ACSA submission into the Productivity Commission Caring for Older Australians Inquiry

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GLOSSARY OF ACRONYMS

ACON	**AIDS Council of New South Wales**
ACSA	**AIDS Council of South Australia**
ATSI	**Aboriginal and Torres Strait Islander**
CALD	**Culturally and Linguistically Diverse**
DoHA	**Department of Health and Ageing**
GLBTI	**Gay, Lesbian, Bisexual, Transgender and Intersex**
MSM	**Men who have sex with Men**
PLWHA	**People Living With HIV/AIDS**
QAHC	**Queensland Association for Healthy Communities**
SSA	**Same Sex Attracted**

Introduction

Due to societal shifts in the acceptance of diversity of gender and sexuality and as the baby boomer generation grows older; GLBTI (gay, lesbian, bisexual, transgender and intersex) populations will have a more visible and prominent presence within discourses surrounding ageing and in aged care settings (Harrison and Irlam, 2010).

In stark contrast, there is considerable evidence, both anecdotal and from within literature that suggests the current generation of GLBTI seniors (particularly those who are in contact with the formal aged care industry) are often apprehensive about disclosing their sexuality for fear of discrimination and vilification in an environment in which GLBTI populations are largely invisible (Harrison, 2004).

The impacts for individuals in concealing their sexuality within aged care settings is significant both for the individual but also for the industry. In aged care settings this leads providers to assume that they have no GLBTI residents and as such no strategies, policies, procedures or training are developed to provide best practice in caring for GLBTI seniors (Harrison & Irlam, 2010). For the individual, continued concealment of the persons sexuality or a return to concealing their sexuality after a period of being 'out' to those around them can have significant impacts on the health and wellbeing of the individual and may lead to unmet care needs (Barrett, 2008).

It is our position that due to the pervasive historical context of stigma, discrimination and invisibility of GLBTI populations, this group should be acknowledged and recognised as a vulnerable group with special needs in a similar way to ATSI and CALD populations. As such, we argue that a national aged care plan be developed and implemented that recognises this vulnerable population to ensure positive outcomes for the health and wellbeing of GLBTI seniors as they access aged care in Australia.

Key areas

The following presents the key areas of this submission that should underpin discussions surrounding appropriate care for GLBTI seniors in the community.

- The development of a national GLBTI aged care plan is crucial to the health and wellbeing of this vulnerable group
- GLBTI seniors need to be recognised by government as a special group with special needs
- Often GLBTI seniors have endured a lifetime of stigma, discrimination, social exclusion and invisibility
- GLBTI seniors can also be socially excluded from GLBTI populations
- GLBTI seniors are essentially absent from aged care policies and programs and as such are as yet not considered a priority group
- As a result of a lifetime of stigma, discrimination, social exclusion and invisibility, GLBTI seniors have specific needs that need to be taken into account within aged care policies, programs and services
- Partnerships need to be developed between decision makers and the GLBTI community to enable the development of appropriate policy development for GLBTI aged care
- Partnerships need to be developed between aged care programs and services and the GLBTI community to enable the development of appropriate programs and services to ensure that GLBTI seniors' needs are met
- Policy makers and aged care services need to acknowledge the impact that HIV accelerated ageing will have on service provision in the future
- To limit the effects of 'ageism', aged care providers need to acknowledge that seniors (including GLBTI seniors) do not forgo their sexuality simply by being elderly, and social and cultural expressions of sexual and gender identities should not be discouraged by service providers

Recommendations

Research

- There should be further research into the health and wellbeing issues of GLBTI seniors
- Research should be conducted into models of care for GLBTI seniors including formal and informal models of care (including community based home care)

Policy

- GLBTI to be formally recognised as a special needs group under the Allocation Principles in the final report.
- GLBTI should be a separately listed special needs group in the final report and not listed within any other heading (such as CALD groups), while many issues for GLBTI are 'cultural', it is more appropriate that GLBTI populations be listed under the 'diversity or special needs, serious problem' headings.
- The Federal government to establish a National GLBTI Aged Care Plan (similar to ATSI Aged Care Plan) involving a strategic plan with specified goals, guidelines and measurable targets over a 5 year period.
- Federal government to establish a National GLBTI aged care advisory council to oversee the process of developing and implementing the GLBTI Aged Care Plan and to advise the Minister for Ageing, on issues related to GLBTI aged care.
- Inclusion of GLBTI populations within Commonwealth and state ageing policies.
- The commission of an audit of current policy and practices to eradicate discrimination against GLBTI people in aged care.

Service provision

- The national rollout of training curricula in both residential and community care sectors. The funding of GLBTI community organisations to provide direct care services to GLBTI seniors in the community.
- GLBTI to receive specific mention in all documentation in relation to policy, service guidelines, accreditation and assessment to ensure the group remains visible. The specific mention of GLBTI should not be within terms such as 'cultural' or 'lifestyle' otherwise it will be counterproductive to making populations more visible.
- The training of service providers to ensure competence in GLBTI issues and needs as well as training in HIV/AIDS competence and care.
- That all government funded aged care service providers be required to develop polices, procedures and protocols that act to eliminate discrimination and promote inclusiveness and understanding for GLBTI seniors, including the recognition of same-sex relationships within aged care settings.
- There needs to be specific mention of sexual orientation, and sex and gender identity should be included in all documents such as user rights documents and charters of residents' rights.

Partnerships

- GLBTI organisations and service providers to share knowledge and develop strategies, policies and program plans for this population.

Legislation

- There is need for Federal anti-discrimination legislation to be implemented to ensure GLBTI populations are protected at a Federal level in relation to the access and provision of aged care services.
- Organisational exemptions (particularly religious organisations) from equal opportunity and anti-discrimination legislation must be removed at state levels to prevent sections of the aged care sector from discriminating against GLBTI seniors.

About the AIDS Council of South Australia (ACSA)

The AIDS Council of South Australia (hereafter called ACSA) welcomes this opportunity to provide commentary, information and community knowledge pertaining to the Productivity Commission's Caring for Older Australians Inquiry in South Australia. The following submission will set out the position of ACSA in regards to the inclusion of GLBTI issues within care discourses and state and federal health and ageing policies, with the ultimate goal of increasing GLBTI ageing visibility and better health outcomes.

ACSA has maintained a leading role in the community response to HIV in South Australia for twenty five years. We have a strong commitment to reducing health inequities amongst our communities and preventing the transmission of HIV and STI's. The principal activities of ACSA are the provision of education, health promotion, advocacy, care and support to members of the GLBT communities, people who inject drugs, sex workers and to all people living with HIV. Our vision is "Equity, Health and Human Rights" and we involve key client groups including gay men, people who inject drugs and sex workers in our prevention and education programs that aim to improve the health and well-being of these communities. Advocacy, education programs, personal development and skills building, information and referrals are all part of the range of programs and services provided by ACSA.

With projections of large numbers of baby boomers, and increasing numbers of GLBTI seniors (many of whom will be 'out' about their sexual and gender identities), reaching pensioner age this year and over the next 15 years , GLBTI senior visibility and how GLBTI aged care issues are incorporated into health and ageing policies is of paramount concern. Therefore this will be an essential element of ACSA's work and community endeavours in the short and longer terms.

GLBTI populations

Current GLBTI seniors as a vulnerable group

In the previous century and beyond, Western attitudes and acceptance of homosexuality has occurred in ebbs and flows. There have been periods in which homosexuality has been tolerated and accepted, and periods in which to be same-sex attracted has been met with intolerance, vilification, discrimination and persecution (Gottschalk, 2007). For many GLBTI seniors reaching retirement age and those who will reach retirement age over the next few decades, their lives as same-sex attracted individuals would have been impacted by an environment characterised by misunderstanding, discrimination, vilification and criminalisation. GLBTI seniors developed their sense of self and their sexual identity within an environment where the disclosure of a homosexual identity could result in enforced medical and psychiatric 'cures', the loss of employment, friends, family and support networks, as well as imprisonment (Barrett, 2008). Within a discourse of GLBTI seniors in aged care policy and within the aged care system it is important to understand the often negative and exclusionary world in which current GLBTI seniors were raised and in which they lived.

Historical and institutional experience of discrimination

While medicine and religion sought to offer explanations to explain homosexuality (based on notions of physical deficiencies, criminology and expressions of evil and sin) by the end of the 19th century, psychiatry sought to offer an explanation of homosexual feelings and acts amongst individuals. These theories - while being more progressive than pathology, criminology and theology, labelled a homosexual person as mentally ill and as such, it was thought that the person could be treated to cure their illness. These erroneous notions lasted until 1973 when homosexuality was finally removed from the Diagnostic and Statistical Manual of Mental Disorders (DSM) but by that time the lives of countless GLBTI individuals were affected by societal views of homosexuality that labelled them as mentally ill and in need of psychiatric care (Herek, 2009).

Further, it wasn't until 1972 that South Australia decriminalised some homosexual acts between males with further reforms taking place in 1975 and 1976. All other mainland states decriminalised homosexuality between 1976 and 1989 when Western Australia became the last of the mainland states to decriminalise homosexuality (Bull, et al, 1991). Tasmania was the last state to decriminalise homosexuality in 1997 after protracted action and lobbying by both the Tasmanian Law Reform Commission and GLBTI lobbying groups (Croome, 2006).

Decriminalisation has been an important step in reducing some of the stigma felt by older SSA individuals. However, the impact that the criminalisation of homosexuality has had on people and the years of concealing their sexuality has lead many people to continue this concealment into their senior years.

Experiences of stigma

While younger SSA individuals are beginning to enjoy life within a world which is generally much more tolerant of minority groups, societal attitudes for older SSA as they were growing up were not as inclusive. As mentioned in the previous section, societal attitudes to homosexuality were influenced by theology, medicine and psychiatry which labeled homosexuality as deviant, sinful, or as the behaviour exhibited by a chronically sick individual. For those who identified as SSA, the stigma associated with being homosexual was and is powerful and has social and personal ramifications as they get older and when they enter care environments. There is a plethora of evidence making the connection between experiences of exclusion and stigma and negative health outcomes for marginalised groups (Cannon and Kaim, 2010).

Compounding the effects of stigma and social isolation is the experience of HIV infection for some SSA seniors. HIV still attracts stigma, misinformation and misunderstanding. The added effects of this stigma can be extensive and have been linked to stress, anxiety, depression, self esteem issues and an overall lower quality of life. In addition, people living with HIV/AIDS (PLWHA) can experience exclusion from their workplaces, their relationships, their families and their communities (Maman, et al, 2009).

Social exclusion and invisibility

Inextricably linked to stigma is the experience of social exclusion and invisibility. For GLBTI individuals, particularly seniors, being socially excluded from the wider heterosexual community would not be a recent phenomenon. Through societal attitudes, GLBTI individuals who chose to be 'out' to friends, families, co-workers and their communities often found themselves to be excluded within their wider communities for not conforming to the social norms of heteronormativity . In addition, with the gay and lesbian community reflecting wider community celebrations of youth, older GLBTI individuals often feel excluded within their own communities (Chamberlain and Robinson, 2002; Barrett, 2008). Invisibility also extends to the experience of GLBTI seniors in aged care settings where non-disclosure of sexuality leads providers to perceive that they have no GLBTI residents (Harrison and Irlam, 2010).

While much of this discussion places the disparities in recognition of GLBTI populations into an historical context, same-sex relationships are still not fully recognised by the law and other institutions to this day. This is leading to a continued perception that same-sex relationships are somehow inferior to opposite sex relationships (as we are witnessing in the current gay marriage debate) (LGBT Health Alliance, 2011).

The special needs of GLBTI seniors

It has to be said that most older people share experiences of marginalisation and invisibility within our Western society regardless of their sexuality. While seniors were once revered in our culture, the continued fascination and celebration of youth and rapidly changing technology and work and social roles have relegated older people to be perceived as essentially obsolete within a market and media driven culture (Chamberlain and Robinson, 2002). However, the experience of GLBTI seniors is significantly different to their heterosexual counterparts with the effects of living on the margins of society compounded by the effects of homophobia, heteronormativity and oppression affecting their health and wellbeing across their lifetimes. As such, it is argued that this protracted negative social and personal environment leads to increasing special needs in later life (Chamberlain and Robinson, 2002).

These specific needs need to be explored, acknowledged and addressed through policy, strategies and programs.

The role of the GLBTI community in aged care provision

According to the LGBTI Health Alliance (2011), there are many GLBTI organisations in Australia who either already work in the area of GLBTI ageing or express a desire to do so. Some organisations have the capacity to deliver services to GLBTI individuals while others have the capacity to partner with existing aged care services to enable the provision of appropriate services to GLBTI individuals in care settings. Ideally, the partnership would involve service providers, the GLBTI community and other stakeholders in an analysis of the lived experience of GLBTI populations and the various needs that they have in aged care and in aged care services. This would facilitate the development of strategies, policies and programs that create safe environments for GLBTI seniors (Barrett, 2008).

Currently there are successful partnerships between aged care groups and GLBTI organisations such as the Aged and Community Services Association and ACON (in NSW and the ACT), as well as Care Connect and Queensland Association for Healthy Communities (QAHC) in Queensland. We contend that there needs to be national replication of these models to ensure appropriate representation from GLBTI organisations within aged care planning, strategy and management (Harrison, 2011).

HIV populations

HIV and accelerated ageing

Compounding the experience of ageing for some SSA individuals is HIV and accelerated ageing. Prior to the advent of combination anti-retroviral therapy, the prognosis for many people living with HIV ranged from a few months to under ten years. Since combination therapy has become widespread, PLWHA have the potential to live for many years whilst managing the virus with medications and lifestyle and behavioural changes.

This has transformed a diagnosis of HIV from a 'death sentence' to a manageable condition that can allow many PLWHA to live relatively healthy lives. However, as is increasingly being discovered, PLWHA often have a higher incidence of co-morbidities predominantly due to drug side effects, some lifestyle factors or the effect that HIV has on the immune system. Depending on how long an individual became infected with HIV prior to diagnosis and treatment , HIV could have already had an impact on their bodies. This all means that we not only have an ageing population of PLWHA but an ageing population with a series of co-morbidities that will impact significantly on their health and the already burgeoning health care system.

HIV accelerated ageing will not only apply to gay populations in the future with South Australian figures showing heterosexual notifications of HIV sitting at 50% (for the last two years) of all new diagnoses (STD Services, 2010). This means many older heterosexual men and women will be entering the aged care system with HIV over the next 20-30 years.

Research on accelerated ageing is still in its infancy but this will likely impact upon aged care programs, policies and services in the near future.

Current South Australian Health Policy for GLBTI seniors

There is currently no specific health policy in South Australia that aims to promote the health and wellbeing of the GLBTI community and there has only ever been a modicum of interest (aside from HIV responses) shown in GLBTI health and wellbeing by the current government. This was not always the case however, as the South Australia government previously maintained a Gay and Lesbian Ministerial Advisory Committee (MAC) whose purpose was to provide key advice and information to the Minister for Health in regards to health needs within GLBTI populations. However the GLBTI MAC was abolished by the current Minister for Health when the new Health Act was introduced in 2008 (Cannon and Kaim, 2010).

Since then, the government in South Australia has been slow to recognise and adopt notions of GLBTI populations as vulnerable groups or priority populations within health related policy. The SA Department of

Health suggests that the South Australia's Health Service Framework for Older People 2009-2016 has been designed to plan for the increasing demand that our ageing population will have on our healthcare system in the future (Department of Health, 2009). Unfortunately, the policy only makes specific mention of ATSI and CALD populations as being vulnerable groups in regards to positive health outcomes (and provides strategies to address the related issues). This framework fails to recognise GLBTI populations as being similarly vulnerable (when there is a plethora of evidence to suggest that GLBTI populations experience marked disparities in health and wellbeing) and having similar specific needs (Department of Health, 2009, cited in Cannon and Kaim, 2010).

The ways in which industry can practise inclusive care

As previously mentioned, there are many GLBTI organisations in Australia who either already work in the area of GLBTI ageing or express a desire to do so. Some organisations have the capacity to deliver services to GLBTI individuals while others have the capacity to partner with existing aged care services to enable the provision of appropriate services to GLBTI individuals in care settings. Ideally, the partnership would involve service providers, the GLBTI community and other stakeholders in an analysis of the lived experience of GLBTI populations and the various needs that they have in aged care and in aged care services. This would facilitate the development of strategies, policies and programs that create safe environments for GLBTI seniors (Barrett, 2008).

There are several ways in which the aged care industry can provide a safe and appropriate environment for GLBTI seniors that allows them to express who they are and enjoy quality of life. These include;

- Eliminating the assumption that everyone is heterosexual
- Use gender neutral language, e.g. partner instead of husband/wife
- Acknowledge that seniors (including GLBTI seniors) still enjoy their sexuality and that the expression of that sexuality should not be discouraged by service providers.
- Learn about issues relating to the health and ageing of GLBTI and HIV-positive people
- Engage with HIV-positive seniors with professionalism
- Develop strategies, programs and service standards (ideally in conjunction with GLBTI organisations) that acknowledges the difficulties of growing up same-sex attracted or gender diverse in a negative social environment while also being sensitive to the specific needs of this population.
- There needs to be specific mention of sexual orientation and sex and gender identity need to be included in all user rights documents, including the charter of residents' rights

The ways in which government can provide the policy and legal environment to protect GLBTI communities when accessing aged care

ACSA suggests that in order for government to respond appropriately to the GLBTI seniors already in its care and prepare for the influx of GLBTI seniors in the short and longer terms the following needs to occur;

Funding

- That aged care providers are adequately resourced to develop policies and processes to discourage discrimination and invisibility and to encourage inclusiveness for GLBTI populations within the aged care system (LGBT Health Alliance, 2010).
- Research to be funded and undertaken that explores and reports on health and wellbeing issues for GLBTI senior populations and on best practice models for responding to GLBTI seniors in residential aged care facilities LGBT Health Alliance, 2010).

Recognition

- GLBTI populations need to be formally recognised as a special needs group under the Allocation Principles (as is outlined in the table [box 9.1] on p.271) in a similar way to care leavers, veterans and the homeless. It is imperative that we have this recognition to enhance the targeting of GLBTI aged care packages, beds and other allocations. GLBTI history of fear, persecution, psychiatric abuses, fear of being outed, invasion of privacy, abuse and fear of being discriminated against needs to be recognised and acknowledged in a similar way to other special needs groups (Harrison, 2011, pers. comm. 17 February; LGBT Health Alliance, 2010).
- Recognise GLBTI populations within Federal aged care and other health policies and related documents to acknowledge this group as 'vulnerable' and assist in raising awareness of GLBTI health issues and increasing better health outcomes for these populations (LGBT Health Alliance, 2010).

Strategic planning

- Federal government work in partnership with the GLBTI sector to establish a National GLBTI Aged Care Plan (similar to the ATSI Aged Care Plan) to strategically address the health and wellbeing of GLBTI seniors (LGBT Health Alliance, 2010). The plan should be strategic, with specified goals, guidelines and measurable targets over a 5 year period. Further, the plan should include targeted funding for education and training, direct care, research, policy development, advocacy and related initiatives. The Department for Health and Ageing (DoHA) should have responsibility for implementing the plan (Harrison, 2011, pers. comm. 17 February).

Training for inclusive care

- With research suggesting that 86% of aged care facilities were not aware of any GLBTI residents in their facilities we recommend the development and implementation of a national training program that addresses GLBTI seniors in aged care focusing on the provision of inclusive services (LGBT Health Alliance, 2010).
- Further, education and awareness campaigns need to be undertaken for aged care services to outline their obligations under equal opportunity legislation (Barrett, 2007).

Supportive frameworks

- The Federal government to establish a National GLBTI aged care advisory council to oversee the process of development and implementation of the plan and to advise the Minister for Ageing on issues related to GLBTI aged care. As the GLBTI senior population swells over the next 15 years (bolstered by marked increases in the baby boomer population reaching retirement age), a national GLBTI Aged Care Plan is critical to ensure appropriate service provision and increased access to aged care services for GLBTI seniors (Harrison, 2011, pers. comm. 17 February).

Legislation

- Finally, there is a pressing need for Federal anti-discrimination legislation to be implemented to ensure GLBTI populations are protected at a Federal level in relation to the access and provision of aged care services.
- Further, organisational exemptions (particularly religious organisations) from equal opportunity and anti-discrimination legislation need to be removed at state levels to prevent sections of the aged care sector from discriminating against GLBTI seniors (Harrison, 2011, pers. comm. 17 February).

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