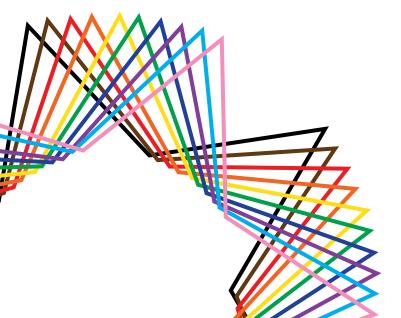




LGBTIQ+ Health Australia – A response to the final report of the Royal Commission into Aged Care Quality and Safety; "Care, dignity and respect."

**April 2021** 



# LGBTIQ+ Health Australia – A response to the final report of the Royal Commission into Aged Care Quality and Safety; "Care, dignity and respect."

## **Executive Summary**

The final recommendations of the Royal Commission into Aged Care Quality and Safety present a number of important opportunities for improving the lives of all older people. The success of these recommendations to specifically improve the lives of older LGBTIQ+ people is dependent on:

- The proposed new Aged Care Act being truly human rights based with a clear focus on tangible outcomes for LGBTIQ+ older people.
- The review of the Aged Care Quality Standards including the concept of cultural safety and traumainformed care as well as physical elements like personal care, nutrition and medication management.
- Specialist LGBTIQ+ awareness training organisations, including Silver Rainbow and other LGBTIQ+ health organisations, receiving increased funding as part of designing for diversity, difference, complexity and individuality.
- Further funding being secured to expand specialist LGBTIQ+ community visitors schemes as part of the Aged Care Volunteer Visitors Scheme.
- Budget allocations for aged care services reaching older LGBTIQ+ people through select tender to LGBTIQ+ specialist organisations.
- The Aged Care Diversity Framework and Action Plans being made mandatory.
- Existing governance and advisory structures being maintained through the transition.
- Timeframes for implementation of the recommendations being accelerated.
- Older LGBTIQ+ people with lived experience of the aged care system participating in advisory groups at all levels.
- The collection of data about LGBTIQ+ communities at all levels conforming to the ABS Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables.

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The Royal Commission into Aged Care Quality and Safety delivered its final report on 1 March 2021.<sup>1</sup> Over five volumes the Commissioners grappled with the systemic problems and common instances of substandard care for older Australians and put forward wide-ranging recommendations for reform.

Older LGBTIQ+ people regularly express concern about their quality of life. Like everyone else accessing aged care services, older LGBTIQ+ people using aged care services suffer neglect, abuse, indifference and poor-quality care and desperately want improvements to every aspect of aged care, from legislation and governance, to workforce, complexity in accessing the system, intricate funding models and the proper regulation of standards for practical aspects of care like personal care, nutrition and medication management. It is clear that the Aged Care Diversity Framework2, in place since 2017, has not been widely embedded in the delivery of services nor enforced across the system, giving strength to the argument that the framework, and particularly the associated Action Plans, should become mandatory, with comprehensive monitoring and evaluation.

In response to the Final Report, LGBTIQ+ Health Australia (LHA)<sup>3</sup> joined with other peak bodies to produce a joint statement<sup>4</sup> presenting a comprehensive list of urgent actions needed to address the failures of the whole aged care system. Enacting these proposals to establish a single entitlement-based aged care system will improve aged care for everyone, including older LGBTIQ

people, and lay a foundation to ensure that all older people are safe, comfortable, well-cared for and treated with respect.

This joint call for urgent action is particularly important given the increasing numbers of people requiring aged care services, and the short period of time older people generally avail themselves of aged care services. The average length of stay for permanent residential aged care, for example, is only 30 months<sup>5</sup> meaning any delay in reform will have the effect of continuing sub-standard care for a further generation of older people.

In addition to the generally inadequate standard of aged care services, our consultations and subsequent submissions identify that older LGBTIQ+ people have particular and unique needs. While recognising that a number of the Royal Commission's recommendations present opportunities for improvement, it is disappointing to note that there are no specific recommendations for improving the experience of older LGBTIQ+ people using aged care services. This paper explores opportunities for improving the experience of older LGBTIQ+ people accessing aged care in response to the Final Report, sets a foundation for discussion with politicians, policy makers and departments at the national level and contributes to a broader discussion about the role of older people in Australia and within our LGBTIQ+ communities. It is also a call to action for communities and allies to continue to advocate and agitate on behalf of older LGBTIQ+ people.

At present, preparations are well underway for a new federal budget, currently due in mid-May 2021. This budget offers an opportunity to fund and fully enact the recommendations of this Royal Commission and in turn improve the lives of older LGBTIQ+ Australians. Notwithstanding the Federal government's stated commitment to respect and care for older Australians, and to immediately inject a further \$452m into the system, it is not clear whether all recommendations have been accepted, particularly those initiatives which would significantly improve the lives of older LGBTIQ+ people. LGBTIQ+ community controlled and specialist health organisations need significant support and strengthening to enable strong representation and services for older LGBTIQ+ people. If the system is improved to ensure that the most vulnerable receive appropriate care, then it will be appropriate for everyone.

The list of recommendations represents an extensive program of change for the sector. While change is taking pace, it is important that the existing structures continue to function, particularly the Aged Care Sector Committee Diversity Sub-group, and support for the work of the National Aged Care Alliance (NACA).<sup>7</sup>

#### Response 1.

The Minister for Health and Aged Care and the Minister for Senior Australians and Aged Care Services meet with LGBTIQ+ Health Australia (LHA) to discuss:

- ensuring budget allocations reach older LGBTIQ+ people through select tender to LGBTIQ+ specialist organisations.
- making the Aged Care Diversity Framework and Action Plans mandatory.
- maintaining existing governance and advisory structures through the transition
- shortening the timeframes for implementation of the recommendations.

## What did the Royal Commission know about the experience of older LGBTIQ+ people?

LGBTIQ+ Health Australia (LHA) was determined to ensure that the Royal Commission received and considered the widest possible array of information about the experience of older LGBTIQ+ people with aged care services. Engaging with the Royal Commission to ensure that the needs of older lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ+) people were heard was critical. LHA acknowledged the importance of collaborating with other health and advocacy groups.

Community consultation and reporting on the needs of older LGBTIQ+ people began immediately, bringing together groups of older LGBTIQ+ people, carers, loved ones and aged care staff in workshops across the country. An initial roundtable discussion with the Commission was held in April 2019, which included representatives of Transgender Victoria, Celebrate Ageing, COTA, Lifeview Residential Care, ECH, La Trobe University and ACON NSW. Sam Edmonds gave a presentation at the Diversity Hearing in October 2019 on behalf of LHA<sup>8</sup>, along with other older LGBTIQ+ people and advocates. A Royal Commission Advisory Group was established, and extensive community consultation resulted in seven submissions to the Commission made between October 2019 and June 2020<sup>9</sup>.

This wide-ranging exploration and documentation of the issues facing older LGBTIQ+ people were also presented to the Commission in submissions from Matrix Guild Victoria, National Association of People with HIV, Australian Federation of AIDS Organisations and HIV Institute of Western Australia.

In this way the Commission received extensive and detailed information about the experience of older LGBTIQ+ people, carers and loved ones, as well as LGBTIQ+ staff with aged care services. Submissions included documented lived experience demonstrating systemic discrimination, inappropriate services, culturally unsafe practices, denial of gender identity, privacy breaches and a myriad of other damaging practices. The submissions put forward many suggestions for improving the system. The Commission was also supplied with critical published documents which described cultural safety<sup>10</sup> and actions which would support older LGBTIQ+ Australians<sup>11</sup>

The Royal Commission into Aged Care Quality and Safety's Interim Report, "A Shocking Tale of Neglect" was delivered in October 2019. Again, LHA responded 12, noting that commentary and observations specific to older LGBTIQ+ people were absent, while agreeing with the overall conclusions. LHA specifically requested that the Final Report address the myriad barriers to equitable care for older LGBTIQ+ Australians.

## What did they say?

There are few references to LGBTIQ+ people in the Final Report. Volume 2 includes the evidence given by Anne Tudor in regard to her partner Edie Mayhew's experience with home care after being diagnosed with younger onset dementia. The couple experienced a lack of acknowledgement of their relationship and a lack of effort to ensure their needs were met. An advocate also describes an example of lack of cultural safety and discrimination towards a transgender woman, including the denial of her gender.

In the report summary, the Commission recognises and defines LGBTIQ+ people as existing within the definition of people from diverse backgrounds. It acknowledges the provision of evidence that LGBTIQ+ people struggle to find appropriate aged care services. There is also an appreciation of the importance of LGBTIQ+ visitors for LGBTIQ+ older people.

# The Final Report contributes to and maintains the invisibility of older LGBTIQ+ people.

Of the 148 recommendations, each with a number of sub-clauses, not one mentions the specific needs of LGBTIQ+ older people. The needs and requirements of older LGBTIQ+ people have been amalgamated into a broad concept of people from diverse backgrounds. This approach risks the development of solutions based on generalisations and a common experience of discrimination. While some common experience may be shared, communities included under the label of diverse are often as different from each other as they are from the mainstream. Even under the LGBTIQ+ umbrella there are communities with vastly different and sometimes competing needs. It is disappointing that the Royal Commission was not able to include any responses to specific issues raised with them about LGBTIQ+ older people and their needs.

Given the potential for intersecting discrimination, it is also regrettable that the needs of older people from Culturally and Linguistically Diverse (CALD) backgrounds are not specifically addressed.

On the other hand, the Commission is to be congratulated for their focus on Aboriginal and Torres Strait Islander elders, who continue to suffer huge healthcare and aged care disparities. However, again there is no acknowledgement of the particular experience of Aboriginal and Torres Strait Islander trans and gender diverse people, Brotherboys and Sistergirls, who are subject to multiple intersecting discrimination.

There is another way that the Commission has rendered LGBTIQ+ people invisible. It fails to identify the need for indicators of sex, gender, variations of sex characteristics and sexual orientation to be included in mainstream data reporting, national surveys and the census. Many of the recommendations quite rightly rely on the collection and analysis of reliable and indicative data about service provision and the demography of those who use aged care services. The Commission addresses the paucity of data, with the concomitant inability to identify failures in the system, or indeed those who are doing well. However, the first general submission LHA made to the Commission noted that: "there is a lack of data on the sexual orientation, gender identity and variations in sex characteristics of the Australian population." Currently we can only use research and estimates to determine the number of LGBTIQ+ people in the Australian population. Notwithstanding the publication of national standards for the collection and dissemination of data relating to sex, gender, variations of sex characteristics and sexual orientation<sup>13</sup>, and against a background where government failed to include sexual orientation and gender identity questions in the 2021 Census, if base data does not exist for LGBTIQ+ people, then those recommendations which rely on data will fail to expose the issues faced by older LGBTIQ+ people in aged care.

## Opportunities in the recommendations.

The overall content of the recommendations is welcome and offers multiple opportunities for older LGBTIQ+ people and their advocates to work together with government, peak bodies and providers to improve aged care services. Integrating long-term care and support, ensuring appropriate pricing, embedding standards for high quality care, addressing the needs of older people living with dementia, tightly regulating the use of restraints, the provision of better information, a single assessment process, the inclusion of allied health and an intention to effect changes for the aged care workforce are all strategies which have the potential to improve the lived experience of older LGBTIQ+ people accessing aged care.

Notwithstanding the paucity of data about LGBTI communities, and the failure to establish enforceable agreed metrics or respectful data collection methodologies, the intention to establish

and produce robust data about the performance of the system and use that data to drive meaningful reform will be a game changer for aged care services.

There are other broader issues of interest and concern. We know how important it is for older LGBTIQ+ people to stay connected to people and activities which affirm and celebrate their identities. Throughout the Final Report, and the recommendations, there are mentions of "older people receiving aged care services and their families". For many older LGBTIQ+ people, their family of choice includes partners, ex-partners, long-term friends, fellow activists, household members, non-biological children and community visitors. It is to be hoped that the intention of many of the recommendations includes family of choice.

Response 2.	Government maintains a commitment to the importance of family of
	choice for older LGBTIQ+ people

The recommendations suggest a variety of forums and advisory groups with the intention of ensuring the broadest possible system of governance and maximising the views and voices of all older Australians. There is a concern, however, that aged care providers and professionals will dominate these groups, and that the voices of older LGBTIQ+ people and their advocates will be lost in a system which is high-level, formal and hierarchical, rather than built on principles of codesign and self-determination.

Response 3.	The Aged Care Commission ensures that older LGBTIQ+ people with lived
	experience of the aged care system are supported in participating in
	advisory groups at all levels.

There are also specific opportunities within the recommendations.

### Recommendations 1, 2 and 3. A New Aged Care Act

In Volume 2 of the Final Report the Commission notes that an objective of the current Aged Care Act is 'to facilitate access to aged care services by those who need them, regardless of race, culture, language, gender, economic circumstance or geographic location'. Section 11-3 of the Aged Care Act gives effect to this object, listing a number of groups as being people with "special needs", including lesbian, gay, bisexual, transgender and intersex people. The lived experience of older LGBTIQ+ people, as reported in our consultations, provides evidence that the intention behind this categorisation of LGBTIQ+ people as having "special needs" has not driven the broad-scale review and re-engineering of services necessary to provide inclusive and positive care. The term "special needs" requires updating, but in a way which still offers the legislative framework to enable the identification of key issues and more importantly, to deliver real change.

The Final Report recommends a new Aged Care Act, and particularly focusses on the rights of older people receiving care, as well as clearly stating that a new act should ensure equitable access to care services. This rights-based approach is welcomed and should offer far-reaching opportunities to ensure that the aged care system delivers appropriate care to older LGBTIQ+ people. However, the right to equitable access does not necessarily mean the right to equitable outcomes.

Establishing and measuring tangible markers of success will be critical in ensuring that any new Act improves the experiences of older LGBTI people using aged care services.

Response 4.	Government, the Department of Health and Aged Care, peak bodies
	and LGBTIQ+ organisations work with LHA to ensure that the new Aged
	Care Act is truly human rights based and has a clear focus on tangible
	outcomes for LGBTIQ+ older people.

# **Recommendation 5. Establishing an Aged Care Commission**

The establishment of a nationwide Aged Care Commission to manage and govern the aged care system is welcome. In particular, a Complaints Commissioner who fully understands LGBTIQ+ issues and acts upon complaints about providers, staff, assessors and care finders would make a tangible difference to older LGBTIQ+ people, who have regularly reported their reluctance to complain for fear of retribution, and their frustration with inaction about legitimate complaints.

Response 5. As soon as possible after its establishment on 1 July 2023, the Aged Care Commission and the Commissioner work with LHA to ensure that the particular needs of older LGBTIQ+ people are understood.

#### Recommendation 9. The establishment of a Council of Elders

Commissioner Briggs recommended the establishment of a Council of Elders, as a high-level advisory body focusing on the rights and dignity of older people. It is unclear how the interests of older LGBTIQ+ people be represented there. It is also worth noting that the use of the term "elder" to describe older LGBTIQ+ people in general is the subject of debate within LGBTIQ+ communities, as it can be seen as undermining the recognition of Indigenous Elders.

Response 6. The Aged Care Commission and the Commissioner work with LHA to ensure that older LGBTIQ+ people with lived experience are included on the Council of Elders.

### Recommendations 19 - 23. Urgent review of the Aged Care Quality Standards

The promised review of the Aged Care Quality Standards, beginning on 15 July 2021, is very welcome. However, the delay (until 1 July 2022) in including minimum qualifications for aged care staff, and ensuring the Standards reflect the Aged Care Diversity Framework and underlying Action Plans is again disappointing, even where there is the stated opportunity to make them mandatory.

Response 7. The Aged Care Quality and Safety Commission immediately begin negotiations with LHA to ensure:

 the needs of older LGBTIQ+ people are included in the review of the Aged Care Quality Standards, in particular to ensure that cultural safety is an element of the standards, as well as physical elements like nutrition and medication management.
 the Aged Care Diversity Framework and Action Plans are made mandatory.

## Recommendation 24. Star ratings system.

A publicly available rating system which allows older LGBTIQ+ people, their loved-ones and carers, to make meaningful comparisons of the quality and cultural safety of services is very welcome. For that outcome to be achieved, the measurable data will need to include elements of best practice care for older LGBTIQ+ people.

Response 8.	Leading up to July 2022, discussions between government and LHA take
	place to ensure that the new star rating system provides transparent and
	relevant information to enable older LGBTIQ+ people to make culturally
	safe choices about their care.

#### Recommendation 26. Improved public awareness.

The Interim report of the Royal Commission into Aged Care Quality and Safety identified ageism as the root cause of the neglect of older people and the aged care system.

"As a nation, Australia has drifted into an ageist mindset that undervalues older people and limits their possibilities." This recommendation, which seeks to educate and inform the Australian public, will address that issue.

Response 9.	Government work with LHA to develop and maintain an educational
	program which challenges ageism, particularly where it intersects
	with homophobia and transphobia, and encourage broad-based
	intergenerational connection.

### Recommendation 30. Designing for diversity, difference, complexity and individuality.

This recommendation offers many opportunities to improve the experience of older LGBTIQ+ people accessing and using aged care services. The expressed need for training on cultural safety and trauma-informed care supports existing training and awareness programs currently delivered at both the state and national level, including the Silver Rainbow training initiative<sup>15</sup>. Ensuring that service providers provide evidence of being able to provide specialised services for groups of people with diverse backgrounds and life experiences will also provide assurance for older LGBTIQ+ people.

•	Government work with LHA to provide further support for Silver Rainbow training, and that provided by other LGBTIQ+ health organisations.
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The intention to formulate a standard dataset which enables monitoring, analysing and using information about the diverse backgrounds and life experiences of older people to improve services is again very welcome. Robust and credible data will enable advocates, for instance, to challenge the often-stated assertion that "we don't have any LGBTIQ people here", with its accompanying neglect of the needs of LGBTIQ+ people, would facilitate strong advocacy. It would also highlight the differences in service provision for older LGBTIQ+ people across Australia and give impetus for improvement in culturally safe service provision in rural, regional and remote areas.

Response 11.	Government to commit to the collection of data about LGBTIQ+ com-
	munities at all levels and the embedding of the ABS Standard for Sex,
	Gender, Variations of Sex Characteristics and Sexual Orientation Vari-
	ables.

However, the availability of baseline data, the lack of agreed protocols and definitions for collecting data, the failure of government to include LGBTIQ+ people in the 2021 Census and the understandable reluctance of some LGBTIQ+ people to provide personal data suggest that a considerable amount of change needs to happen before this recommendation provides real evidence of the experience of older LGBTIQ+ people using aged care services. The one-off national audit proposed for July 2024 will not produce a complete picture because of the lack of this baseline data. To enable benchmarking, variations in service provision and tracking of trends in service provision for older LGBTIQ+ people, auditing needs to be a regular event.

Response 12.	Government to commit to regular audit of aged care data.
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While the substance of this recommendation is welcome, the timeframes, which suggest implementation between July 2022 and December 2024, seem a long way off. While acknowledging that this recommendation is ambitious, it would be wrong to view it as aspirational, and deny the resources to make it happen.

## **Recommendation 44. Aged Care Volunteer Visitors scheme**

The recommendation to increase funding for support organisations and community groups to recruit, train and support volunteers who provide assistance to older people answers a call which has been made for many years by LGBTIQ+ organisations that currently provide Community Visitors Schemes. This will allow expanded support services to the growing cohort of older LGBTIQ+ people and allow them to remain living in their communities for longer.

Response 13.	Government works with LHA and collaborates with state based LGBTIQ+
	health and ageing organisations to secure funding to expand communi-
	ty visitors schemes.

## Recommendation 63. Access to specialist telehealth services

The proposed expansion of telehealth services is welcome. Older LGBTIQ+ people have reported the advantages of telehealth services, particularly during COVID-19. It has facilitated access to specialist services from anywhere, and has other benefits of providing confidentiality, particularly for people living in residential aged care and regional and rural areas where physical visits with medical services are highly visible. However, access to telehealth assumes equal technological access and doesn't address the digital divide caused by poverty or geography or service provision, nor the wide variation in computing skills in older people.

Response 14.	Government continue to provide and expand telehealth services, partic-
	ularly by LGBTIQ+ specific health providers, and to identify and support
	initiatives which aim to overcome the digital divide.

## Recommendation 94. Greater weight on experience of people receiving care

In principle this recommendation has the potential to be very beneficial, particularly in presenting the reality for older LGBTIQ+ people accessing aged care services, but also in challenging the ageism which was identified so clearly in the Interim Report. However, the suggested 20% interview rate could easily miss LGBTIQ+ people, and it is not clear how the majority who access services at home or in the community be included.

Response 15.	Government and state-based organisations collaborate with LHA to
	investigate the potential to collect information through interviews and
	online mechanisms.

### Recommendation 108. Data governance and a National Aged Care data asset

This recommendation comes towards the end of a document which is permeated with the requirement for robust and credible data about the aged care system. The recommendation suggests that the Australian Institute of Health and Welfare take responsibility for collecting, storing and managing aged care data in consultation with the Australian Bureau of Statistics.

As noted against Recommendation 30, a great deal of work needs to be done before we achieve reliable data about the experience of older LGBTIQ+ people using Aged Care services. The intention to develop specialised statistical standards and classifications, standard formats for presentation of data, and to make the Aged Care Dataset open, when achieved, would facilitate clear visibility of the issues faced by older LGBTIQ+ people accessing aged care services. In turn, this would underpin programs of improvements.

Response 16.	Government seeks out and presents technical advice on the best way to
	ensure LGBTIQ+ data is included in the Aged Care dataset.



# What will the Royal Commission into Aged Care Quality and Safety achieve for LGBTIQ+people?

The recommendations of the Royal Commission have been received with high expectations. There is genuine optimism that despite a history of Royal Commission recommendations being ignored by government, these will be fully accepted and enacted.

During the extensive consultation process undertaken to produce the seven submissions to the Royal Commission into Aged Care Quality and Safety, many brave and articulate older LGBTIQ+ people told of their experiences in accessing and utilising aged care services. These people were overwhelmingly hopeful, giving their time and exposing their vulnerabilities by speaking out publicly about very private matters. They all expressed the desire to help improve a system which is widely acknowledged as failing.

Has the Final Report reflected their concerns and validated their contributions? And has it justified the effort of LGBTIQ+ health organisations in pulling together and submitting a vast amount of material about the lives of older LGBTIQ+ people for the Commission to consider? On the face of it, with no specific recommendations and no responses to our submissions, the Royal Commission into Aged Care Quality and Safety has failed our communities.

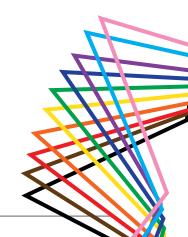
However, there is enormous room to be hopeful. Within the detail of the recommendations there are a number of clear opportunities to influence the application of recommendations to improve the lives of LGBTIQ+ older people. It is the critical responsibility of government to listen to those LGBTIQ+ health organisations who lobby and advocate on behalf of vulnerable community members. Community members who offered their voices courageously and with the expectation that they would make a difference.

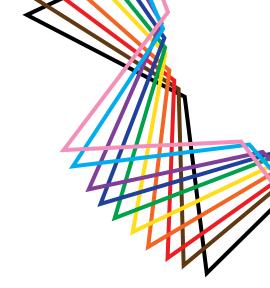
#### **Endnotes**

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- 2 Australian Government. Department of Health. Aged Care Diversity Framework. December 2017. <a href="https://www.health.gov.au/sites/default/files/documents/2019/12/aged-care-diversity-framework.pdf">https://www.health.gov.au/sites/default/files/documents/2019/12/aged-care-diversity-framework.pdf</a>
- All submissions to the Royal Commission were made under the name of the National LGBTI Health Alliance, which was the former name of LGBTIQ+ Health Australia. For consistency, in this paper the name LGBBTIQ+ Health Australia will be used throughout.
- 4 LGBTIQ+ Health Australia et al, Joint Statement by Aged Care Consumer Organisations Actions to be taken following the Royal Commission into Aged Care Quality and Safety Final Report: Care Dignity and Respect. April 2021 <a href="https://d3n8a8pro7vhmx.cloudfront.net/lgbtihealth/pages/773/attachments/original/1618184939/Post\_ACRC\_Final\_Report\_Joint\_Statement\_by\_12\_Aged\_Care\_Consumer\_Organisations\_ENDORSED\_10-04-2021.pdf?1618184939</a>
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- 8 Statement of Samantha Edmonds to The Royal Commission into Aged Care Quality and Safety. 27 September 2019. https:// agedcare.royalcommission.gov.au/system/files/2020-06/ WIT.0396.0001.0001.pdf

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- 11 Aged Care Sector Committee Diversity Sub-Group. Australian Government Department of Health. Actions to Support Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex Elders. February 2019. <a href="https://agedcare.royalcommission.gov.au/system/files/2020-06/CTH.0001.1001.2255.pdf">https://agedcare.royalcommission.gov.au/system/files/2020-06/CTH.0001.1001.2255.pdf</a>
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- 15 Silver Rainbow <a href="https://www.lgbtiqhealth.org.au/silver-rainbow">https://www.lgbtiqhealth.org.au/silver-rainbow</a>









LGBTIQ+ Health Australia

Gadigal land of the Eora Nation. 100 Harris St, WeWork, Pyrmont 2009 Switch: 02 7209 6301

www.lgbtiqhealth.org.au

