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

Response to Interim Report - National LGBTI Health Alliance Submission

30 June 2020

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.

Introduction

The Royal Commission into Aged Care Quality and Safety's Interim Report, "A Shocking Tale of Neglect" was delivered in October 2019. The report found that the Australian aged care system fails to meet the needs of older, vulnerable citizens, and concluded that the aged care system does not deliver uniformly safe and quality care, is unkind and uncaring towards older people and, in too many instances, it neglects them.

Commissioners identified three areas where immediate action could be taken:

- to provide more Home Care Packages to reduce the waiting list for higher level care at home
- to respond to the significant over-reliance on chemical restraint in aged care, including through the seventh Community Pharmacy Agreement
- to stop the flow of younger people with a disability going into aged care, and speed up the process of getting out those young people who are already in aged care

The National LGBTI Health Alliance strongly supports these findings, and the intention to act immediately to address them.

The Interim Report considered evidence given in hearings held before the end of July 2019 and submissions received before 13 September, meaning that our submissions and the evidence that we gave at the Diversity in Aged Care hearings in Melbourne on Monday 7 October 2019 were not included in its findings or recommendations. No information specific to LGBTI communities was included in the Interim Report.

While understanding the difficulty of dealing with the huge volume of material being submitted to the commission, and the need to set a cutoff date for production of the Interim Report, we are greatly concerned that a significant consumer voice was omitted.

Older members of LGBTI communities expressed their disappointment and frustration at this omission and the impression it may give to aged care service providers. In reading the report, mainstream service providers could assume that LGBTI people don't use aged care services nor have any specific needs. Given that the report was highly anticipated and widely read when published, a significant opportunity was missed to glean insight, raise awareness and make recommendations in relation to the needs of older LGBTI people.

"The fact that we didn't even feature in the report contributes to our invisibility in aged care." – older lesbian, regional NSW

"Providers are constantly saying that they don't have anyone here from the LGBTI community, even though we know there are." – aged care worker, urban gay man

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 community controlled 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. So as to ensure we collected the views of bisexual people, we elicited advice from bisexual community organisations and launched a national online survey designed to elicit the views and experiences of bisexual people. 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. Key themes were identified and the detail arising from consultations considered.

NEGLECT – key themes

1. **The structure of the aged care system is broken and results in neglect**

LGBTI community members generally agreed with the main findings of the Interim Report and were not surprised by the characterisation of aged care services noted by the Commission. There was unanimous agreement with the findings that the aged care system is designed around transactions, not relationships or care, that it devalues the voices of people receiving care and their loved ones, that it is hard to navigate and does not provide the information people need to make informed choices about their care. LGBTI people agreed that the aged care system relies on a regulatory model that does not provide transparency, accountability nor any incentive to improve and has a workforce that is under pressure, under-appreciated and that lacks key skills.

Unfortunately, there is little expectation amongst the LGBTI community that aged care providers will deliver inclusive practice, and an acceptance that if the service delivery is bad for the general community, then it will be worse for the LGBTI community.

2. **The nature of neglect for older LGBTI people**

The term neglect was seen by many as a strong word, but perhaps not strong enough.

"Neglect is understood to be physical neglect, but for us it must also include concepts of emotional and psychological neglect." - Older urban trans woman.

Where older LGBTI people have not felt safe to come out to their aged care service provider, where the induction process at the care home is superficial, or where they have felt forced to hide their sexuality, gender identity or intersex status, the concept of neglect needs to be broadened to encompass invisibility, or absence from the system of care.

"It is neglect. In the aged care home I visit there's a transgender lady – they use the wrong pronouns. She stated who she is – correct pronouns are to be used but they don't. She can't articulate, she's had a stroke, but she is aware of her surroundings." – Aboriginal gay man in his mid fifties from regional NSW

The failure to provide LGBTI-inclusive aged care services in policy, system design and service delivery is flagrant neglect of the needs of older LGBTI people.

3. **The ability to complain**

At the root of the problem, for older LGBTI people, is the lack of cultural safety to make a complaint, the fear of being dismissed, ridiculed or facing retribution, and the reluctance to draw attention to oneself. Some aged care services supply advocates for vulnerable older people, but issues can be compounded where these advocacy organisations, or their individual staff, are not sensitive to LGBTI issues.

"Elders don't rock boat, we LGBTI people are more vulnerable and less willing to speak up. Because of shame, secrecy and concealment." – seventy-four-year-old urban trans woman.

HOME CARE PACKAGES – key themes

1. **Long waiting times**

The Interim Report acknowledges that long waiting times for home care packages result in a heavy toll of stress and anxiety for older people and their carers, and that the assessment process is both inconsistent and unpredictable.

"I hold Power of Attorney and Enduring Guardianship for an elderly lesbian friend who has been waiting almost two years after being assessed as eligible for a more comprehensive Level 4 Home Care Package." – seventy-three-year-old urban lesbian.

Long waiting lists impact disproportionately on those in the upper age groups. An LGBTI person in their late eighties or nineties who recognises that they need help, and overcomes their reluctance to engage with a system that they believe to be discriminatory by applying for an aged care package, needs to be offered assistance in a timely manner, rather than waiting months or sometimes years.

"We grew up in an era where you made the most of what's available to you, you didn't have a sense of entitlement – basically 'I'm OK I don't need anything more' which could make some people more vulnerable to neglect or falling through the cracks." – eighty-six-year-old urban Aboriginal gay man.

2. The wish to stay at home

LGBTI older people enjoy the familiarity, comfort, and safety of their own homes, and generally would prefer to stay at home rather than go into residential care. The lack of sufficient home care packages, being forced to rely on lower level care packages when assessed as having higher care needs and the delays in being allocated packages, mean older LGBTI people frequently can't stay at home and are prematurely forced into residential care.

Many community members noted that just making more home care packages available doesn't solve the problem for older LGBTI people. It is vital that service providers work with LGBTI community controlled organisations to ensure the cultural safety and appropriateness of their services, and where possible, older LGBTI people are given the option of using services provided by LGBTI community controlled organisations.

"I don't want someone coming into my house looking down their nose at me like I am something green that crawled out from under the carpet. You can pick up easily from someone that they are homophobic and I don't want them in my house." Lesbian in her late seventies in regional Tasmania.

Informal systems of care for older LGBTI people are limited because many older LGBTI people have not had biological children or are alienated from their families of origin, who may also have been the instigators of violence and trauma. But in the absence of family defined by biology or formal frameworks, many older LGBTI people have intimate connections to a network of others, characterised by shared values, common beliefs, collective histories, mutual support and deep respect. These families of choice usually

include ex-partners, long-term friends, fellow activists, household members and non-biological children. These families of choice may not be recognised or understood by aged care service providers when looking for advocates or supporters for the older LGBTI person, and can be denied information, left out of decision making and ignored in their role as next of kin.

"I care for my ex-partner. We split up many years ago but we stayed friends. You are having to explain your home situation again and again, because you are dealing with 2-3 different people- this is difficult especially if you are not totally out to community in a small town that is more conservative." Older lesbian, regional NSW.

Compared to the general older population, older LGBTI people are also more likely to live alone, not be in a long-term relationship, be socially isolated and to experience loneliness. In this situation, when a critical event occurs, like an accident or a new medical diagnosis, home care services need to be responsive and agile to the set of new challenges. It is not unusual for older LGBTI people experience delays in adjustments to care services to accommodate their evolving needs.

The shortage of home care packages results in pressure for family members to provide the care for older parents. In some families the most appropriate person to take on this role is the one perceived to be unencumbered with their own family life, which often places a heavier burden on LGBTI people. There may be a complex relationship between parent and child, where the parent may have been dismissive or disapproving of their child's sexuality or gender identity. They may have been actively abusive, denied care and comfort, or forced their child to undertake cruel therapies and health interventions. In a situation where that child is then expected to be the primary carer for the abusive parent, support may be needed to deal with new tensions and old traumas.

"The LGBTI child in the family is often relied upon to take on the caring role." Fifty-three-year-old gay man, primary carer for elderly parents, ACT.

ACCESSING THE AGED CARE SYSTEM – key themes

1. The complexity of access

The Australian Government is to be congratulated on the work already done to ensure inclusivity for LGBTI people accessing aged care services. It recognises that; "Older people of diverse sexual orientation and gender identity should be able to access aged care services that are responsive and respectful of their care needs and consider their history and any

experiences of discrimination and marginalisation."[1] The Aged Care Diversity Framework, launched in December 2017, includes action plans for government, aged care providers and consumers, as well as a number of useful supporting tools and resources, with the aim of ensuring that everyone has fair and equal access to aged care[2]. The Government has also produced a number of targeted resources to help LGBTI people getting started with the My Aged Care system, including *Aged care for LGBTI elders: Getting started with My Aged Care factsheet* and *Finding LGBTI Inclusive Home Care Packages on the Service Finder factsheet.*[3] In addition, the government has funded two aged care navigator services for LGBTI people in Perth and Darwin, specifically to assist LGBTI people to access appropriate aged care services.

However, for the majority of older people, entering the aged care system is a challenging experience. Older LGBTI people describe it as complex, confusing, difficult to navigate and requiring computer skills. This can be challenging and can often be beyond the skill and the resources held by many older LGBTI people.

2. Management and advocacy

Once an older person has been awarded a care package, managing the identified residential and home care services is difficult and requires regular attention and the ability to describe needs, compare services and identify whether they will be appropriate and safe.

"If you are good at self-advocating you can use the system to your benefit, but if you don't have those skills you are likely to be neglected in some way." – seventy-seven-year-old urban gender diverse woman.

3. Finding appropriate services

The way information is organised in the My Aged Care system does not enable older LGBTI people to find appropriate, culturally safe services.

LGBTI or community-controlled navigator programs support older LGBTI people to access the aged care system, and address questions about whether a service is appropriate. Unfortunately, these navigator programs are only available in Perth and Darwin, which leaves large numbers of older LGBTI people across the country without culturally safe advice when accessing aged care services.

[1] Australian Government MyAgedCare https://www.myagedcare.gov.au/sites/default/files/2019-04/aged-care-for-lgbti-elders-getting-started-with-my-aged-care.pdf accessed 25 May 2020
[2] Australian government, *Aged Care Diversity Framework*, https://www.health.gov.au/initiatives-and-programs/aged-care-diversity-framework-initiative#supporting-tools-and-resources accessed 22 June 2020
[3] Australian Government, *Support for lesbian, gay, bisexual, transgender and intersex people,* https://www.myagedcare.gov.au/support-lesbian-gay-bisexual-transgender-and-intersex-people accessed 15 June 2020

If older LGBTI people see themselves and their lives reflected in promotional material issued by aged care providers it goes some way to help them identify appropriate LGBTI-friendly services.

The concept of a culturally safe aged care environment includes the idea that all other people involved in the service are welcoming and friendly to LGBTI people. Some older LGBTI people worry about the attitudes of other residents in aged care homes, or other users of community-based services, and the impact it may have on them. Even where there are other older LGBTI people, they worry about their own personal choices regarding privacy, and the choices of others.

"There's a lot of people who are in the closet. They tend to not like you talking about identity stuff. They don't like other people to know about it. Not just Indigenous, people struggle to see a person grow up as one gender to another." – fifty-two-year-old urban sistergirl

RESTRAINT – key themes

Commissioners identified the significant over-reliance on chemical restraint in aged care. This raises two issues for LGBTI people in aged care; the standards of behavior used to assess whether a person requires restraint, and the necessity to obtain informed consent from the person or their representative.

1. **Decision making**

Too often LGBTI older people are considered to be difficult clients and little time is spent by service providers to understand the background and needs of those clients. For LGBTI people in residential aged care, it is important that distress, for example, is investigated in context. It is reasonable to express distress at being discriminated against. It is reasonable to want to escape an environment where an older LGBTI person feels unsafe, or where they are denied access to their normal support structures.

"I know a person who becomes agitated when their partner goes home after a visit. Because their relationship isn't seen as valid, they don't get proper comfort or reassurance from staff, and then their behavior is seen as difficult." – non-binary aged care worker, regional Victoria.

Decisions about the use of restraint may also be related to expectations of stereotyped behaviour. When older LGBTI people behave or present outside of those expectations, they may be seen as disruptive or troublesome.

"Many people including aged care services want women to be docile, compliant, quiet "sweet old ladies". That is also with regards to lesbians." Seventy-five-year-old lesbian, regional NSW.

2. Informed consent

Informed consent is another particular issue for LGBTI people, and is a process which is seen as complex, not easily understood, regularly mismanaged and incorrectly documented. In a case where a person has reduced decision making capacity, an authorized substitute decision maker is called upon. In some instances, this may be a family member who is not comfortable with the person's LGBT and/or I status, and who is unlikely to understand the complexity of an older LGBTI person's experience and needs.

3. Related treatments and experiences

Care needs to be taken with related consequences of restraint because of historical and contemporary practices of attempted psychiatric 'treatment' of LGBTI people, such as aversion therapy, which is still legal and used in some parts of Australia.

"I grew up in an institution so I associate places like residential aged care with mistreatment. What happened in those institutions was not good for the kids. I got lots of beltings. I don't like to be mistreated." -seventy-eight-year-old urban transgender woman.

The majority of aged care services are provided by faith-based organisations. Some faith-based organisations continue to advocate for the efficacy of conversion therapy despite there being no evidence that it is successful in changing a person's sexual orientation or gender identity. Older LGBTI people understand that conversion therapy practices are ineffectual and harmful and feel vulnerable to any kind of physical intervention related to their behaviour. LGBTI older people with a lived experience of electro-convulsive shock therapy can experience added trauma if chemical restraint is used. The implications of the looming Religious Discrimination Bill only add to the real possibility that older LGBTI people will be forced to use aged care services provided by faith-based organisations where discrimination against them will be lawful.

"Some workers have beliefs from their faith and their culture which are backed up by management. They believe that being LGBTI is sinful." – fifty-year old urban bisexual woman, carer for a disabled younger person in residential aged care.

Older LGBTI people describe many different scenarios where restraint could trigger previous trauma or disrupt current healthcare regimes. For a person in recovery from substance use, chemical restraint could be breaking their sobriety. And for people living with HIV, or trans

and intersex older people, chemical restraint may interfere with their medication. If these complex issues are discussed with the individual or their loved ones before the use of chemical restraint, further health problems can be avoided.

There is a very strong view from older LGBTI people, their carers, family and friends that chemical restraint should be the very last resort.

WORKFORCE – key themes

1. **Impact on aged care workers**

Using such a strong term as "Neglect" in the title of the report and uncovering systemic problems as well as individual instances of abuse has a negative impact on aged care workers. This is a concern for the ongoing attraction and retention of aged care staff. In a previous submission to the Royal Commission about the aged care workforce, the protective value of attracting aged care workers from LGBTI communities was recommended. This positive initiative would also be impacted by a negative view of aged care work. In addition, many faith-based organisations which provide aged acre services are supportive of the proposed religious discrimination Bill. They may not be good employers of LGBTI people.

"We need to encourage good people to want to work in aged care, to make a career, make it attractive. But how do you do that? I can earn $2 an hour more working at ALDI. There's something wrong with the system. It's hard works and there's burn out for good workers." – sixty-year-old urban gay man.

2. **An under-resourced system**

LGBTI aged care workers report increasing strain impacting on their ability to do a good job, and in particular to advocate for a positive response to the needs of older LGBTI people.

"There are lots of pressures – dollars make it very difficult, privatisation. The system and structures, it's very demanding." - sixty-year-old urban gay man, aged care worker.

The increasing casualisation of the aged care workforce disrupts the potential for long-term connection with older LGBTI people, and understaffing forces workers to concentrate on tasks rather than relationships.

"Low morale can also come about through having to work to very fixed budgets: per meal per resident per day – can cause strain on the kitchen staff to provide that. That's my big concern. I have changed employers and that was one of the reasons." - forty-year-old gay man, aged care worker, regional Tasmania.

Conclusion

The lack of information specific to LGBTI communities has made it difficult to respond to the Interim Report. In general, older LGBTI people, their carers, family, friends and LGBTI staff working in aged care agree with the findings of the Interim Report.

The final report of the Royal Commission into Aged Care Quality and Safety is currently due on 12 November 2020, but this date may change in response to the unforeseen challenges to aged care services presented by COVID-19. The content of the final report will understandably be impacted by the issues raised by COVID-19, which have been substantial for all older people using aged care services.
Up to this point, the Commission has done an excellent job in including the voices of those with lived experience of the aged care system in its deliberations, both directly and through national peak and community organisations, and at its hearings. The National LGBTI Health Alliance, and other LGBTI organisations, have provided extensive material through a range of submissions to ensure that older LGBTI people are fully represented in the work of the Commission.

However, at this stage there appears to be no mechanism for socialising the draft recommendations for comment before they are published in the final report. A further hearing on Diversity would go a long way to ensuring that older LGBTI people, their families, friends, carers and LGBTI aged care staff, as well as other diverse populations, are exposed to the draft recommendations and have the opportunity to comment and give feedback before they are finalised.

As a once-in-a-generation opportunity for the overhaul of aged care services, we expect the Commission to address the significant disadvantages faced by LGBTI older people in accessing aged care services.

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.

1. That a further Diversity Hearing is conducted to allow public feedback on the impact of recommendations on diverse populations, particularly inviting National Aged Care Alliance NACA) members and representatives of the National LGBTI Health Alliance to give evidence.
2. That draft recommendations of the Royal Commission into Aged Care Quality and Safety are circulated for feedback before the publication of the final report.
3. That the final report of the Royal Commission into Aged Care Quality and Safety:

- clearly describes the experience of older LGBTI people accessing the aged care system
- recommends systemic changes to provide transparency, accountability and incentive to improve services for LGBTI people
- Addresses the long waiting times for aged care packages and supports LGBTI specific navigator assistance services
- Strengthens complaint and feedback procedures, and supports advocacy services in their work to represent the specific needs of older LGBTI people
- Recommends support for LGBTI older people to remain in their homes wherever possible
- Recommends simplification of access to the aged care system, and a greater flexibility in managing aged care packages
- Recommend funding and extending LGBTI aged care navigator services
- Establishes clear ways of identifying those services which understand and respond to the needs of older LGBTI people
- Recognises and addresses the issues faced by LGBTI children when caring for previously abusive parents
- Creates standards which minimise the use of restraint, improve the process of informed consent and recognise the adverse traumatic historical experiences of older LGBTI people
- Supports all initiatives to improve the skills, training, standing and remuneration of workers in the aged care sector, particularly in delivering services within the Aged Care Diversity Framework