



BUILDING OUR COMMUNITY'S  
HEALTH & WELLBEING

**Submission to:**

The Productivity Commission on  
*Caring for Older Australians: Draft  
Inquiry Report*

March 2011

## About ACON

ACON (formerly 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 works to improve the health and wellbeing of the GLBT community and people with HIV, and reduce HIV transmission.

ACON is home to the Community Support Network (CSN), the Positive Living Centre (PLC), the Luncheon Club, the Lesbian and Gay Anti-Violence Project (AVP) 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 has a long history of providing services for ageing and older members of the GLBT community and people with HIV. Recognising the increasing importance of this work, ACON developed *Ageing Disgracefully: ACON's Ageing Strategy 2006-9*, which continues to guide our work with ageing and older GLBT people and people with HIV.<sup>1</sup> ACON is currently working in partnership with Aged and Community Services NSW and ACT on the development and piloting of GLBT sensitivity and diversity awareness workshops and resources for residential aged care services in NSW.

ACON also made submissions to the *Review of Accreditation Processes for Residential Aged Care Homes*, and the *Review of Aged Care Complaints Investigations Scheme*.

## Caring for older gay, lesbian, bisexual and transgender people and older people with HIV

ACON considers that a specific focus is required on the aged care needs of gay, lesbian, bisexual and transgender (GLBT) people, as well as people with HIV.

### *Caring for older GLBT Australians*

Older GLBT Australians share many of the same issues facing all older people. They would prefer to maintain their independence as long as possible often in their own home. Older GLBT people are at risk of social isolation, have increasing complex health needs and may need formal or informal help with normal activities of daily living.

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<sup>1</sup> Available for download at <http://www.acon.org.au/about-acon/Strategies/ageing> .

The existing literature shows that there are a number of specific issues facing older GLBT people linked to experience and fear of discrimination and a general lack of understanding of the lives of older GLBT people among aged care providers.<sup>234</sup> These issues have been covered in previous submission to the Productivity Commission, particularly submissions by Gay and Lesbian Health Victoria and the GLBTI Retirement Association. This is supported by international research and is consistent with ACON's experience of working with older GLBT people.

There is evidence that:

- Older GLBT fear discrimination from aged care providers.<sup>5</sup> Older GLBT people are very likely to have experienced discrimination in their lives, including from institutions. Older GLBT people are more likely to expect discrimination from aged care providers who are affiliated with religious groups that have taken a strong stance against homosexuality or same sex-relationships.
- Many older GLBT people hide their sexuality from aged care services. This means that aged care providers may be unaware that older GLBT people have same sex partners and important friendship groups.
- Discrimination and insensitive treatment does occur in aged care. Other submissions and published literature have provided numerous case studies. There is currently no Federal protection from discrimination on the grounds of sexuality, relationship status or gender identity. Religious providers are also likely to be exempt from State and Territory discrimination laws.
- Aged care services are often described as 'prudish' environments. Aged care services tend to operate on the assumption that older people are not sexual, let alone gay, lesbian, bisexual or transgender.
- Older GLBT people are largely invisible to most aged care providers and are not specifically considered in organisational policies, procedures and staff training. Several studies in Australia and overseas report that aged care staff believe that they do not care for any older GLBT people. They also consider that they provide the same service to all care recipients and are not aware of any particular issues.

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<sup>2</sup> GRAI (GLBTI Retirement Association Inc) and Curtin Health Innovation Research Institute (2010). *We Don't Have Any of Those People Here: Retirement accommodation and aged care issues for non-heterosexual populations*. Perth, Western Australia, Curtin University.

<sup>3</sup> Barrett, C. (2008) *My people: Exploring the experiences of gay, lesbian, bisexual, transgender and intersex seniors in aged care services*. Melbourne, Matrix Guild Victoria Inc and Vintage Men Inc

<sup>4</sup> Birch, H (2008) *Dementia, Lesbians and Gay Men*. *Alzheimer's Australia*, Paper 15 (see <http://www.glhv.org.au/node/581>).

<sup>5</sup> Jackson NC, Johnson MJ, Roberts R (2008) The potential impact of discrimination fears of older gays, lesbians, bisexuals and transgender individuals living in small- to moderate-sized cities on long-term health care *J Homosexuality* 54(3):325-39.

- Some aged care staff fear older GLBT people. Staff may fear older gay men because of a perceived risk of HIV transmission. Staff may fear older transgender people because they have not met a transgender person before.
- Discrimination and harassment can come from other care recipients. Other aged care residents can be extremely intolerant of GLBT people. Older GLBT people feel greater pressure to hide their sexuality and same-sex partners and to stop participating in activities that may 'out' themselves.
- Older GLBT people are likely to have different informal care networks.<sup>67</sup> Most informal care is most likely to be provided by same sex partners of older GLBT people, with greater amounts of care provided by close friends or 'chosen family'. Older GLBT people are less likely to receive informal care from biological family members.
- Carers will only receive support and assistance if older GLBT people are confident that they are able to openly disclose their relationships to aged care staff. Same sex partners face the same difficulties as heterosexual partners but can be left out of care plans and support because their relationship is not considered by aged care providers. Similarly aged care providers may discount the strength of relationships with close friends or 'chosen family'.

Older GLBT people want all aged care services to be sensitive and accessible to their needs. Many GLBT people would also like to see providers emerge that specialise in providing care for older GLBT people, either from existing aged care providers developing particular expertise or from new providers entering the market.<sup>8</sup>

Currently the report discusses GLBTI people in greatest detail at section 9.2 as part of a wider discussion of people from culturally and linguistically diverse backgrounds.

ACON recommends that a discussion of GLBT ageing be a separate part of Chapter 9. This discussion should be of the same status as the discussion of the needs of other special needs groups such as Indigenous people, financially disadvantaged people, people living in rural and remote areas and people who are socially disadvantaged. The section should go beyond issues of cultural appropriateness and sensitivity to discuss the need for greater policy development in response to the needs of older GLBT people.

## **Recommendation**

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<sup>6</sup> Fredriksen-Goldsen KI, Kim HJ, Muraco A, Mincer S (2009) Chronically Ill Midlife and Older Lesbians, Gay Men, and Bisexuals and Their Informal Caregivers: The Impact of the Social Context. *Sex Res Social Policy*. 2009;6(4):52-64.

<sup>7</sup> Hughes M.(2010) Expectations of later life support among lesbian and gay Queenslanders *Australasian Journal of Ageing*. 2010 Dec;29(4):161.

<sup>8</sup> Hughes, M (2007) 'Older Lesbians and Gays Accessing Health and Aged-Care Services', *Australian Social Work*, 60: 2, 197 — 209

**1. The Final Report of Caring for Older Australians should include a separate discussion of GLBT ageing of the same status as its discussion of other special needs groups.**

*Caring for older people with HIV*

Older people with HIV share many of the same issues as older GLBT people. The largest group of older people with HIV are gay men.

Older people with HIV also fear discrimination on the basis of their HIV status. There is evidence that aged care staff fear gay men because of a perceived risk of HIV transmission.<sup>9</sup> This is also likely to be the case for other aged care residents.

It is likely that aged care workers will know that an older person has HIV through access to medical records. This is sensitive personal information that should not be shared with other residents without the permission of the individual involved.

For people from specific cultural backgrounds, such as from some African communities, someone's HIV status can be extremely sensitive information. It is very likely that family members may not be aware of an individual's HIV status because of stigma.

It is critical that aged care workers adopt high standards of privacy and confidentiality and are careful not to make assumptions regarding the availability or likelihood of support in 'communities of origin', especially those that are numerically small in Australia.

It is well documented that many people with HIV, particularly those who have been using HIV medications for many years, are developing additional medical problems at relatively young ages.<sup>10</sup> This includes a number of conditions commonly associated with ageing such as diabetes, hypertension, liver problems, cardio vascular disease and dementia.

Many people with HIV will require greater levels of community care and support to manage the impact of multiple chronic medical conditions on people's functional ability.

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<sup>9</sup> Barret, C et al (2009), Permission to Speak : Determining strategies towards the development of gay, lesbian, bisexual, transgender and intersex friendly aged care services in Victoria Matrix Guild of Victoria in conjunction with Vintage Men.

<sup>10</sup> Lyons A, Pitts M, Grierson J, Thorpe R, Power J (2010). Ageing with HIV: health and psychosocial well-being of older gay men. AIDS Care. 22(10):1236-44.

Most often this support will be provided in the home. The service types most people require are commonly funded under the Home and Community Care Program or other disability and aged care programs.

In some cases people with HIV will experience a short term need for community care based on other health events or changing treatments. Many people with HIV will need to be able to access community care episodically, preferably without the need to repeat full assessments. Many people with HIV will also benefit from rehabilitative services that help people to regain function after a period of ill health.

HIV is a complex medical condition. People with HIV will have been on complex medication regimes for many years. The effectiveness of their treatments in controlling HIV needs to be closely monitored and varied if they are not effective. HIV treatments have many adverse interactions with other medications and with complementary therapies that can compromise the health of people with HIV.

People with HIV need aged care services and health care services to work together on a common care plan. This is the case for both community and residential care.

There have not been large numbers of HIV positive people using aged care services to date, meaning that staff and other residents are likely to be unfamiliar with HIV. Aged care staff, including most general practitioners attending residential facilities, are unlikely to access to specialist information and advice on HIV treatment. This will impact on the quality of care received by ageing people with HIV.

ACON considers that the issues facing older people with HIV should be referred to in the final report of Caring for Older Australians. This discussion should be included in the existing Chapter 9.

## **Recommendation**

- 2. The Final Report of Caring for Older Australians should include a separate discussion of issues affecting older people with HIV.**

## **The Productivity Commission's Approach**

ACON supports the broad direction of the Productivity Commissions recommendations for the funding, organisation and regulation of aged care in Australia.

ACON supports the direction of major recommendations including:

- Setting subsidies at more sustainable levels that directly relates to the costs of care and accommodation;
- The uncapping of aged care places;
- Obliging providers to provide a proportion of aged care places to low income clients;

- Taking a consistent approach to fees and co-contributions;
- Establishing a single gateway to services to replace existing programs and services that operate in this area;
- A specific focus on diversity and the interests of special needs groups;
- The creating of a single regulatory and complaints commission, streamlining existing standards.

ACON wishes to see a reformed aged care system providing a higher standard of non-discriminatory care to older GLBT people and older people with HIV.

Currently the needs of specific groups of older people might be considered in both the allocation processes and in the quality, accreditation and regulation of aged care services.

Under the current allocation processes, Aged Care Planning Advisory Committees consider the needs of named special needs groups in making recommendations about allocations of aged care places. This has given some preference for aged care providers with particular expertise in working with Aboriginal and Torres Strait Islander people, people who have been homeless and other groups. If these processes are retained, then older GLBT people should be included as a new special needs group.

If the Productivity Commission's preferred model is accepted, allocation processes will not be used to ration places. It will also not be possible to use allocation processes to give preference to providers that are more likely to meet the needs of special needs groups.

Under this model, it becomes more important that quality, regulatory and accreditation standards adequately guarantee a minimum level of services for special needs groups including older GLBT people and older people with HIV.

Under the current quality and accreditation processes, the interests of older people from special needs groups may be considered through the existing standards, particularly those related to resident's lifestyles. The existing standards do not adequately cover the needs of GLBT people or older people with HIV.

ACON considers that the Productivity Commission should more clearly recommend that the quality, accreditation and regulatory requirements of a reformed aged care system should have stronger measures in relation to all special needs groups, including GLBT and people living HIV. These should include stronger guarantees of sensitive and non-discriminatory service delivery.

#### **Recommendation:**

### **3. The Productivity Commission should adopt the following recommendation:**

**'In order to better meet the needs of special needs groups (including groups not currently identified as special needs such as older GLBT people and older people**

**with HIV), the quality standards and accreditation system should include stronger standards including:**

- **A guarantee of non-discriminatory service delivery;**
- **Sensitivity to all kinds of relationships, friendship networks and social supports'**



## Policy Development on GLBT Ageing

ACON welcomes the recognition of the particular needs of GLBTI people in the report and in other submissions to the Productivity Commission.

Unlike most other special needs groups GLBT ageing is poorly understood. For other special needs groups there have been many years of research and practice knowledge in delivering appropriate care. Culturally and linguistically diverse communities have been the subject of extensive research understanding the relationship between ethnicity, language skills, migration and aged care.

A full response to the care needs of GLBT people requires more than cultural appropriateness and sensitivity at the service level. While these issues are important, there is also a need for greater policy work to consider what changes may be needed to the core policy settings of the aged care system, particularly in planning principles and quality assurance.

To date, there has been no comprehensive policy work done by government on GLBT ageing.

GLBT people are not specifically mentioned in core aged care policies including principles determined under the Aged Care Act such as the *User Rights Principles*, *Charter of Resident Rights and Responsibilities*, *Allocation Principles*, *Advocacy Grant Principles*, *Residential Aged Care Standards*, *Residential Aged Care Manual*, *Accreditation Standards* and other policies.

ACON considers that GLBT people should be listed as special needs groups under the Act and that relatively minor amendments to the core principles would better focus the aged care system on caring for older GLBT people. Possible examples include:

- including a clear non-discrimination clause, that includes sexuality and relationships in accreditation standards;
- referring to relationships in all their forms in the current standard referring to the emotional support.

Awareness and sensitivity to GLBT people are not currently included in accreditation standards and quality frameworks for aged care providers. Again, relatively minor amendments to these documents would require aged care providers to consider GLBT issues in their operation and quality improvement processes. These changes may go some way to addressing a lack of anti-discrimination coverage for sexuality, relationships and gender identity.

A comprehensive policy process on GLBT ageing should consider any implications for the aged care workforce. Relatively minor changes to competency frameworks, curriculum and

training standards is likely to deliver better results for GLBT people in the same way as they have for other special needs groups.

It would be useful to undertake some market analysis in response to GLBT ageing. Older GLBT people would prefer to have the choice of both specialist GLBT providers and a responsive mainstream system. A comprehensive policy process would consider the feasibility of that service mix and the industry development that may be required to achieve it. Specific issues to be considered include:

- The partnerships that are required to improve the quality of services for GLBT people;
- Possible demand for GLBT specific providers and the regions that may support a specialist provider;
- Whether new entrants are required and whether there are unreasonable barriers to their entry;
- The number of aged care places in operation that may not be covered by laws preventing discrimination on the grounds of sexuality or relationship status in relation to care provision and staffing decisions.

ACON strongly recommends that the Australian Government develop a time limited GLBT Aged Care Strategy, in the spirit of the *Aboriginal and Torres Strait Islander Aged Care Strategy* and the *Ethnic Aged Care Framework* that have previously been developed at the Commonwealth level for specific groups that have different needs.

The strategy should be administered by the Commonwealth Department of Health and Ageing and include the following for the GLBT community in the aged care sector:

- GLBT specific policy;
- program guidelines;
- targeted funding;
- consumer safety;
- market conditions to support responsive providers;
- research; and
- education and training for departmental staff and sector staff.

The GLBT Aged Care Strategy should also oversee implementation of the recommendations of the policy development process.

This work should be developed in partnership with industry and with organisations with specific expertise in GLBT ageing.

#### **Recommendations:**

- 4. The Productivity Commission should adopt the following recommendation:**

**‘The Australian Government should develop a time limited GLBT Ageing Strategy in partnership with industry and organisations working with older GLBT people. The Strategy should start with a review of existing policy such as principles under the Aged Care Act, accreditation standards and regulatory frameworks and identify any amendments that would result in a better response to older GLBT people. The Strategy should also analyse the market conditions and workforce and training requirements that are needed to meet the aged care needs of GLBT people.**

## **Care and Support Systems and Integration**

ACON welcomes the proposal to develop a single entry point to the aged care system to better facilitate the comprehensive coordination of their aged care needs. As the Australian Seniors Gateway Agency (ASGA) will screen potential clients across Australia, it will be important for ASGA to be aware of particular groups such as older GLBT people and people with HIV.

ACON also welcomes the proposed reform which states that ‘the proposed Australian Seniors Gateway Agency should cater for diversity by providing interpreter services and diagnostic tools that are culturally appropriate for the assessment of care needs’ and that ‘newer diversity needs will be better recognised including gay and lesbian care recipients and refugees’.

The new Gateway should use assessment and diagnostic tools that are appropriate for all clients including GLBT people and people with HIV. In particular these tools will need to consider:

- Same sex partners, particularly where the client is less open about their relationship;
- Close friends as informal carers;
- Past experiences of discrimination;
- Whether the service need is ongoing, temporary or likely to recur
- Coordination between community care, primary health care and specialist services.

The new Gateway should provide staff with training to respond sensitively to the needs of GLBT people and people with HIV. This should also be incorporated into quality assurance processes.

ACON recommends that the Seniors Gateway work with organisations such as ACON that have not traditionally been seen as part of the aged care system but who have considerable expertise in working with older GLBT people.

The current report says very little about the interface between aged care and health care and makes recommendations only with respect to medical in-reach to residential aged care.

All older people with complex medical conditions, including older people with HIV, need health and community care providers to operate as a team.

The draft report does not discuss integration between aged care and primary health care, particularly for people living in the community.

Older people with HIV do better when general practitioners, allied health and other community care providers operate from a single care plan. Ideally aged care providers, particularly providers of packaged care, would work with general practitioners and allied health to assist people to achieve the best nutrition, manage medications and maintain functional capacity. These may be associated with HIV or with a host of other related conditions such as diabetes, hypertension and cardiovascular disease.

People with HIV are more likely to need periods of care for medical reasons. For example someone living with HIV may require home care or meals assistance for a few weeks after changing HIV treatments. It should be possible for people with HIV to access these services without needing to repeat lengthy assessments and care plans.

ACON recommends that the final report discuss the need for joint care planning and coordination between primary health care and aged care services, particularly for those with long term chronic conditions such as HIV.

ACON also recommends that the Seniors Gateway be expected to coordinate care with general practitioners and allied health providers, particularly for those with chronic conditions.

#### **Recommendations:**

- 5. The Seniors Gateway work with organisations such as ACON that have not traditionally been seen as part of the aged care system but who have considerable expertise in working with older GLBT people.**
- 6. The Final Report of Caring for Older Australians should discuss the need for joint care planning and coordination between primary health care and aged care services, particularly for those with long term chronic conditions such as HIV.**
- 7. The Seniors Gateway should be expected to coordinate care with general practitioners and allied health providers, particularly for those with chronic conditions.**

## **Supported Residents**

Many of the older people ACON comes into contact with are on lower incomes. Many people with HIV have had broken employment histories, accessed superannuation before retirement and continue to have the higher costs of living with a chronic illness.

Many lesbians are at higher risk of poverty than other women. In general terms, lesbians are less likely to have been employed in higher paying jobs and industries and have less access to retirement savings through male partners.

Transgender people are also more likely to be on extremely low incomes due to widespread discrimination in the workplace.

ACON supports the draft report's recommendation that all providers should be obliged to provide a proportion of services to low income residents.

Detailed work is required to determine the number of places required by low income residents. The quotas for each provider should be determined by the level of need from this group.

The report further recommends that this obligation should be tradeable between providers. This would allow an aged care service to contract with a second provider to care for supported residents on their behalf.

ACON can see some benefits from a tradeable system. It is possible that this may lead to specialist providers emerging that cater specifically for particularly groups, such as people with HIV who are also far more likely to be supported residents.

If a trading system is adopted it must be closely monitored on an at least annual basis. In large metropolitan planning regions, a trading approach may see fewer places for supported residents in inner city areas with high land values and capital costs in favour of more places in outer suburban areas. This would not meet the needs of a large number of low income people with social connections and networks in the inner city, such as many GLBT people and people with HIV.

This approach would also need to:

- guard against poor quality providers specialising in supported care at lower prices;
- maintain the number of supported resident places if a specialist provider collapses or fails financially. It may be that organisations that have traded out of their obligation to accommodate supported residents would need to meet their obligations in another way.

The report also recommends that the accommodation subsidy for supported residents be increased so that the provision of aged care to people with low incomes and low assets is commercially viable.

ACON strongly supports increasing the subsidies for accommodation for supported residents. Funding rates should be set at a level that is high enough to provide an adequate service and eliminate the need for providers to cross subsidise.

However, the draft report recommends that accommodation subsidy rates for supported residents should be set at the average cost of providing a place in a two bed room with a shared bathroom.

A shared bedroom and bathroom is well below the standard that most low income residents would have had prior to entering residential care. Older public housing tenants, for examples, are entitled to live alone or with their partner.

Having to share a room is likely to be a major concern for many older GLBT people and people with HIV. It will contribute to people feeling like they need to hide their sexuality or health conditions for fear of harassment and discrimination.

ACON considers that a higher standard should be used to provide low income people with access to at least a single room and preferably their own bathroom. It is understood that this may require some years to achieve as residential facilities are redeveloped. It is also understood that residents will prefer to share. In the first instance facilities that provide single rooms to low income residents should receive a higher subsidy.

## **Research**

Although ageing and aged care are established fields of clinical and social research, there is very little research into the experiences and needs of GLBT seniors in aged care. This is partly because the phenomena of many people openly being GLBT and having experienced living life as an open GLBT person is relatively recent. However, as more GLBT people are ageing and require aged care services, funding is required to examine their experiences and needs. This research will then form a stronger evidence base upon which future policies and programs can be further developed.

### **Recommendation:**

- 8. The Productivity Commission recommends funding specific research into the experiences and needs of GLBT seniors in the aged care sector.**

## List of Recommendations

1. The Final Report of Caring for Older Australians should include a separate discussion of GLBT ageing of the same status as its discussion of other special needs groups.

2. The Final Report of Caring for Older Australians should include a separate discussion of issues affecting older people with HIV.

3. The Productivity Commission should adopt the following recommendation:

‘In order to better meet the needs of special needs groups (including groups not currently identified as special needs such as older GLBT people and older people with HIV), the quality standards and accreditation system should include stronger standards including:

- A guarantee of non-discriminatory service delivery;
- Sensitivity to all kinds of relationships, friendship networks and social supports’

4. The Productivity Commission should adopt the following recommendation:

‘The Australian Government should develop a time limited GLBT Ageing Strategy in partnership with industry and organisations working with older GLBT people. The Strategy should start with a review of existing policy such as principles under the Aged Care Act, accreditation standards and regulatory frameworks and identify any amendments that would result in a better response to older GLBT people. The Strategy should also analyse the market conditions and workforce and training requirements that are needed to meet the aged care needs of GLBT people.

5. The Seniors Gateway work with organisations such as ACON that have not traditionally been seen as part of the aged care system but who have considerable expertise in working with older GLBT people.

6. The Final Report of Caring for Older Australians should discuss the need for joint care planning and coordination between primary health care and aged care services, particularly for those with long term chronic conditions such as HIV.

7. The Seniors Gateway should be expected to coordinate care with general practitioners and allied health providers, particularly for those with chronic conditions.

8. The Productivity Commission recommends funding specific research into the experiences and needs of GLBT seniors in the aged care sector.