ACON SUBMISSION

# ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY

1 October 2019

HERE FOR HEALTH

**ACON SUBMISSION - ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY**

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## Acknowledgment of Traditional Land Owners

ACON acknowledges the Traditional Owners of the lands on which we work and pay our respects to Elders past, present and emerging.

### Who we are

ACON is Australia's largest health organisation specialising in community health, inclusion and HIV responses for people of diverse sexualities and genders. Established in 1985, ACON works to create opportunities for people in our communities to live their healthiest lives.

We are a fiercely proud community organisation, unique in our connection to our community and in our role as an authentic and respected voice.

Members of Australia's sexuality and gender diverse communities experience health disparities when compared to health and wellbeing outcomes experienced by the total population. They may also face significant barriers to accessing traditional healthcare pathways. These issues can be compounded by other factors in a person's life, such as living with a disability or being from a culturally diverse background.

We recognise that members of our communities share their sexual and gender identity with other identities and experiences and work to ensure that these are reflected in our work. These can include people who are:

- Aboriginal and Torres Strait Islander people
- people from culturally and linguistically diverse backgrounds
- people who use drugs
- mature aged people
- young adults
- people with a disability

We know that how our communities define and describe themselves changes, and we strive to ensure that all people we work for feel welcomed by the services we offer and the language we use.

ACON offers support, companionship and advice for older members of the lesbian, gay, bisexual and trans community (aged 50 and older), including through the Community Visitor Scheme program and the LOVE project (Living Older Visibly & Engaged).

We also deliver the Silver Rainbow LGBTI Aged Care Awareness Training program for aged care sector workers.

## Executive Summary

Finding aged care services that meet the needs of lesbian, gay, bisexual and trans people (LGBT) and people living with HIV (PLHIV) is extremely difficult, in large part because of the scarcity of options available. While hundreds of providers are listed as LGBT 'specialised' services on *myagedcare.gov.au*, the lack of adequate accreditation processes raises serious doubts about the veracity of providers' claims and ability to deliver inclusive services for our communities.

In this context, the care of LGBT people and PLHIV is often relegated to providers who have highly variable levels of inclusion practice and are reluctant to invest in adequate person-centred care that address our communities' needs.

Due to a lack of systematic data collection, aged care outcomes for our communities are not fully known. Our experience suggests, however, that the care and services our communities receive are often inadequate, and sometimes harmful.

Many people in our communities fear aged care homes because of the risks of being stigmatized, discriminated against or disconnected from their friends and family. For some older LGBT people, this can mean spending later life 'back in the closet' and unable to live authentic and fulfilled lives.

There is a need for appropriate mental health care for older LGBT people, for access to gender affirming care, and for adequate responses to the needs of PLHIV who can now live longer but have a higher prevalence of comorbidities and other age-related conditions compared with HIV-negative people.

Verification, accreditation and accountability mechanisms need to be strengthened to ensure that our communities' rights are upheld. Everyone has the right to safe and high-quality care and services, to be treated with dignity and respect and to have their identity, culture and diversity valued and supported.[1]

ACON recommends six priority action areas to improve aged care services for our communities:

**1/ Collecting adequate data to measure aged care outcomes for LGBT people and PLHIV**;

**2/ Improving workforce capabilities,** including through training on working in culturally appropriate ways to meet the needs of sexuality and gender diverse clients and clients living with HIV;

**3/ Improving the enforcement of standards** to ensure the provision of quality care for any LGBT person or PLHIV accessing any aged care service, including by increasing auditors' capabilities and understandings of issues affecting our communities;

**4/ Improving accreditation processes** including ensuring ongoing reaccreditation considering the casual nature of the workforce**;**

**5/ Improving the effectiveness of complaints mechanisms**, including by increasing the capabilities and knowledge of the workforce throughout the assessment and complaints continuum; and

**6/ Making it easier for people to navigate the system and make decisions**, including through a dedicated website and peer support.

[1] Australian Charter of Aged Care Rights.

## Introduction

ACON welcomes the opportunity to provide a submission to the Royal Commission into Aged Care Services Quality and Safety.

As Australia's largest health organisation specialising in community health, inclusion and HIV responses for people of diverse sexualities and genders, our submission focuses exclusively on the state of aged care services for lesbian, gay, bisexual and trans people (LGBT) and people living with HIV (PLHIV) in NSW.

Many Australians are affected by substandard aged care services resulting from a range of systemic issues, including the weakness of standard enforcement mechanisms and (some) providers' cultures of neglect[2] that have been revealed over the course of the Royal Commission's work.

For LGBT people and PLHIV, the aged care system presents another set of challenges, including the scarcity of inclusive providers who will treat them with respect and provide adequate care.

While national policy frameworks[3] seem to have raised awareness and visibility of issues relating to LGBTI-inclusive aged care, the extent to which improved awareness has led to tangible changes in service provision is unclear.[4] Due to a lack of systematic data collection, outcomes for LGBTI people in aged care have not been properly evaluated and remain unclear.

This submission highlights the specificities of LGBT and PLHIV health needs (I) and the inadequacies of the current system for our communities (II), in large part because of the lack of inclusive providers. Finally, our submission offers six recommendations (III).

Our organisation also endorses the recommendations provided to the Royal Commission by the Australian Federation of AIDS Organisations (AFAO) and NAPWHA.

## I. What is different for older LGBT people and people living with HIV

### 1) Discrimination

LGBT people and PLHIV who access aged care services today are likely to have experienced abuse, violence and discrimination in their lives. This population has lived through times when homosexuality was criminalised (until 1984 in NSW), when transgender was classified as a disorder of mental health and when our communities were at risk of being harassed or even killed for being same sex attracted or transgender[5].

Discrimination and poor treatment throughout their lives and/or within aged care programs mean that LGBT people often fear disclosing their sexuality, gender identity or HIV status to aged care professionals, which may leave some of their needs ignored or inadequately addressed. Being open

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[2] The Guardian, *'Something is wrong at the top': how Bupa's aged care homes hit rock bottom*, 12 September 2019.
[3] These include the *2015 National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy,* the *2017 Aged Care Diversity Framework* and corresponding *2019 Actions to support Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex elders*.
[4] Australian Government, Department of Health, June 2017. *Review of the National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy*.
[5] ACON 2018. In Pursuit of Truth and Justice, Documenting Gay and Transgender Prejudice Killings in NSW in the Late 20th Century.

about one's sexuality or gender identity in residential aged care facilities is a risk for many, and as such, the choice is to revert to the 'closet'. This can lead to a sense of social isolation, as individuals move away from any established peer networks, and can also mean that people may avoid the company of long-term partners. Further, this reversion means that individuals are not able to explore the development of new authentic friendships and relationships with residential aged care facilities or through social interaction.

### 2) Isolation, families of choice and community care

A higher exposure to discrimination and a higher prevalence of mental illnesses may contribute to increased risks of experiencing loneliness and isolation, which are reported by our elders as a major concern.[6]

LGBT communities and PLHIV have, however, a long history of developing formal and informal models of community care that can enhance their resilience and health outcomes. This was particularly the case in the 1980's and 1990's when our communities cared for each other during the peak of the HIV epidemic.

LGBT people may have a range of family structures and support networks that play important roles in their care as they age. LGBT people, for instance, may have children raised by more than two parents, and chosen family of friends may be the most important element of LGBT people's support network. Community networks and programs like the Community Visitor Scheme also play an important role in maintaining social connection and supporting individuals to advocate for their rights in aged care.

The importance and diversity of LGBT people's family structures and care networks is, however, often overlooked in aged cared planning and service delivery. The need for LGBT people to arrange wills, enduring power of attorney, advance health care directives and enduring guardianship is especially pertinent for LGBT people.

Providers must ensure that when working with our communities, credence is given to these unique structures. For many in our communities, these models have been overlooked.

During the HIV/AIDS crisis, many people experienced members of their support networks being actively locked out of their care by the medical system. It is not difficult for them to draw a potential parallel between the aged care sector and the health sector and have founded fears that this may happen again.

Effective training (and related accreditation) for aged care service providers should ensure that the concept of care and kinship shared through our community is understood. In many cases (although recent legislative reform aims to minimise some of this) people's legal documentation may not represent the real and pragmatic sense of family that is understood by an individual in care. A person may not be listed as a parent on a birth certificate if their child was born from surrogacy, a spouse may have no formal recognition of a relationship, and a person's legal documents may use an individual's deadname (typically the name a person used before a gender transition of any kind).

Understanding the complexities of our communities' structures of family and support is vital to a person feeling honoured, respected and safe in a facility or activity.

[6] ACON, Health Outcome Strategy 2017-2021 – Ageing.

## 3) Mental and physical health

### A range of health disparities

LGBT people face disparities in terms of their mental health[7], sexual health[8] and rates of substance use[9], which may continue in older age and require appropriate care. The effects of ageing, however, manifest unevenly across our communities.

LGBT people's experiences of discrimination and abuse affects their mental health and are linked to higher rates of psychological distress[10], depression[11], anxiety[12] and suicide. Social exclusion and loneliness affect a person's capacity to engage with services.

### Gender affirming care

Access to gender affirming care is essential for older trans and gender diverse people to be able to maintain care initiated prior to accessing aged care services, as well as for people who may wish to initiate a gender affirmation care plan. This may include the provision pharmaceutical products (e.g. hormones) and surgical aftercare (e.g. dilation).

Gender affirming care also includes day-to-day care activities, such as showering, dressing, and addressing a person in ways that are inclusive and respectful of their gender identity (e.g. addressing a person with their correct name and pronouns).

### HIV and ageing

In April 2019, the National Association of People Living with HIV Australia (NAPWHA) released *HIV and Ageing in Australia – the New Frontier*, a comprehensive report which discussed the evidence base on HIV and ageing and presented insights into the lived experiences of older PLHIV.[13]

According to the NAPWHA report, evidence suggests that the prevalence of comorbidities and other age-related conditions is higher amongst PLHIV than in older HIV-negative people. Frailty and chronic inflammation are especially a concern, and older people living with HIV are also more likely to report limitations in their capacity to undertake daily tasks due to poor health. The vulnerability to develop health problems is increased among people who have been living with HIV for many years.

It is vital services catering to the needs of PLHIV ensure that the best service or care possible is available, and that this service is delivered free from stigma, discrimination or treatment that may cause a person

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[7] ABS (Australian Bureau of Statistics) 2008. National Survey of Mental Health and Wellbeing 2007: summary of results. ABS cat. no. 4326.0. Canberra: ABS.

[8] Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2018. Sydney: Kirby Institute, UNSW Sydney; 2018.

[9] Claydon C, Webber K, Sweeney J. National Drug Strategy Household Survey 2016: detailed findings. Canberra: Australian Institute of Health and Welfare. 2017.

[10] Mooney-Somers, J, Deacon, RM, Scott, P, Price, K, Parkhill, N (2018) Women in contact with the Sydney LGBTQ communities: Report of the SWASH Lesbian, Bisexual and Queer Women's Health Survey 2014, 2016, 2018 Sydney: Sydney Health Ethics, University of Sydney.

[11] Hyde Z, Doherty M, Tilley PJM, McCaul KA, Rooney R, Jancey J.2014. The First Australian National Trans Mental Health Study: Summary of Results. School of Public Health, Curtin University, Perth, Australia. Executive summary, page iv.

[12] ABS (Australian Bureau of Statistics) 2008. National Survey of Mental Health and Wellbeing 2007: summary of results. ABS cat. no. 4326.0. Canberra: ABS.

[13] NAPWHA, 2019. HIV and ageing in Australia, the New Frontier.

living with HIV to feel different from any other client in the service. This includes staff being trained in the proper application of universal precautions and understanding the importance of laws regarding disclosure of HIV status. In the normal course of duty for aged care workers, who are undertaking universal precautions, there is no need for disclosure to occur.

## II. Inadequacy of aged care services for LGBT people and PLHIV

### 1) A lack of inclusive services

Market-driven reforms of the aged care system[14] have attempted to increase choice for aged care consumers, however, there are very few LGBT inclusive aged care options. There is only one Rainbow Tick-accredited provider operating and finding an aged care provider that meets individual needs in NSW remains complex or, in some areas, even impossible.

Like most issues facing our community, the issue is compounded for people living in rural or regional areas, who may have to travel far from established community connections and family in order to access an appropriate service.

#### Inadequate levels of home care

Reforms that have encouraged the provision of services to support people to remain in their own homes are consistent with the desires expressed by members of our communities who, very often, want to avoid or delay entry into a residential aged care facility.

However, due to a lack of services and capacity, there is a gap between the levels of home support needed and the levels of care that are provided under the Commonwealth Home Support Program. Many of ACON's Community Visitor Scheme clients are currently receiving *Home Care Level 3 – intermediate care needs* packages, despite being assessed as requiring *Home Care Level 4 – high care needs* packages

As a result of the lack of *Home Care Level 4 – high care needs* packages, many people are prematurely entering residential aged care facilities.

ACON and other LGBT and PLHIV community care networks also play a significant role in providing social support and peer support that contribute to improved health outcomes.

#### A lack of inclusive residential aged care providers

There is a lack of services that provide inclusive services for LGBT people and PLHIV. For many people in our communities, inclusive and affordable aged care is simply not available.

Uniting Care remains the only Rainbow Tick provider operating in NSW. The Rainbow Tick accreditation involves a thorough process that verifies whether a provider's commitment to improving the quality of care to their local LGBTI community is reflected in its practices.

Many aged care providers claim being inclusive but gaps in the accreditation system and confusing or misleading information make it difficult to verify whether inclusive practices are indeed in place.

[14] Australian Government Department of Health, Ageing and Aged Care webpage – Increasing Choice in Home Care https://agedcare.health.gov.au/increasing-choice-in-home-care [accessed 19 September 2019]

The bar for being listed as LGBTI friendly on *Myagedcare.giv.au* is also too low. A service can be listed as a LGBTI specialist if it is or is in the process of being Rainbow Tick accredited, or if it meets 3 cumulative criteria (completion of a self-assessment and planning tool for LGBTI inclusive aged care; policies on non-discrimination, LGBTI inclusive practice and conflict resolution; and staff and management have undertaken or are undertaking the LGBTI Sensitivity Training.)

A rapid search on *Myagedcare.gov.au* for an 'aged care home' within a 250km radius of the inner Sydney postcode of 2010 yielded 120 facilities listed as having a 'specialisation' in LGBTI care, however, our experience suggests these claims may not be reflected in practice.

Many residential aged care facilities are also operated by religious institutions that may not be suitable for members of our communities due to perceived or actual discrimination.

The lack of options is particularly acute in regional NSW where the only option may be a single aged care provider operating in the area. Relocating to access a more inclusive provider may present significant challenges, including the risk of eroding existing informal care networks.

### A lack of affordable options

For many people in our communities, the difficulty to find inclusive aged care services is compounded by affordability issues.

With significant progress having been made in HIV treatment, older gay men living with HIV can live longer, however, they often experience significant financial disadvantage.[15] In NSW, early in the epidemic many cashed in their super and retired to the Northern Rivers following their diagnosis. Older LGBT people and PLHIV are anxious about financial instability, housing unaffordability and fear of losing friendships and community as a result of isolation.[16]

A lack of affordable housing options, combined with financial stress and limited superannuation, limit the options that many LGBT and PLHIV can choose from in an aged care services market that is vastly under-supplied and un-adapted for our communities.

## 2) Substandard or unsafe services

The scarcity of inclusive aged care services and the casual nature of the workforce can mean that the vast majority of PLHIV and LGBT people's care is delivered by providers and services who are not invested in tackling discrimination and addressing their specific health needs. The limited understanding of the needs of this population can result in failures to detect or appropriately manage health conditions.

### Stigma, discrimination and abuse

Today, discrimination against LGBT people and people living with HIV in aged care persists, which has significant impacts on their health. LGBT communities are subject to discriminatory attitudes and, too often, verbal abuse from staff, aged care facility residents and visitors. Aged care services often do not have any plans to prevent such discrimination from occurring.

[15] NAPWHA, 2019. HIV and ageing in Australia, the New Frontier.
[16] ACON, Health Outcome Strategy 2017-2021 – Ageing.

HIV-related stigma and discrimination in aged care remain a major concern. There is a limited understanding of HIV among the aged care workforce, which may result in stigmatising practices (e.g. double gloving) that are at odds with evidence-based medical guidelines. This perceived or actual experience of stigma and discrimination can lead to HIV-positive people hiding their HIV status.

### Inadequate support for daily living and breaches of people's right to independence.

Standard 1 requires organisations to support consumers to exercise choice and independence and respect their privacy. Standard 4 requires organisations to provide safe and effective services and supports for daily living that optimise the consumer's independence, health, well-being and quality of life.

Aged care facilities, however, can be reluctant to accommodate living arrangements that enable of people of diverse sexualities to maintain intimacy with their partners. It is our belief that disallowing such living arrangements, and broader issues related to this, such as residents or clients feeling uncomfortable about disclosing information relating to their partner or partners, or their gender identity or sexuality breaches these standards.

Even in situations where direct discrimination is not present, the environment perpetuated by homophobic attitudes can lead to clients feeling they need to hide their sexuality or gender identity. Not only does this lead to a reduced standard of life for those individuals but it may limit their ability to access health and support services.

### Poor treatment of trans and gender diverse people

The needs of trans and gender diverse people are often poorly understood and not properly addressed in aged care. Access to gender affirming care (with general practitioners and/or nurses) can be difficult or delayed.

ACON can unfortunately report instances of trans clients being routinely mis-gendered or forced to de-transition, with significant consequences for their mental health (see case study below) and in breach of Standard 1 - Consumer dignity and choice, which highlights the right to be "treated with dignity and respect" and to "maintain [one's] identity" and Standard 3 - Personal care and clinical care.

The importance of advanced care directives that clearly articulate a person's gender affirmation wishes cannot be understated.

**Case Study: Hanna, misgendered in residential aged care**

Hanna lived as a woman for over 30 years and up until recent years had been strongly connected with her community. Two volunteers reported emerging symptoms and Hanna was diagnosed with rapid onset dementia that, over the course of three months, meant she was unable to live at home safely and was moved into a residential care facility in the outer suburbs of Sydney.

Prior to going into care, Hanna contacted a trans and gender diverse service who were able to support her to go into the facility. They also offered training, however the facility declined.

Hanna worked as a mechanic prior to going into care and continued to wear the flannelette shirts she had been accustomed to, and was comfortable in. Due to the era that she was born, however, Hanna's legal documents were still registered in her former name as well as the gender she was assigned at birth

(male), this meant that when she went into care she was referred to by the incorrect name. Hanna was also provided only with masculine clothing.

When the facility was asked about why Hanna's former name was on her door, and why she was dressed in masculine clothing, they stated that since Hanna had dementia she wasn't able to be clear about her gender. Hanna still used makeup when she was able to and continued to paint her nails.

Hanna was visibly distressed when misgendered and when the incorrect name was used to address her.

The facility claimed that due to Hanna's dementia she could not consent to updating her records, although another trans and gender diverse support service assisted Hanna to legally change her name.

Hanna was successfully matched with two volunteers from the trans and gender diverse community through a Community Visitors Scheme program. Both volunteers had known her well from previous years and were both very clear that Hanna would want to be known by her affirmed name.

Hanna continued to be misgendered and called the incorrect name until her death.

### Inadequate HIV care

As highlighted previously, evidence suggests that the prevalence of comorbidities and other age-related conditions, including frailty and chronic inflammation, is higher amongst PLHIV than in older HIV-negative people. The vulnerability to develop health problems depends on how long a person has been living with HIV and can be influenced by earlier treatments for HIV which came with significant long-term side effects.

In some areas, it is particularly difficult to maintain access to General Practitioners who have a good understanding of HIV treatment and care. This can result in delays in diagnosing, treating or managing HIV-related co-morbidities such as HIV-related neurocognitive disorders.

### Unclear outcomes

Due to a lack of data collection in Government and community services the full extent of health disparities in our communities is not known. The inclusion of sexuality indicators in ageing, disability and health services is not systematic and large epidemiological studies remain inconsistent and incomplete (e.g. data is often reported only by sexuality and not by sexuality and gender).

## III. Recommendations

While national frameworks have contributed to raising awareness of LGBT-related issues in aged care, the extent of progress on the ground is unclear, and many in our communities receive sub-standard non-inclusive care.

Through advocacy, community support and working with aged care providers (e.g. inclusion training), community organisations can play a significant role to make sure that our communities are treated with respect and receive the care they need, in their own homes or in residential facilities, including gender affirmation and HIV-related care.

**Systemic changes are, however, required for the standards of care and outcomes for our communities to be lifted and monitored.**

High quality care for LGBT people and PLHIV should be available in all aged care services.

A more robust accreditation process is necessary to ensure that services listed as LGBT-specialised effectively meet the needs of our community.

### **Recommendation 1:** collecting adequate data to measure and monitor aged care outcomes for LGBT people and PLHIV

Opt-in data collection regarding sexuality, gender identity and intersex status should be encouraged in aged care, as well as in health and human services more broadly, to enable the assessment of outcomes for LGBT people and PLHIV against the National *2019 Actions to support Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex elders*.

### **Recommendation 2**: improving workforce capability, including through inclusion and HIV training

Staff training on inclusivity and HIV is important to improve workforce capabilities. To ensure a minimum knowledge and skills level, assessing competencies should be required. General population education on HIV would also contribute to reducing HIV-related stigma and discrimination.

### **Recommendation 3**: improving the enforcement of standards

Appropriate levels of home care are required to enable people to stay in their own homes for longer. The lack of *Home Care Level 4 – high care needs* packages should be addressed as a matter of priority.

The enforcement of standards in residential aged care needs to be improved to ensure high-quality care for any LGBT person or PLHIV accessing any aged care service. This is particularly important in regional areas where only a single provider is often operating.

Community Aged Care Packages and Commonwealth Home Support initiatives need to be examined to determine whether they are addressing the needs of LGBTI people, and specifically HIV+ people. The delivery of packages by appropriate LGBT or HIV community organisations should be encouraged.

To improve the **enforcement of standards** and ensure the provision of quality care for all LGBT person or PLHIV accessing any aged care service, it is important that the auditing and standard enforcement workforce understand the issues affecting our communities, particularly the many ways in which discrimination can occur.

### **Recommendation 4**: improving accreditation processes

The accreditation system needs to ask providers to demonstrate *how* they are inclusive and require more verification. This process should also be ongoing, ensuring that providers remain upskilled in the best ways to provide services for our community.

### **Recommendation 5**: improving the effectiveness of complaints mechanisms

Complaints mechanisms are important tools to ensure system accountability, detect breaches and improve care.

It is important that the workforce responsible for conducting assessments and reviewing complaints is aware of issues affecting LGBT people and PLHIV and ways to resolve them. This includes home support assessors (RAS), Aged Care Assessment Team assessors (ACAT), Aged Care Assessment Program Reconsiderations officers and other complaints assessors.

### Recommendation 6: making it easier for people to navigate the system and make decisions

A separate (but linked) website for LGBT Aged Care may be required to overcome the limitations of the *myagedcare.gov.au*.

ACON has also found that peer-based support and assistance with system navigation is a very useful strategy – this kind of approach could be useful to assist older LGBT people to make choices and/or navigate the system.