



Submission to the Productivity Commission Inquiry into the Aged Care System in Australia 'Caring for Older Australians'

30 July 2010

Introduction

The National LGBT Health Alliance welcomes this inquiry into the aged care system in Australia. The needs of lesbian, gay, bisexual, transgender and intersex (LGBTI) older people, now and into the future, is a key issue of concern for LGBTI communities across the country. Most states and territories have an LGBTI senior's project, organisation or advocacy group, although these remain largely unfunded.

The focus of the Alliance's submission is related to the following specific term of reference for the inquiry:

The Commission is specifically requested to examine how well the mainstream service system is meeting the needs of specific needs groups.

Alliance key points:

- 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
- There is a need for a National LGBTI Aged Care Plan at Federal level to strategically address LGBTI ageing health & wellbeing
- LGBTI seniors have less access to carers/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 represents a barrier to many LGBTI people
- Need for diversity of independent living options and choice in aged care services
- Key role for LGBTI community in supporting and providing care for LGBTI seniors
- Key role for LGBTI seniors in advocacy, education of service providers, peer support and self determination

About the National LGBT Health Alliance

The National LGBT Health Alliance is a newly formed alliance of organisations across Australia that provide programs, services and research to improve the health of lesbian, gay, bisexual, transgender, intersex and other sexuality, sex and gender diverse (LGBTI) people. We have a growing membership of over 90, including 54 organisations covering the vast majority of LGBTI health and community organisations/services in Australia.

The Alliance advocates on LGBTI health issues at the national level, seeks commitment from all sides of politics to support and develop LGBTI health through research and service development, and builds capacity among LGBTI health organisations across the country.

The Alliance is governed by a Board of Directors, with representation from each state and territory. Key areas of work for the Alliance include alcohol, tobacco and other drugs, mental health, ageing, LGBTI research, sexual health (including HIV and STIs), violence, health and wellbeing of people living with HIV, relationship recognition and the link between health and human rights.

Stigma, Discrimination and Exclusion

Homosexuality was not decriminalised in most Australian states until the 1980s and 1990s. The World Health Organisation did not remove homosexuality from its International Classification of Diseases (ICD) until 1992. Gender Dysphoria/Gender Identity Disorder is still considered a mental illness in Australia and internationally. Even today same-sex relationships are not fully recognised, with no ability to legally marry and relationship registers only existing in a few states and territories. The process for transgender people in having their gender recognised is long, expensive unduly complicated and unattainable for many transgender people. It was only in 2008/9 that 85 pieces of legislation were reformed to recognise same-sex de-facto couples in the federal sphere. Although a minority of the population, a significant proportion of Australians hold homophobic and transphobic attitudes that impact on their interactions with LGBTI people. For example, studies reveal that 25% of Australians would not want a gay neighbour¹ and 35% of Australians believe homosexuality to be immoral, increasing to over 50% in some regional areas and among older age groups².

This means today's LGBTI seniors have lived well over half their lives being considered criminals by the state, diseased by the medical profession and excluded by mainstream society. LGBTI people, and especially older LGBTI people, have developed protective mechanisms to shield themselves from stigma, discrimination and violence. For example, 67% of LGBTI Australians sometimes modify their daily behaviour due to fear of prejudice or discrimination.³

It is important that providers of aged care services understand the abuse and harm that many LGBTI people have suffered throughout their lives, harm that in many instances has not been healed. Services need to be in a position to proactively demonstrate to LGBTI seniors that their service is knowledgeable and inclusive of LGBTI people and a safe place for them. It must be recognised that many older LGBTI seniors will not identify with terms such as 'gay', 'lesbian', 'bisexual' or 'transgender' and/or may actively hide their identity for fear of discrimination. If they do come out to service providers they are likely to be very concerned with confidentiality and privacy. Service providers need education and training which addresses issues of sensitivity and cultural appropriateness in relation to LGBTI needs so that it is understood that having consumers 'come out' is not in itself the measure of a 'good' service.

The 'baby-boomer' generation and those following may well have different expectations of aged care services. These are often people who have fought for their rights and many have been out about their sexual/gender identity for most of their lives. It cannot be assumed that they will be prepared to go into the closet when dependent on aged care services in the home or when requiring accommodation in aged care facilities. This generation will more than likely openly demand services that meet their needs and lifestyles.

¹ Borooah, V. & Mangan, J. (2007) *Love Thy Neighbour: How Much Bigotry Is There In Western Countries?* University of Ulster, University of Queensland.

² Flood, M. & Hamilton, C. (2005) *Mapping Homophobia in Australia*. The Australia Institute. (general population self-complete survey n=24,718)

³ Pitts, M., Smith, A., Mitchel, A., & Patel. S. (2006) *Private Lives: A report on the health and wellbeing of GLBTI Australians*. La Trobe University, Australian Research Centre in Sex, Health & Society, Melbourne.

National Aged Care Policy

LGBTI people and our needs are largely absent from national health, community and other policy areas, including aged care. LGBTI people are not currently afforded formal recognition in Federal aged care policy as a 'special needs group'. This has a 'downstream' impact on federal and state government programs and policies and on service providers. Without inclusion in national policy, there is no mandate to provide specific, targeted funding for LGBTI people or services (e.g. community aged care packages). There are currently no specific services funded for LGBTI seniors anywhere in Australia. Mainstream services are not required to consider or report on the needs of LGBTI clients. National client monitoring databases don't ask the sexuality or gender identity of clients, rendering LGBTI people invisible in services and aged care policy.

Recommendation: *Explicitly and formally recognise LGBTI people as a 'special needs group' in Federal aged care policy.*

The lack of inclusion of LGBTI people in other health and related policies contributes to higher risk factors, less access to health services and poorer health outcomes. Recent analysis of data from the Australian Bureau of Statistics⁴ shows that 'homosexual/bisexual' people are:

- 4 times more likely to have ever been homeless (12% 'homosexual/bisexual' v. 2.9% 'heterosexual')
- more likely to be a current smoker (35.7% v. 22%)
- twice as likely to have used illicit drugs (64.6% v. 33.2%)
- more likely to have had a chronic condition in the last 12 months (51.3% v. 46.9%)
- twice as likely to have a high/very high level of psychological distress (18.2% v. 9.2%)
- almost 3 times as likely to have had suicidal thoughts (34.7% v. 12.9%)
- 5 times as likely to have had suicidal plans (17.1% v. 3.7%)
- 4 times as likely to have attempted suicide (12.6% v. 3.1%)

Gender identity was not asked in this survey, but other research indicates that these figures are likely to be worse for transgender and intersex people.

A lifetime of lower levels of access to health services and of higher risk factors is likely to have a particular impact on the health and well-being of LGBTI seniors. LGBTI seniors are more likely to suffer from poorer health and less likely to access health services. LGBTI seniors will therefore experience higher needs for complex services, at higher cost. They are more likely to experience social isolation and anxiety, risk factors for depression and suicide.

Recommendation: *LGBTI people to be recognised as a priority population group in other health and related policies.*

National LGBTI Aged Care Plan

In order to address the urgent and wide-ranging needs of LGBTI older people at a national level, we need a strategic Federal approach. Such a plan could provide a blueprint for addressing the needs of older LGBTI people across arenas including research, training, education, service provision, advocacy, policy development and legal reform. Similar plans relating to Indigenous older Australians and to those with Alzheimer's Disease and related disorders have set out a program to address the needs of a special

⁴ Australian Bureau of Statistics (2007) *National Survey of Mental Health and Wellbeing*.

needs group over time. Such a plan needs to be developed in partnership with LGBTI people and communities. Older LGBTI people need to be specifically included in this process.

Recommendation: *That the government work in partnership with the LGBTI community sector to develop a national LGBTI Aged Care Plan to strategically address the health and wellbeing needs of older LGBTI Australians.*

A range of activities are happening in many states and territories around the needs of LGBTI seniors, however there are few opportunities to bring these approaches together, share information, develop best practice and advocate at a national level. The National LGBT Health Alliance has been established to play this role, but without funding has little capacity to deliver.

Recommendation: *Fund a national LGBTI aged care policy & development position in the National LGBT Health Alliance to facilitate national action on LGBTI ageing within LGBTI communities and coordinate national advocacy.*

Carers/Family Support

As the Commission's issues paper notes, much care for older Australians is provided by family members, particularly children and extended families. However the majority of LGBTI people do not have children and many are estranged from their extended families due to stigma and discrimination. Twice as many LGBTI people live alone compared with heterosexual older people. Data from the ABS show that 'homosexual/bisexual' people are twice as likely to have no contact with family or have no family to rely on for serious problems (11.8% v. 5.9%) compared to heterosexuals. These figures are likely to be even higher for transgender Australians. This means that LGBTI people are highly reliant on aged care services.

LGBTI people have often formed 'families of choice', that is networks of friends, associates and LGBTI community support groups to provide care and support. These care networks are poorly understood and poorly supported by aged care and carers services. The people involved often do not recognise even themselves as 'carers'.

Recommendation: *Research be resourced that investigates patterns and models of formal and informal care for LGBTI seniors.*

Recommendation: *That the care networks of LGBTI people, including 'families of choice' be recognised and supported as key carers of LGBTI seniors.*

Social Isolation

Many older LGBTI people experience or fear isolation from LGBTI friends and community infrastructure and isolation within aged care services. Much LGBTI community infrastructure is focused on younger people (e.g. bars, clubs, gay media) and can exclude older people. Research undertaken in Queensland⁵ showed that 82% of LGBTI people felt there was not adequate representation of ageing issues in LGBTI media.

Suburbs in which high numbers of LGBTI people tend to live and in which commercial venues and social groups are based, are in the inner-city areas. Rental and housing prices in these areas have skyrocketed in the past 10 years, making it difficult for LGBTI seniors to remain or move into these areas. This

⁵ Queensland Association for Healthy Communities (2007) *The Young, The Ageing & The Restless*.

means LGBTI seniors are forced to leave their community and support networks. Retirement villages and other types of seniors' accommodation are often based far away from town centres and gay community infrastructure. People living in rural and isolated areas of Australia have less access to LGBTI community members, LGBTI community groups/services and LGBTI aware and inclusive mainstream services.

One survey of LGBTI concerns related to ageing reported the top three concerns related to ageing as⁶:

- 61% - Not having LGBTI specific accommodation (e.g. residential care facilities, retirement villages, other residential services)
- 58% - Being alone
- 42% - Maintaining social networks & LGBTI friends

For those people that do move into residential facilities, there is a significant concern that they will have to hide their sexual/gender identity for fear of stigma and discrimination from other residents or staff. This is reflected in the number one concern of LGBTI people relating to ageing being not having LGBTI specific accommodation.

Recommendation: *LGBTI community organisations be funded to provide formal client-based advocacy services, and related outreach or 'buddy support' services for LGBTI seniors, to maintain contact with LGBTI community and reduce social isolation.*

Recommendation: *Residential facilities be required to have clear policies about the inclusion of LGBTI people, anti-discrimination policies and measures and policies to eradicate harassment.*

Recommendation: *Residential facilities provide support for LGBTI seniors to maintain connections with their LGBTI friendship networks and community (e.g. access to LGBTI media, books, DVDs, outings to LGBTI events).*

Aged Care Services

Recent research by GRAI (GLBTI Retirement Association Inc) in association with Curtin University in Western Australia found⁷:

- 86% percent of aged care facilities surveyed were unaware of any GLBTI residents within their facility;
- 30% of respondents agreed that their facility recognises that GLBTI residents have specific needs;
- 66% felt that they provided a GLBTI-friendly and trusting environment which "treated everyone the same";
- No facilities provided staff training specific to GLBTI issues;
- 37% stated organisational policy and procedures made specific reference to GLBTI people; and
- 5% of services used any means of indicating an inclusive environment to GLBTI people.

While generally not actively discriminatory, most aged care services assume that their clients are heterosexual, and with the reluctance of many LGBTI people to be out about their sexuality/gender identity, this renders LGBTI people invisible in aged care services. This 'heterosexism' can take many

⁶ Ibid

⁷ GRAI (GLBTI Retirement Association Limited) (2010) "We don't have any of those people here" Retirement Accommodation and Aged Care Issues for Non-Heterosexual Populations.

forms, e.g. intake forms not allowing for same-sex/de-facto couples, assumptions about the partner and interests of clients, lack of training for staff because it's felt the service doesn't have LGBTI clients.⁸

Recommendation: Roll out of a national program of training and development for aged care services, focusing on providing inclusive services and working with LGBTI clients.

Recommendation: That aged care services audit their own practice relating to LGBTI clients and develop an action plan to respond to gaps or concerns.

A significant proportion of services across the aged care sector is provided by religious based organisations. This represents a barrier for many LGBTI people who have had a negative experience of discrimination by organised religion. Most main religions still consider LGBTI people to be sinners or immoral and do not support equal human rights for LGBTI people (e.g. same-sex marriage). Yet these organisations are put in positions of caring for vulnerable older people.

Recommendation: That all aged care providers funded by government be required to develop policies and organisational processes to combat -discrimination and promote inclusion of LGBTI people, including recognition and respect for same-sex relationships, and that funding is provisional upon formal commitment to implement such policies.

Independent Living Options and Choice in Aged Care Services

As mentioned previously, the number one concern for LGBTI people about growing old is the lack of LGBTI specific accommodation. Even though a minority of Australians enter a residential care facility, many LGBTI people are concerned that if it happens to them, it will be a very negative experience in relation to their sexuality/gender identity. Many LGBTI people want to live with others who are 'like them'. They fear having to hide their sexual/gender identity from other residents in mainstream settings and being particularly vulnerable to homophobia, transphobia or rejection due to intersex status given their dependence on care.

Three approaches should be taken:

- better development and promotion of independent living options ('care in place') suitable for LGBTI people
- ensuring residential facilities are inclusive of LGBTI people
- the provision of LGBTI specific accommodation options

A significant majority of LGBTI people (as with most Australians) will receive most of their care in the home. However more needs to be done to promote and prepare people for their care needs in older age, with an understanding that a variety of supports can be provided in the home. Many LGBTI people will want to know that the carers being let into their home will be respectful and knowledgeable of LGBTI issues (see previous section on Aged Care Services). Other LGBTI people will want LGBTI carers, either from a mainstream care provider or from an LGBTI specific care provider. LGBTI people should have the choice of carer wherever possible.

Recommendation: LGBTI community organisations should be funded to provide LGBTI care services (home care), including in partnership with mainstream care providers.

⁸ See for example Harrison, J. 2001. 'It's none of my business': Gay and lesbian invisibility in aged care. *Australian Occupational Therapy Journal* 48: 142-145. Harrison, J., and D. Riggs. 2006. Editorial: GLBTI ageing. *Gay & Lesbian Issues and Psychology Review* 2 (2): 40-103. http://www.rainbowvisions.org.au/GLIP_Review_Vol2_No2.pdf

If LGBTI people do enter a residential facility or a retirement village this is most likely to be a mainstream facility. As discussed above, these facilities will need to ensure that they are welcoming, inclusive and knowledgeable of LGBTI people and issues, and support LGBTI residents' connection with LGBTI community.

Given the high level of interest by LGBTI people in LGBTI specific accommodation options, more should be done to explore appropriate models and the viability of these models. While LGBTI retirement villages are the most cited, other models such as shared housing, group ownership, and small purpose built accommodation (e.g. by friendship groups) should be explored.

Recommendation: *Research should be conducted on desired models of accommodation/residential facilities for LGBTI people.*

Recommendation: *Mainstream service providers/developers should partner with LGBTI community organisations to provide LGBTI specific accommodation/residential facilities (where economically feasible).*

Role of the LGBTI community

As mentioned previously many LGBTI organisations are already working in the area of ageing or have expressed a desire to do so. Unfortunately this work remains largely unfunded. There are a wide range of types and scale of LGBTI organisations. Some organisations have the capacity to directly deliver care services and projects for LGBTI seniors. Other organisations would wish to partner with mainstream aged care organisations, combining their expertise and connection to LGBTI community with the expertise in aged care delivery of mainstream services. Smaller LGBTI organisations would have a role in advocating for LGBTI seniors or providing social support.

Recommendation: *LGBTI community organisations should be consulted and resourced to be actively involved in the identification, delivery and evaluation for aged care/seniors services.*

Recommendations: *LGBTI community organisations should be resourced to partner with mainstream aged care providers in the delivery of aged care services for LGBTI people.*

In the 1980s the LGBTI community responded to care needs of people with HIV/AIDS, including by providing volunteer care teams. This same model of the provision of formal advocacy as well as 'buddy support' could be applied to LGBTI seniors. LGBTI volunteers could be trained and supported to deliver low level care and social support to isolated LGBTI seniors, either in their own home or in residential facilities.

Recommendation: *LGBTI community organisations be funded to provide formal advocacy services as well as to co-ordinate buddy support programs for LGBTI seniors.*

It is widely recognised that the aged care sector is complex and difficult to navigate for older people, their carers and even service providers. Added to this complexity, LGBTI seniors may not have prior personal experience of the aged care system (e.g. through providing care for parents) and may be reluctant to access mainstream services for fear of stigma and discrimination. Many LGBTI seniors want to access a service that they know and feel comfortable with as a 'first port of call' or trusted guide to the aged care system. In a Queensland study⁹, 64% of LGBTI people wanted information and referrals around aged care services from LGBTI community organisations.

⁹ Queensland Association for Healthy Communities (2007) *The Young, The Ageing & The Restless*.

Recommendation: *LGBTI organisations be funded to provide information and referral services for LGBTI seniors.*

Role of LGBTI seniors

At the centre of all developments relating to aged care must be LGBTI seniors themselves. LGBTI seniors have a crucial role to play in identifying and advocating for their needs as well as providing care as workers, educators and trainers, volunteers, partners and friends. While some LGBTI seniors will already be involved in mainstream seniors/aged care networks, they may not be out about their sexual/gender identity. LGBTI seniors could provide significant support to LGBTI community groups and services as volunteers, management committee members and staff, but there are few resources to enable and support their involvement or provide mechanisms to train seniors to take up such positions.

Recommendation: *Support and resource opportunities for LGBTI seniors to come together to develop and pursue a shared advocacy agenda.*

Recommendation: *Support the involvement of LGBTI seniors in mainstream and LGBTI aged care/seniors initiatives (e.g. training, carers, project delivery) and wider community service work.*

Related Documents:

National LGBT Health Alliance (2009) 'Submission to the Department of Health and Ageing Review of the Accreditation Process for Residential Aged Care'.

<http://www.LGBTIhealth.org.au/sites/default/files/Alliance-Submission-Accreditation-Process-Residential-Aged-Care-July-2009.PDF>

National LGBT Health Alliance (2009) 'Submission to the Department of Health and Ageing, Office of Aged Care Quality and Compliance, Review of the Aged Care Complaints Investigations Scheme'.

<http://www.LGBTIhealth.org.au/sites/default/files/200908-Alliance-Aged-Care-Complaints-Submission.pdf>

ACON (2006) 'Ageing Disgracefully: acon's healthy glbt ageing strategy 2006-2009'.

<http://www.acon.org.au/about-acon/Strategies/ageing>

The ALSO Foundation (2004) 'About Time! GLBT Seniors ALSO Matter – Strategic Plan'.

<http://www.glhv.org.au/files/abouttime.pdf>

Alzheimer's Australia (2009) 'Dementia, Lesbians and Gay Men'.

http://www.alzheimers.org.au/upload/Paper_15_final_web.pdf

Barrett, C., J. Harrison, and J. Kent. 2009. Permission to speak: Determining strategies towards the development of gay, lesbian, bisexual, transgender and intersex friendly aged care agencies in Victoria

<http://www.matrixguildvic.org.au/project.html>

GRAI (GLBTI Retirement Association Limited) (2010) "We don't have any of those people here" Retirement Accommodation and Aged Care Issues for Non-Heterosexual Populations'.

<http://grai.org.au/wordpress/wp-content/uploads/2010/07/We-dont-have-any-of-those-people-here.pdf>

GRAI (GLBTI Retirement Association Limited) (2010) *'Best practice guidelines: Accommodating older gay, lesbian, bisexual, trans and intersex (GLBTI) people'*. <http://grai.org.au/wordpress/wp-content/uploads/2010/07/Best-Practice-Guidelines.pdf>

Harrison, J. 1999. A lavender pink grey power: Gay and lesbian gerontology in Australia. *Australasian Journal on Ageing* 18 (1): 32-37. Wiley Interscience.
<http://dx.doi.org/10.1111/j.1741-6612.1999.tb00086.x>

Harrison, J. 2004. Towards the recognition of gay, lesbian, bisexual, transgender and intersex ageing in Australian gerontology. PhD Thesis, School of Health Sciences, The University of South Australia, Adelaide.

Harrison, J. 2005. Pink, lavender and grey: Gay, lesbian, bisexual, transgender and intersex ageing in Australian gerontology. *Gay and Lesbian Issues and Psychology Review* 1 (11-16).
<http://www.rainbowvisions.org.au/HarrisonGLIPReview.pdf>

Harrison, J and Irlam, C B (2010) *The removal of same-sex discrimination: Implications for lesbian, gay, bisexual, transgender & intersex (LGBTI) aged care* – Discussion Paper Adelaide. Australian Coalition for Equality and Diversity Futures.
<http://www.coalitionforequality.org.au/LGBTI-AgedCareDiscussionPaper.pdf>

Matrix Guild Victoria and Vintage Men (2008) *'My People: A project exploring the experiences of Gay, Lesbian, Bisexual, Transgender and Intersex seniors in aged-care services'*.
<http://www.matrixguildvic.org.au/MyPeopleReport2008.pdf>

Queensland Association for Healthy Communities (2008) *'The Young, The Ageing and The Restless: Understanding the experiences and expectations of ageing and caring in the QLD LGBTI community'*.
http://www.qahc.org.au/files/shared/docs/Ageing_Report.pdf

Developed by the National LGBT Health Alliance, with particular thanks to the following for their assistance in preparing this submission:

- Dr Jo Harrison. University of South Australia
- Gay & Lesbian Health Victoria
- GLBTI Retirement Association Limited (GRAI – Western Australia)
- Queensland Association for Healthy Communities
- Coming Out Proud Program (COPP – Tasmania)

The views in this paper are those of the National LGBT Health Alliance, and do not necessarily represent those of the organisations or individuals that contributed to the paper.

*National LGBT Health Alliance
July 2010*

Contact:

info@LGBTIhealth.org.au

Phone: (02) 9206 2054 | Mobile: 0422015380

Postal: PO Box 350 Darlinghurst NSW 1300 Australia

www.LGBTIhealth.org.au