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**NATIONAL LESBIAN, GAY, BISEXUAL,
TRANSGENDER, INTERSEX (LGBTI)
AGEING AND AGED CARE STRATEGY REVIEW**

SUBMISSION FROM ALZHEIMERS AUSTRALIA

MAY 2017

Submission template

National LGBTI Ageing and Aged Care Strategy Review

Submissions close 5pm, 12 May 2017

Instructions:

- Save a copy of this template to your computer.
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The Department’s APP privacy policy (required by APP 1.3) can be accessed at [the Department’s APP privacy policy web page](#). The APP privacy policy explains how the Department handles personal information generally, including its collection, storage, security, access, use and disclosure.

All submissions received will be treated with discretion, and no personally identifying information from your submission will be released to any third party.

Thank you for your interest.

1. Tell us about you

1.1 What is your full name?

First name Kaele

Last name Stokes

1.2 What stakeholder category do you **most** identify with?

Peak body - consumer

1.3 Are you providing a submission as an individual (**go to question 1.4**) or on behalf of an organisation (**go to question 1.6**)?

Choose an item.

1.4 Do you identify as a:

Lesbian

Intersex

Gay

Other _____

Bisexual

Would rather not say

Transgender

None of these apply

1.5 Do you identify with any other of these special needs groups?

Choose an item.

1.6 What is your organisation's name?

Alzheimer's Australia

1.7 Which category does your organisation **most** identify with?

Consumer Peak Body

1.8 Do you **consent** to potentially being contacted to discuss the contents of your submission?

Yes

1.9 Do you wish for your submission to remain **confidential**?

No

2. Aged Care Sector and LGBTI Care

2.1 How prepared do you think the aged care sector is to meet the needs of the LGBTI communities?

Like many issues relating to diversity within ageing and aged care services, the sector has progressed to meet the needs of consumers from diverse backgrounds but there is much more to be done.

By the year 2050, it is estimated that nearly 1 million people in Australia will be living with dementia. As LGBTI people are estimated to make up 11% of the Australian general population, based on current rates there will be approximately 100,000 LGBTI people with dementia by that time.

In addition to the challenges faced by many consumers when it comes to dementia services (lack of choice, access and information), people who identify as LGBTI may also face additional challenges, such as social isolation, relationship recognition and steering through a complicated legislative environment. Significantly, many LGBTI consumers who are now facing a dementia diagnosis became adults at a time when social and legal discrimination was prevalent. As a consequence, the invasion of privacy that community services and residential care may involve can create a fear of coming out to services providers and may lead to anxiety and depression.

Many LGBTI people have been rejected from their biological families. They may have experienced discrimination and stigma. Their access to service may be further hampered by cultural diversity within LGBTI communities: for instance, some groups historically have had more of a voice than others.

Within the LGBTI umbrella, some groups are less represented than others: for instance, bisexual people have spoken to us about feeling less represented than other LGBTI groups.

It is therefore important that the aged care sector is able to consider more marginalised members of the community when developing strategies for inclusiveness.

2.2 As an individual or carer, do you think the aged care sector has been adequately supported to deliver LGBTI inclusive services?

Not applicable.

2.3 As an organisation, do you think the aged care sector has been adequately supported to deliver LGBTI inclusive services?

Alzheimer's Australia believes that more targeted funding in the aged care sector for LGBTI inclusive services is both warranted and required.

While the National LGBTI Ageing and Aged Care Strategy addresses a range of sound principles and goals, in practice there has been inadequate resourcing and funding to drive implementation on the ground. Incremental change has largely been the result of representative bodies from LGBTI communities targeting specific aged care issues rather than systemic change throughout the aged care sector.

2.4 Before receiving notification of this submission open round, were you or your organisation aware of the existence of the National LGBTI Ageing and Aged Care Strategy (the LGBTI Strategy)?

Yes

3. Principles of the LGBTI Strategy

The Strategy is based on the following five principles:

- **Inclusion** - The rights and needs of older LGBTI people, their families and carers are included in the development of Australian Government aged care policies and programs.
- **Empowerment** - Older LGBTI people, their families and carers are supported with the knowledge and confidence to maximise their use of the aged care system.
- **Access and Equity** - All areas of aged care understand the importance of, and deliver, LGBTI-inclusive services.
- **Quality** - Care and support services provide quality services that meet the needs of older LGBTI people, their families and carers and are assessed accordingly.
- **Capacity Building** - LGBTI individuals and communities have the capacity to both articulate their aged care needs and be involved in the development of services and the workforce to meet these needs.

3.1 What concrete steps, if any, have you seen towards the implementation of the 'Inclusion' principle over the past 5 years?

From a government policy perspective, the principle of inclusion for LGBTI people is increasingly (though not routinely) reflected in information and materials which make explicit reference to the importance of ensuring that dementia services are inclusive of and responsive to the needs of LGBTI people.

However, it is clear that there are still fewer references/case studies/photographs of people who identify as LGBTI in resources and information relating to older people and care. Similarly, from a program or service perspective, the ability for a carer to exercise choice or influence on behalf of a same-sex partner with dementia varies.

Alzheimer's Australia is aware of a number of effective programs and services that cater to LGBTI needs and preferences, though typically they have been delivered as distinct, time-limited programs or are limited to specific geographies.

Some successful inclusive strategies include:

- The National LGBTI aged care training program, which was funded to 2016.
- Delivery by ACON in NSW of the Community Visitor Scheme to older LGBTI people across Sydney, the Hunter, Nepean, Illawarra and Central Coast regions. It should be noted that other areas of NSW are not serviced.
- The development of projects, services and resources by Val's Café in Victoria.

3.2 What concrete steps, if any, have you seen towards the implementation of the 'Empowerment' principle over the past 5 years?

As Alzheimer's Australia has emphasised in other submissions, there is still a significant gap between the principle and the practice of empowerment in the ageing and aged care system. Many consumers faced with a diagnosis of dementia, as well as their families and carers, struggle to navigate the aged care system or maximise their use of services. For people with diverse needs, including consumers (and partners) who identify as LGBTI, a lack of empowerment is compounded by a lack of appropriate services.

There are, of course, examples of good practice across the country but they must be viewed as specific (often time-limited) programs rather than being representative of a more systemic shift in service delivery.

- Alzheimer's Australia's Service Delivery Pathways projects (SDPP) have been working towards increased inclusion of LGBTI clients through an understanding of background, experience, acknowledgement of intimate relationships, social connectedness and advance care planning amongst other elements.
- Alzheimer's Australia has developed a range of help sheets and resources that support consumers and providers to be more inclusive and inform consumers on how to exercise their choice and control. These include *Caring for LGBTI People with Dementia: A Guide for Health and Aged Care Professionals* and the *We are Still Gay* resource.

3.3 What concrete steps, if any, have you seen towards the implementation of the 'Access and Equity' principle over the past 5 years?

Consumers who identify as LGBTI typically tell us that the principles of access and equity have been variable in their application across the aged care sector – both in terms of quality dementia care more generally and in terms of LGBTI appropriate care. Discrimination – whether intentional or unintentional – is still a very real experience for many older Australians who identify as LGBTI. Care partners too, can face discrimination. A residential service may take an inclusive approach to sleeping arrangements, for example, but not recognise the authority of a partner in making clinical or end of life decisions. Support may be lacking for carers after the death of their partner, despite support being particularly important for those who are socially isolated or for whom experiences and relationships have not been validated.

Access and equity can also be impacted by geography: people who identify as LGBTI are often geographically dispersed, making it difficult for service providers to provide appropriate, responsive and inclusive services for both practical and financial reasons.

On the balance of what our consumers and providers tell us, therefore, the principles of access and equity are perhaps the most underdeveloped of the five included in the LGBTI Strategy.

3.4 What concrete steps, if any, have you seen towards the implementation of the 'Quality' principle over the past 5 years?

There are very few systemic examples on which Alzheimer's Australia can draw to describe proactive ways of ensuring quality dementia care services for people who identify as LGBTI. We do hear of individual services that have supported LGBTI clients in accordance with their preferences and have reviewed service quality against that individualised approach but the extent of quality review depends on the service itself. However, formal quality assessment is still very much clinically driven (especially in residential aged care) and provider awareness (and in some cases acceptance) of LGBTI issues is inconsistent.

In speaking to our consumers it would seem that LGBTI older people are generally more aware that aged care services should not discriminate service provision or quality of care and that much of this awareness has resulted from government information around quality and compliance systems in aged care as well as the tailoring of information by some organisations.

3.5 What concrete steps, if any, have you seen towards the implementation of the 'Capacity Building' principle over the past 5 years?

Alzheimer's Australia is aware of a number of important and effective capacity building programs over the past few years, spanning specialised education and resource development.

For example, Alzheimer's Australia is funded by the Australian Government to deliver the Service Delivery Pathways Project (SDPP), which is delivering excellent results in reaching special needs groups, including people with LGBTI needs. The community development, community partnership and capability building approach taken throughout this range of projects demonstrate the value in investing in dementia specialist facilitators and

enablers that can unlock and leverage community resources and pathways for hard to reach consumers. These projects provide a high return on investment by drawing on existing strengths and access opportunities within communities and empowering community members to drive change. The focus of jurisdictions has thus predominantly been on capacity building and sector development: advocating with residential care facilities, upskilling the services sector, providing staff training on specific diversity issues for LGBTI people with dementia and structured partnerships to build workforce capacity and service sector capability.

Another important initiative has been the resource, *We Are Still Gay: An evidence based resource* developed in partnership with Val's Café, Latrobe University and Australian Research Centre in Sex Health and Society. Designed for professional and carer education, it details the complexities for the LGBTI audience. The resource was developed to provide service providers with an evidence base on the experiences and needs of LGBTI people living with dementia. The aim is to promote the development of LGBTI inclusive services for people living with dementia.

3.6 Are these Principles still relevant?

Alzheimer's Australia sees the principles as relevant and has developed its own LGBTI and Dementia Framework, which seeks to build on the six goals of the Australian Government to provide equity, acknowledgement, responsiveness and person centred support to LGBTI people with dementia, their carers, partners, friends and relatives. Additionally, while the National Strategy specifically relates to older LGBTI Australians, the Alzheimer's Australia LGBTI Framework also encompasses people with younger onset dementia.

4. Goals of the LGBTI Strategy

The Strategy's high-level Principles were complemented by six specific goals:

- Goal 1 - LGBTI people will experience equitable access to appropriate ageing and aged care services.
- Goal 2 - The aged care and LGBTI sectors will be supported and resourced to proactively address the needs of older LGBTI people.
- Goal 3 - Ageing and aged care services will be supported to deliver LGBTI-inclusive services.
- Goal 4 - LGBTI-inclusive ageing and aged care services will be delivered by a skilled and competent paid and volunteer workforce.
- Goal 5 - LGBTI communities, including older LGBTI people, will be actively engaged in the planning, delivery and evaluation of ageing and aged care policies, programs and services.
- Goal 6 - LGBTI people, their families and carers will be a priority for ageing and aged care research.

4.1 What concrete steps, if any, have you seen towards the implementation of the 'Goal 1' over the past 5 years?

While the goals listed above have not yet been attained, they remain entirely relevant. Alzheimer's Australia has seen increased awareness of LGBTI communities; however, we are far from achieving full inclusion.

In just one element of access, LGBTI representation is still largely absent from Government health guidelines and strategies for older people. For example, the 2016 Best Practice Clinical Guidelines for Dementia from NHMRC Cognitive Decline Centre mention CALD and ATSI groups specifically when talking about individualised care and diversity but LGBTI people are not represented as a special needs group.

As discussed further above, meaningful access to LGBTI inclusive services is variable – and the experience can vary even within different elements of a single service.

4.2 What concrete steps, if any, have you seen towards the implementation of the 'Goal 2' over the past 5 years?

Aside from specific aged care funding pools that are used to support the development of new resources and education to implement LGBTI-appropriate care, there seems to be little activity to translate the principles and goals outlined in the LGBTI Strategy into systemic practice.

Some providers have aimed to address the needs of LGBTI people: for example, the Riviera Health Group opened a residential facility in Katoomba in 2012 that has a specific LGBTI inclusive policy and sensitivity toward supporting transsexual people receive appropriate aged care.

Uniting Aged Care was the first faith-based aged care organisation in Australia to be officially recognised as LGBTI friendly and received Rainbow Tick Accreditation in 2015.

Tertiary education has also been explicit in including LGBTI education in online education: examples include work undertaken by the Dementia Collaborative Research Centre and the University of Wollongong.

Groups like Val's Café have focused on improving the skills and understanding of service providers and consumers alike.

4.3 What concrete steps, if any, have you seen towards the implementation of the 'Goal 3' over the past 5 years?

A limited number of examples in which aged care services are supported to deliver LGBTI services come to mind. In 2012 The National LGBTI Alliance received government funding to work collaboratively in ageing and aged care issues, of course led to the LGBTI Ageing and Aged Care Strategy.

The Silver Rainbow Project was funded for the development and training of aged care workers. Several hundred aged care facilities have completed Rainbow project programs.

ACON in NSW operated the national LGBTI Aged Care Training for Aged Care workers from 2012 – 2016. They also provide the ACON Love Project: Living Older and Visibly Engaged, and the ACON Community Visitor Scheme for older people.

The Val's Café initiative focuses on supporting providers to deliver appropriate care through a range of education programs.

4.4 What concrete steps, if any, have you seen towards the implementation of the 'Goal 4' over the past 5 years?

LGBTI representative bodies have introduced specific education and developed programs for care staff about older LGBTI people in the past 5 years. Alzheimer's Australia is not aware if these programs receive government funding except for the LGBTI Alliance project.

4.5 What concrete steps, if any, have you seen towards the implementation of the 'Goal 5' over the past 5 years?

Monitoring and evaluating the delivery of ageing and aged care services to ensure that they meet the care needs of older LGBTI people, their families and carers remains an inadequately assessed goal.

Measuring consumer satisfaction is a vital element in measuring service quality, and LGBTI consumer involvement in the quality process is also critical. Consumers and carers should be engaged as key partners in aged care quality and compliance processes. Consumers have told Alzheimer's Australia that they are keen to have a more central role in these processes.

For example, involving care recipients, carers or former carers as part of assessment teams would utilise their expertise as well as give consumers more confidence in the system. There are of course questions to be explored around developing appropriate training and exploring how consumers could be equal members of the assessment team, or play an advisory role. Involving consumers in the quality monitoring process may assist to reducing the hesitation some consumers feel in providing honest feedback about the services they are receiving to a reviewer as well as provide the assessment teams with additional information to support the review.

The National Safety and Quality Health Service (NSQHS) Standards provides an example on how this can be built into the draft standards. The focus in the NSQHS Standards on consumer involvement and data collection has led the states to release data on patient experiences surveys. For example, most states have publically available reports of patient experience data from specific patient groups and provides comparisons across hospitals.

4.6 What concrete steps, if any, have you seen towards the implementation of the 'Goal 6' over the past 5 years?

There has been work around this goal, with La Trobe University and the Australian Association of Gerontology being funded to contribute to the knowledge base and practice guidelines for providing LGBTI appropriate care.

4.7 Are these Goals still relevant?

As with the Principles of the strategy, the goals are also still relevant, but need to be better resourced and the outcomes measured to assess performance.

5. Experience of the LGBTI Strategy

5.1 In terms of the LGBTI Strategy, what do you think the government and aged care sector has done to improve the LGBTI access to inclusive ageing and aged care services?

As mentioned above, there has been both variable and varied improvement in access and provision of inclusive services for people who identify as LGBTI.

Although a range of service providers, programs, initiatives and resources have been developed (and supported by government), however, they have not yet translated to sector-wide transformation and tend to be funded in specific program or project pockets.

5.2 In terms of the LGBTI Strategy, do you think it aligns with broader aged care reform like 'Increasing Choices'? If so, please specify.

While the principles and goals of the LGBTI Strategy align with broader aged care reform, increasing choice is also about assisting people to make adequate informed decisions about their care; in this element the aged care system requires further development. Navigating and understanding the processes and services that sit within aged care is difficult for even savvy consumers and carers let alone those who have more specific needs.

Through various submissions to aged care reforms, Alzheimer's Australia has emphasised the importance of ensuring a focus on informed decision-making. For people living with dementia, having a say in their everyday lives is a basic desire and underpins a sense of purpose and wellbeing. Consumers have also identified the need for greater transparency across the implementation of aged care reform, including the operationalisation of consumer-directed care.

5.3 In terms of the LGBTI Strategy, where do you think the government and aged care sector need to improve?

Ongoing support for capacity-building at a sector level is imperative, along with support for consumer to understand their choices and how to enact them. In addition, this model needs to recognise that there is diversity within LGBTI communities and that services should be resourced and tailored to address individual goals and needs.

6. Diversity Framework

The Strategy is going to be replaced by a broader Aged Care Diversity Framework aimed to build on existing efforts to provide guidance for providers to embed better practice in their service delivery to better meet the diverse needs of older people.

Under the Diversity Framework, an Action Plan for Lesbian, Gay, Bi-sexual, Transgender and Intersex (LGBTI) elders and communities will be developed.

Your feedback will help to identify broader issues to be incorporated in the development of the LGBTI action plan in the Diversity Framework.

6.1 What themes or issues do you believe the Diversity Framework should include/address?

Everyone's journey with dementia is unique, even though there are many shared pathways. To serve the needs of people with dementia it is important to engage, listen and provide services in a flexible and adaptive way. Alzheimer's Australia spends a great deal of time and energy seeking to move beyond stereotypes and labels to achieve genuinely responsive care. A one size fits all is definitely not an option for people with dementia – regardless of their gender or sexuality or culture or age or orientation. Fundamentally, consumers don't want a system that erases and separates them from the person they once were, their friends and their community.

Emerging themes could include:

- The importance of treating consumers with dignity, respect and an acceptance of the person that they are rather than for the condition they have;
- The importance of community support for individuals to remain engaged and valued;
- The importance of access to a multi-faceted range of services and supports, such as a timely diagnosis, respite, social support, exercise and cultural activities.

LGBTI people have also raised a number of specific concerns which should be reflected in a Diversity Framework. These include:

- Acknowledgement of social isolation (LGBTI people are more likely to live alone and lack access to children and families to support them);
- The alienation of care partners (they are less likely to have legal standing or be an accepted part of the care team); and
- The barriers to expression of LGBTI identity (many older LGBTI people have kept their sexuality private, but dementia can force it into the open in ways that are difficult for the person and those around them).

6.2 What issues or specific actions do you believe should be included in the LGBTI Aged Care Action Plan that will be developed under the Diversity Framework?

Responsive, individualised care needs to be the focus of the new Diversity Framework.

In terms of LGBTI needs, the Action Plan should address orientation, experience, discrimination, the role of partners, carer support, social connectedness, formal and informal advocacy, and advanced care planning.

This can also inform better measures of quality. The availability of appropriate information and active consumer engagement in care planning and delivery, being listened to, complaints being encouraged and acted upon, measures around respect and dignity – these are all part of the measurable consumer experience and should be used to inform and drive real improvement in care systems.

Other Comments

As the peak advocacy body for people living with dementia, their families and carers in Australia we look forward to further consultations regarding the Aged Care Diversity Framework as it develops.