3rd National Lesbian, Gay, Bisexual, Transgender and Intersex Ageing and Aged Care Roundtable

REPORT
National LGBTI Health Alliance
23 October 2019
Held at Novotel on Collins
270 Collins St Melbourne, VIC 3000
Acknowledgements

The National LGBTI Health Alliance gratefully acknowledge the assistance of the Commonwealth Department of Health for providing funding to hold the Roundtable.

This Summary Report has been drafted and compiled by the Silver Rainbow project team, based on input from participants at the Roundtable. The advice and information from all participants is gratefully acknowledged.

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The National LGBTI Health Alliance acknowledges the Traditional Owners of country throughout Australia, their diversity, histories and knowledge and their continuing connections to land, water and community. We pay our respects to all Aboriginal and Torres Strait Islander peoples and their cultures, and Elders of past, present and future generations.
1. Introduction

Since its inception in 2007, The National LGBTI Health Alliance (the Alliance) has included ageing and aged care as a priority in its work. Over time that area of work has developed into the Silver Rainbow project and is funded by the Commonwealth Department of Health.

Since the inaugural 2011 Roundtable, the following has been achieved in the LGBTI ageing and aged care sector:

- Living Longer Living Better aged care reform package, which included LGBTI people as a special needs group under the Aged Care Act (Cth), 2012
- National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy (the Strategy), 2012
- Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 (Cth), 2013
- National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy Review (the Strategy) 2017
- Aged Care Diversity Framework: Actions to Support LGBTI elders, 2019

The timing of this years’ Roundtable coincided with the Royal Commission into Aged Care Quality and Safety. The Royal Commission was expected to release its Interim Report by 31 October 2019. As such, a key agenda item for the Roundtable included:

- recap of the Alliance’s Royal Commission Advisory Group planned work
- recommendations from delegates on policy areas the Advisory Group should focus on

Additionally, the new Aged Care Quality Standards became fully legislated in July 2019, following a twelve-month transition period. These accreditation Standards apply to all Commonwealth subsidised aged care services, which is approximately 80% of services provided in Australia. The Standards have diversity sprinkled throughout and address important areas for people with diverse backgrounds. Standard 1 is a foundation Standard which states:

- Each consumer is treated with dignity and respect, with their identity, culture and diversity valued.

A key recommendation from this 3rd Roundtable is for the Alliance to take a leadership role in developing a set of minimum standards to guide organisations to implement strategies that reflect inclusive practice. Delegates identified the financial difficulties smaller organisations experience undertaking Rainbow Tick accreditation; a more financially accessible resource may be useful to assist smaller providers to achieve these outcomes.
Thirty-five delegates attended the 3rd Roundtable and the collective wisdom produced some clear directions for the Alliance to work towards in the ageing and aged care space. This report highlights the key recommendations from the workshops on the Royal Commission into Aged Care and the Roundtable objectives.

Aunty Vanessa is a strong and proud Sistergirl who was unable to join us on the day for the Roundtable. We showed Aunty a draft of the report and in her feedback, she reminds us all to be mindful of all minority groups and ensure they are included all along the way in our planning, programming and resource development. And to engage with diverse community wherever we can.

We look forward to working collaboratively with our LGBTI partners, community organisations and government/s to enhance the physical and mental health outcomes of LGBTI older people.

2. Roundtable Objectives

The below objectives guided the Roundtable discussions and activities:

1. Explore what resources are needed to support spirituality and end of life planning for LGBTI people.
2. Explore next steps to promote inclusive practice within the ageing and aged care sector to respond appropriately to LGBTI people within the aged care system.
3. Discuss the mental health needs of LGBTI older people, including what supports are available and/or needed to improve their mental health and wellbeing.
4. Identify key resources needed by the aged care sector and by LGBTI older people that the Alliance can develop over the next 9 months.

3. Roundtable Overview

2nd Roundtable Recommendations

Zed Tintor and Heath Reed provided a presentation of the 2014 Roundtable recommendations. The presentation focused on what has been achieved since the 2014 Roundtable, what work is still ongoing and what recommendations continue to be relevant. Key areas of work that require more attention from the sector moving forward are:

- Homelessness
- Mental Health
- Research on the long-term use of medications for hormone replacement and HIV antiviral treatments
- End of Life Planning & Decision Making
4. Royal Commission

Heath Reed presented a brief history of the Royal Commission into Aged Care Quality and Safety and the Terms of Reference (ToR). To date, the Royal Commission has conducted 12 hearings, 10 community forums and published 8 papers. An Interim Report entitled ‘Neglect’ was released on 31 October 2019, after this 3rd Roundtable was held. The diversity hearings held in early October 2019 were not included in the Interim Report due to the timing of the hearing. The Interim Report recommended immediate action on the use of chemical restraints, waiting times for home care packages and young people with a disability living in residential aged care facilities. The final report will be released on 12 November 2020.

The work of the Commission is to inquire into:
- The quality of care provided, and the extent to which those services meet the needs of the people accessing them, the extent of substandard care, including mistreatment and all forms of abuse, the causes of any systemic failures, any actions that should be taken in response.
- The challenge of providing care to Australians with disabilities living in residential aged care, particularly younger people with disabilities.
- The challenge of supporting the increasing number of Australians living with dementia, regarding the importance of dementia care for the future.
- The future challenges and opportunities for delivering aged care services in the context of changing demographics, including in remote, rural and regional Australia.
- Any other matters that the Royal Commission considers necessary.

Teresa Savage outlined the Alliance’s work in consulting with the LGBTI sector to gather information, stories and evidence, to inform the Alliance’s response to the Royal Commission. The following consultations were conducted:

- COTA South Australia’s Rainbow Hub
- LGBTI Community Ageing Network, Caloundra, Maroochydore and Noosa.
- Melbourne, Celebrate Ageing’s Embolden Conference
- Aids Action Council ACT
- Tasmania, Susan Ditter
- Online survey for people who may not be able to attend consultations or who prefer to provide input this way

These consultations provided information about the lived experience of LGBTI older people accessing aged care services. The information was used to inform the Alliance’s submission statement to the Aged Care Royal Commission, for which the deadline was brought forward by the Commission, limiting time for further consultations.

Additionally, the Alliance has created an LGBTI Royal Commission Advisory Group as the key stakeholder engagement strategy to inform the Alliance’s work for the Royal Commission. The Advisory Group consists of 10 representatives from the LGBT&I, ageing and HIV sectors.
The first meeting will be held on the 12 November 2019. At this meeting it is expected a response to the Interim Report will be discussed.

A workshop with Roundtable delegates was conducted, to develop a list of recommendations that the Alliance’s Royal Commission Advisory Group should look at, based on the ToRs and the following 2 key questions:

- What do you think the Advisory Group should consider?
- How do we drive transformative change?

4.1 Key Recommendations

The key recommendations from Roundtable delegates for the Alliance’s work on the Royal Commission are:

**Workforce Development**

- Improved staff ratios to provide better quality of care
- Ensure better awareness of HIV/AIDS health specific needs & HIV related dementia.
- Introduce mandatory pre-service and ongoing training for the aged care workforce including accreditation assessors, clinicians, care providers, nurses and allied health workers at all levels including management (and at University, TAFE and in professional development). Resourcing and enabling staff to attend training is critical.
- Develop multiple ways of delivering training (eg through telehealth, video, online)
- Implement comprehensive screening at recruitment level for LGBTI inclusiveness and criminal histories.
- Include LGBTI training and awareness in performance reporting and annual reports.
- Develop toolkits to support staff to become LGBTI inclusive and understand what good professional practice is, incorporate an education program, encourage organisations to take up the toolkit, with central funding allocated to support implementation (and supporting service providers to meet the accreditation Standards).

**Use Personal Stories to Increase Awareness**

- “We shouldn’t have to avoid inappropriate aged care by dying.”
- “We should always include positive stories from consumers, that showcase best practice.”
- “Being aged does not equate to being senile or stupid. Assessments should recognise individual ability and diversity.”

**Accreditation**

- Assessors and staff of the Aged Care Quality and Safety Commission should have mandatory training in LGBTI awareness and a minimum knowledge base.
- Standard 1 should be a mandatory threshold.
• Funding allocations should be focused on best practice, with liabilities or sanctions for non-compliance, including holding back funding.
• There should be established criteria for confirming that a service is LGBTI friendly in My Aged Care – not just ticking a box. Aged care providers must be required to demonstrate that they are safe for the community before they can claim the or say they are LGBTI friendly.

Complaints
• Establish and maintain National, independent LGBTI advocacy service and work with current independent advocate groups, to represent individual consumer concerns, in a culturally competent way.
• Establish Forums or framework for reporting LGBTI elder abuse.
• Use of CCTV in corridors and common areas and/or other ways of putting measures in to collect evidence in a complaint case.

Mental Health
• Support the mental health of LGBTI adult children who are carers for ageing parents (including recognising trauma retriggered by caring for a parent who may have caused the trauma).
• Provide support for mental health concerns during the process of transitioning to using aged care services, particularly residential. A transition process should be established which includes social workers, psychologists, allied health and whatever is needed to help people on that journey.
• Funding should be available for mental health support services in both home care and residential aged care and should target older LGBTI people as a special needs group.
• Better understanding amongst aged care sector that exclusion of LGBTI elders or care that is not culturally safe is a form of elder abuse.

Access to Services
• Redesign the RAS & ACAT assessment process to make it safe to disclose and talk about sexuality.
• Reduce the amount of personal questions asked on My Aged Care, so that more intimate details can be discussed person to person, once trust is established.
• Redesign the entry structure so that it builds a relationship of inclusion and trust before the assessment process takes place.

Other areas
• We need research on the long-term use of hormone & HIV medications.
• Increased funding should be made available for social support programs including rural, regional and remote.
• Increase the capacity of the LGBTI Community Visitor Schemes.
• Establish referral pathways to LGBTI appropriate services.
• Include codesign principles in any training and review systems.
• Religious Freedoms Bill should not apply to aged care, either staff or consumers.
• Establish national awards for LGBTI best practice in aged care.
• Acknowledging that LGBTI issues are an integrated aspect of diversity – what applies to LGBTI also applies to cultural and religious diversity.

5. Workshopping Roundtable Objectives

In the afternoon over the course of 2 hours, delegates participated in workshops to explore the Roundtable objectives. Facilitators for each objective were selected from their area of expertise and relevant skills which were identified through the Expression of Interest process.

Delegates formed four smaller working groups and the facilitators changed tables at half hour intervals. At the end of the workshops facilitators reported back to the whole delegate group and nominated the key recommendations from their sections. Two topics that arose across all groups were:
• potential impact/s of the Religious Freedoms Bill and the uncertainty of how it will affect LGBTI people’s access to and experience in services.
• the need for research in the long-term use of HIV antiviral medication and hormone replacements.

5.1 Objective One

Explore what resources are needed to support spirituality and end of life planning for LGBTI people.

Facilitated by Ken Moala and Jack Powell

Key Recommendations
1) Research and develop resources, supports and workshops on wills, advance care directives, power of attorney and end of life planning.
2) Support older LGBTI people with palliative care (including complex grief) with peers who have lived experience.

Other Aspects for Consideration
• Supporting people with the process of death and dying, includes working with complex grief and spirituality (noting spirituality means different things to different people), and having a palliative care focus with LGBTI peers. This is
about creating connections and relationships, sharing love and compassion, and making people feel comfortable at the time of death. Stories, talking and connecting can help with healing, especially when reframing lived experience as strengths.

- Community education is required to better equip people to have end of life planning in place, funeral plans, gravestones (correct name & pronouns on death notices) and ensuring the right person/people are in charge of carrying out these wishes. This could include developing toolkits, updating the resource ‘Safeguarding the End of the Rainbow’ (Developed by COTA Victoria), encouraging LGBTI organisations and community groups to get involved with ‘Dying to Know Day’ events, the Groundswell project and consulting with LGBTI culturally competent Death Doulas. Overall delegates felt that the community would benefit from a greater understanding of the processes, planning and legal aspects. Look at ways of bringing more people into the conversation of death and dying to experience the reassurance and comfort it can bring.

- There needs to be a greater recognition of primary relationships, families of choice and a better understanding of the complexities between some biological families.

- There is generally poor access to affordable, LGBTI specialist legal services.

- We need to have a national conversation about ‘choice of death’ or ‘dying with dignity’ or ‘assisted dying’ – delegates acknowledged that all too commonly we hear from LGBTI elders that they have a plan in place and will choose to end their own life when the time comes. How can we approach this from a human rights point of view and harm minimisation, including taking into account the impacts on loved ones and carers?

**NOTE:** This does not include and is completely different to people choosing to end their own life rather than enter aged care which may be perceived as poor quality and not LGBTI inclusive.

### 5.2 Objective Two

Explore next steps to promote inclusive practice within the ageing and aged care sector to respond appropriately to LGBTI people within the aged care system.

**Facilitated by Graham Lovelock, Teresa Savage and Heath Reed**

**Key Recommendations**

3) Mandated minimum standard (tier system) endorsed by National LGBTI Health Alliance in partnership with Aged Care Quality & Safety Commission (for training of aged care workforce and better quality of training for assessors). Including building an extra module in to the accreditation assessors’ training.

4) Recognise that LGBTI discrimination is elder abuse

5) Develop training in other areas such as sex, diverse bodies (including clinical care), privacy/ confidentiality/ disclosure, trauma informed care, HIV related
dementia, HIV specific care packages linked with the National Association of People with HIV Australia (NAPWHa) & the Australian Federation of AIDS Organisations (AFAO).

6) Communities of Practice (Champions) to be tasked with tackling discrimination on a local level in consumer groups (considering the social environment) through workshops and resources.

7) Get endorsement (of Silver Rainbow Training) from relevant professional bodies for formal programs such as Continuous Professional Development (CPD).

Other Aspects for Consideration

- We need better and more reliable data to inform practice, this includes research on the benefits of inclusive practice and the uptake amongst providers and data on older LGBTI people and their needs. Including an economic impact study of the ‘pink’ dollar and its value to providers (both government subsidized and self-funded service delivery). As well as inclusive data in the Census and in other Australian Bureau of Statistics work.
- Establish an independent auditor for aged care services (auditing inclusive practice against aged care standards). Recognising that LGBTI discrimination is elder abuse and that better protections are required.
- Specific training for community is required so that LGBTI people know their rights and can be empowered to seek supportive advocacy services. This includes exploring ways in which people who make complaints are protected.
- Develop specific LGBTI services within advocacy organisations and the Aged Care System Navigators program.
- Shift views of LGBTI people’s behaviours to be affirmative, using positive stories to promote affirmative practice and build greater respect for diversity and LGBTI people’s lived experience and identities.
- Expand funding for Silver Rainbow training to create packages or frameworks that are enduring. For example, if a staff member that has championed inclusive practice leaves an organisation, the framework is still embedded within the organisation and the tools continue to be used.
- The Alliance should continue to engage with senior staff and seek to partner with big aged care organisations and peak bodies to promote inclusive practice being embedded across organisational structures.
- Develop a recognition or awards program for organisations that are getting it right – acknowledging best practice.
- All national screening and assessment forms need to include inclusive language and questions.
- Work with Unions (e.g. Nurses and midwives) and their LGBTI committees to promote the uptake of inclusive practice.
5.3 Objective Three

Discuss the mental health needs of LGBTI older people, including what supports are available and/or needed to improve their mental health and wellbeing.

Facilitated by Dr Daniel Parker and Susan Cadman

Key Recommendations

8) Effective programs and events exist (e.g. Coming Back Out Ball & LGBTI Community Visitor Schemes). There is scope to learn from what is working and expand on existing programs, which includes broadening eligibility to increase accessibility and intergenerational activities.

9) Peer support is key, we need more outreach programs.

10) There are significant delays in accessing services and barriers in affordability, additionally we need more specific research on older LGBTI people and mental health. We also need better mapping of LGBTI specific mental health services (and the eligibility criteria for older people).

Other Aspects for Consideration

- Maintaining connections is very important and some people who are not out are not being reached by either mainstream or LGBTI services.
- Ageism negatively impacts mental health as do the impacts of long-term minority stress. We need to develop campaigns around anti-ageism within LGBTI communities, and stigma of mental health amongst older people and promote wellbeing.
- Some women need access to women only services.
- Proactive early intervention for depression in older adults.
- Services need to include younger LGBTI carers.
- Aged Care System Navigators needs to have specific LGBTI peer support, or specialist service. Which in turn needs (within services) greater visibility of LGBTI Champions and elders.
- LGBTI organisations need to partner with mainstream aged services to expand the reach, awareness, visibility and to foster good mental health. This should include networks of LGBTI inclusive services.
- Encourage LGBTI mental health forums and general mental health forums to specifically include ageing.
- Alliance to collect data on effectiveness of psychologists entering aged care services, mental health support and services within aged care (home care & residential) and provision of support during transition.
- Develop a list of LGBTI friendly mental health services (eligible to the aged) and map what already exists.
- Review standards for frontline older persons mental health workers and ensure they are culturally appropriate.
- Raise awareness in the community of younger early onset dementia and also work with NAPWHA & AFAO on raising awareness of HIV related dementia.
5.4 Objective Four

Identify key resources needed by the aged care sector and by LGBTI older people that the Alliance can develop over the next nine months

Facilitated by Cris Davis and Campbell Smith

Key Recommendations

Noting that the facilitators chose not to limit discussion to nine months.

11) Audit and collate existing resources, what is already out there?
12) Develop a quality resource pack (in tiers) helping people move towards pathways to develop quality best practice, without the barriers Rainbow Tick presents.
13) A more coordinated resource on end-of-life planning, combined with legal issues and rights.

Other Aspects for Consideration

- Refresh ‘10 things to Ask’ resource for consumers.
- Refresh Relationships, Bodies & Gender passport.
- DL flyer for aged care providers – 10 things to check for inclusive practice, how to ‘come out’ as LGBTI trustworthy.
- Low cost, in-house alternative to Rainbow Tick for smaller organisations, including flyers, fact sheets, prompts for staff to have conversations and an ‘LGBTI Allies Pack’.
- Audit and collate existing resources.
- All state and territory based advocacy services to develop LGBTI targeted promotion of their services.
- Promotional campaign to combat LGBTI ageism (internally to LGBTI community).
- Videos or webinars of simple scenarios to help staff understand LGBTI issues.
- Elder abuse webinars and resources, specific to LGBTI people (e.g. refusal of hormones, to trans people).
- End of life planning and death literacy and include who can assist people in this area.
- Brochure summarising the LGBTI and ageing legal issues, including rights.
- Fact Sheets on LGBTI dementia issues and HIV related dementia.
- Develop resources for GPs who don’t understand hormone replacement (so that if they are altering medications, hormones are considered with specialist advice).
- Develop resources in other languages to promote inclusive practice to the multicultural aged care work force.
- Fund an update to ‘Safeguarding the End of the Rainbow’ and make it nationally relevant.
- Research the effects of taking medications long-term such as hormones and antiviral medications.
6. Conclusion

While recognising the considerable advances that have been made, the Roundtable identified many opportunities to improve the experience of older LGBTI people interacting with aged care services. The guidance, information, lived experience and time shared with us by the Roundtable delegates is highly valued and appreciated. We wish to acknowledge the richness of conversation on the day of the Roundtable. We also recognise that there are other important areas that need careful consideration, but due to time constraints, it was necessary to limit the objectives to work productively and progressively. Homelessness, disability, alcohol and other drugs, family violence and other health and community issues remain an important part of our work at the Alliance. We will endeavour to incorporate these areas into our work in other ways in future funding opportunities.

As the peak body for LGBTI health, we will use the collective wisdom shared on the day to inform our work in the Silver Rainbow Ageing and Aged Care project to advocate on policy, provide resources to the sector, further entrench LGBTI inclusive practice and to plan for the future.

In the short term, we will be sharing this report with the Alliance’s Royal Commission Advisory Group as we commence working with them for the next 12 months, as well as mapping out what resources the Alliance can produce within the next nine months of our current funding period. In the mid to long term we will incorporate the recommendations from this report into our planning and future funding applications.

7. Roundtable Delegates

Ann Matson – Queensland AIDS Council, LGBTI Community Visitors Scheme (QLD)
Bernard Gardiner - Queensland AIDS Council, Ageing & Aged Care Action Groups (QLD)
Campbell Smith – Thorne Harbour Health (VIC)
Coleen Clare – Matrix Guild, Chair (VIC)
Craig Gear, Older Person’s Advocacy Network, CEO (NAT)
Cris Davis – Council of The Ageing SA, Rainbow Hub Chair (SA)
Dr Daniel Parker – Tillver Counselling, Clinical Psychologist (WA)
Desmond Ford – Council of The Ageing SA & LGBTI Health Alliance Board Member (SA)
Eleanor Kennett-Smith – North Western Melbourne PHN Lead, Older Adults (VIC)
Graham Lovelock – Glove Communications & LGBTI Health Alliance Board Member (WA)
Jack Powell – Older Person Mental Health, Lismore Base Hospital (NSW)
Dr Jaimie Bloom – Bent Twig Alliance (VIC)
Jill Bolen – Advocate & elder (QLD)
John Guppy – AIDS Action Council (ACT)
Kathryn Wilson – Transgender Victoria (VIC)
Kathy Mansfield – Advocate & elder (VIC)
Ken Moala – Gold Coast University Hospital Palliative Care, Chaplin, ILGA Oceania Board Member (QLD)
Dr Kieran O’Loughlin – Australian College of Applied Psychology, Senior Lecturer in Counselling & Psychotherapy (VIC)
Malloy - Advocate & elder (SA)
Mark Morein – LGBTI Community Ageing Network Sunshine Coast (QLD)
Meaghan Holden – Switchboard, Director of Services (VIC)
Robyn Lierton – ECH, Community Engagement & Diversity Manager (SA)
Russell Westacott – Seniors Rights Service, CEO (NSW)
Susan Cadman – North West Melbourne PHN, Manger, Suicide Prevention (VIC)
Terena Barnes – Bent Twig Alliance (VIC)
Tonye Segbedzi – Australian Association of Gerontology, Senior Policy Officer (VIC)

National LGBTI Health Alliance Staff
Heath Reed, Ageing & Aged Care Project Officer
Teresa Savage, Policy & Research Manager
Zed Tintor, Programs Coordinator, Capacity Building Manager (Roundtable Chair)

8. Glossary
AAC – Ageing & Aged Care
ACAT – Aged Care Assessment Team (also implies the Aged Care Assessment)
AFAO- Australian Federation of AIDS Organisations
Alliance – National LGBTI Health Alliance
Champions- A trained ‘Champion’ of inclusive practice
Communities of Practice- local professional network of Champions
COTA – Council of the Ageing
CPD – Continuous Professional Development
DL- dimension lengthwise, common size for flyers and brochures
HIV – human immunodeficiency virus
ILGA – International Lesbian, Gay, Bisexual, Trans & Intersex Association
LGBTI – Lesbian, Gay, Bisexual, Trans and Intersex
NAPWHA- National Association of People with HIV Australia
OPAN – Older Person’s Advocacy Network
PHN – Primary Health Network
Rainbow Tick- an LGBTI inclusive accreditation process through Quality Innovation Performance (QIP)
RAS - Regional Assessment Service

9. Appendix
Living Longer, Living Better, Commonwealth of Australia 2012
National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy (the Strategy), 2012
Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act 2013 (Cth), 2013
Review of the National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy, 2017
Aged Care Diversity Framework, 2018
Actions to Support Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex elders, 2019
The Aged Care Quality Standards, as of 1 July 2019