ACON SUBMISSION

REVIEW OF THE NATIONAL FRAMEWORK FOR ADVANCE CARE PLANNING

4 March 2020

About ACON

ACON is NSW's leading 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 living with HIV (PLHIV)
- 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.

Acknowledgment of Traditional Land Owners

ACON acknowledges the traditional owners of the lands on which we work. We pay respect to Aboriginal elders past, present and emerging.

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Executive Summary

ACON recognises the need to review the Advanced Care Planning Framework and welcomes the overall direction towards a simpler, more personalised and harmonised advance care planning process across states and territories.

The move to a more person-centred approach to advance care planning (ACP) is a great step forward, as is the recognition of the specific needs of the communities as listed in 6.12 principal 1, including people who are *"lesbian, gay, bisexual, transgender, intersex, queer and/or gender-diverse".*

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, and against the direct wishes of community members.

Many people in our communities fear the aged care system because of the risks of being stigmatised, discriminated against or disconnected from their friends and family, which may result in LGBTQ people hiding their sexuality and poorer health outcomes.

A lack of understanding of our communities needs and family structures exposes LGBTQ people to the risk of having their wishes ignored. There is a lack of guidance on how to best uphold an LGBTQ person's choices when conflicts arise between their biological family and partner and/or family of choice.

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, to be treated with respect and to have their identity, culture and diversity valued and supported.[1]

ACON recommends four areas to improve the proposed ACP framework for our communities:

1. **Ensure adequate data collection to measure aged care outcomes for lesbian, gay, bisexual, transgender and queer (LGBTQ) people**;
2. **Explicitly acknowledge in the framework the variety of family structures within LGBTQ (and other) communities,** including biological families, families of choice, peer carers and other forms of relationships;
3. **Invest in communication, training and support targeting LGBTQ communities** to make it easier for LGBTQ people to understand and navigate a complex process around end of life care; and
4. **Adopt culturally sensitive ACP storage options;** ensuring that sensitive data is readily accessible but that private and sensitive information such as trans experience, health needs and carer relationships are not publicly available until needed.

[1] Australian Charter of Aged Care Rights.

Introduction

ACON, NSW's leading health organisation specialising in community health, inclusion and HIV responses for people of diverse sexualities and genders, welcomes the opportunity to provide a submission to the Review of the Advanced Care Planning Framework.

This submission focuses on avenues to improve advance care planning (ACP) outcomes for LGBTQ people. It echoes several issues raised by ACON in a recent submission to the Royal Commission into Aged Care Quality and Safety[2], which highlighted systemic deficiencies in understanding our communities' needs, a lack of inclusive providers and accountability mechanisms.

ACON welcomes the ACP review's intention to further personalise advance care planning, and in particular the recognition of the specific needs of the communities as listed in 6.12 Principal 1, including people who are *"lesbian, gay, bisexual, transgender, intersex, queer and/or gender-diverse"*.

This submission provides an overview of the needs of LGBTQ people, which should be considered in advance care planning, as well as recommendations to ensure that the ACP works better for these communities.

I. Why is advance care planning different for LGBTQ people?

Effective ACP for LGBTQ people should be informed by an understanding of discrimination, diverse family structures and specific health needs.

a) Discrimination

LGBTQ people who are ageing 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[3].

Discrimination and poor treatment throughout their lives and/or within aged care programs mean that LGBTQ people often fear disclosing their sexuality, gender identity or HIV status to health and care professionals, which may leave some of their needs ignored or inadequately addressed. Being open about one's sexuality or gender identity in care 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. It also means they are unlikely to be honest in their ACP about their "values, beliefs and preferences." or they may not bother recording one at all.

[2] 2019.10.01 ACON submission to the Aged Care Royal Commission.
[3] ACON 2018. In Pursuit of Truth and Justice, Documenting Gay and Transgender Prejudice Killings in NSW in the Late 20th Century.

During the introduction of online medical records many of the community expressed their concerns about privacy, access and confidentiality of their records. Similar fears would also be held for ACP documents stored centrally, with questions around registered provider access, and who at a registered provider could access the information. For example, a hospital was a registered provider and could access ACP records, would all hospital staff have access to it, or only the treating clinician or would the administration teams?

b) 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.[4]

LGBTQ communities 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.

LGBTQ people may have a range of family structures and support networks that play important roles in their care as they age. LGBTQ people, for instance, may have children raised by more than two parents, and chosen family of friends may be the most important element of LGBTQ 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 LGBTQ people's family structures and care networks is, however, often overlooked in aged cared planning and service delivery. The need for LGBTQ people to arrange wills, enduring power of attorney, advance health care directives and enduring guardianship is especially pertinent for LGBTQ 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).

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

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.

Many LGBTQ community members may also be estranged from their biological family after they have disclosed their gender identity or sexual orientation. However, this divide may not be apparent to care providers or articulated in an ACP. This leaves the community vulnerable to having their wishes overridden by biological family, when family of choice or peer group carers are not recognised.

c) Mental and physical health

Mental Health and Capacity

LGBTQ people face disparities in terms of their mental health[5], sexual health[6] and rates of substance use[7], which may continue in older age and require appropriate care. The effects of ageing, however, manifest unevenly across our communities.

LGBTQ people's experiences of discrimination and abuse affects their mental health and are linked to higher rates of psychological distress[8], depression[9], anxiety[10] and suicide. Social exclusion and loneliness affect a person's capacity to engage with services.

It is vital that during any decisions around capacity that a person's sexuality or gender does not get used as reason for reduced capacity, as there is a history of pathologisation of the community and in linking with mental health diagnoses. It is also important that any mental health needs are also not used as a rationale for reduced capacity, given it is often this experience of discrimination that has a mental health impact.

Other Health Needs

The LGBTQ community also has many specific care needs including gender affirming care and HIV health that may not be present in the wider community. These specific needs should not have to be spelt out in ACPs to ensure they are enacted. It is the responsibility of the care provider to be adequately trained and up to date on best practice for the community (see the ACON submission to the Aged Care Royal Commission for more details)

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[5] ABS (Australian Bureau of Statistics) 2008. National Survey of Mental Health and Wellbeing 2007: summary of results. ABS cat. no. 4326.0. Canberra: ABS.
[6] Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2018. Sydney: Kirby Institute, UNSW Sydney; 2018.
[7] Claydon C, Webber K, Sweeney J. National Drug Strategy Household Survey 2016: detailed findings. Canberra: Australian Institute of Health and Welfare. 2017.
[8] 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.
[9] 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.
[10] ABS (Australian Bureau of Statistics) 2008. National Survey of Mental Health and Wellbeing 2007: summary of results. ABS cat. no. 4326.0. Canberra: ABS.

II. Recommendations

While national frameworks have contributed to raising awareness of LGBTQ-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.

The future of advance care planning is largely dependent on much needed reforms of the aged care system more broadly. As raised by ACON with the Royal Commission into Aged Care Quality and Safety, stronger accountability and accreditation mechanisms are required across the aged care system, as well as investments in training and peer support programs that can assist older LGBTQ people to break social isolation and navigate the aged care system.

Once this occurs, we are more likely to see consumers who are sexuality or gender diverse utilise the ACP framework, once there are confident the system will support them and their "values beliefs and preferences".

In the interim the framework needs to specifically address the inequities faced by the community from a legal, systematic and person-centred perspective.

Recommendation 1: Collecting adequate data to measure and monitor aged care outcomes for LGBTQ people

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 LGBTQ people against the National *2019 Actions to support Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex elders*. This will also normalise diversity making the conversation around Advanced Care Planning easier.

Recommendation 2: Explicit acknowledgement of the variety of family structures within the LGBTQ (and other) communities; this includes the acknowledgement of biological families, families of choice, peer carers and non-traditional relationships such as polyamorous relationships.

The current guidelines go a long way to include family community and carers, in the ACP process but needs to go further to overtly include all family types in their definitions section. This will allow people to see that their choices are valid, and that biological family isn't the only type of family acknowledged. Without being explicit people will assume that family structures apart from biological family will not be recognised.

Principals 9 and 10 state; *"Where a family member, professional or whistle-blower suspects a decision-maker has misused or abused their power, they can undertake dispute resolution"* (see Principle 10). and *"Decision-makers, family members, health professionals and whistle-blowers may seek dispute resolution if they are concerned by a decision about care made on behalf of an individual with reduced or lacking competence. The dispute resolution process should focus on timely resolution, involvement of all relevant parties and be carried out in line with jurisdictions' legislative and common law requirements."*

Clarity is also needed hear about the currency of relationships. Should, for example, current carers have a greater say in the dispute and resolution process than a biological family member who has been estranged from the person receiving care?

Contemporaneous decision-making should be enacted along with contemporaneous relationship acknowledgement. This should also be clearly articulated within the framework to clarify currency of relationships to avoid potential disputes when the ACP is enacted.

Recommendation 3: Utilising LGBTQ organisations for the communication, training, support and collection of LGBTQ community ACPs; making it easier for LGBTQ people to navigate a complex and confusing process around end of life care.

As mentioned in Principal 1 *"Individuals should be supported to think about their future care in a person-centred way. This may include: … linking with other services who provide health and/or personal care to under-served population groups.".* We agree with this statement and believe that LGBTQ community organisations can not only support the provision of care, but also become key partners in the support of the LGBTQ communities in their education, understanding and storage of their ACPs.

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 LGBTQ people to make choices and/or navigate the system.

Recommendation 4: Culturally sensitive ACP storage options; ensuring that sensitive data is readily accessible but that private and sensitive information such as Trans experience, health needs and carer relationships are not publicly available until needed.

Principal 6 state "*Individuals should also be encouraged to upload their ACP Documents to national databases such as My Health Record. Additionally, jurisdictions may consider the value of a central repository of ACP Documents*." Given the inherent distrust of the government, the concerns about confidentially and discloser, health care systems and data collection agencies it is recommended that LGBTQ organisations be consulted on the feasibility and cultural sensitivity of any proposed repository.

We recommend that any centralised repository of ACP documentation be an opt in process and non-mandatory due to the communities existing concerns.