



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

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Royal Commission into Aged Care Quality and Safety

Future Design of the Aged Care System 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.

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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 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.



SILVER RAINBOW

Introduction

The National LGBTI Health Alliance (the Alliance) welcomes the opportunity to provide a submission to the Royal Commission on the future design of the aged care system. The entire aged care system needs to be re-designed so that LGBTI older people are at the centre of the system rather than resorting to ‘safety nets’ or adding things onto the system to make it inclusive.

This submission is informed by a co-design process involving the establishment of a Royal Commission Advisory Group with expert representatives of LGBTI communities and organisations across Australia, facilitated by the Alliance, and evidence from community consultations. Our responses will be informed by the Aged Care Charter of Rights and the Quality Standards, with a specific focus on diversity.

The Alliance would like to take this opportunity to reiterate its strong commitment to the Aged Care Diversity Framework and the corresponding Action Plans for consumers and providers.

This submission will be framed in response to the questions outlined in the Consultation Paper 1, and present key recommendations for an aged care system that adequately meets the needs of LGBTI older people.

What should be the underlying principles of a redesigned aged care system, which meets the needs of LGBTI people?

“I need carers to help me shower. That’s really personal and hard. I really need people who are totally fine with my sexuality and my body.”

The Alliance welcomes the proposed principles in the Consultation Paper to address the systemic failure to provide high quality clinical and personal care. In particular, we welcome the inclusion of rights, dignity, choice and respect in Principle 1. Trauma-informed and person-centred care must be central to any system re-design to ensure older LGBTI people are not left behind.

A trauma-informed approach encompasses the historical experiences of discrimination, abuse and exclusion, and encourages service providers to consider these experiences when providing appropriate care. A person-centred approach acknowledges the distinct care needs of the 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.

Many older LGBTI people experience multiple, interconnected and reoccurring forms of harm related directly to their sexuality, gender identity and/or their sex characteristics, which reinforce barriers to accessing aged care. An intersectional approach will help address

the unique challenges that those who sit at the intersections of overlapping systems of discrimination. This will be essential to remove those multiple systemic access barriers.

Recommendation: Trauma-informed and person-centred care approach be embedded in the principles to ensure high quality and culturally safe care.

How could we ensure that any redesign of the aged care system makes it simpler for older LGBTI people to find and receive the care and supports that they need?

The aged care system can be difficult to navigate and understand for older LGBTI people. The Diversity Framework provides a raft of changes that are needed to ensure the overarching imperatives of Framework are achieved. Further systemic changes are needed to ensure older LGBTI people find and receive the care and supports they need.

While the Alliance acknowledges the role that system navigators play at the entry point to aged care, a case manager and care coordinator framework will enhance the navigator role to assist older LGBTI people to feel supported and safe throughout the aged care journey.

Information around aged care and local services need to be available in print and accessible for example via GPs, medical centres, and community centres.

Adopting a 'no wrong door' approach to the aged care system will reduce access barriers and enhance support for older LGBTI people who are already subject to marginalisation and stigma. This will also ensure older LGBTI people have timely access to the supports and services they need, and prevent issues escalating to the point of crisis.

Recommendation: Establish a case management and care coordination model within the aged care system.

Recommendation: Ensure that information around aged care is available at multiple access points.

Recommendation: Adopt a 'no wrong door' approach to the aged care system.

What is the most appropriate way for older LGBTI people to access the aged care system initially? (for example, by phone and website or face-to-face services)

"I've tried to get into the Aged Care system on the computer. It's just so confusing."

The Alliance supports the Commission's view that regardless of the first type of care a person uses and the setting for that care, the system must be much simpler and easier to understand, and people need to be supported to access care when, how and where they need it.

Due to many older LGBTI people 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 them.

When determining the most appropriate delivery mode for access to the aged care system, in addition to understanding and responding to individual needs, the diverse and remote geographical locations where people live, technology access and technology literacy also need to be considered. While face to face is often regarded as the best option to build trust and rapport, it is important that these engagements are provided by trained, inclusive, empathetic professionals.

It is important that services that focus on maintaining and supporting autonomy and independence are appropriate for the needs of older LGBTI people. A key challenge for them is that they may be living alone with no family support making them more vulnerable and socially isolated. This may reduce their ability to access and navigate the aged care system, and advocate on their own behalf. A culturally safe face to face access point is essential to ensuring that vulnerable individuals do not get left behind.

It is important to note, that the government's proposed Religious Discrimination Bill will exacerbate the real and/or perceived fear of being discriminated by religious providers. This experience is heightened when faith-based service providers are the only provider in their area. In this instance the 'no wrong door' principle articulated above is being compromised.

Recommendation: Easy to understand and accessible information including printed materials.

Recommendation: The Royal Commission address the potential adverse implications of the government's proposed Religious Discrimination Bill on older LGBTI people.

How should government support older LGBTI people to meet their domestic and social needs?

"There are so many cleaners to choose from. Why can't I just choose one that has a little rainbow flag next to it in the list? That would make me feel much better."

The Alliance supports the Commission's view that framing the policy discussion around 'markets' and describing older people needing aged care services as 'consumers' reduces the issue to one of transactions rather than relationships or care.

Most older LGBTI people would prefer to live at home for as long as possible, regardless of their support needs. Aged care systems need to be constructed in a way that enables LGBTI older people to choose and identify LGBTI-friendly service providers.

We acknowledge the vital role that LGBTI Community Visitor Schemes play in meeting the social needs of LGBTI older people in maintaining connection to LGBTI communities. It is important to recognise that this service is not available in each jurisdiction with some of these services not delivered by LGBTI organisations. It is crucial that funding is provided so that this service can be delivered across each jurisdiction and delivered by LGBTI health organisations who have the most expertise in providing culturally competent programs.

We believe more investment in local governments and local services is crucial in building their capacity to provide LGBTI specific social support programs. Applying a cultural and diversity lens to these programs is needed to ensure that days of significance, festivities and community events for LGBTI people are recognised, and the appropriate linking to LGBTI services is conducted.

Recommendation: Funding provided to LGBTI Community Visitor Schemes to ensure it is delivered in every jurisdiction.

Recommendation: Further investment in local government and local services to provide LGBTI specific social supports and foster connection with LGBTI communities.

What are the most important interventions for older LGBTI people experiencing a crisis?

In times of crisis, a flexible system that enables quick responses in services provided, particularly in areas of mental health, homelessness, health, family rejection, and financial stress is critical to LGBTI older people. Peer-led initiatives are fundamental to providing culturally safe care to LGBTI people experiencing a crisis.

It is imperative that all crisis interventions are undertaken with the informed consent of the individual. An important consideration when providing services to LGBTI older people, as well as in times of crisis, is the recognition of the fact that for some individuals their family may not be supportive or embracing of their sexuality and/or gender identity and expression. The voice and consent of the individual being heard and respected is paramount to avoid family control and discrimination. Therefore, to ensure LGBTI older people's wishes are carried out and their partner's rights protected (if they have one), service providers need to carefully consider these issues. This may involve case managers and care coordinators regularly reviewing documents associated with Advanced Care Directives, Enduring Guardianship and Power of Attorney, and mental health care plans to ensure LGBTI older people are appropriately supported.

People who care for LGBTI older people need flexible respite options that are culturally appropriate and safe, and must be respectful of caring relationships in a LGBTI context. This may include in-home respite or residential respite.

Recommendation: Care coordinators and Case managers regularly reviewing documents and plans.

Recommendation: The aged care system is flexible and responsive to multiple crises.

Recommendation: Culturally appropriate and safe respite care available to LGBTI older people.

How could existing provision of personal care, as well as nursing and allied health, be reoriented so that they are focused on individual needs, and not on whether the older LGBTI person is at home or in a residential facility?

“Do I have to censor my home before services visit me?”

Given that LGBTI older people prefer to stay in their own homes, we would like to reinforce the importance of embedding person-centred and trauma-informed care initiatives, irrespective of the individual’s location. This would involve community nurses and allied health services providers undertaking LGBTI-awareness training. Furthermore, it is imperative that these services are interconnected to ensure appropriate continuity of care.

Many LGBTI people speak about their experience of hiding signifiers of their sexuality and/or gender identity and modifying their behaviour, experiences or history to avoid discrimination from home care service providers.

For LGBTI older people their home is often the only safe space they have. Proposals to transition residential care over time to a less institutional and more home-like physical environment must avoid disrupting that sense of safety.

Recommendation: Community nurses and allied health service providers undertake LGBTI-awareness training.

Recommendation: Community nurses and allied health service providers enact processes to ensure continuity of care.

Recommendation: LGBTI older people are treated with respect and dignity in their own home and in residential settings.

How could the aged care and health systems work together to deliver care which better meets the complex health needs of LGBTI older people, including dementia care as well as palliative and end of life care?

Access to quality, inclusive and individually tailored palliative care is critical to ensuring older LGBTI people with dementia die with dignity. Aged care staff must be skilled to deliver

palliative care in the various care settings and provide training on the needs of LGBTI communities. Services also need to be better coordinated and integrated, and therefore be able to work together to ensure older LGBTI people have access to palliative care services and the support they need during end of life care regardless of the care setting.

A major issue is the lack of dementia prevalence data combined with the lack of data on how many older LGBTI people live in Australia. The inclusion of sexual orientation, gender identity and intersex status in the 2021 Census may have addressed this issue in part. Unfortunately, this data will not be collected. Accurate data is needed to collaboratively, effectively and efficiently plan and deliver dementia care, palliative and end of life care to older LGBTI people.

Changes in behaviour, as a result of dementia, may result in people being less able to maintain their privacy and hide their sexuality, gender identity and expression. This can result in unintentional disclosure and can be upsetting for family, as well as to the person themselves. There is no evidence that dementia leads to LGBT people 'forgetting' their gender or sexual identity and reverting to being heterosexual and/or cisgender.

It is important to note that aged care and health systems are adequately skilled and knowledgeable of HIV Associated Neurocognitive Disorder or HAND, which is a type of dementia that may affect 20-40% of people living with HIV.

Interference in the lives of intersex people is considered one of the greatest issues facing ageing intersex people. More research is needed on the effects of surgeries and behavioural modifications, coupled with long terms drug therapies (often imposed without informed consent). Currently, there are no long-term follow-ups taking place in Australia, and handovers from paediatric to adult services result in limited healthcare access by adults, and a lack of clinical data on adult outcomes.

For trans and gender diverse people:

- Ongoing monitoring of people on hormone therapy can help to reduce the risks of some cardiovascular conditions, strokes and thrombosis for trans women.
- There is a need for hormones to reduce the risk of osteoporosis, preserve immune function, and ensure optimal psychological health.
- It may be dangerous to discontinue an older person's hormones.

Recommendation: Access to quality, inclusive and individually tailored palliative care.

Recommendation: Heteronormative standards of behaviour should be challenged in the context of providing care to LGBTI older people living with dementia.

Recommendation: The Aged Care Quality and Safety Commission support the collection data on sexual orientation, gender identity and intersex status of the Australian population in the 2021 Census.

Recommendation: At the interface of aged care and health services, there needs to be an understanding of the unique needs of trans and gender diverse people, and intersex people.

How should the design of the future aged care system take into account the needs of LGBTI people in urban, regional and remote locations?

Culturally safe care and trauma-informed care should be applied universally, regardless of an individual's location. For example, in areas where there are limited number of aged care service providers, it is critical that the individual needs of older LGBTI people are addressed sensitively and appropriately.

As previously mentioned, currently there is limited data collected on LGBTI populations, both at a national Census level and throughout the aged care system. Limited or no data means that we do not know who is receiving aged care, who has attempted to access aged care but has dropped out and who is not engaging with aged care services. Access to quality and robust data on LGBTI populations is crucial in order to address barriers to access for LGBTI older people.

Robust processes around confidentiality and privacy need to be embedded in the aged care system across in different locations, particularly in small population areas, to ensure LGBTI older people can access the supports they need in a safe and affirming environment.

In addition, maintaining and expanding specialised LGBTI Community Visitor Schemes in regional areas is essential in addressing social isolation and community connection for LGBTI people. A nationally coordinated approach to these schemes is something supported by the National LGBTI Health Alliance.

Recommendation: Maintain and expand CVS schemes to capture isolated LGBTI older people.

Recommendation: System design ensures confidentiality and privacy of the individual is enforced.

How would the community be assured that the services provided under a new model are being delivered to older LGBTI people to high standard of quality and safety?

Successful assessment of services for LGBTI older people should not be solely measured by the completion of tasks. A holistic approach needs to be embedded when evaluating the appropriateness of services for LGBTI older people.

The aged care system needs to report on the number of LGBTI older people who are accessing aged care services, and those who fall out of the system. This data needs to be made publicly available to ensure equity in service provision for LGBTI older people.

Aged Care Providers are required to have Diversity Action Plans that demonstrate the policies and practices the provider has in place to deliver safe and quality services to diversity groups. In their annual reviews of these plans, ACQSC or Diversity Advisors need to employ robust processes that are supported by strong evidence.

Significant improvements need to be made to the structure of audits and the knowledge and skills of assessors. Consumers, families, carers and all levels of staff should participate in assessments. There needs to be much more rigour, accountability and sanctions for non-compliance.

It is important to involve older LGBTI older people at the organisational governance level. This will strengthen transparency and ensure accountability to maintaining high standards of quality and safety.

Robust and protective complaints and feedback mechanisms provide essential tools for addressing instances of discrimination and abuse of LGBTI older people. Appropriate tools and knowledge enable complaints to be fairly investigated and addressed. However, relying on people to make complaints about poor or discriminatory care unfairly puts the onus on the person to be able to speak up for themselves. Many LGBTI older people do not feel empowered or safe to do this. Embedding processes that enable people accessing aged care services to provide critical feedback in ways that are not perceived as making a complaint will enable LGBTI older people to engage in a safe way.

There needs to be consequences for non-inclusive practices. When service providers cannot demonstrate that they are providing high quality, culturally safe inclusive services this should be reported and acted upon as a serious failure in meeting the requirements of the standards with serious consequences. Failing to be inclusive can cause significant harm to LGBTI older people.

Recommendation: Collection of data in relation to accessing the aged care system.

Recommendation: Robust processes to assess Diversity Action Plans.

Recommendation: Robust and protective complaints and feedback mechanisms to be in place.

Recommendation: Better resource, build the capacity of, and provide appropriate powers to the Aged Care and Safety Commission to adequately resolve complaints in a timely manner.

Conclusion

Overall, there is a demonstrated need for the current aged care system to be made more accessible for and inclusive of LGBTI older people. This includes all service elements, practice and systems ensuring that LGBTI older people are affirmed and will receive culturally safe, effective, appropriate and accessible services that meets their individual needs, free from discrimination. Moving forward, it is important that any changes made to the aged care system are undertaken through a co-design process with LGBTI older people. Also, it is vital that any system redesign encompasses the reality of Australia's ageing population and increasing diversity, and embeds flexible service models to adequately respond to an individual's care needs.