



BUILDING OUR COMMUNITY'S
HEALTH & WELLBEING

Submission to:

NSW Health on the Draft NSW Dementia
Services Framework 2010-2015

August 2010

About ACON

ACON (formerly known as the AIDS Council of NSW) was formed in 1985 as part of the community response to the impact of the HIV/AIDS epidemic in Australia. Today, ACON is Australia's largest community-based gay, lesbian, bisexual and transgender (GLBT) health and HIV/AIDS organisation. ACON provides information, support and advocacy for the GLBT community and people living with or at risk of acquiring HIV, including sex workers and people who use drugs.

ACON is home to the Lesbian and Gay Anti-Violence Project (AVP), the Community Support Network (CSN), the Positive Living Centre (PLC) and the Sex Workers Outreach Project (SWOP). ACON has its head office in Sydney as well as branches in the Illawarra, Northern Rivers, the Hunter region and the Mid North Coast.

ACON's work in mental health includes prevention and early intervention. ACON's counselling services are available to the GLBT community, people living with and affected by HIV, and sex workers. We provide priority/emergency counselling for people newly diagnosed with HIV as well as more general counselling services during day time and after hours. ACON also provides referral advice to other services where appropriate.

ACON also works with community services and the aged care sector by providing in home care and support services through the Community Support Network and a peer social group called Mature Aged Gays. ACON has recently received a grant from the Commonwealth Government to develop an education program for the aged care sector that focuses on issues specific to older GLBT people.

General Comments

ACON welcomes the opportunity to discuss the very important issue of dementia. As Australia's largest GLBT health organisation, ACON helped to launch Alzheimer Australia's Paper on *Dementia, Lesbians and Gay Men* in late 2009.

While dementia is a significant mental health issue impacting on all Australian communities, members of the GLBT community and people with HIV have unique factors that impact on their experiences of dementia. The biological factors behind these experiences of dementia may vary; however, both communities share a history of stigma and discrimination that compound the effects of dementia due to barriers of access to appropriate care or a lesser standard of care.

This submission provides a background to the issues experienced by the GLBT community and people with HIV. We have included recommendations to enable inclusivity of the GLBT community and people with HIV in the draft *NSW Dementia Services Framework 2010-2015* (hence forth, the *Framework*).

Section 1 Inclusion of the GLBT community

The explicit inclusion of the GLBT community in the *Specific Population Groups* section is welcomed by ACON. Acknowledging that sexual and gender diversity need to “be recognised and addressed in the provision of health, community and residential care services” is an important step forward in developing a sound *Framework*. This acknowledgement, however, is not included throughout the sections relating to the delivery of programs and services, nor is it expressed within the recommendations of the document.

The *Framework* discusses the different experiences faced by Aboriginal people and people from culturally and linguistically diverse (CALD) backgrounds in multiple sections throughout the document. However, GLBT people and people with HIV, as specific population groups, have been omitted from this illustration. In order for adequate programmatic and service delivery responses to be incorporated to reach this population group, we feel such discussions relating to GLBT people must be included following a similar approach to that of Aboriginal and CALD people.

Specifically, discrimination remains an important issue. Whilst attitudes are slowly changing towards the GLBT community, there are still incidences of prejudice and discrimination that exist across the health, community services and aged care sectors. The experiences of discrimination are reflected in the latest analysis of Australian Bureau of Statistics (ABS) data which show that GLBT people were more than twice as likely to experience ‘any mental disorder’.¹ Alarming, homosexual and bisexual people were more than three times more likely to have had an affective disorder compared to heterosexuals.²

Discrimination is important to point out and address in the *Framework* because it can act as a significant barrier of access for the GLBT community, both perceived and actual, and can lead to lesser standards of care delivered to this population group. The Alzheimer’s Australia Paper on dementia in the GLBT community outlines some of the discrimination issues experienced by people who have dementia or people who care for someone with dementia in the GLBT community. Examples in this paper include experiences of a lesser standard of care after a carer discovered their sexual orientation.³

Further to experiences of discrimination in service provision, the impact of insensitive or vilifying comments is also discussed in the paper. Both forms of action work to make a service less welcoming to GLBT clients, patients or consumers and thus create barriers of access to these much needed services. In addition, the impacts of such actions and comments may negatively impact on the mental health of these clients, patients and consumers.

An additional concern that should be noted and addressed in the *Framework* is the inconsistent recognition of same-sex relationships and legal rights, such as power of

¹ Australian Bureau of Statistics, *National Survey of Mental Health and Wellbeing*, (2007).

² *Ibid.*

³ Alzheimer’s Australia, *Dementia, Lesbians and Gay Men*, (2010), p. 16.

attorney. Although same-sex couples have recently gained legal equality in most aspects of NSW and Commonwealth law, this legal equality is not well understood by service providers across the health, community services and aged care sectors.

Recommendation:

1. That the *NSW Dementia Services Framework* includes GLBT people as a special population group in discussions throughout the document, including in the programs and services section.
2. That the recommendations section explicitly includes a recommendation targeting GLBT people.
3. That the *NSW Dementia Services Framework* acknowledges discrimination faced by the GLBT community as an issue that needs to be addressed and the need to develop programs to reduce discrimination by service providers.
4. That the *NSW Dementia Services Framework* promotes an improved understanding of same-sex couples and their legal rights through developing and providing education and training for dementia related service providers.

Section 2 Inclusion of HIV Associated Neurocognitive Disorder

The availability of HAART (highly active anti-retroviral therapy) in the late 1990's has seen a marked decline in the incidence of brain disorders such as ADC (AIDS dementia complex) for people living with HIV.

There is, however, growing evidence that an excess of 50% of people living with HIV will still experience some form of cognitive impairment - even when taking effective HAART.⁴ Research suggests that such impairment is a result of the direct effect of HIV related activity on the brain. The term most commonly used to describe these symptoms is HAND (HIV associated neurocognitive disorder).

The symptoms of HAND, are on many levels similar to mild forms of dementia, and can include:

- Difficulty concentrating
- Poor attention
- Problems with memory
- Reading difficulties
- Being easily distracted
- Losing train of thought
- Tremor of one or both hands
- Low energy
- Disturbance in mood
- Everyday tasks take longer and become laborious
- Becoming isolative – declining or reducing social activities

⁴ S L Letendre, R J Ellis, B M Ances & J A McCutchan, 'Neurologic complications of HIV disease and their treatment', *International AIDS Society Conference Highlights – Neurologic Complications*, vol 18(2), 2010.

- Irritability
- Difficulty managing multiple tasks at once.

HAND is not well understood by many service providers and people with HIV, which often leads to symptoms being misdiagnosed. However, HAND may be able to be treated through new or different combinations of pharmaceutical products. Therefore, it is important that symptoms are recognised and diagnosed correctly and not be conflated with dementia, even if certain symptoms and required services are similar.

There are, however, still some people with HIV that develop AIDS related dementia, and often at an earlier age than the general population. Those who develop AIDS related dementia have the additional concern of service providers maintaining privacy and confidentiality. Stigma still exists in relation to HIV/AIDS and those living with the virus are often confronted with the fear that by revealing their HIV status they are at risk of having their confidence breached which could lead to experiencing discrimination or a lesser standard of care. The importance of gaining and keeping the confidence of people with HIV is imperative to the delivery of equitable health care to people with HIV.

Recommendations:

5. That the *NSW Dementia Services Framework* includes specific discussions of HIV associated neurocognitive disorder in relation to AIDS related dementia.
6. That the *NSW Dementia Services Framework* acknowledges HIV/AIDS discrimination as an issue that needs to be addressed and develop education programs to reduce discrimination by service providers.
7. That the *NSW Dementia Services Framework* ensures strict confidentiality guidelines relating to HIV status are understood and adhered to by service providers.

Section 3 Services and Programs

The *Framework* acknowledges that CALD and Aboriginal communities “may be likely to approach an identified CALD or Aboriginal service in the first instance for support in accessing a mainstream service. Therefore it is crucial that mainstream services reach out with culturally appropriate information and develop partnerships with CALD and Aboriginal services.” This strategy to accessing special population groups should also apply for the GLBT community. GLBT people, similar to Aboriginal and CALD people share common experiences of discrimination, perceptions of discrimination and may have had experiences of culturally inappropriate care from mainstream services. The need to encourage mainstream services to reach out with culturally appropriate information and develop partnerships with GLBT services is essential to accessing this population and ensuring that equitable health services are offered and provided.

ACON has a strong history of working in a partnership model with government and other mainstream services such as clinicians and hospitals in the area of HIV health promotion and treatment, care and support. To ensure that government, mainstream services and specialised services reach the GLBT community, the government should consider a

partnership approach with ACON to improve referral pathways and improve access to services for the GLBT community.

The importance of culturally competent training for mainstream services across the health, community services and aged care sectors noted in the *Framework* is important not only for CALD and Aboriginal communities, but also for the GLBT community and people with HIV. The intersectional relationship between confidentiality and experiences of discrimination are complex issues faced by GLBT people and people living HIV. Additionally, GLBT people are vulnerable to experiences of discrimination through the potential lack of recognition of their same-sex relationship and recognition of legal frameworks by service providers such as power of attorney and living power of attorney.

As the *Framework* acknowledges, the general Australian community does not have a strong understanding of dementia and related issues. This knowledge gap would also exist in the GLBT community. A similar approach to improving understanding in Aboriginal and CALD communities is also required in the GLBT community so that health promotion messages reach this target population group. This would be achieved most effectively by working with community organisations that have a strong history of developing and delivering health promotion messages and services to the GLBT community, such as ACON.

Recommendations:

8. That the *NSW Dementia Services Framework* recommends a partnership with ACON to improve referral pathways to dementia services to assist the GLBT community in accessing mainstream services.
9. That the *NSW Dementia Services Framework* includes GLBT and HIV issues in cultural competency training for service providers.
10. That the *NSW Dementia Services Framework* recommends a partnership between NSW Health and ACON to promote awareness of dementia and related issues.

Conclusion

Dementia is an important issue to ACON and our communities. We commend the *Framework* for including GLBT people and people with HIV in parts of the document. Our submission provides recommendations for the *Framework* to systematically include the GLBT community and people with HIV throughout the policy framework so that these population groups have access to more equitable health care services on par with the general community.

ACON would welcome further opportunities to discuss this submission with NSW Health. If you wish to receive any further information, please contact Li Zhou, ACON Policy Advisor, on 9206 2085 or email lzhou@acon.org.au.