Health and wellbeing for
lesbian, gay, bisexual, trans, intersex [LGBTI]
people and sexuality, gender, and bodily
diverse people and communities
throughout Australia

www.lgbtihealth.org.au
info@lgbtihealth.org.au
(02) 8568 1123

Royal Commission into Aged Care Quality and Safety

National LGBTI Health Alliance Submission

4 October 2019

National LGBTI Health Alliance

The National LGBTI Health Alliance (the Alliance) is the national peak health organisation in Australia for organisations and individuals that provide health-related programs, services and research focused on lesbian, gay, bisexual, transgender, and intersex people (LGBTI) and other sexuality, gender, and bodily diverse people and communities. We recognise that people's genders, bodies, relationships, and sexualities affect their health and wellbeing in every domain of their life.

Formed in 2007, the Alliance includes the major providers of services for LGBTI people in Australia, with Members drawn from each State and Territory. The Alliance provides a representative national voice to: develop policy and to support 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.

Contact
Nicky Bath
Executive Director
222 King Street
NEWTOWN NSW 2042

P: 02 8568 1120
E: nicky.bath@lgbtihealth.org.au
W: lgbtihealth.org.au

Silver Rainbow

Silver Rainbow is the name given to the Alliance's Ageing and Aged Care Project. It provides national coordination and support activities promoting the well-being of LGBTI elders. This is achieved through providing policy and program advice to the Department of Health and the ageing and aged care sector, ongoing delivery of LGBTI awareness training to the aged care sector, and working in partnership 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.

"We are often more worried about not upsetting non-LGBTI people than in taking care of LGBTI people"

Introduction

In Australia, the acronym 'LGBTI' refers collectively to people who are lesbian, gay, bisexual, transgender, and/or intersex. LGBTI is often viewed as and referred to as single category that is used to speak about using broad generalisations. However, LGBTI communities are not homogenous. Within the LGBTI acronym are several distinct, but sometimes overlapping, demographics each with their own histories, experiences and health needs. Furthermore, LGBTI people are part of all population groups including Aboriginal and Torres Strait Islander people, people living in rural and remote areas, as well as culturally and linguistically diverse populations. Fundamentally, older Australians display the same diversity in genders, bodies, relationships, and sexualities as the broader Australian population.

The category of 'LGBTI' people and populations are now recognised by the Commonwealth Government in some federal legislation, policies, and programs. It is assumed that LGBTI people and those who have a diverse sex, sexuality or gender identity exist in a worldwide context and represent a significant proportion of the population. However, there is a lack of data on the sexual orientation, gender identity and variations in sex characteristics of the Australian population. National population data that is LGBTI-inclusive will provide a more accurate picture of the number of LGBTI people living in Australia. Current estimates put LGBTI people as representing 11% of the population. LGBTI people are likely to be represented by at least the same proportion in older populations.

LGBTI elders and older people

"Do visibility safely – so that gay consumers/staff aren't the only people who become advocates for inclusion"

"People who come out are vulnerable"

"Remove the pervasive idea that our communities are controversial"

LGBTI elders and older people have experienced prejudice and discrimination (which may include bullying, harassment, verbal, physical, psychological and/or sexual abuse) over the life course, from government, agencies, faith-based organisations, health providers, businesses, LGBTI communities, families, friends, and individuals. This includes a fear of prejudice and discrimination, which may or may not be warranted. These experiences cause LGBTI older people to: remain in or return to the closet; be reluctant to reveal their sexual orientation and/or sex and/or gender identity to government agencies and service providers; and be reluctant to make complaints when they experience prejudice or discrimination.

As a result, these elders often do not disclose their identities or histories to aged care services and therefore remain isolated or invisible in the sector and the broader community. Combined with general societal ignorance around LGBTI issues, this results in a lack of awareness of the unique needs of LGBTI elders and older people, including targeted services to support them. In addition, the

fear of being mistreated from aged care providers can lead to LGBTI elders and older people delaying seeking care until their health deteriorates or a crisis occurs. LGBTI elders and older people may suffer many forms of discrimination within the aged care environment. These include:

- threats of eviction and refusal of admission to aged care facilities;
- denying of visitors or personal care services;
- refusal to allow LGBTI elders to display public affection, to display cultural tokens, artefacts, pictures or memorabilia or couples to share rooms;
- preventing partners from participating in medical decision making;
- withholding medications;
- physical or psychological abuse, neglect and/or abandonment;
- being involuntarily 'outed' or threatening to out somebody's gender or sexuality; and
- being prevented from dressing or presenting according to ones identified gender.

Fear and mistrust of services due to historical instances of discrimination

LGBTI elders and older people grew up in a society that still considered homosexuality a mental illness and risked being imprisoned or forced to undergo medical "cures" if their sexual orientation or gender identity was revealed. As a result, many LGBTI older people have learned to hide their sexual orientation, gender identity or intersex status in order to be safe, particularly when interacting with the health or social services sector. The fear and mistrust of these services in the past have led LGBTI elders and older people to be reluctant in utilising mainstream services, including aged care. Therefore, it is crucial for aged care workers to understand the impact historical discrimination has on LGBTI people's mental health and overall wellbeing. LGBTI elders and older people have suffered decades of stigma, family rejection and social isolation. Many have also had a life experience of fear of rejection and persecution, as well as adverse mental health effects associated with potential or actual instances of discrimination. Reliving past discrimination when encountering new forms of discrimination in the aged care environment exacerbate feelings of anxiety and/or depression and social exclusion.

LGBTI elders and older people and rights

Very few LGBTI elders are comfortable with asserting their rights within the aged care environment. Staff working in the aged care sector need to understand the legal responsibilities of aged care service provision in relation to anti-discrimination legislation. Under the federal *Sex Discrimination Act 1984*, it is unlawful for a federally funded aged care service to discriminate against residents on the basis of sexual orientation, gender identity and intersex status. Additionally, few aged-care providers have been given adequate training relating to issues surrounding LGBTI ageing and sexual expression. Service providers need to understand what expression means to LGBTI seniors, what it encompasses and how opportunities for expression can be provided.

LGBTI elders and older people and family control/discrimination

Many LGBTI elders and older people rely on family members to advocate for them with aged care service providers. However, some family members can take advantage of this dependency and opportunity to control the sexual expression of these elders. This can occur through a number of ways, including preventing access to their partners. Also, some family members may be not be

aware of and/or hostile to their relatives being LGBTI. As a result, LGBTI elders and older people may be vulnerable to having their wishes disregarded by relatives or carers when making financial, property and medical decisions. To ensure LGBTI elders and older people's wishes are carried out and their partner's rights are protected (if they have one), service providers need to carefully consider these circumstances, as the rights and needs of LGBTI residents are always paramount. This may involve regularly reviewing documents associated with Advanced Care Directives, Enduring Guardianship and Power of Attorney, to ensure LGBTI elders and older people are appropriately supported.

LGBTI Cultural Safety

Due to many LGBTI elders and older people having suffered historical instances of discrimination and enduring barriers to accessing aged care services, it is critical that aged-care services are inclusive, accessible and culturally safe for LGBTI elders. In order to achieve this, there are a number of organisational practices that can be implemented. These include:

- Ensuring LGBTI elders and older people feel comfortable and safe with divulging personal information including their sexual orientation, gender identity, or intersex status and giving them multiple opportunities to do so (as their comfort and trust builds over time they are more likely to inform staff about who they are)
- Ensuring that aged-care staff, at all levels of the organisation, and volunteers are adequately and appropriately trained to provide LGBTI-inclusive services
- Ensuring LGBTI elders and older people can easily and confidently access these services through the implementation of welcoming physical environments within aged care facilities
- Ensuring LGBTI residents are consulted about, and participate in, the planning, development and review of services relevant to their needs
- Assessing and analysing LGBTI-inclusive aged care practices to identify elements that will improve the cultural safety of residents

LGBTI communities are not homogenous. Aged care service providers should consider implementing a policy framework that incorporates organisational planning to connect with less visible LGBTI residents. For example, LGBTI residents from Aboriginal or Torres Strait Islander communities and Culturally and Linguistically Diverse (CALD) backgrounds. Recognising the complexities of LGBTI elders' needs and affirming and respecting each individual ensures high quality and LGBTI-inclusive care.

Data Collection

Current national policies, strategies and programmes identify LGBTI people as a priority population for action. This is due to an overwhelming amount of research evidence consistently demonstrating that LGBTI people experience significant health disparities compared to their non-LGBTI counterparts.

This includes poorer mental health outcomes and higher risk of suicidal behaviours. LGBTI people are also at higher risk of a range of mental diagnoses and are more likely to be diagnosed with anxiety and depression, and psychological distress.

LGBTI people are in their lifetime more likely to attempt suicide, have thoughts of suicide, and engage in self-harm.

It is also clear that members of LGBTI communities use alcohol, tobacco and other drugs at elevated rates compared to the broader population and are significantly more likely to experience drug dependence.

We also know that LGBTI communities experience a disproportionate cancer burden, and face unique psychosocial challenges, such as higher rates of cancer related distress and sexual concerns, lower levels of family support, difficulties in accessing general health care or cancer services, gaps in patient-provider communication and lower satisfaction with cancer care.

The collection of quality and robust data and evidence will help increase social inclusion and reduce stigma and discrimination in the lives of LGBTI people. Being counted will result in a more supporting and accepting societal environment that will act as a protective factor for the mental health and wellbeing of LGBTI people.

The appropriate and meaningful collection of data will also enable us to measure who is and is not accessing aged care and where they are falling through the gaps. This is exacerbated by little to no data being collected in the aged care sector. This means that we do not know how many LGBTI elders and older people:

- are accessing aged care services
- have been assessed for aged care but have not accessed services
- have accessed aged care but then withdrawn
- are not accessing aged care

In addition, where questions are asked about sexuality, gender or intersex status the questions are inappropriate. For example, we are aware of one older trans woman who openly identified as trans but there was no option to indicate this on the original assessment form used by My Aged Care. Instead the box indicating indeterminate/undecided/intersex was ticked (this is completely inappropriate language to use in reference to intersex people as well). Fortunately, the assessor who this woman was referred to was experienced in working in an inclusive way and was able to correct the mistake and make the woman feel safe and included. It could have easily gone the other way with the woman refusing to continue the assessment process and falling out of the aged care system and more than likely not engaging with the system again. As well we do not know how common it might be that LGBTI elders and older people are not following through on or after assessment as no data is collected. It should also be noted that we do not know what the current questions are about gender and sexuality or being LGBTI on the assessment form.

How many LGBTI Elders and Older People?

With a lack of data available we can only estimate the number of LGBTI peoples there are based on research. The following are estimates based on a number of recent studies and polls:

- 1.7% of population is intersex[1]

[1] Intersex Human rights Australia, https://ihra.org.au/16601/intersex-numbers/

- Nationally representative study of New Zealand high school students: 1.2% identified as "transgender" + 2.5% unsure = 3.7% trans or questioning (Clark et al., 2014).
- In another study homosexuals accounted for 1.9% of the male population and 1.2% of the female population, a non-significant difference between the sexes. Bisexuals accounted for 1.3% of the male population and 2.2% of the female population. Women were significantly more likely than men to identify as bisexual, and less likely to report exclusively other-sex or same-sex attraction and experience.[2]
- A later report stated that although over 95% of participants identified as heterosexual, 19% women, 9% men had prior same-gender attraction and/or experience (Richters et al., 2014)
- Between 2006 and 2014 Roy Morgan Research asked almost 180,000 Australians (14+) to agree or disagree to the statement, "I consider myself a homosexual". In 2006-08, around 1 in 42 people (2.4%) agreed. By 2009-11, this had risen to around 1 in 32 (3.1%). And during the latest triennium 2012-2014, the figure was higher again, at around 1 in 29 (3.4%). The proportion of people who say they are homosexual is increasing across all age groups, but inconsistencies remain: 4.6% of Australian teenagers (14-19) now agree they are homosexual (up from 2.9% in 2006-08), rising to a peak of around 1 in 15 people in their 20s (6.5%, up from 4.4% in 2006-08). From there, the rate declines to 4.2% of those in their 30s (up from 2.5%), to 2.8% in their 40s (up from 2.4%), down to less than 1 in 55 people aged 50+ (1.7%, up from 1.3%). Overall, 4.1% of men and 2.8% of women agree, with those in their 20s the most likely among both genders: 7.6% and 5.5% respectively.[3] The low numbers in the older age group correlates with LGBTI elders and older people to be more likely to be hiding their sexuality.

Response to the Terms of Reference

The National LGBTI Health Alliance conducted a brief series of consultations to gather the experiences of LGBTI elders and older people in aged care or supporting someone in aged care to share with the Commission. The following is a summary of the issues raised at these consultations. The consultations were held in Melbourne, Canberra, Adelaide, Tasmania and on the Sunshine Coast.

The quality of aged care services provided to Australians, the extent to which those services meet the needs of the people accessing them, the extent of substandard care being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;

"*You have to assess so many things all the time before accessing aged care. A heterosexual person says I am going to get the care I want; we're thinking will I get the care I need because I'm rainbow or will I not*"

[2] Smith, A. M.; Rissel, C. E.; Richters, J; Grulich, A. E.; De Visser, R. O. (2003). "Sex in Australia: Sexual identity, sexual attraction and sexual experience among a representative sample of adults". *Australian and New Zealand Journal of Public Health*. 27 (2): 138–45

[3] http://www.roymorgan.com/findings/6263-exactly-how-many-australians-are-gay-december-2014-201506020136

"You shouldn't have to have an internal conversation about how you will be treated; but there are enough experiences of discrimination out there in care companies"
"The dominance of religious based service providers are perceived as a barrier to accessing service by LGBTI elders."

Good Experiences

Several attendees said they felt that receiving good care could be like a game of chance and can be dependent upon location and the goodwill of staff. While others stated that they had no negative experiences as they remained hidden and remained "under the radar". It was also noted that sometimes being "out" can be fraught with expectations of discrimination. For example, a mother-in-law who had a picture of her son with his partner. When the aged care staff member asked her who the photo was of, she became really worried about what would happen but luckily the staff member commented "that's wonderful".

Others spoke of positive experiences including being able to nominate an LGBTI carer for in-home domestic care, which made it less stressful and safer. Having pets allowed was also viewed in a positive light with a person commenting that "pets are very important to many LGBTI elders". A case study was also provided of a "lifestyle worker" encountering a "cross dresser" in an aged care service. The organisation sought out ways to make this both comfortable and respectful.

LGBTI elders who are currently carers

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. There is very limited understanding of, support for, or resourcing of services for LGBTI people in this type of caring role.

Privacy and Sexual Expression

There were several comments about the right to privacy, especially in residential aged care and particularly around sharing intimacy and sexual expression. For example, anyone whether LGBTI or not, who has sexual interests such as dominance/submission must hide or can no longer enjoy their sexual expression due to the attitudes of the aged care provider and/or staff. People mentioned that even where you put a sign on the door requesting privacy, as you cannot lock your door, staff still barge in. There were also discussions about a lack of access to sex toys, again whether LGBTI or not, and people improvising with other items.

Another issue that is specifically faced by LGBTI elders and older people is in negotiating new partnerships as sometimes families of origin intervene and prevent this from happening. Staff need to be skilled in supporting the LGBTI elder or older person in being able to have their relationships of choice and connecting the person to advocacy and support networks, as well as having clear policies and protocols on how the provider will support the LGBTI elder or older person.

Ignorance

There is a high level of ignorance from aged care professionals and workers about the lived experience of being LGBTI and what LGBTI elders and older people have experienced throughout their lives. For gay men in particular the lack of awareness about the history of entrapment and

HIV/AIDs. In terms of LGBT there is poor knowledge about the experiences of illegality, violence, rejection and discrimination.

Trans-specific Concerns

"Not educated in trans issues. Large number of care workers are from overseas cultures who haven't heard of trans and don't like [us]. Trans hurtful jokes. Not providing the correct clothes and underwear and toiletries for me. I'm getting less able now and extremely concerned as no one knows I'm trans at my residential care facility. What will happen when they find out I'm biologically female?? Will my health be adversely affected due to prejudice and ignorance? Very scared. Also humiliated often. I'm lucky I have good family help. Not everyone does."

A number of specific aged care needs were raised in relation to trans and gender diverse people including specialist care around transition as an older person, a lack of knowledge and understanding amongst staff about hormone therapy ("*it's not HRT*") and the importance of having the needs of trans and gender diverse people taken into account upfront during ACAT assessments. Examples of the experiences of trans and gender diverse people in aged care included the transwoman who had her hormones stopped by staff, and the impact this would have on the woman and the transwoman who is continually misgendered and while she can stand up for herself the ongoing discrimination takes its toll on her health and wellbeing.

Homophobia, Biphobia and Transphobia

"It's amazing how easy it is for someone to pull the rug from under you; one cruel comment can have big consequences."

"*A lesbian woman with deep spirituality moved into faith based provider and was told 'you don't need to share this with everyone' – heterosexual people are allowed to flaunt their heterosexuality – LGBTI you have to be discrete; you can't make others uncomfortable, you have to go back in the closet – deeply insulting to everything these people have achieved*."

People noted that aged care providers "treat everyone the same" and do not acknowledge that in fact they have LGBTI people within their services or are the carers/family/friends of people receiving their services. While providers do not actively state that they do not accept LGBTI people it is in their behaviour, attitudes and practices. This results in the person not accessing the service or hiding who they are and, if possible, leaving the service. One person stated that they were on their 4th aged care provider in seven years due to the experiences of their partner in each of those previous services. Another noted they were "*not discriminated against actively by aged care providers but staff made clear support of homophobic statements, therefore I visit alone*".

It was agreed that aged care providers should be "moved on" if they are being discriminatory in how they treat people.

Fear of Residential Aged Care

"*We've given you equality, we've even given you marriage – we've given what you want, so be quiet*"

"*A history of institutionalised care doubly-terrifies us about aged care*"

"*Older lesbians that have grown up with abuse and sexual abuse and take this with them into aged care and don't want to talk about being afraid*"

"*The [LGBTI Ageing and Aged Care] Strategy came in but what's happening on ground is not reflective of that – no monitoring and checking; people are being pushed back into the closet – provider wants to be a successful business model and doesn't want major group upset by a small group*"

Entry into residential aged care is one of the most feared aspects of accessing aged care services. Not only due to the feeling of loss of control over yourself and your life but because the person can no longer control their environment and who they share that environment with. It was noted that in the community you can choose your friends and in residential aged care you cannot. It was also stated that each time a person hears a story on the news about poor or abusive care it adds to the fear of not wanting to access residential aged care.

Many people spoke about hoping that euthanasia is available before they will have to access residential aged care. This included having clear plans in place and having purchased what they would need to end their own lives. One person spoke about needing to know that dignity and respect are the factors to be guaranteed of before entering aged care or they will kill themselves. Others spoke about 'throwing themselves in front of a train' or 'taking pills'. This highlights the significant fears and concerns LGBTI elders and older people have about ongoing discrimination and abuse and having to hide themselves in residential aged care.

Other Concerns

"*Lack of access to appropriate medical services – A limited number of GPs visit nursing homes. This can be a particular problem for people living with HIV. Many GPs have no specific HIV awareness training*."

There were a range of other concerns and issues raised regarding aged care services. These include:

- Lack of staff training and awareness regarding LGBTI issues.
- No acknowledgement or compassion after death for same-sex partners.
- Other residents of the aged care facility discriminating against LGBTI residents
- Isolation of LGBTI residents
- Nursing homes have limited knowledge of HIV – how HIV is transmitted and how to care for someone with HIV. Hence stigma and exclusion persist.

Recommendation

One of the original recommendations at the First National LGBTI Ageing and Aged Care Roundtable was to require all government-funded aged care providers to develop policies and organisational processes to combat discrimination and promote inclusion of LGBTI people.

a. Mandatory
b. Evidence of implementation
c. Annual Reporting
d. Complaints process
e. Enforceable penalties (e.g. tied to funding).

How best to deliver aged care services to:

- people with disabilities residing in aged care facilities, including younger people; and
- the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;

Younger People with disability

There are currently no youth specific facilities for young persons living with a disability – regardless of whether they identify as LGBTI or not. A potential solution could be the creation of small youth specific homes or a separate wing of existing nursing homes with a different look and feel and different youth related activities.

Young people's sexuality was also a concern not just for LGBTI people but for all young people in residential aged care. It was agreed that providers must acknowledge and facilitate sexuality awareness for staff and to enable young people to express their sexuality. It was felt that the biggest barrier to this was that most providers are religious based and appear to be anti – sexuality. An example was given of a young person with a disability in a faith based residential aged care facility where the parent and the provider ignored the sexual needs of this young person. In the end a staff member who was from LGBTI communities discreetly enabled the young person to regularly visit a brothel with Touching Base training (a sex worker service specific for disability & older clients).

LGBTI People Living with Dementia

"*I have a friend who is frantically worried about getting dementia as both parents have dementia. She is worried she is going to wake up and say 'oh I've got boobies and a willy' she is dead set, even though we know that we don't revert*"

"The gay and lesbian community are my family. I have no other support structures. The people who raise issues are the family of the people in trouble and if I lose the ability to monitor my situation – who is going to look out for me?"

"Caring for her at home became too difficult as I was not getting sufficient support. The assessment allowed/dictated 4hours of support. I believe the assessor was under qualified to decide that my partner did not have behaviour issues. She needed dementia specific support. During respite there was an episode and I learnt that there was nowhere for her at the facility and I would need to find her a new location by the following Monday. I was shocked and the staff were appalled."

There is a need to recognise the unique needs of LGBTI people living with dementia, their carers and their families. There is very little information and knowledge around the specific needs and experiences of trans people who are living with dementia and how to support them particularly where their family of origin (biological family) does not support their gender identity. An example was given of a trans person being buried in their birth-assigned sex clothing rather than their preferred clothing at the insistence of the person's family.

LGBTI older people with dementia need:

- Staff in aged care services to understand that the grief/loss associated with the death of a same-sex partner with dementia is the same as that experienced by a heterosexual couple;
- To have their relationships affirmed and respected by aged-care providers, other clients and families;
- To be protected from discrimination and abuse from other residents and their families in aged-care facilities;
- To be supported in providing informed consent in relation to sexual expression and/or gender expression;
- To understand and support intersex people with dementia who may relive childhood trauma associated with their treatment and bodies;
- To be cued around gender/sexual identity if required; and
- To recognise and respond to the person re-experiencing times of fear and abuse.

Aged care service providers and their staff need to employ a range of strategies in order to provide LGBTI inclusive care and improve the everyday experience of LGBTI older people living with the behavioural and psychological symptoms of dementia (BPSD). Some of these include:

- A person-centred approach to dementia care that includes culturally appropriate assessment of BPSD;
- Using consistent language across organisational policies, procedures and staff training practices;
- Working closely with identified family of choice members to inform individualised strategies to support their LGBTI older person with BPSD;
- Appreciating and recognising LGBTI diversity through encouraging active participation in LGBTI-cultural activities and events; and
- Putting strategies in place to minimise homophobic, biphobic or transphobic abuse from co-consumers, some of whom may also have dementia.

An awareness of the overall lived experience of LGBTI older people with dementia is essential to adopting a person-centred approach to managing BPSD. Rather than focusing solely on the BPSD, a person-centred approach provides a holistic framework for understanding the BPSD in the context of the person with dementia.

Aged-care service providers that fail to recognise, validate and support the special needs of LGBTI older people with dementia increase their distress and violate their basic human rights. Therefore, everyone involved with dementia care must be supported to ensure that LGBTI older people with dementia receive inclusive, person-centred care in a culturally safe environment.

Other recommendations around providing LGBTI inclusive dementia care included:

- Support for families to keep loved ones at home
- More facilities that focus on quality of life
- Better access to alternative therapies
- Workers supported and empowered with appropriate LGBTI training & resources
- Staff to patient ratios need to be improved,
- Ongoing LGBTI awareness training for providers
- Awareness education & training to the LGBTI communities; prior to accessing aged care services; about funding and availability of LGBTI appropriate services.

- Advanced Care Planning specific for the LGBTI communities – having conversations with family & support persons before aged care services are needed.

The future challenges and opportunities for delivering accessible, affordable and high-quality aged care services in Australia, including:

- in the context of changing demographics and preferences, in particular people's desire to remain living at home as they age; and
- In remote, rural and regional Australia;

Home Care

"*No one wants to make complaints – people know where you live and I am conscious I live in a 'right wing' area; these are not people you willingly invite into your home but you are required to as they are the ones providing the service*"

While overall people felt somewhat safer in receiving home care services there were still many fears and uncertainties about letting people into your own home. People spoke about the body language and tone of voice used by home care staff, so that while nothing was said the staff made it very clear that they do not accept LGBTI people. In this instance the person receiving care was very scared about letting these workers into his home as he didn't know what they would do. Another example given was where a home care worker said the photos of the person and their partner in the care recipient's home made them uncomfortable about being in the home.

Others spoke about the issue of letting someone into the home and then something happening. In this instance the person can't go back in time to change the event and the home then becomes an unsafe space (and often the home is the only safe space LGBTI elders and older people have).

People spoke about the lack of awareness of home care providers, and their sub-contractors, about same-gender relationships. For example, for one lesbian couple the person kept referring to her partner as her daughter. They were not 'out' to the provider and so did not want to correct the assumption.

Remote, Rural and Regional Australia

"I did not have sufficient support to enable my visits to doctors etc. for myself. I live 2 hours out of town. There needs to be more support in regional and remote areas to ensure we can look after our partners, parents and loved ones at home".

There were several issues highlighted for LGBTI elders and older people living in rural, regional and remote areas of Australia. These are:

- Lack of support for LGBTI people living in regional Australia
- Social isolation for LGBTI elders can be extreme for those living in the regions
- Few options for in-home care in the regions
- Forced relocation from home and community due to lack of services
- The limited services that do exist are rarely LGBTI friendly
- Limited Respite Care

- Most services are provided by religious based organisations who are not inclusive

What the Australian Government, aged care industry, Australian families and the wider community can do to strengthen the system of aged care services to ensure that the services provided are of high quality and safe;

"*I don't trust the system. There are no safe feedback systems. The services immediately are on the defence. The priority is procedural areas not personal care and this is again about trusting the system … There were negatives about being out. Needed to be careful. The death of your significant other is not understood by others and that is really hard*."

"There is no understanding of the importance of using my correct name and not defaulting to the title Mrs which I have never been! No one referred to me by my name. If I had been able to speak, I would have asked people not to call me darling."

"Aged Care Providers need to "come out" but won't put things on website as not wanting to put off the "straights"

"Keep me connected to LGBTI community – I depend on the community they need to be part of my life"

Aged-care Standards

"Aged care service providers do not understand what LGBTI safe practices actually mean."

The Aged Care Diversity Framework and supporting Actions for LGBTI Elders – A Guide for Providers and A Guide for Consumers are not mandatory so there is no compulsion for aged care providers to implement these or follow the actions. They are not attached to the Aged Care Quality Standards so there are no consequences if providers are not inclusive of LGBTI elders and older people. This needs to be changed.

Legislation

"*It needs to be acknowledged that LGBTI staff exist*"

The only way change will happen is if the government legislates change. While significant changes have happened as a result of including LGBTI people as a special needs group in the Aged Care Act and changes to the Sex Discrimination Act (making it unlawful for government funded aged care providers to discriminate against LGBTI people in the delivery of services), as well as the National LGBTI Ageing and Aged Care Strategy and the new Action Plans there is still some way to go before all providers engage in LGBTI inclusive care.

Participants in our consultations highlighted the issues of faith-based providers still being able to fire staff on the grounds of sexual orientation, gender identity and intersex status, or not hire them in the first place. It was argued that no provider can describe themselves as LGBTI inclusive if employment practices are discriminatory. LGBTI elders and older people receiving services from such a provider will be concerned about how truly inclusive they are. It was argued that non-Commonwealth funded providers should not be able to refuse care to LGBTI elders and older people and that there should be a single Act that covers funded and private services. In addition, people

spoke about faith-based retirement villages being able to throw LGBTI people out of their homes, though it is acknowledged that this is outside the scope of the Royal Commission.

Specific Training

Ongoing regular LGBTI inclusivity training should be mandatory for all staff whether they are part of the governance structure, a care worker or a gardener. The culture of LGBTI inclusivity should be embedded throughout the organisation.

'LGBTI' is often viewed as and referred to as single category that is used to speak about people using broad generalisations. However, LGBTI communities are not homogenous. Within the LGBTI acronym are several distinct, but sometimes overlapping, demographics each with their own histories, experiences and health needs. Furthermore, LGBTI people are part of all population groups including Aboriginal and Torres Strait Islander people, people living in rural and remote areas, and culturally and linguistically diverse populations. Fundamentally, older Australians display the same diversity in genders, bodies, relationships, and sexualities as the broader Australian population. Mandatory training should be provided to staff that focuses on how intersectionalities with other identities and experiences may impact on an individual's health care needs. LGBTI awareness training should be refreshed on a regular basis to take into account staff turnover.

Silver Rainbow delivers a range of training through its partners in every state and territory from an online eModule to a 4-hour face to face session and soon to be released specific modules on how to work with lesbian or gay or bisexual or trans or intersex elders and older people. While a significant number of aged care providers have accessed training there are still many more that need training and high staff turnover means that previously trained staff may have left, resulting in new staff needing training.

Advocacy

"*Promote the idea that we have choice, and don't have to put up with things that aren't right for us"*

"*Advocates need to know your history – we need someone to stand up for us"*

"Sometimes it's left up to LGBTI staff to "beat the gay drum" and be the sole advocates responsible for LGBTI inclusiveness when it should be a whole staff approach."

Advocates are essential in ensuring inclusive services and that the voices of LGBTI elders and older people are heard. Advocates need training and support but there also needs to be training and support to enable LGBTI elders and older people to be self-advocates where they are able to do so.

However, advocacy services must work with people 'where they are at' recognising that many current older people have grown up at a time when you did not challenge the 'professional' or the 'provider' or where these bodies had extensive control over you and your life. In particular, older LGBTI people being sent for 'treatment' to 'cure' them. While there are always exceptions to this and there are strong older people who are great at self-advocacy it is about enabling those that do not have strong self-efficacy as a result of the environment, the culture and times in which they grew up.

There is a need to recognise that some people may prefer to go out of their local area for support, so they are not identified, but travel could be a hardship financially and logistically. There are privacy

issues for people in small regional, rural and remote communities where the advocate may be a neighbour who does not know the person is LGBTI.

Systemic advocacy is also intrinsic to any advocacy system as while individual advocacy can improve the lives of individuals, and possibly the people immediately around them; systemic advocacy improves the whole system and benefits the broader community. In addition, the need for individual advocacy often arises out of systemic issues. To separate the two has the potential to leave the causes of the issues in place while applying 'band aids' to the outcomes from those issues.

Best Practice

"We would like to be asked directly about our sexuality – staff often pussy foot around or just don't ask any questions which would elicit us coming out."

"*Many organisations are doing good things – how do we spread those messages? – public service announcements?"*

"Homogenous services don't suit us"

"Those of us using services need to do more to share our experience and knowledge with others."

The following is a non-exhaustive list of suggestions, recommendations and ideas on how aged care services can be high quality and safe for LGBTI elders and older people:

- Progressive leadership that explores different models of care delivery (e.g. more flexible services)
- Partnerships between LGBTI community organisations, other organisations and aged care providers to maintain community and social connections for LGBTI elders and older people. For example, in South Australia Catalyst, COTASA and ECH share a calendar of social programs
- Rainbow Tick accreditation
- Training – accessed both internally and externally and that forms part of the induction process for all staff across all levels and service delivery types of the organisation
- LGBTI inclusion forms part of staff performance appraisals – what have you done as a staff member to ensure that you have been culturally safe and sensitive? These can be read by the senior executive to identify where further action or work is needed and can be utilised as a type of report card on how the aged care provider is going with delivering LGBTI culturally safe services
- Community spaces where the person can have LGBTI community activities and be part of their community – getting the person out to the community – in terms of emotional wellbeing that is important for LGBTI elders and older people
- Establish a register of advanced care directives and end of life directives by LGBTI elders that must be honoured by aged care providers – current directives are not always adhered to.
- Aged care agents that are trained and aware of LGBTI issues to assist in the transition process from in-home to residential aged care.
- HIV issues - Aged care staff appropriately aware and trained; access to GPs that can prescribe HIV medications
- Nurse practitioners need to have prescribing rights of HIV drugs & Trans medications
- Trans medications – staff who dispense medication in residential facilities need to be aware of medication issues for Trans people.

- Need to do more to ensure people understand what services are available. My Aged Care is very difficult to navigate and needs to be restructured.

How to ensure that aged care services are person-centred, including through allowing people to exercise greater choice, control and independence in relation to their care, and improving engagement with families and carers on care-related matters;

"I have worked in aged care services and delivery for 40 years. Of the thousands of people I have met and worked with I do not know of one 'out' person I have met in that time though I have heard of people. This is a clear message. I have heard that one care facility asked that a same sex couple kiss each other on the nose so as not to upset others. There is no effort to hear people's stories."

"I don't want to go into a place where I am tagged – just want to be with people – just part of the general community"

"Organisations must be brave – inclusion isn't about expecting us to fit in, but accommodating for us"

Aged Care Assessment Teams/Regional Assessment Services

For assessment providers to be inclusive of LGBTI diversity, a trauma-informed and person-centred approach is required. A trauma- informed approach views the historical experiences of discrimination, abuse and exclusion that many LGBTI people have experienced as trauma and encourages assessors to consider these experiences when providing appropriate care. A person-centred approach acknowledges the consumer as a unique individual and ensures that they are at the centre of all decision-making around their care, and that this care recognises their personal journey, identity, needs and wishes. Due to many LGBTI elders having suffered historical instances of discrimination and endured barriers to accessing aged care services, it is critical that entry processes are inclusive, accessible and culturally safe for LGBTI elders.

Other Comments

"*Acknowledge "double minorities" – disability/Aboriginal/Muslim, etc. (intersectionality) – these populations can feel excluded from the LGBTI community*"

There was quite a bit of cross-over with the previous Term or Reference above. In addition to the ideas proposed above people spoke about:

- The need for open and honest communication and being able to ask questions whether positive or negative.
- Education – Regular mandatory In-Service training ie. Religion, Cultural, Educational, and LGBTI
- Empower LGBTI staff to be more visible so they can be matched with LGBTI clients
- Offer meaningful, relevant experiences, activities and programs (not bingo!) drawing on all the LGBTI experiences over time (Mardi Gras, Dykes on Bikes etc)
- LGBTI elders and older people are provided with a greater understanding of options (availability of care, be that Residential or in-home care)

- There is inclusion of pharmaco-therapies – LGBTI communities have a higher drug use rate and may wish to continue this drug use when receiving aged care.
- More services that are flexible ie. Offering Respite Care, more staff and more infrastructure.
- Greater empowerment of residents
- Safety a must
- Transparency, confidentiality, integrity, humanity
- Individuals before profit
- More options for cross-generational communal communities independent of aged care
- Intergenerational communication – elders to mix with other age groups

How best to deliver aged care services in a sustainable way, including through innovative models of care, increased use of technology, and investment in the aged care workforce and capital infrastructure;

"Many of those folk, because they did not work (due to illness) during that period, will not have the benefit of superannuation or the incidental wealth that comes with having been able to buy into the property market when it was affordable, and consequently, they are far from likely to have the kind of $$ or assets that will allow them access to any but the most severely modest residential living facility, precisely those institutions that may have a surfeit of people likely to have difficulties with gay people and HIV+ and hepC+ people. It is prospect ripe for those who wish to end their lives under their own steam."

"The Aged Care Act and the Standards need to be critiqued and changed to facilitate much more creative ways of looking at the provision of aged care homes and services."

Workforce Issues

There needs to be the creation of staff retention strategies for people who want to continue to work in aged care and there should be some form of reward for staff staying in hands-on roles rather than having to move into administration and other roles for higher wages and job security. It should be enforced with staff they have to leave their prejudice at the door. There also needs to be consideration of different funding models that enable staff ratios.

There were a number of discussions around better utilisation of staff skills, for example in terms of cooking meals those with experience in cooking meals from different cultures should be given an opportunity to do this rather than cooking to a pre-determined menu.

In terms of specific issues for LGBTI elders and older people it was stated that being LGBTI inclusive should be part of staff selection processes and induction. In addition, high staff turnover and a lack of continuity makes it difficult for LGBTI elders and older people as they have to continually "come out" to new people. As well many staff come from different cultures where LGBTI people may not be accepted or evident, so they are not familiar with the issues that LGBTI people face.

Other Suggestions and Recommendations

- We love the Dutch model for people living with dementia
- There should be pods of small co-housing projects.

- Create intentional communities
- Create homes which promote independence
- Aged Care package with the flexibility to bring in LGBTI specific social support
- Linking existing LGBTI community services into aged care
- Concentrate more funding & support for in-home care – because residential facilities are not an option is the LGBTI person is to be mainstreamed into a heteronormative service.
- Technology utilised and made available to link the elder with LGBTI social community groups
- Provision of government funded Allied Health services in residential aged care facilities.
- Specific LGBTI aged care services – similar to the ethnic based aged care services.

Conclusion

Overall, this consultation and previous consultations have clearly confirmed the need for the current Aged Care system to be made more accessible for and inclusive of LGBTI older people and elders. Participants called for all service elements, practice and systems that ensure LGBTI elders are affirmed and will receive culturally safe, effective, appropriate and accessible services that meets their individual needs, free from discrimination.

Therefore, it is important that LGBTI people are not treated as a homogenous group and that aged care providers educate themselves and design and deliver culturally safe inclusive services that address the specific needs of each group rather than having an "LGBTI" response. Consideration also needs to be given to the impacts of dementia on LGBTI people and people living with HIV and responding to intersectionality.