinert et al, 2010)[13] concludes that many GLBT people in Australia are being denied their legal rights due to ongoing lack of recognition of their partnerships and kinship rights, leading to loss of entitlements to visiting, decision-making and end-of-life care. Barriers include fear of being 'outed', combined with the heteronormative culture of services and lack of information.

On-going stigma and discrimination remain serious obstacles for GLBT individuals and carers to communicate with health care professionals about end-of-life care. Too often, GLBT people's fears lead to isolation, late presentation to health services, crisis management and premature hospitalisation, all of which mitigate against their ability to seek appropriate end-of-life care (Leinert 2010:9). The Leinert study identified a clear need for advocacy, specially tailored information resources around end-of-life care, and GLBT specialists and specialist services informing GLBT people of their rights.

3.5 Availability and funding of research, information and data about palliative care needs

There is a paucity of high quality information about the care needs of GLBTI elders. Researchers are hampered by a lack of both comprehensive and accessible data from the Aged Care area, where collection of information on sexuality and gender diversity is seldom collected, making it difficult to provide an accurate picture of this cohort. Therefore GRAI calls for:

- A system to be developed to routinely collect data related to the gender diversity and sexuality of clients receiving palliative and/or aged care in either residential or community care settings. This would provide useful feedback to the Palliative and Aged Care sector, the community and to GLTBI health researchers. Due to the sensitivity of the area, this should be undertaken in consultation with GLBTI researchers working in the area.
- The Government to fund and promote research into the health and wellbeing of older GLBTI Australians, including dementia sufferers, carers of older GLBTI people, GLBTI families, and social isolation.

[13] Leinert, T. Cartwright, C. Beck, K. , 2010, *The Experiences of Gay, Lesbian, Bisexual and Transgender People around End-of-Life Care,* Aged Services Learning and Research Centre, Southern Cross University, NSW.

- The Government to fund and promote research into the patterns, models and outcomes of formal and informal care of older LGBTI Australians.

4. GLBTI specific services

The importance of understanding, empathy and trust has been highlighted in a study of older GLBTI people in Victoria.[14] Many study participants felt that GLBTI specific service providers would be better able to meet their needs. GRAI appreciates the limitations of our demographic in the Australian context make this a challenging goal. In the absence of specific GLBTI services, mainstream providers must step up to the plate and ensure their policies and staff training will provide a safe and high quality service for their GLBTI clients. It is manifestly unacceptable for GLBTI elders and their caregivers to feel they need to retreat into the closet at this vulnerable time of their lives.

Safeguards such as a GLBTI ombudsman within the Complaints Service are worthy of consideration as an important protective measure. However, from the perspective of promoting the well-being of GLBTI elders, steps to ensure GLBTI-positive services are more rewarding.

4.1 HIV/AIDS

People with HIV/AIDS can need prolonged palliative care, and may experience premature ageing and early onset dementia. It is generally assumed these clients are gay (although this is not necessarily the case) and research reveals they may encounter double discrimination from care staff, based on disapproval and/or misplaced fears about contagion (Barrett 2008:51).[15] Although HIV/AIDS has attracted special care packages and educational materials, there is evidence of a need to make these much more widely available. There is also concern about the suitability of aged care services for younger clients, who are culturally marooned in an aged and heterosexual environment.

Conclusion

Recent times have seen significant changes in societal attitudes towards diverse sexuality and gender expression. It is hoped that these more enlightened attitudes can now be translated into the palliative and aged care sector, and that legal reforms and appropriate training can provide the necessary urgent changes to support their GLBTI clientele.

Any services, projects or research that serves to combat the invisibility of GLBTI elders in aged care services is to be encouraged, and government support for and funding of such services will be invaluable in reducing the disparities for this cohort.

The palliative and aged care sectors are renowned as agencies who take their care giving roles very seriously, and many will be appalled to realise current practices may be causing harm. Here, the main obstacles to change are lack of adequate resources to provide the necessary educational materials. A workforce well-educated in GLBTI cultural awareness, supported by organisational policies which promote a GLBTI-positive environment, will be able to ensure GLBTI people are safe from overt and covert discrimination and discrimination by neglect. Importantly, these services will

[14] Barrett, C., 2008, *My People: A project exploring the experiences of Lesbian, Bisexual, Transgender and Intersex seniors in aged-care services,* Matrix Guild, Victoria, pp. 17-19.

[15] Barrett, C., 2008, *My People: A project exploring the experiences of Lesbian, Bisexual, Transgender and Intersex seniors in aged-care services,* Matrix Guild, Victoria, pp 51-60.

be able to affirm the legitimacy of GLBTI people's sexual/gender identities; understand and value their relationships and friendships; and enter into meaningful dialogue about their care needs.

The recent Productivity Commission's report into an ageing Australia[16] is one of the few federal reports that have made specific mention to the needs of GLBTI elders. The Commission's report acknowledges both the need for special attention to GLBTI elders' needs and some of the ways forward to achieve this. The current Inquiry into Palliative Care in Australia also has the opportunity to support this approach and assist in providing a uniform message to the aged and palliative care sectors that they must attend to this area that to date, has not received the attention it deserves.

We thank you for your consideration of this important issue and look forward to seeing the results of the Committee's Inquiry into palliative care. If we can be of further assistance, please contact us either by email, info@grai.org.au or by phoning the Chair

Yours sincerely

June Lowe (Board Member)

Jude Comfort (Chair)

GLBTI Retirement Association Inc. (GRAI)

[16] Productivity Commission 2011, *Caring For Older Australians*, Report No. 53, Final Inquiry Report, Canberra.