



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) 7209 6301

Royal Commission into Aged Care Quality and Safety

Focusing on specific communities - National LGBTI Health Alliance Submission

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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.

Contact

Nicky Bath
Chief Executive Officer

P: 02 7209 6301

E: nicky.bath@lgbtihealth.org.au

W: lgbtihealth.org.au

Silver Rainbow

Silver Rainbow is the name given to the National LGBTI Health Alliance's Ageing and Aged Care Project. It provides national coordination and support activities promoting the well-being of LGBTI older people. 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 older people by ensuring aged care services are inclusive and accessible.



SILVER RAINBOW

Introduction

The National LGBTI Health Alliance was funded to coordinate responses from LGBTI communities nationally, produce submissions to reflect LGBTI experience of aged care, and make recommendations for improved aged care services for LGBTI older people. A range of inclusive recommendations has been developed in previous submissions to the Royal Commission into Age Care Quality and Safety, available on the website at www.lgbtihealth.org.au, which cover issues common to all LGBTI communities. In developing this submission, however, it is important to remember that the term 'LGBTI' is not monolithic and homogenous. Aged care services cannot assume that all lesbian, gay, bisexual, transgender and intersex people have an absolute common set of needs and an automatic sense of affinity with one another. To address this issue, this submission covers the specific needs of each group in the LGBTI cohort and describes the unique experiences of older Aboriginal and Torres Strait Islander people as well as older LGBTI people living with dementia.

Consultation

The material in this submission was gathered through a thorough and systematic consultation process with LGBTI communities across Australia. In addition to the consultations undertaken for the first round of submissions to the Royal Commission, a second round involved face to face consultations in Sydney, Adelaide and Perth, and then, after the onset of the COVID19 crisis, over eighty individual telephone interviews conducted by our state-based partners with local members of LGBTI communities. All LGBTI people with a connection to the aged care system were invited to participate and give their views. Older LGBTI people accessing aged care, their friends and family, LGBTI aged care workers and representatives of aged care providers offering specific LGBTI targeted services participated.

As well as working with general LGBTI partners, the Alliance engaged specialist LGBTI organisations to collect the specific views of those communities who may not be reached easily through the usual LGBTI communication channels. Aboriginal and Torres Strait Islander older people, and trans and gender diverse older people were interviewed by trusted partners within their own communities. An online survey designed to elicit the views and experiences of bisexual people was promoted nationally. In addition, a general survey was made available for anyone who was unable to get to a consultation or was not able to be interviewed.

The National LGBTI Health Alliance Royal Commission Advisory Committee, made up of consumers, academics, and representatives of providers of aged care services, provided valuable input and reviewed all submissions.

Lesbians

1. Cultural values and practice in aged care

While many older lesbians interviewed see themselves as part of broader LGBTI communities, a small number did not. Some older lesbians expressed the view that they are most comfortable using aged care services broadly targeted at women.

Several older lesbians asserted that aged care staff who care for older lesbians need an awareness of the history of lesbian and feminist activism and the reality that many lesbians have been out, proud and comfortable about their identity throughout their adult life, despite having also faced discrimination and marginalisation. They expressed expectations of leveraging this activism by being enthusiastic participants in establishing their own aged care arrangements.

“We want to be part of the role of change not just recipients. I think the government are afraid of a militant ageing population.” – eighty-year-old urban lesbian

Patterns of working together and historical living arrangements were seen as strengths to bring to the issue of appropriate aged care for older lesbians.

“Collective living, it is a strength that lesbians bring into ageing, collective living experiences might keep us out of aged care.”- older urban lesbian

Many older lesbians were concerned about critical lifestyle issues. Some mentioned the importance of their dietary needs (being vegetarian, vegan, gluten-free etc) which related to political or social personal commitments, or existing health conditions. These older lesbians saw their dietary requirements as central to who they are, and also were aware that again, their needs were outside of the mainstream. They were afraid that aged care services would not cater to them.

Companion animals and pets were very important to many and very much appreciated for their positive impact on physical and mental wellbeing, providing companionship, touch, and the need for social connectedness. These benefits could be enhanced by the integration of companion animals into aged-care services. Having a pet was also a source of anxiety about who would care for animals as owners become less able.

“For lesbians it needs to be recognised that their animals are a huge part of their life. This is a big reason why they want to stay at home.” – forty-two-year-old regional lesbian, aged care worker

Lesbian relationships in old age were also regularly mentioned by interviewees. They noted a broadly held assumption that older women are not sexually active and objected to aged care services being delivered as if they were sexually incompetent or asexual. Supporting existing relationships, by ensuring, for example, that partners share a room, is critical in maintaining healthy ageing.

“We want to be able to share a room. People say different things, we are still not sure if this is possible. When you have lived with someone for 40 years, the last thing you want to do is live alone. It’s worrying.” – eighty-six-year-old regional lesbian

Beyond supporting existing relationships, some older lesbians lamented the loss of a partner, and needed that loss to be fully acknowledged by aged care workers. Others expressed the view that the confines and structures of residential aged care did not facilitate the establishment of new relationships for older lesbians.

“I’d like to leave this place and get a partner. I’ll never find a partner here.” – older lesbian living in urban residential aged care

2. Discrimination

There were many reported instances of lack of acceptance of older lesbians in aged care services. Some involved the unfair and negating exclusion of older lesbians from care routinely offered to other residents.

“When my friend died, they did not offer to hold her wake at the facility, even though I have previously seen other families have wakes there. We had to use a café. I think this neglect was based on staff discomfort and homophobia.” – seventy-five-year-old regional lesbian

Heterosexism in aged care services was experienced in many ways. Staff or other residents assume heterosexual attraction, which is insensitive to older lesbians and undermines their sense of self and identity. Older lesbians expressed frustration at having to challenge these assumptions repeatedly or experience the distress and confusion of remaining silent in the face of being rendered invisible.

“I’ve heard staff say to older women, “he’s keen on you” or “we will make you look nice because there’s a new fella in here today””- seventy-five-year-old lesbian

Heterosexist assumptions were particularly problematic for older lesbians living with dementia and their partners. Where there is little choice of service, or where they are unfamiliar and located far away from home, there is an increased pressure to pre-emptively “come out” to service providers so as to protect a loved one from damaging heterosexist assumptions.

“I had both my knees replaced so my partner needed to go into respite for 2 weeks. Both times she had to go to a place 2 hours away. It was so far away, she was unlikely to have visitors or community visits, and unless I made the point to tell them about us, I knew they’d start asking her about husband and kids.”-seventy-three-year-old regional lesbian

Overlapping common disadvantage with all older women was noted. Significant numbers of older lesbians experience poverty, which results in inequitable access to some aged care services like private nursing homes or private health and allied health practitioners. The concept of choice in aged care services is belied by the ability to pay, and several older lesbians expressed anxiety about long waiting times for services, and the inability to shorten those waiting times by paying.

3. Ageism

Older lesbians mentioned the damaging impact of ageism on them as they grow older. Stereotypes of all older women, regardless of sexuality or identity, are that they are passive, weak, cute, insular in their interests and resistant to change. Despite contributing huge amounts to the economy through unpaid care and volunteering, older women are seen as a burden on society. In addition to this, older lesbians suffer the indignity of being defined by their reproductive capacities as “grandmas” when they may never have had the opportunity to have children, or they may never have wanted them. Aged care workers and managers are not immune to these stereotyped views.

“When they talk about older people there are the stereotypes of knitting, assumptions that we are all the same. There is no reason for older lesbians to stop our activism.” – fifty-nine-year-old lesbian carer

4. Good experiences

Some older lesbians reported very good experiences with aged care and felt acknowledged and supported by staff and management. While they recognised that this may be different for others, they were very appreciative of efforts to provide culturally safe and inclusive services. They felt that it was important to speak out about their positive experiences so as to build confidence amongst older LGBTI people and their carers, families of choice and allies that aged care services are available for them. They also wanted to acknowledge and thank those aged care staff who work hard to support older lesbians in aged care.

“A nurse asked us one day about our relationship. She was a warm person and had shown us lots of kindness. We told her we were partners and she asked us if we were married (we were not). This was not long after marriage equality went through and word about our relationship spread around the home. Everyone was so supportive and welcoming of us. We don’t believe in marriage, but we did want to make a formal commitment to each other. This seemed more important now that we were separated (one still at home & the other in residential care). The staff helped us to plan and hold a ceremony at the residential care home, with our family, friends, and other residents. We have been so welcomed and well cared for and we have not only been encouraged but supported to celebrate our relationship (40+yrs).” Seventy-two-year-old lesbian

Other older lesbians expressed positive views in relation to living in smaller rural communities, where they had been established and accepted for many years. This experience of being deeply connected to local community was seen as a protective factor in ageing.

“When it comes to aged care in my little town, I don’t foresee problems moving into care as this whole town has known me forever. I don’t anticipate problems based on sexuality.” – sixty-seven-year-old regional lesbian

Gay men

1. Disclosure

Several older gay men expressed their fear of being ostracised by other residents and staff at aged care facilities if they were open about their sexuality. A history of discrimination and stigma, of being judged or denied services, results in a great deal of realistic caution about coming out.

“I’m a good and honest man and yet I must tell lies to protect my ‘guilty secret’.” – older gay man living in regional residential aged care

On entering aged care, older people are subject to lengthy and detailed assessment of their needs, including nutrition, mobility, personal care, and toileting. Little or no consideration is given to the person’s sexuality, identity, relationships and need for intimacy. The adverse health effects of not being genuine, of not being able to express important features of your sexuality and identity, can be devastating. Older gay men express concern about being “forced back into the closet” where they have to hide their sexuality and suffer a repeat of the trauma they may have experienced as a younger man.

“ I often fear that if I were in a nursing home my buzzer might be the last answered, I would be the last given food or last to have a shower. Also there is the issue of going back into the closet, toning it down or keeping your real self a secret.”- fifty-nine-year-old gay man caring for parents in residential aged care

In residential care, where the facility is their home, the experience of being inauthentic in their everyday activities and relationships is deeply disturbing.

“It is very important for me to feel I can talk freely about my life as a gay man and not be judged.”- eighty-one-year-old gay man living in residential aged care

The fear that other residents would not treat them with respect means that some gay men would prefer to live in residential aged care with a population of other LGBTI people. Living with other people who hold shared views and experiences and who understand the experience of ageing as an LGBTI person, was seen as an ideal for residential aged care.

“I hate the thought of living with 40 straight people for the rest of my life.”- older gay man living in residential aged care

2. Staff and visitor perspectives

Gay men working in aged care offered valuable perspectives about connecting with other LGBTI people. They felt they were able to empathise and make meaningful connections with other LGBTI people in their care.

“I met a person with HIV at a suburban Melbourne hospital where I worked in the 80s. He was facing huge prejudice and told me that the nurses drew straws as to who would service him. I met his boyfriend and we had a good chat about 1980s club scene. That was one of my best shifts ever!”- older gay man, aged care worker

On the other hand, there are staff in aged care who hold personal views not conducive to the good health of older LGBTI people, and who may then act on those views when in their caring role. This was raised as a particular concern in faith-based services.

“As a gay person I would struggle to have someone else washing me, particularly if I thought they weren’t in-sync with my beliefs.”- sixty-seven-year-old regional gay man

“My friend had known this out gay man for years. The moment he went into this facility, he was told he had to suppress his gay identity. He was told this! He felt he was back in the closet for the first time in 40 years. Some of these hardwired workers need years of therapy to unlearn their homophobia. People may pretend to be very open minded, but when it comes to the crunch [they’re] not.” – seventy-two-year-old regional gay man

Prejudice and stigma aimed at LGBTI people may extend beyond the older people themselves to their partners, family, friends and carers. Visitors to residential aged care need to feel safe and welcomed if they are to maintain close relationships with their loved ones and continue to advocate for them effectively. Older people want to feel comfortable talking about their LGBTI family members or friends to other residents and staff, and to receive the same levels of interest and concern about their family members as the other residents.

“I feel compelled to ‘straighten up’ whenever I visit Mum and Dad.”- fifty-three-year-old gay man, carer for parents in residential aged care

Older gay men felt the need to remain connected to LGBTI communities and events and expressed the desire to be part of ongoing political discussions about LGBTI human rights. They were concerned that these connections would be broken if or when they entered residential aged care.

3. Ageing and health care

Older gay men also noted the need for stronger activism and advocacy about ageing and aged care.

“It’s the same as in the 80s. We have experience developing community response to HIV/AIDS. It starts with the community caring –but where’s the LGBTI community response to ageing?”- sixty-one-year-old urban gay man

Since the 1980s, the experience of being diagnosed with HIV has changed from what was once a fatal illness to a now being a manageable chronic condition. Today, the life expectancy of Australians living with HIV has been steadily increasing and is approaching that of the general population.¹ Some gay men lacked assurance that their HIV status would be kept confidential, and also that their treatments and medications would be maintained when they engaged aged care services, both home care and residential.

Bisexual people

Establishing appropriate mechanisms for the bisexual community to express their views is challenging. Several bisexual people were interviewed for this consultation. They emphasised the problems of being invisible even within the broader LGBTI cohort, and the pain of feeling judged. So, for the purposes of this report we also established an online survey targeted specifically at the bisexual community, which allowed for greater reach across the country and provided greater anonymity for respondents.

Older bisexual people universally rejected any judgement about their sexuality and saw prejudice against them in aged care as part of a much wider problem within LGBTI communities and across society as a whole. They describe experiences where others deny that bisexuality exists or accuse people who identify as bisexual of being confused about their sexuality. They are frequently charged with being immoral or unstable. They are assumed to be polyamorous, particularly by people who see polyamory as an undesirable life choice. All of these views impact negatively on the care of older bisexual people as they access aged care services.

“Love is an equal right and who you love is your own business. Other people should respect that.” -sixty-eight-year-old bisexual man

While some older bisexual people urge everyone to talk about the specific bisexual experience, others respond to anticipated or actual discrimination in aged care services by not disclosing their status. Responding to the fear of discrimination and stigma by hiding an essential part of themselves has a negative impact on bisexual people and can result in poor mental health.

“I don’t discuss my sexuality with the workers. As far as they’re concerned, my photos can just be a friend. I don’t see the carers enough to trust them and explain my life to them.” – older regional bisexual woman

Older bisexual people describe experiencing many of the same discriminatory treatments as other LGBTI people, particularly if they are in a same-sex relationship when engaging with aged care services. They also expressed the view that unless they continually spoke out,

their bisexuality became invisible when they are in different-sex relationships. Aged care services can provide safe care for bisexual people by being accepting and by not making assumptions about a person's sexuality.

“Just ask them to be open and audibly and provocatively accepting of all flavours and preferences.” – older bisexual non-binary person

Older bisexual people value connection to the LGBTI community, and in particular to other bisexual people and organisations. There is always the potential to feel isolated, which can be ameliorated by strong, supportive relationships where their sexuality is celebrated.

“Find ways to keep us connected with our support networks, our friends, and the humans who understand us and accept us for who we are without condition.”- older urban bisexual man

Transgender and Gender Diverse people

1. Respect

The most frequent issue raised by trans and gender diverse people accessing the aged care system was the right to be respected, and concerns about when that respect was not forthcoming. Recording, pronouncing, and using the correct salutation, name and pronouns for an older trans or gender diverse person was seen as one of the most basic marks of respect, but there were many examples where that didn't happen.

“They still call me he and him and it hurts, it really hurts.”- thirty-nine-year-old transwoman, aged care worker

There was a view that strict policies and procedures, while setting common standards, can be too clinical, inflexible and de-humanising, as for example in the amount of time an aged care worker is allowed to spend with an individual, regimented meal times or shower times. Sometimes unnecessary and invasive questions are asked, without acknowledging that it is a person's right to choose what they disclose of their private and personal information. Sometimes facilities are not appropriate, particularly where there is a binary segregation of male and female, which leaves trans and gender diverse people with the sense of not fitting in.ⁱⁱ

“Will all aged care services have all gender toilet facilities?” – older non-binary urban bisexual person

Older trans and gender diverse people urged aged care services to develop comprehensive complaints systems and demonstrate a willingness to enforce rules around discrimination. Complaints are often evidence of hurt or harm to the individual and need to be treated sensitively, respecting the privacy of the complainant, with no possibility of reprisal.

“We don't want to punish people. We want them to see a complaint as a chance to improve.” – older regional trans man

2. Physical care

Older trans and gender diverse people clearly asserted that personal appearance, dress, style and grooming are very important to how a person feels about themselves, with a demonstrable effect on both psychological and physical health and further, is a matter of human rights and human dignity. This is a very important part of appropriate aged care but is often neglected for older trans and gender diverse people.

“A transgender woman I visit never seems to have hair or makeup done as part of a daily “routine” offered to other women, only when an LGBTI visitor attends to do this care voluntarily.”-non-binary regional aged care worker

In addition, judgmental attitudes and stereotyped views about the way people present physically are not conducive to the best health outcomes for older LGBTI people. Non-binary people described their experience of how health and aged care workers responded to their physical presentation negatively.

“Sometimes you can see that people are uncomfortable with the way I look and don’t take me seriously.”- forty-year-old non-binary carer for grandmother

“My non-binary partner presents however they feel on the day. Aged care workers just don’t seem to be able to cope with that.” Thirty-six-year-old trans man, carer

Ensuring that older trans and gender diverse people get the medical treatment they require is critical. Traditional, rigid structures of general medical practice in residential facilities can seriously impact continuity and efficacy of health care.

In some circumstances in aged care, trans and gender diverse people do not feel empowered to continue hormones based on their own autonomy, and experience a system which prioritises the expertise of specialists rather than the trans person’s knowledge and awareness of their own needs.

“The GP who is a regular at my residential facility has no specialisation in gender diversity. They stopped my hormone treatment. They reckon it would cause cancer because my mum had breast cancer. They didn’t speak to my psychiatrist. The loss of hormones has drastically affected my mood and my mental health.” – older trans woman in residential aged care

3. Aged care staff

Training of aged care staff is an enormous concern and creates fear for older trans and gender diverse people. High staff turnover in both home and residential aged care results in a lack of continuity and the need for older LGBTI people to continually reiterate their needs.

“Some care staff laugh at me. On my wardrobe doors are rainbow signs. The staff asked me, and I told them what it was about. It’s mostly with new staff, which seem to be coming

through all the time. It is little bit hurtful. I can't be bothered educating every new person though, I'm too old." – older trans woman in residential aged care

"The turnover of GPs, with doctors moving on, and no 'warm' referrals, it is very difficult to find a doctor who understands the needs of older LGBTIQ people ." – forty-year-old non-binary lesbian, aged care worker

While it's important that aged care services employ trans and gender diverse staff, it is acknowledged that they also face discrimination.

"I used to work as an aged care worker. With residents and elderly people, they don't care if you're trans as long as you give them the service they require. If you're doing well, they respect you. The problem comes from management."- thirty-nine-year-old trans woman, aged care worker

"From my experience I am an employee, and the employers and employees will often misgender me and mispronounce my name."- transwoman, aged care worker

Intersex people

Intersex Human Rights Australia (IHRA) have regularly advocated for the needs of older intersex people. ⁱⁱⁱ The Darlington Statement^{iv}, asserts: "We call for equitable access to social and welfare services for people with intersex variations. The needs of people with intersex variations in aged care, home care, state care, and disability services require further investigation, with full and meaningful participation by intersex-led organisations."

Including intersex people under the overall LGBTI umbrella highlights the common experience of facing discrimination because of not conforming to social expectations about what it means to be a real man or a real woman. However, because intersex people have a wide range of gender identities and sexualities many intersex people do not identify with LGBT communities. Still, given that intersex people are now included in the LGBTI cohort, they often face the associated stigma and discrimination.

The life experience of older intersex people may include a history of traumatic medical interventions. These older people may have been subjected to surgeries many decades ago which are now considered unnecessary or even harmful.

"I've had surgeries. I wouldn't have them now but at the time I didn't really get a choice."- sixty-year-old intersex woman

Receiving assistance for personal care can revisit the trauma caused by these historical experiences.

"I would feel really uncomfortable receiving personal care, just because of the scars and the memories of being examined by so many doctors." – sixty-year-old intersex woman

Aged care services could alleviate that risk of trauma by ensuring that all staff are trained to understand the experiences of older intersex people and have the communication and empathy skills to establish trust.

Older intersex people emphasise that if available, they would rely on recommendations by others before they approached specific aged care providers. Currently there is no way of accessing peer review of aged care services.

“If possible, I would like to be able to seek out a specialist service or a known, recommended service provider.” – fifty-five-year-old intersex woman

Older intersex people also noted that aged care staff work under enormous pressure to complete assigned tasks within tight timeframes, and that developing understanding and rapport with an older person takes time and requires consistency in staffing.

“People don’t have time to get to know older people. Workloads are huge and too often it’s a case of move on to the next highest priority.”- fifty-five-year-old intersex woman

Aboriginal and Torres Strait Islander people, Brotherboys and Sistergirls

Older Aboriginal and Torres Strait Islander LGBTI people were consistent in describing a lack of culturally appropriate care, and their fear of disclosing their LGBTI identity and cultural status when engaging with aged care services. There was a general sentiment that their experience of aged care services was for the most part, unpleasant at best.

“As a Sistergirl, it’s hard enough to be accepted in society and then at that age having to go into a place that doesn’t accept you with other aged care clients that don’t accept you.”- older urban Sistergirl

Those living in rural and remote communities had difficulty accessing the aged care system, particularly where access is dependent on unreliable local internet service provision. They felt the resources provided to them were not culturally appropriate, easily interpreted nor easily accessible. Problems with isolation, living away from country and being disconnected to kinship has a massive impact on social and emotional wellbeing, and it was felt that aged care providers did not understand or respond to this reality.

“There is no understanding of LGBTQ aged mob. Isolation is a huge issue. I have seen mob be removed and relocated to areas not familiar or known and soon comes death” – late fifties Aboriginal trans woman

Several older Aboriginal people raised their reluctance to talk about ageing because of its association with death. Loss, grief and bereavement are difficult for Aboriginal people. It is important to older Aboriginal LGBTI people that essential cultural practices take place for them to feel comfortable.

“An important thing for us is the cleansing of rooms people are moving into in aged care, particularly if people have died in those rooms. The rooms don’t feel right as they have not had a smoking ceremony. This cultural belief should not be neglected.” – mid-seventies urban Aboriginal lesbian

Other aspects of daily life which make Aboriginal people feel comfortable in aged care were also seen to be missing.

“There are no culturally appropriate traditional foods for our mob within these aged care facilities.” - late fifties Aboriginal trans woman

The ways in which aged care services are offered can significantly impact uptake of services by older Aboriginal LGBTI people.

“Older Brotherboys and Sistergirls will not ask. They need to be told what is being offered to them and given time to think it over. It may take time before people allow themselves to accept support and services.” - mid-seventies urban Aboriginal lesbian

These issues were compounded by a perceived lack of choice in service providers for older Aboriginal and Torres Strait Islander LGBTI people, and the inability of the sector to grow in response to need. Coupled with a lack of support for carers, and very few opportunities for respite, these issues were seen to be significant factors for the risk of homelessness.

The lack of Aboriginal or Torres Strait Islander staff to provide culturally safe and LGBTI inclusive services was noted by many. Older Aboriginal and Torres Strait Islander people believed the sector is not seen as desired employment and therefore requires a targeted employment strategy to increase its Aboriginal workforce, to become more sensitive to the needs of LGBTI older people and carers. The community is asking for aged care services to be run *“by Mob for Mob”*, with a willingness to accept responsibility for the management of Aboriginal-controlled aged care services.

“As First Nations people we should already have services set up where we are not constantly asking for a hand up. We need a better position at the table of decision making” – Aboriginal lesbian, aged care worker

“Educating a black workforce that are sensitive to LGBTIQ+ needs is an essential part of the assurances needed. “Aboriginal gay man, carer for Mum

Older Aboriginal and Torres Strait Islander people were very aware of the impact of various health conditions as they aged. Aged care and health services were characterised as having inadequate capacity to cope with the complex health needs of older Aboriginal people.

“Health care in Australia is not designed for older Aboriginal LGBT people. Aboriginal people suffer low life expectancy. We are prone to diabetes, heart problems, renal

disease, depression, hearing loss, high blood pressure, post-traumatic stress disorder and other health issues and challenges. Many of our people live in poverty or are surrounded by poverty. We need crisis care, palliative care and end of life care. Community outreach interventions, adequate home care services to care and protect our older and disabled rainbow mob.” -older Aboriginal gay man

In addition, poverty and social disadvantage are impacting on the ability of Aboriginal communities to take care of their older people in the way they would like.

“The harsh reality for Aboriginal people is, due to overcrowding in communities family members are not capable to care for the elderly and frail. Houses in remote, rural and metro housing would need to be modified. Bedrooms, bathrooms, toilets, entrances both front and back of the homes.” – older Aboriginal gay man

Several older Aboriginal and Torres Strait Islander LGBTI people expressed concern about the intersection of culture and identity and some community members not acknowledging LGBTI experience, resulting in further isolation.

“We as Aboriginal rainbow mob need to discuss our partners rights with whether our partners are able to be with us. Why are same sex unions not recognised within the aged care sector?” – older Aboriginal gay man

Older Aboriginal and Torres Strait Islander LGBTI people described differing experiences of utilising residential and home-based aged care services. This raised questions about the application of standards across the sector, and the lack of oversight of the application of standards, particularly relating to person-centered and culturally safe care.

LGBTI people living with dementia

There is a commonly held view that when diagnosed with dementia, older lesbian, gay, bisexual and transgender people revert to cis-gendered and heteronormative sexualities and identities experienced earlier in their lives. There is no research which proves this theory. Its continued prevalence in aged care discussions, with its implied assertion of heterosexuality or assigned sex as the most genuine presentation of the older person, can be seen as homophobic or transphobic.^v

“It’s a myth that trans and gender diverse people with dementia want to revert to their gender assigned at birth. It’s just an excuse to squash their authentic self.” – older trans woman

For older LGBTI people living with dementia, and their partners, the availability of inclusive respite care is critically important, and enables loved ones to remain at home for as long as possible. Respite care needs to be nearby and must be culturally safe and delivered as part of an overarching plan for continuity of care. This can significantly decrease the burden of coming out over and over again to temporary carers.

Many older LGBTI people expressed fear about dementia impacting their behavior and putting them in danger or placing an increasing burden on partners and friends. Some felt that it may increase the potential for aged care workers or their family to treat them disrespectfully.

“I am planning to ‘de-gay’ my unit until I know I can trust the workers, but I’m worried I’ll forget and something might slip out.” – fifty-four-year-old regional Aboriginal gay man

“There’s a gay man here with dementia – the dementia outed him, now family don’t visit him.” – sixty-three-year-old gay man living in residential aged care

Older LGBTI people with dementia were also seen as vulnerable and difficult to protect. Sexual assault was seen to be under-reported, and there was little awareness of programs or policies to combat the risk of sexual assault in residential or home-based aged care.

“I think sexual assault happens a lot in these aged services – especially if you have dementia.” – older gay man

A lack of clarity about the expression of sexuality and disagreements about appropriate sexual behaviour may also negatively impact LGBTI older people living with dementia.

“If you’re someone with dementia and you act in line with your sexuality and some staff member or doctor has a problem with that the behavior could be seen as more of an issue than it is.” – older gay man in residential aged care

The number of people in the general population diagnosed with dementia is increasing, which inevitably means that the number of LGBTI people diagnosed with dementia is also increasing. People living with HIV may be diagnosed with specific HIV related dementias^{vi}. Ensuring appropriate care for all older LGBTI people living with dementia is critical.

Conclusion

This submission covers some of the specific needs of each group in the LGBTI cohort and describes the unique experiences of older Aboriginal and Torres Strait Islander people as well as other older LGBTI people living with dementia. The material is presented in the hope that aged care service providers develop plans, practices, systems, and policies with a nuanced approach to the needs of older LGBTI people.

The observations and recommendations in this submission arise from a number of general group consultations and the transcripts of individual interviews with over 80 LGBTI older people, their carers, friends and family, LGBTI carers and LGBTI aged care workers.

In staying true to the interviews, some broader issues may not be included as they may not have been mentioned. Those broader issues impacting older LGBTI people who access aged care are presented in other submissions provided to the Royal Commission by the National LGBTI Health Alliance and are available at www.lgbtihealth.org.au

Recommendations

The National LGBTI Health Alliance welcomes any opportunity to work with the Aged Care Quality and Safety Committee to address the recommendations in this submission.

Recommendation 1 – Training and education

Compulsory training and education for all aged care staff in culturally safe practice for LGBTI people to include:

- a. Information about the dangers of cissexist, heterosexist and ageist attitudes*
- b. An emphasis on professional standards and diversity frameworks*
- c. Specific material relating to the experience of lesbian, gay, bisexual people, trans and gender diverse people and intersex people*
- d. Information about appropriate respite care*
- e. Initiatives to educate all residents in aged care*

Recommendation 2 – Cultural safety

- a. The aged care system is encouraged to provide a range of specialist services responding to the specialist needs of different sections of LGBTI communities*
- b. Aged care service providers recognise, facilitate and celebrate intimate relationships and explore ways of enabling new intimate relationships to form.*
- c. Protocols around the best practice for LGBTI older people in aged care are extended to include the experiences of LGBTI family and friends*
- d. Aged care standards related to cultural safety and personal care be applied consistently everywhere across the aged care service, including in services run by community providers*
- e. LGBTI health services and other providers publicise positive experiences of older LGBTI people using aged care services*
- f. Aged care service providers to facilitate and encourage older LGBTI people's connection to LGBTI organisations and activities*

Recommendation 3 – Staff and systems

- a. Aged care service providers establish systems to attract and retain LGBTI staff*
- b. Aged care service providers to establish robust and independent complaints systems, with protection for complainants, consequences for poor practice and action plans for improvements and monitored by an effective regulator*
- c. Aged care service providers establish a public system of peer review and recommendation for aged care services*
- d. Government funding models need to be designed to enable Aboriginal and Torres Strait Islander people to establish their own aged care services.*

- e. *Government and research facilities fund and conduct more research into the impact of dementia on LGBTI people*

Recommendation 4 – Care and personal needs

- a. *The need for gender compatible personal care, dress, style and grooming should be addressed for all older people in aged care*
- b. *Aged care service providers ensure the maintenance of health care and medication for older LGBTI people, including hormonal therapy and HIV medications*
- c. *Aged care service providers ensure the provision of nutritious food catering to a wide variety of dietary requirements*
- d. *Aged care service providers put in place processes to enable older people to remain connected to their pets*

ⁱ Woods, R. *HIV and Ageing in Australia – The New Frontier*, National Association of People with HIV Australia, 2019, <https://napwha.org.au/wp-content/uploads/2019/04/HIV-and-Ageing-in-Australia-New-Frontier-April19.pdf> accessed 22 June 2020

ⁱⁱ J.R.Latham and Catherine Barrett, *We're people first: Trans Health and Ageing, an evidence based guide to inclusive services*, Melbourne, 2015
https://www.researchgate.net/publication/293489252_We're_people_first_Trans_Health_and_Ageing_-_An_evidence-based_guide_to_inclusive_services Accessed 17 June 2020

ⁱⁱⁱ Intersex Human Rights Australia (IHRA) <https://ihra.org.au/category/issues/ageing/> accessed 11 June 2020

^{iv} *The Darlington Statement: a joint consensus statement by Australian and Aotearoa/New Zealand intersex organisations and independent advocates*. March 2017. <https://darlington.org.au/statement/>

^v Catherine Barrett et al, *We are still gay: the needs of LGBTI Australians with dementia*. Australian Journal of Dementia Care, 12 October 2015 <https://journalofdementiacare.com/we-are-still-gay-the-needs-of-lgbt-australians-with-dementia/> accessed 17 June 2020

^{vi} Alzheimer's Australia, *Living with HIV-associated neurocognitive disorders (HAND)*, Sydney, 2014
<https://www.dementia.org.au/files/VIC/Dementia%20%20HIV%20Consumer%20Brochure%20%20Dec%20web%20%282%29.pdf> Accessed 17 June 2020