

Permission to speak

*Determining strategies towards the development of
gay, lesbian, bisexual, transgender and intersex friendly
aged care services in Victoria.*

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A Project of Matrix Guild Victoria Inc
in conjunction with
Vintage Men Inc

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For further copies of this or the *My People* report, go to (www.matrixguildvic.org.au) or (www.geocities.com/vintagemen).

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Glossary of terms

Aged care services: Care provided for seniors including: (a) in their home such as community nursing; domestic assistance; personal care; meals on wheels; home maintenance; transport, and community-based respite care; (b) community services provided in community centres; day-care centres; day hospitals; medical centres; (c) residential aged care services such as nursing homes and hostels.

Bisexual: A man or woman who is sexually and emotionally attracted to both men and women.

Closet: An historical term used to describe non-disclosure of sexual/gender identity.

Cross-dresser: A person who dresses in clothes typical of the opposite sex.

Gay: A man whose primary sexual attraction is towards other men.

Gender: The socially defined roles assigned to males and females.

Gender identity: a person's own sense of identification as male or female.

GLBTI: An acronym for gay, lesbian, bisexual, transgender and intersex.

Heterosexism: Bias towards heterosexuals which ignores the presence and the needs of gay men, lesbians and bisexuals.

Heterosexual: A person whose primary sexual and emotional attraction is towards the opposite sex.

Hostel: residential aged care service for people with low level needs. Also referred to as 'low care'.

Homo/transphobia: A dislike of people who are homosexual or transgender that may manifest as discrimination or violence.

Intersex: A person born with sex chromosomes, external genitalia, or an internal reproductive system that is not exclusively male or female.

Lesbian: A woman whose primary sexual/emotional attraction is towards women.

Non-heterosexual: A person who is gay, lesbian or bisexual (also know as queer).

Nursing home: Residential aged care facility for people with high level of needs. Also referred to as 'high care'.

Out: The disclosure of sexual/gender identity.

Residential aged care facility: Nursing home and hostels which provide permanent residential or respite care.

Senior: A person 65 years or older.

Sexual identity: A person's identity, an established mental picture of self, can be a specific and fixed sexual identity, although this can also be somewhat fluid. e.g., heterosexual, homosexual, lesbian or bisexual.

Transgender: refers to individuals who do not identify with the gender assigned to them at birth. The terms male-to female and female-to-male transgender persons are used to refer to individuals who are undergoing or have undergone a process of gender affirmation.

Transsexual: A transgender person who is in the process of seeking, or has successfully completed, sexual reassignment surgery.

Executive summary

This is the report from Stage Two of a Matrix Guild Victoria and Vintage Men research project.

The report from Stage One, *My People: A project exploring the experiences of Gay, Lesbian, Transgender and Intersex seniors in aged-care services* is available online at

www.matrixguildvic.org.au

and

www.geocities.com/vintagemen

Background

Stage one of the project revealed that many gay, lesbian, bisexual, transgender and intersex (GLBTI) seniors do not feel safe disclosing their sexual or gender identity in aged care services. This is not surprising, given that many of these men and women grew up in an era when disclosure could result in imprisonment, enforced medical ‘cures’, loss of employment and rejection by family and friends. However, the decision to hide one’s sexual/gender identity in aged care services is also reinforced by recent anecdotal reports of discrimination when disclosure occurs.

One of the consequences of closeting, or hiding one’s sexual/gender identity is that aged care service providers are unaware of GLBTI clients and their particular needs. This invisibility, and the lack of evidence regarding the experiences of GLBTI seniors, perpetuates the status quo in which discrimination often goes unchallenged. Aged care service providers are also often unaware of the importance of providing GLBTI-friendly services.

Aged care service providers may also be unaware of their legal responsibilities in relation to GLBTI seniors. The Victorian Equal Opportunity & Human Rights Commission (2006) identifies that the human rights of all Australians, including GLBTI seniors receiving aged care services, are recognised. In particular, under the *Charter of Human Rights and Responsibilities* (2006), public agencies are obliged to consider that people have the right to enjoy their human rights without discrimination and the right to enjoy their identity and culture. Additionally, the *Equal Opportunity Act* (1995) makes it unlawful to discriminate against someone on the basis of her or his sexuality or gender, including discrimination in the provision of goods and services such as aged care services. Furthermore, the *Statute Law*

Amendment (Relationships) Act (2001) recognises that people in same-sex relationships have the same rights as heterosexual couples to authorise medical treatment and access information about their partner's health and hospital visitation.

To assist aged care services to achieve the necessary reforms, Matrix Guild Victoria Inc., in conjunction with Vintage Men Inc., developed a four-stage Program for aged care services in Victoria. The overall aim of the Program is to reduce disparities for GLBTI seniors in aged care. The first two stages of the Program, which conclude with the publication of this report, explored the experiences of GLBTI seniors in aged care services and the perspectives of aged care service providers in order to provide a catalyst for change. The additional Program stages aim to support the development of GLBTI friendly services.

Stage One: The perspectives of GLBTI seniors

Stage one of the Program, conducted in 2007, included two phases to explore the experiences of GLBTI seniors in aged care services. The *first phase* involved in-depth interviews which explored the experiences of GLBTI seniors receiving aged care services. The *second phase* involved extending interviews to inform the construction of case study narratives. Participants were invited to describe: their perceptions and/or experiences of being GLBTI in the early twentieth century; their needs as a GLBTI senior; their experiences disclosing sexual/gender identity; any positive or discriminatory experiences of aged care services; the impacts of aged care services on their lives; and any changes required to enable seniors to feel safe disclosing their sexual/gender identity. Interviews were audio-recorded and participants verified interview notes before a thematic analysis was conducted.

Interviews were conducted with 25 participants. The stage one study clarified that some GLBTI seniors are exposed to discrimination in aged care services. The study also identified strategies to address this issue. Firstly, participants expressed their support for GLBTI-specific aged care services. Secondly, the need for staff education related to the needs of GLBTI seniors was also identified.

The need for the education of aged care service providers was explicitly described by some participants. That such education is imperative was also implied in the issues presented. Most participants referred explicitly to the importance of 'My people'. This referred to family,

friends and aged care service providers with whom they could be themselves. Analysis of the conversations around 'My people' highlighted five key characteristics that can be applied to aged care service providers for the development of GLBTI-friendly aged care services. These characteristics were understanding, empathy, trust, advocacy and leadership. The underlying theme of understanding was pivotal to staff education around eight core issues identified as follows.

Core issues for GLBTI seniors

- 1. The impact of historical experiences of discrimination:** The current generation of GLBTI seniors was coming of age at a time when their sexual/gender identity could result in enforced medical 'cures', imprisonment or loss of family, employment and friends. Consequently, they have special needs which need to be understood by aged care service providers.
- 2. Invisibility as an impact of current discrimination:** Some GLBTI seniors closet their sexual/gender identity in aged care services and there are reasons behind this occurrence.
- 3. The impact of identity concealment:** GLBTI seniors who feel unable to disclose their sexual/gender identity may: feel unable to be themselves and therefore feel devalued or depressed; experience stress and pressure from maintaining a façade of heterosexuality; have unmet care needs; and have limited opportunities for sexual expression.
- 4. The impact of inadvertent visibility:** Some GLBTI seniors are exposed to discrimination from staff, co-clients and visitors because they are unable to hide their sexual/gender identity.
- 5. The impact of dementia:** Some GLBTI seniors have dementia and need staff to understand that the grief and loss involved in having a same-sex partner with dementia is no less than that experienced by a heterosexual couple
- 6. Enabling sexual and cultural expression:** Sexual and cultural expression is important for the mental health of GLBTI seniors in many respects.
- 7. Inadequate standards of care: Inadequate standards of care:** Some aged care services discriminate against GLBTI seniors by failing to create GLBTI-friendly services.
- 8. Achieving a safe environment:** A positive response to the disclosure of sexual/gender identity can result in GLBTI seniors feeling understood, valued and safe.

These themes were presented to aged care service providers in stage two to determine their perspective and develop strategies to create GLBTI-friendly aged care services.

Stage Two: The perspectives of aged care service providers

Stage two of the Program, conducted in 2008, included two phases to determine the experiences of aged care service providers and strategies to create GLBTI- friendly aged care services. The *first phase* involved conducting three focus groups with aged care service providers. The *second phase* involved 16 interviews with aged care service providers who were unable to attend focus groups. Participants were presented with the findings from the *My People* report. They were then invited to describe their experiences in caring for GLBTI seniors and determine strategies to create GLBTI-friendly aged care services. Two focus groups were audio-recorded and all participants verified interview notes before a thematic analysis was conducted.

The focus groups were attended by a twenty aged care service providers. Focus group one included a care co-ordinator, a diversional therapist, a physiotherapy assistant, division two nurses (2) and personal care attendants (3). Focus group two involved the director of nursing and chief executive officer of a private nursing home and the director of nursing for a private hostel. The third focus group involved representatives from nine community support agencies and advocacy groups which provided seniors' services. Phone interview participants included a chief executive officer, director of nursing, geriatrician, academic, educator, division two nurse, personal care attendant, division one nurses (2) and service managers/coordinators (7). Participants worked predominately in the government sector (12) in Melbourne (12) and provided services in residential aged care (3), home and community care (8), aged care assessment service (1) and GLBTI support and advocacy (4).

Seven themes relating to the aged care context emerged following data analysis.

The context of aged care services

- 1. Ageism, homo/transphobia and the community:** The homo/transphobic and ageist views of aged care service providers were considered to reflect the views of the community. However the dependency of GLBTI seniors on aged care services meant that these views were more damaging when held by service providers. Homo/transphobia in rural communities, family members and heterosexual seniors in shared services were also reported to create obstacles for GLBTI seniors.
- 2. The question of sexuality in aged care:** Aged care service providers considered that their industry was prudish and conservative. Sexuality was understood to be about sex and seniors were not expected to be sexual or sexually diverse. Sexual expression was

regarded as problematic and management strategies aimed at eradicating sexual expression included libido suppressants. A recurrent theme was the lack of permission to speak about sexuality. This was reflected in the reported consequent need for change to create GLBTI-friendly aged care services.

3. **The unknown needs of GLBTI seniors:** Many aged care service providers did not understand the needs of GLBTI seniors. There was a common perception that being GLBTI was about 'who you had sex with' and seniors were not expected to have sex. Consequently, seniors that were GLBTI were not considered to have special care needs. However, there was a genuine interest in stories about and from GLBTI seniors and in learning about their care needs.
4. **The challenge of shared services:** Aged care service providers were aware of the challenges for GLBTI seniors in shared services. However, the uncertainty around the needs of GLBTI seniors created uncertainty for some aged care service providers around how they could be supported in shared services. The balance of client rights and responsibilities appeared to be clouded by the levels of comfort some staff had with GLBTI seniors.
5. **The value of change champions:** GLBTI service providers shared stories of championing change by role modeling or advocating for particular clients. Having a GLBTI member of staff appeared to be correlated with aged care service provider comfort for GLBTI seniors. Some teams and organisations had significant numbers of GLBTI staff and were renowned for providing leadership in the GLBTI community and excellence in the care of GLBTI seniors. Several heart warming stories were told of aged care service providers that had never met a GLBTI person but championed change from a compassionate perspective. Others suggested reliance on organisational systems rather than individual champions to ensure GLBTI seniors who disclosed their sexual/gender identity were supported if a champion left the service.
6. **Gay men and the fear of HIV/AIDS:** Aged care service providers reported a general fear in the industry about gay men and the contagion of HIV/AIDS. These fears could result in staff withdrawing physical contact from a gay senior. They could also result in gay and/or HIV positive seniors choosing death rather than entering residential aged care.
7. **Fear of the unknown - transgender seniors:** Fear was also apparent in the conversations around transgender seniors. These seniors appeared likely to receive a negative response including in some rural areas where staff had never met a transgender

person. Stories were shared of transgender seniors encountering discrimination from co-clients in shared services and of cross dressers being prohibited from cross dressing. Concerns were also expressed about the readiness of aged care service providers to support transsexuals to maintain their gender identity.

Conclusion

This report presents the experiences of aged care services providers regarding GLBTI-friendly aged care services in Victoria. The complimentary perspectives of GLBTI people themselves and these service providers offers a strong foundation for the future development of an action plan to create GLBTI-friendly aged care services. No previous studies in Australia have sought feedback from service providers and recipients to develop an action plan to create GLBTI-friendly aged care services. The program has generated interest in the media, discussion in the community and debate amongst aged care service providers and the GLBTI community. This level of attention has increased the visibility of GLBTI seniors and raised concerns about their experiences in aged care services. This increased awareness will serve as the bedrock for the future development of policies, programs and services on the ground which will reduce discriminatory experiences and enhance cultural competence.

Background

You cop it sweet and shut up.

My family and I don't talk because I'm gay and they disapprove.

Having 'shock therapy' was supposed to teach me how to be straight.
All it taught me to keep my mouth shut.

Some older women would be terrified of talking.

My brother said that I shouldn't tell his children that I was having gender reassignment surgery.

I couldn't tell the staff that I'm gay.

People of his vintage didn't really have the words to describe what was in them.

I keep my mouth shut. I have to be careful what I say. I have no conversation. I can't talk to the staff in here.

(Collage of quotes from conversations with GLBTI seniors).

We don't even have language for it. We have to start the conversations.

There is a silence.

Some of the staff whisper and snigger.

They don't talk about it. It's not part of their lexicon.

We need to acknowledge our discomfort.

It requires constantly working with staff to say that it is OK to talk about it.

(Collage from conversations with aged care service providers).

In 2007 a pioneering study co-ordinated by Matrix Guild Victoria in conjunction with Vintage Men (Barrett, 2008) explored the experiences of gay, lesbian, bisexual and transgender (GLBTI) seniors in aged care in Victoria. The study challenged decades of silence around homo/transphobia in aged care services by presenting evidence that discrimination occurred. The report, entitled *My People*, was reported on and debated in the

national and international media (see media interest register at Attachment 1) creating intense interest in a group of people whose needs have been ignored for too long. The Australian population is ageing and it is expected that by 2050 a quarter of the population will be aged 65 years and older (Australian Institute of Health and Welfare, 2002). While there are no accurate figures on the percentage of seniors who are GLBTI the proportion of the general population that is not 'exclusively heterosexual' is thought to be between eight and eleven per cent (Australian Medical Association, 2002) and increasing (Birch, 2004). The ageing of the Australian population and the growing numbers of GLBTI people have contributed to the growing interest in the experiences of GLBTI seniors.

The Australian Institute of Health and Welfare (2002b) has identified that, of Australia's 2.4 million seniors (aged 65 and over), 42% need assistance to stay at home and around 5.2% require permanent nursing-home or hostel care. The experiences of GLBTI seniors accessing these and other aged care services are unique. For example, many were coming of age at a time when homosexuality was illegal or considered to be a sickness from which they could be cured. Consequently, many individuals 'closet' or hide their sexual identity to avoid discrimination.

Recently, it has been recognised that as a result of their experiences of discrimination, GLBTI seniors have special needs (Chamberlain and Robinson, 2002). However, given their history of discrimination, many GLBTI seniors do not feel safe disclosing their sexual/gender identity to aged care service providers and so their special needs are not always identified or met.

Strategies for change involve promoting positive experiences of ageing and addressing ageism and invisibility in the general community as well as the GLBTI community (Hughes 2007) and conceptualise sexuality as culture. In considering strategies to address issues in Victoria, the challenge of aged care reforms has also been supported by Matrix Guild Victoria Inc, a group founded to promote appropriate caring support for older lesbians, combat ageism and advocate on behalf of older lesbians. Matrix Guild facilitates home-based services for older lesbians, which involves organising the provision of services by appropriately qualified lesbian professionals for older lesbians who want to stay in their home. It has also conducted two studies regarding the needs of older lesbians (Bryer, 2004)

(Testro, 1997). Similarly, Vintage Men provides support to mature gay and bisexual men and their friends, including pastoral care to those in residential aged care. The commitment of Matrix Guild and Vintage Men to the needs of lesbian and gay seniors led to the development of this Program.

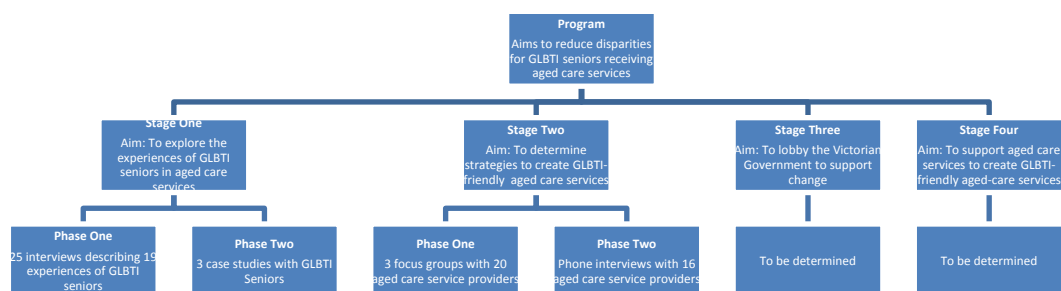
Program outline

Matrix Guild was concerned about the anecdotal reports of discrimination affecting GLBTI seniors in aged care services and thus identified the need to gather first-hand accounts of aged care experiences which could serve as a catalyst for change. They worked in conjunction with Vintage Men to develop a program that would promote the well-being of GLBTI seniors by challenging their invisibility in aged care services.

The four stage program aims to support the well-being of GLBTI seniors in Victoria and assist GLBTI seniors to feel safe disclosing their sexual/gender identity and ensure that their needs are met. The four stages have been clearly identified, (see Figure 1). The first stage gathered evidence of the experiences of GLBTI seniors in aged care services.

This report of the second stage seeks to determine strategies to enhance aged care services by presenting the findings from stage one to aged care service providers and seeking feedback on strategies for change. Stage three will involve lobbying state policy-makers, agencies, private bodies, organisations and government departments with influence, such as the Council on the Ageing, the Department of Health and Ageing and the Office of Senior Victorians to support the required changes.

Figure 1. The Four Stage Project



All stages of the Program are designed to create new understandings, generate responsive action and to reinforce the importance of hearing the voices of GLBTI seniors. To achieve the over-arching aim of reducing disparities for GLBTI seniors, this report shows how stage two seeks to engage aged care stakeholders including service users, service providers, organisational managers and policy makers. The engagement of service users provides evidence which can increase the potential efficiency of change strategies, increase the interest of service providers, create ownership of the issues identified (Barrett et al., 2005b) and assist in questioning existing practices and beliefs (Bouras and Barrett, 2007). This engagement, in conjunction with government consultation, can ensure support for sustainable change (Barrett et al., 2005a). Given the importance of engaging stakeholders, the methods will be further refined as the Program progresses to enable Program responsiveness to the stakeholder input. The methods employed in stage two are described in the following section.

Credibility and trustworthiness

To maximise the value of the study's findings, particular attention was paid to the methodological approach employed in the research. The trustworthiness and authenticity of the methods were considered to ensure that the study was credible, or did not contain *biased distortion of data* (Patton, 2002). Authenticity is described as giving *direct expression to the*

'genuine voice', which 'really belongs' to those whose life-worlds are being described (Winter, 2002). To promote genuine voices the participants in both stages were provided with interview and focus group notes for verification. Increasing the trustworthiness of the study by making the study practices visible (Sandelowski, 1993) was achieved by developing an audit trail, or list of program records, providing a picture of what occurred (Kemmis and McTaggart, 1982).

Ethical considerations

A study protocol highlighting the ethical considerations was developed for stage one and two and reviewed by the Program Steering Committee. These documents complied with the Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council, 2007). Ethical approval was also gained from the Victorian AIDS Council Ethics Committee for stage one in relation to an interview with a client of their service. All participants were provided with a plain-language statement describing the study and the possible risks. These included the potential limits to confidentiality for focus group participants. All participants signed a consent form before participating. Ethical considerations included the need to protect confidentiality, and the possible vulnerability of those who were providing the critique of a service.

The following ethical considerations and strategies related to the focus groups. Participation in the Project was voluntary and information sheets were provided to participants informing them of possible risks from being in the stage two study. To ensure the ethical conduct of the study a number of strategies were identified.

The first strategy related to the issue of confidentiality for focus group participants. In particular, the confidentiality of comments made by focus group participants could not be assured. All participants were informed that although comments made during the focus groups should be kept confidential, it could be possible that participants repeat comments outside of the group at some time in the future. Therefore, participants were encouraged to be as honest and open as they could be, but to remain aware of limits in protecting confidentiality.

To protect their identity, focus group participants were invited to introduce themselves to the group using their first name or to use a pseudonym. Furthermore, to protect the identity of their organisation participants were invited to describe the service they provided without naming the organisation or agency. Most participants chose to de-identify their service and themselves by using a pseudonym.

Also the recording of focus group interviews could contain information that may identify participants. However, interviewees were told that this information would be checked to ensure details such as participant names and organisation names were not included. Participants were also invited to de-identify information before it was included in the project report. It is also stated that it could be possible that in such group interaction participants may feel peer pressure, embarrassment or discomfort with the views of others. They were told that the facilitator would be mindful of this and would endeavour to create a discussion in which diverse views were valued and expressed in a respectful manner.

The second strategy related to the potential for focus group participants to present a range of views and experiences. It was stated that participants could be reluctant to express homo/transphobic views given that the facilitator was employed by the Matrix Guild Victoria Inc and that the Community Development Worker for the Matrix Guild would also be present. However, it was stated and the facilitator would reiterate the importance of learning from a range of views and experiences. The facilitator would also be aware that hearing such a range of views may be challenging for participants, particularly if they are GLBTI themselves.

Data analysis

This report presents the findings from stage two of the program. The focus of this stage was the identification of issues that might inform strategies to create GLBTI-friendly aged care services.

The principles which underpinned the process of collection and analysis of data throughout both stages of the research are presented in the report from stage one *My People*. Matters of methodological rigour are outlined, and commitment to credibility and trustworthiness as aspects of the research approach is confirmed. The critical methodological approach, focused

on the achievement of social justice, is outlined in reference to its application across the qualitative research driven stages of the program. The process of collection and analysis of data, including that the research took place within a context of commitment to ethical practice, is elucidated.

As is outlined in the methods section of the stage one report, a process of thematic analysis was applied to the data from interview and focus group transcripts, through a process of identification of coding categories and codes so that specific themes could emerge. Findings which were replicated or contrasted were identified (Yin, 2004) and presented to participants for feedback. The thematic analysis used the five stages of ‘framework’: familiarisation; application of a framework; indexing; mapping; and interpretation (Ritchie and Spencer, 1994).

The perspectives of GLBTI seniors receiving aged care services

To further explore the themes identified in stage one, précis from the case studies presented in the stage one *My People* report are provided in the following tables. The first précis presents the story of a gay man living with HIV/AIDS in a nursing home. The narrative is presented by Tom and has been edited in collaboration with Lizzi, Tom’s Community Support Officer from the Victorian AIDS Council. The second tells the story of Maureen who cared for her partner Thelma at home with palliative care staff and home supports. The final précis is told by Nancy, a transsexual woman in supported accommodation, and by Maggie her carer.

The stories begin with a title selected by participants. The participants then speak for themselves, with expletives and colloquialisms retained.

Table 1: Précis from case study 1

Why not take all of me?

All of me, why not take all of me?

Can't you see I'm no good without you?

My name is Tom and I have been in a nursing home since I had a stroke four years ago. I had the stroke because I've got HIV. I've got two brothers and one sister, but we don't talk because I'm gay and I've got the HIV and they disapprove. I've got no-one in my life now that loves me. Except the old girl, she loves me. When mum goes I'm done. Because I'm gay I'm a lonely man. Oscar Wilde said: City life, millions of people living lonesome together.

When I came here I told the staff I was married and they started asking to see the pictures of my wife. Of course I didn't have any and because they knew I had HIV they worked out that I'm gay. I can't talk to the staff about being gay because I am worried my care will be worse. I'm not able to live a gay man's life here because there is no privacy, and there are rules and some people think gay is disgusting. I keep my mouth shut. I have to be careful how I act and be careful what I say.

I'm only 64 but I am an old man. The HIV makes me feel old and this place makes me feel old. I've got no-one to talk to here because the residents sleep all day and they have dementia. My mind is still good, but I have no conversation. I talk to Lizzi; she's my Community Support Officer from the Victorian AIDS Council. I talk to her about how much I miss sex, touch and intimacy but I can't talk to the staff in here about that. When I realised there was nothing for me in here; that I had to forget about a sexual relationship with a male, my libido was extinguished. For a few years I rallied against this place, then I got depressed and I succumbed to it. I need to meet interesting people to make me feel alive for a while. Then back to this deadness. What else is there? I can't talk to them. I am a reasonably intelligent man. It's been depressing being in here so I started antidepressants. They're called happy pills. I had to go on them when I came in here, it's depressing.

I've got extra services because of the HIV. People who know about HIV come here to help the staff look after me. I have Lizzi who organises volunteers to take me out for a latte, a beer or a drag show. They have helped with my HIV and they have changed the way staff treat me. See they are used to gay men and I can be a gay man when I'm with them. They've educated staff about how to care for me so I get better care. They check that I'm getting the right care. The staff here know that there are people who are interested in what happens to me, that makes a difference.

The services that come in for my HIV have made some staff take interest in gay culture; one nurse wants to come to a drag show with me. That's good because a lot of straight people don't understand gay people. The other benefit is that the services understand gay men, so it's my chance to be with my kind of people, when I am with them I come alive. We can talk about old times and I can be myself. Lizzi says there are more gay men like me with HIV who are going to need aged care. Can you tell them my story so that they get looked after well and don't get lonely like me?

Table 2: Précis from case study 2

Show a little fight girls, don't be too polite.

Thelma, she was born in 1936 and was diagnosed with cancer in 2002 and died six months later. We were together for 19 years. Thelma was, is and always will be the love of my life. She was a wonderful woman and a very strong lesbian. She went in all the marches, spoke on the steps of parliament house and chained herself to the arbitration buildings for equal pay for women.

Thelma was able to be cared for at home because of this wonderful chain of lesbians who stick together and give support because we love each other and are committed to each other. The chain also allowed me to survive after her death. If they weren't around I think I would go mad. Caring for Thelma at home was the greatest blessing for both of us. Every day was a new day for us. I could see her nearly every second of the day. I could look at her, I could smile at her and I could talk with her. I could spend my time with her and I had all the help I needed.

We had three close friends who were nurses that we trusted to care for Thelma. They were trusted because they were friends and they were lesbians. They knew us both. We had a palliative care service come in and the district nurse. When they came to see Thelma I said: "We are lesbians and we would like to be recognised as a couple and we ask for your respect and I don't want any male nurses coming here to wash Thelma or whatever you people are going to do." They agreed. The case manager used to sit out the back and have a yarn with us. She knew we were lesbians. She told me afterwards that she knew immediately she came in because there was this beautiful sense of eyes looking at each other, the way I looked at Thelma, the way that Thelma looked at me. She knew but she said that she appreciated me coming out to her. She would go to Thelma and kiss her on the top of the head. That was really nice. On Christmas day the palliative care nurse came dressed as a rainbow fairy, which was amazing.

The palliative care service was there for advice, support and they were very much in the background to let Thelma die the way she wanted to die with the people around her that she wanted to have care for her. We were surprised at how supportive they were of us as a lesbian community. They said to us that they had never come across this kind of support before. After Thelma's death, the case manager asked whether there anything else that they could have done for us as a community. They used the word 'community' and 'your community'.

The lesbian chain becomes more important as you get older. In your area there's always a lesbian, you know what I mean? There is always a lesbian for a little bit of a talk, a little bit of a smile, a little bit of a joke. That is part of the wonderful chain of lesbians caring for and loving one another. That is more important as you get older, it is very, very important. If older lesbians do not have the support we had, and if they are not going to speak up then they are going to lose a chance of having a wonderful life on their last years. If you don't talk up you die very lonely. You might have got some flack but who cares? You have to talk up, ask for help. If the worst comes to the worst, well you are not a murderer, you are not a thief, you are just a very great lesbian who loves women.

Table 3: Précis from case study 3*I am who I say I am*

Nancy: Me name is Nancy, I was born a boy in 1928 and me parents called me Brian. I worked as a female impersonator with Les Girls and I went into the navy during the Second World War. In 1959 I had a sex change operation. I could only have the breasts done; they couldn't do the change below. I'm not a pure male any more; I'm a trans; both; fifty-fifty. Staff here know who I am.

Me life is hard. Its hard being in here. The people here are a lot of bludgers. I should keep away from them. That's why I never leave me room except for some meals. See! I've got me bags packed. I'm leavin'. They're not my kind of people, they're not sociable people. One of the other residents wants to flatten me because I'm a transsexual. Had I been a normal sex it would have been a different story then. People judge me because I've got a penis, I'm a transsexual. If I didn't have the penis, if I was a full female, then it would be a different story. They wouldn't know I was a transsexual then. Sometimes I don't want to funkin' eat. Sometimes I feel like I wanna die. Me life's too fuckin' hard.

Maggie: When I first met Nancy my heart went out to her. To me Nancy was Nancy. Sometimes she would pee standing up with the toilet door open and I would walk past and do a double take and then go: 'Oh! That's right!' Nancy dressed very inappropriately when I first met her. The staff used to think it was funny when she walked out in a bikini with half her genitals falling out the bottom of her bikini pants. They thought it was funny to watch her get around like that. When I took over the place I fired the lot of them and helped Nancy to feminise herself. We were teaching her how to be feminine and she blossomed.

Nancy was married to Frank for 18 years. When Frank was dying they took him to hospital. Frank's family told Nancy that she couldn't visit him because it was 'family only'. Well that was the wrong thing to say to me, I said to Nancy: 'You go upstairs, tidy yourself up, put a bit of lippy on and get your coat; I'm going to take you to the hospital.' Nancy stayed with Frank for about an hour before he died, she was so happy.

I was at home the day after Frank died and the staff rang me to say that Frank's nephew had just arrived and was taking everything out of Frank and Nancy's bedroom. They were trying to take the rings off Nancy's fingers. I reckon I must have broken all the speed rules to get there. I went flying up the stairs and into the bedroom and I said to him: 'Get out of here, before I ring the police; how dare you! She hasn't even had time to mourn and you're trying to wipe out every memory she's got. Get out of the building before I call the police.'

Since Frank died Nancy has been lonely, she would talk to anybody and everybody. She is very vulnerable, especially now. The staff here are so great, we are all very protective of her. I try to teach my staff that what you see is what she is. Don't think that's Brian; that's Nancy. That's Nancy through and through and to you she is a woman. If you get that through to them there's no dramas after that.

She is a woman. That's how I have always treated her.

The components of GLBTI-friendly aged care services identified in stage one

The report *My People* presented the experiences of 19 GLBTI seniors receiving aged care services in Victoria. In the following section the implications of the research findings for aged care services will be explored. The stage one study clarified that some GLBTI seniors are exposed to discrimination in aged care services. The study also identified strategies to address this issue. Firstly, participants expressed their support for GLBTI-specific aged care services. Secondly, the need for education related to the needs of GLBTI seniors was also identified. An exploration of these strategies follows.

GLBTI-specific aged care services

Most participants were supportive of GLBTI-specific residential aged care because of the importance of being with ‘my people’. The support for GLBTI specific services was articulated by Joseph. The staff working in such a facility, *would know what to expect. If it offends them personally and professionally, then they would be smart enough not to offer their services* (Joseph, 61 years, queer).

Educating aged care service providers

The need for the education of aged care service providers was explicitly described by some participants. Perhaps the most pressing need for education relates to the legal responsibilities of aged care service providers to provide non-discriminatory care. Other opportunities for the education of aged care service providers were highlighted such as the phenomenon of ‘my people’ and the associated service characteristics that enabled participants to feel cared for and valued.

‘My people’

Most participants made explicit reference to the importance of ‘my people’. This referred to family, friends and aged care service providers with whom they could be themselves. Analysis of the conversations around ‘my people’ highlighted five key characteristics that could be applied to aged care for the development of GLBTI-friendly aged care services. These characteristics were understanding, empathy, trust, advocacy and leadership.

Understanding and empathy

Some participants thought that GLBTI service providers were better able to understand their needs and empathise. Participants indicated that aged care service providers needed to understand the needs of GLBTI seniors before they could feel safe to disclose their sexual/gender identity. See Appendix 1 for some of the particular issues that arose related to the need for staff understanding.

Trust

Most participants felt that they needed to trust their carers, particularly if they were dependent on the aged care service provided. A sense of mistrust and fear was apparent in many stories.

Advocacy

The majority of participants who reported positive experiences of aged care services had an advocate. In some cases the advocate was a family member or friend; in other cases it was an aged care service provider. Advocates generally understood GLBTI seniors, demonstrated empathy, were trusted and played a pivotal role in crisis management around incidents of discrimination

Leadership

The need for strong leadership in policy and practice areas was also identified. Leadership is based on the knowledge of existing legislation which prohibits discrimination on the grounds of sexual/gender identity. However, the practical implementation of such legislative requirements has fallen short in some aged care services.

The significance GLBTI seniors' stories

The stories shared by GLBTI seniors in the stage one report provided evidence of discrimination and a catalyst for change. The stories demonstrate the way in which discrimination is perpetrated by staff, co-clients and visitors and by an aged care system that does not acknowledge GLBTI seniors.

There remains the opportunity to create aged care services in which GLBTI seniors are given permission to express their sexual or gender identity. Rather than giving lip service to the notion, participants wanted to see service providers demonstrate genuine commitment to ensuring their safety and understanding of their needs.

These new understandings bridge some of the gaps in our knowledge of the experiences of GLBTI seniors in aged care services and provide guideposts as to how to affect change. The

findings from stage one provided a basis for service review and policy development at government and provider level. Stage two of the Project involved focus group and one-to-one interviews with aged care service providers.

Stage two: The perspectives of aged care service providers

There is a common notion that older people are sexuality-less; they shouldn't be having sex. That goes hand-in-hand with the dirty old man syndrome. Those two things together: dirty and old. It is part of the capitalist notion that when we are young we work and contribute to society and that once we retire we are uselessness and go off and should not be seen or heard.

That is part of the social conscience, that older people should not be seen or heard. If an older person is gay they stand out more and society says: How dare you do this!

(Patrick; coordinator, GLBTI support and advocacy group).

Stage two of the program sought to explore the perspectives of aged care service providers and determine strategies to create GLBTI-friendly aged care services. The project involved two phases. The first phase included three focus groups with aged care service providers to seek their feedback on the *My People* report and to determine strategies to create GLBTI-friendly aged care services. The second phase involved telephone interviews with aged care service providers who were unable to attend the focus groups.

Data collection

The primary method of data collection involved focus groups and phone interviews with aged care service providers. Participants were sought through the project steering committee networks and direct contact with aged care service providers listed on the internet. Three focus groups were conducted. The first involved carers in a privately run nursing home (referred to here as 'Hibiscus Heights'). Staff in the home initially made contact with the project researcher to discuss the care of a gay resident.

The second focus group comprised team leaders in residential aged care services. The third focus group consisted of representatives from community support agencies and advocacy groups. Sixteen phone interviews were conducted with a range of aged care service providers who were unable to attend focus groups.

All participants were provided with the executive summary of the *My People* report and an information sheet and consent form. The participants were invited to respond to the report, describe their experiences caring for GLBTI seniors and to identify strategies to create GLBTI-friendly aged care services. Those participants who had not cared for GLBTI seniors were invited to comment on the preparedness of their service to care for GLBTI seniors described in the following vignettes adapted from the *My People* report:

1. A gay man with HIV/AIDS who is lonely and misses the gay community.
2. A lesbian feminist who has a loving partner and close circle of lesbian friends.
3. A transsexual woman who has a penis and forgets how to feminise her appearance and behaviour.
4. A man who feels depressed and suicidal if he is not allowed to dress as a woman.

Notes taken during focus groups and phone interviews were presented to participants for verification and de-identification. Focus group two and three were also digitally recorded.

Characteristics of participating aged care service providers

The focus groups were attended by 20 aged care service providers. Focus group one, consisting of participants from one private nursing home named here as Hibiscus Heights, included: a care co-ordinator, a diversional therapist, a physiotherapy assistant, division two nurses (2) and personal care attendants (3). Focus group two involved the director of nursing and chief executive officer of a private nursing home (high care facility) and the director of nursing for a private hostel (low care facility). The third focus group involved representatives from nine community support agencies and advocacy groups which provided seniors' services.

The phone interviews involved 16 aged care service providers including one chief executive officer, director of nursing, geriatrician, academic, educator, division two nurse, personal care attendant, two division one nurses and seven service managers/coordinators. The participants worked predominately in the government sector (12) in Melbourne (12) and provided services in residential aged care (3), home and community care (8), aged care assessment service (1) and GLBTI support and advocacy (4).

Table 5: Characteristics of aged care service providers participating in phone interviews

No	Pseudonym	Role	Sector	Service
1	Alan	Chief executive officer	Government	Hostel
2	Penny	Division two nurse	Private	Nursing home
3	Hazel	Division one nurse	Government	Nursing home
4	Jenny	Educator	Government	Home & community care
5	Jean	Academic; health professional	Government	GLBTI care & advocacy
6	James	Health services manager	Government	GLBTI care & advocacy
7	Jack	Division one nurse	Government	District nursing services
8	Vanessa	Health service manager	Government	Home & community care
9	Penelope	Director of nursing	Private	Nursing home
10	Lisa	Team leader	Government	Home & community care
11	Patrick	Community group co-ordinator	Private	GLBTI support & advocacy
12	Elizabeth	Community group co-ordinator	Private	GLBTI support & advocacy
13	Denise	Personal care attendant	Government	Home & community care
14	Marg	Acting Manager	Government	Aged care assessment
15	Aviva	Geriatrician	Government	Hospital and community care; education
16	Angela	Team leader- social worker	Government	Home & community care

To protect the identity of participants no further demographic details are provided. However, it is interesting to note that some participants disclosed that they were gay or lesbian. Certainly their sexual identity may have contributed to their awareness of issues for GLBTI seniors and their willingness to participate in the project.

Findings: The context of aged care services

The key findings from the focus groups and interviews include description of the experiences of aged care service providers and their suggestions for change. The experiences of aged care service providers are described in this section. These experiences are drawn from a number of themes relating to the context of care. These contextual factors, which need to be understood and taken into account if change is to be successful, include:

1. Ageism, homo/transphobia and the broader community
2. Prudishness about sexuality in aged care
3. Cultural isolation for GLBTI seniors
4. The unknown needs of GLBTI seniors
5. The value of change champions
6. Gay men and fear of HIV/AIDS
7. People like that – fear of the unknown

1. Ageism, homo/transphobia and the broader community

Many participants reflected that ageism and homo/transphobia in the broader community influences the aged care services provided to GLBTI seniors. It was generally agreed that the community did not value seniors nor consider them to be sexual or sexually diverse. These views were reported to be reflected in the care provided in aged care service services. Angela, for instance, suggested that society was, *extremely discriminatory towards GLBTI people and what happens in aged care is another symptom of that.*

(Angela, team leader, home and community care)

Elizabeth pointed out that older lesbians don't want to face ageing, because of having to face ageism & deal with how they will be confronted with society's ageist treatment. *They fear getting older and being disabled. ... There is a fear of being old and a fear of elder abuse behind the fear of being old. Women fear being vulnerable to abuse from their families, their partner and aged care service providers.* (Elizabeth; coordinator, GLBTI support and advocacy group)

Others such as Patrick suggested that:

It is part of the capitalist notion that when we are young we work and contribute to society and that once we retire we are uselessness and go off and should not be seen or heard. That is part of the social conscience, that older people should not be seen or heard. If an older person is gay they stand out more and society says: How dare you do this!

(Patrick; coordinator, GLBTI support and advocacy group)

Ageism was also thought to exist within the GLBTI community with younger generations feeling confronted by their own ageing. This lack of intergenerational support needs to be challenged to ensure that the efforts of seniors' advocacy and support services are valued. As Elizabeth suggested, *...it can be difficult to attract younger lesbians. Younger lesbians want older lesbians as role models but they wonder how much the issues for older lesbians are of concern to them. They think that by the time they are our age we will have paved the way.*

(Elizabeth; coordinator, GLBTI support and advocacy group).

The extent to which the creation of GLBTI-friendly aged care services needed to take into consideration the community context was highlighted in relation to community care. Vanessa described how a female home care provider was unable to provide home services to a lesbian client because; *her husband would not allow it.* (Vanessa: manager, community care). As indicated by Vanessa, aged care services providers are influenced by the homophobic views of the community in which they live. The context of ageism and homophobia in the community can also have a negative influence on the experiences of GLBTI seniors when manifested through their families, other clients in shared services and when amplified in rural communities.

Family control

Ageism and homo/transphobia, particularly from family members, had negative effects on GLBTI seniors. Several participants shared stories of family members, who were *shocked if their parents would do anything other than be old* (Focus Group 2: residential aged care managers). Some family members had sought to control sexual expression in dependent relatives; some family members would not recognise the sexual or gender identity of their family member or their choice of partner. This was highlighted by Vanessa who described a lesbian grieving after the death of her partner of 28 years. The couple's relationship was not recognised by their families. Consequently, the devastated lesbian *had no input into the*

funeral; her partner's family took over; she sat at the back. Vanessa also highlighted that this exclusion can come about because older rural lesbians are invisible. *In rural Victoria a lot of lesbians are not out. Some of them have been living together for many years but haven't come out to work or to their family. So, when their partner dies they are devastated because they can't tell anyone.*

(Vanessa: manager, community care).

Heterosexual seniors

Homo/transphobic views were also reported to be held by heterosexual clients in shared services. For example, in Hibiscus Heights several residents refused to be showered by a male staff member who was openly gay. One hostel manager reported being approached by a resident who had seen a television report on a lesbian marriage and said, *it's disgusting and you should see them; one of them looks like my father* (Focus Group 2: residential aged care managers). While these responses were directed at staff they presented an obstacle to the creation of GLBTI-friendly aged care services and meant that GLBTI seniors would, *need to be very brave to disclose in aged care* (Focus Group 3: community support and advocacy groups).

Sexual diversity and rural communities

Ageism and homo/transphobia were particularly apparent in rural areas. Aged care service providers from these areas believed that rural communities were less aware of their GLBTI seniors and less tolerant. Consequently, GLBTI seniors were more isolated and had fewer opportunities to express their sexuality. Others suggested that in some rural communities there are *a hell of a lot of people who are bigoted because they don't encounter sexual diversity* (Lisa, team leader, home and community care). This presents a challenge for GLBTI seniors who have community members coming into their homes to provide aged care services and for those mourning the death of a same sex partner in a closeted relationship.

Issues related to people coming into the home are significant for GLBTI seniors who want home support services. This is one of the most significant issues relayed to senior GLBTI advocacy groups. As Vanessa stated, *for someone who is that closeted to have a carer come into their home; they are in dire straits in rural areas because they're not out.* (Vanessa: manager, community care).

Jean also pointed out that *most GLBTI seniors receive aged care services in their own home. It is difficult for people in their own home if they have to de-gay their home because aged care service providers are coming in.* (Jean, lesbian, academic and health care professional)

Uncle Noel had services coming in from the start and they were not gay- friendly. There were snide remarks made about being gay by the carers that were coming in. He had gay stuff around in his house and the carers sniggered about that. But by virtue of his strength he got what he demanded. Not everyone has that. Not everyone is that assertive.
(Patrick; coordinator, GLBTI support and advocacy group).

The context of ageism and homo/transphobia in the broader community was an important consideration in the development of GLBTI-friendly aged care services. It was argued that the views of aged care service providers may not be any more discriminatory than those of the general community. However, the dependency of GLBTI seniors on aged care services meant that the negative ramifications could be greater. Furthermore, it was felt that ageism meant that there were puritanical attitudes amongst aged care service providers.

2. Puritanical attitudes and sexual activity in aged care

Aged care service providers noted that many of their colleagues did not expect seniors to be sexual. Carers were reportedly surprised if heterosexual couples were sexually active, shocked if male client masturbated and appalled if female clients masturbated. It was suggested that, *the whole aged care industry can't get over the fact that any older person would have sex* (Focus Group 3: community support and advocacy groups). It was also postulated that because sexual expression and ageing were not expected to coexist issues related to sexuality did not need to be addressed

As soon as you mention sexuality people think that you are talking about sex. There is not enough distinction made between sex and intimacy. There is very little discussion about intimacy and how we relate to a person in an intimate way. I think that we have to be very careful not to proscribe this in a narrow way.
(Focus Group 3: community support and advocacy groups)

Elizabeth also talked about the importance of clearly defining the relationship between GLBTI issues and culture. *GLBTI activism is often seen to be only about sex rather than also being about a range of issues related to our sexualities. GLBTI activism and sexualities are defined as just about sex.* She also pointed out that repressive attitudes have silenced lesbians.

We need to be able to say this is what it is like to be a lesbian; this is what our sex is like. ... It has been taboo to speak about this for long enough. ... We need to

celebrate what we do and talk openly about our sex and female sexuality generally. (Elizabeth; coordinator, GLBTI support and advocacy group).

Exploring the phenomenon of puritanical attitudes revealed numerous stories of service providers who were frightened by residents who masturbated or too embarrassed to discuss a rash in a resident's groin or clean a resident's penis. As Hazel noted, some of the staff are, *a bit funny about residents having sex, a bit prudish, a bit sniggery, a bit conservative. They don't expect older people to have sex. It just doesn't happen here* (Hazel: nurse, nursing home). As sexual expression was not discussed many service providers were not prepared or comfortable acknowledging seniors as sexual. Furthermore, as sexuality was often understood as 'sex' and seniors were not considered to be sexually active, they were not considered to be sexual.

Understanding sexuality and sex

Seniors were generally considered to be asexual. Consequently, sexual expression was not acknowledged or welcomed. When sexual expression occurred the response was often an intervention aimed at eradication. The meanings and stories for individual seniors were often lost as Aviva noted:

Geriatricians are not good at acknowledging sexuality. There is increased awareness when there are issues but it is addressed from a medical rather than psycho-social perspective. Some geriatricians are positive about sexuality; others struggle and are homophobic (Aviva: geriatrician, hospital/community care and education).

At the base of a lot of homophobia is a fear of a different sexuality. There isn't an understanding of how a person can have a different sexuality, also that a woman could be a lesbian but might also be straight for some of her life. Some women deny their sexuality because they don't want to deal with the oppression that they might find. (Elizabeth; coordinator, GLBTI support and advocacy group).

The indifference to sexualities can also be understood as indifference towards the cultural isolation a GLBTI senior often experiences in aged care provision. Just as the concept of sexuality was reduced to 'sex', being gay was often believed to be nothing more than the choice of sexual partner. This happens in society generally, well before aged care provision occurs.

The notion that seniors are considered to be asexual was highlighted at Hibiscus Heights when a staff member reported that, *we have got a new resident; he used to be gay* (Focus Group 1: Hibiscus Heights). The meaning of sexuality for gay seniors was debated by staff. One focus group participant suggested that if Hibiscus Heights had several gay residents they would need a 'gay lounge' so that residents could have sex. This was challenged by another participant who argued that the residents, *might not even like each other; just because they're gay doesn't mean they are going to want to have sex with each other* (Focus Group 1: Hibiscus Heights). In that instance staff were willing to discuss their understanding of and comfort with homosexuality and sexual expression. Participants in other services reported that sexual expression was viewed as problematic and rarely discussed.

Problematic sexual behaviour

Regardless of sexual identity, residents' sexual expression was generally considered to a problem. As Aviva noted, *sexuality is an issue where there is aberrant behaviour, when someone has dementia and there is sexual disinhibition, and it is raised as a management issue* (Aviva: geriatrician, hospital/community care and education). The response of staff involved eradicating sexual expression to relieve their discomfort and embarrassment. Unable to articulate their discomfort staff provided an assortment of 'irrational' reasons why sexual expression should be stamped out. One example involved a heterosexual couple who were prevented from sharing a room by staff because staff, *were worried that if there was a gastroenteritis outbreak the husband might pass it on to his wife* (Focus Group 3: community support and advocacy groups).

These responses promoted calls for aged care service provider to consider whether they, *put their own values onto residents. We have to ask staff at what point they bring in their own values. What about the resident? What matters to the resident?* (Focus Group 3: community support and advocacy groups).

Aviva shared numerous stories of sexual expression being labelled as problematic or deviant. In relation to 'sexual disinhibition,' Aviva considered that, *the staff's initial reaction was to assume it was a sexual problem and they would not tolerate anything sexual. Sexual expression was viewed negatively and had to be stamped out. No-one tried to think of other reasons* (Aviva: geriatrician, hospital/community care and education). Behaviours which

appeared sexual were eradicated, rather than explored. Perhaps the most striking example of this was the use of medication such as Androcur to suppress libido (Australian Prescription Products Guide, 2008; Bayer, 2008; Queensland Corrective Services, 2006).

The suggestion that a libido suppressant needs to be a last resort was explored with the staff at Hibiscus Heights. The nursing home contacted the researcher to discuss the needs of Edward, a gay resident. Edward required nursing home care after his partner of 45 years died. Suffering from dementia Edward believed that Phillip, another resident, was his partner. Consequently, Edward would sit and hold Phillip's hand and was once observed touching Phillip's thigh. This was discussed with Edward's brother who informed staff that his brother was gay. In the period after this Edward was prescribed Androcur and the staff contacted the researcher to seek support in understanding Edwards's needs.

Talking around sexuality and gender identity

Several aged care service providers noted that aspects of care that related to sexuality and gender identity were considered, *not part of their lexicon* (Focus Group 2: residential aged care managers). Conversations about this area were avoided because staff were uncomfortable or unsure of a client's sexual identity. Penny described talking 'around' the sexuality of nursing home resident:

I looked after an old lesbian who would have been older than 70 and her partner Beryl used to visit. We would talk with her around their relationship. We couldn't say the word lesbian because they never told us that they were. But we knew that Beryl was the person who took home the clothes to wash and she was the one who was recorded as the next of kin in the medical records (Penny: nurse, high care).

Many participants reported that they 'suspected' that a client was gay or lesbian. Gay men were generally considered to be more identifiable than women. The pattern of 'talking around sexuality' created challenges for some carers who felt that more open dialogue could improve client care. One such example was presented by Dana, who told of a colleague assisting a male client to shower at home.

She has been caring for a gentleman who had quite large breasts. I remembered (someone telling me of) a transsexual woman with a penis. This girl experienced that. I asked her what she did and she said that she just kept her mouth shut. She said that she just got taken aback. It opened her eyes and she just treated him like

any other client. She didn't say anything to him. I asked whether the council had given her any information about him and she said that they hadn't. When we go to someone for the first time they will give us a care plan or a 'words up' about a client but they didn't say anything to her. (Dana; personal care attendant in home care)

Dana felt that if the carer had been briefed she may have been able to ease the client's embarrassment.

The silence around sexuality and ageing was considered to perpetuate the status quo. Some managers felt that their staff required constant reassurance to say, *it is ok to talk about it* (Focus Group 2: residential aged care managers). Others clarified that, while it was ok to talk about sexuality, it was inappropriate to ask a client whether they were gay or lesbian because, *it is none of your business* (Lisa, team leader, home and community care).

Talking about sexual and gender identity amongst team members was considered a useful means of creating a team that could support GLBTI seniors. Some aged care providers readily identified and responded to these opportunities. Others were more reluctant to, *acknowledge what they know or see* (Focus Group 3: community support and advocacy groups) or respond. Invisibility remained a significant barrier to education of staff. For instance, Marg responded to the summary of the *My People* report in this way:

It was interesting reading but I don't really know if we would do anything. We don't really have enough numbers of (GLBTI) clients to warrant education not up to now. But things change all the time. We see about 5000 clients a year. With everything else going on this would not be a priority unless we had the clients (Marg, acting manager, aged care assessment service).

In other aged care services, participants noted that sexual and gender identity was not discussed and discrimination often went unreported. In some services the only such communication between staff was, *gossipy stuff; people would whisper and talk* (Penny, nurse, high care) or, *laugh and snicker* (Hazel: nurse, high care) amongst themselves. Some participants were concerned that this was also a symptom of an, *industry not well regulated* (Jack: nurse, district nursing services). However, it also seemed apparent that, without education and dialogue, aged care service providers did not understand what it was that they needed to do.

3. The unknown care needs of GLBTI seniors

Many aged care service providers were reported to believe that sexual identity was about sex. Furthermore because seniors were expected to be asexual, being GLBTI was considered to be inconsequential aspect of ageing. Consequently, there was a limited understanding of the needs of GLBTI seniors. This “asexuality” was explored with the staff at Hibiscus Heights who reported that the needs of their gay resident were no different from any other residents because he was not sexually active. However, when the care needs of GLBTI seniors were explored further, some staff reported that there was a need for, *awareness and sensitivity to any discrimination from other residents or staff that may occur* (Focus Group 1: Hibiscus Heights).

One could argue that unknown care needs means unmet care needs. This is a significant area of concern. Whether a person’s sexuality is a matter of privacy is a matter for debate. There are many facets to the question of privacy and if sexual and gender identity are rendered ‘private’ then GLBTI seniors remain invisible.

I don’t believe clients should have to tell their carers that they are gay; it isn’t anyone else’s business. I think that carers need to be given the information to make them aware generally. There is an issue of privacy and confidentiality. I would hate to think that in my later years that I would have to tell carers that I was a lesbian. You would have female carers coming in and doing their top button up because they would be worried that I was staring at their breasts. It’s about privacy and courtesy. (Dana; personal care attendant in home care)

Understanding a person’s sexuality should really start before they enter the service so that as they navigate the service system ... at every step their needs are understood and they will not slip the out of the net. We have to be careful that a promised service is delivered. (Vanessa: manager, community care).

The third focus group consisting community support and advocacy groups gave this question of privacy significant thought.

Care planning is geared for a particular purpose, around funding. The best we do after the assessment is ask (the resident questions). ... culture is paid lip service. We have the Standards and Guidelines for Residential Aged Care Services and there is a formula to follow. If you follow the formula and the Aged Care Standards and Accreditation Agency comes in and if you meet that formula you will be accredited. But if you scratch below the surface you realise that nothing is

happening. (The cultural needs of residents are) ...given lip service. The aged care standards are good, (but the problem is) ...how they are interpreted.

The staff (doing assessments and care planning) ask residents questions that fit in with their idea of a good resident in a good facility. We need to ask residents the question: What does that mean to you? (Focus group 3; community support and advocacy groups).

Hiding the sexual and gender identity of GLBTI seniors from aged care staff and assessors results in these seniors' unmet needs remaining invisible.

In all the years that I have been doing this work I have not come across an older person who was gay. We did have one person who made it known that he was gay but he had to because he was HIV positive. ... I can think of a couple of women that we visited. They described themselves as really good friends. They said that they used to work together and they lived together. I just accepted that because I'm pretty stupid. I can think of a couple of older school teachers, librarians and nurses who used to live together. There was nothing to say that they were sexual but they may have been lesbians. (Marg, acting manager, aged care assessment service).

The staff at Hibiscus Heights did not expect to care for a gay resident but sought support from the researcher to meet his care needs. They had the courage to voice their discomfort and seek strategies to improve Edward's care. Their efforts highlight the opportunities to create GLBTI-friendly aged care services through the education and resourcing of aged care service providers. Having supportive staff provided the opportunity to assist GLBTI seniors to manage the challenges of shared services such as residential aged care and day care services.

4. The challenge of shared services

The limited privacy in residential aged care facilities presented particular challenges for GLBTI seniors. Staff at Hibiscus Heights were aware of right of residents to privacy and the responsibility not to infringe of the rights of other residents. Some staff noted that achieving this balance meant compromises: *What you can do in your own bedroom at home is different. You can run around in the nude at home. In here you have to quell that* (Focus Group 1: Hibiscus Heights). The need to 'quell' sexual expression was one of the catalysts in the prescription of a libido suppressant for Edward. Another was the perception that Edward's behaviour was predatory.

Well if it was a heterosexual or gay couple they would be okay if it was just a peck or a hug. If they are doing a 10 minute snog then we have to tell them where they can have some privacy. They've got the right to kiss, but they also have a responsibility to the comfort of the other residents. The residents have the responsibility to show tolerance. They are not living in their own home; they are all living together (Focus Group 1: Hibiscus Heights).

A different situation was mentioned in the second focus group

One story that sticks out in my mind was this male resident that never told me he was gay. He was a retired nurse and he never said that he was gay but you just knew in a thousand little ways. He had a friend come in every day and he told me that it was his nephew... It so wasn't his nephew, it probably was his life partner. ..They couldn't hug, he couldn't stay the night and they had to pretend. I think that it is very sad that this man is unable to have contact with his partner. (Focus Group 2: residential aged care managers).

Other issues related to the challenge of shared services were also mentioned in focus groups and included abuse from other residents and effect of lack of personal privacy on GLBTI seniors.

Transgender people are between rock and hard place. We had a client who was male to female who ended up in a facility for HIV positive women. The other women there rejected her because they considered her to be a man so she was sent to the male facility. The clients in the male facility considered her to be a woman and rejected her. I am sure this kind of discrimination continues. Our members pick on transgender clients. That's another chapter. They are not large in number but they have specific challenges and needs. We do have positive transgendered people who are discriminated against. (James: health services manager, GLBTI care/ advocacy).

I know of a gay couple who were both in low care. For some time they wanted to have a commitment ceremony. One started to deteriorate and so his partner put forward the ceremony. The staff were very supportive. One of them was transferred to high care before the ceremony could take place. The staff in high care said that they would not support the commitment ceremony. They were worried about finances. They were looking for reasons not to support the ceremony. They were worried about privacy and so on. Who owns the privacy? – (Focus group 3: community support and advocacy groups).

One of the things that worries me with support is that we need to educate not just staff but other residents who are homophobic as well. (GLBTI seniors) need to be very brave to disclose in aged care. (Focus group 3: community support and advocacy groups).

5. The value of change champions

Most aged care service providers shared stories of GLBTI staff who championed change. It was generally seen as role modelling. However, Vanessa coined the term “change champions” in her interview.

We need care coordinators who can talk to their staff about these issues. We also need champions who can work on behalf of particular clients. A champion might just be someone from the community who can champion on the clients behalf. Staff need to understand that there are different ways of doing things. They need to provide a flexible service. (Vanessa: health services manager).

Having GLBTI staff was seen to bring, *awareness or normalness to being gay: we are here to stay, its no big deal* (Penny: nurse, high care). Some organisations were reported to have, *just enough staff there that it would have made a difference. They have an affect on staff. They educate the other staff* (Focus Group 2: residential aged care managers).

Both focus groups 2 and 3 saw the importance of change champions. It was stressed in Focus Group 3 that the champions need to be non-GLBTI as well as GLBTI.

When I worked as a manager in residential aged care staff knew that I was a lesbian and all the gay and lesbian staff came out. ... If I say I am lesbian it helps people to come out. ... I think (let's) get some GLBTI older people out there to provide education. ... If you do have lesbian or gay men in (an) organisation being the leaders it can easily come back against you. People can say that you are only interested because it is about you. It is so important to have non-GLBTI people involved in the change. ... To get change we have to get a whole heap of people as our allies. (Focus group 3: community support and advocacy groups).

Other stories of change champions involve aged care service providers who had exposure to the GLBTI community in their personal lives. In Hibiscus Heights the staff who nominated themselves as Edwards primary carers had family or friends who were gay or lesbian. Consequently they felt, *more comfortable with caring for a gay man. We have had life experience.e* (Focus Group 1: Hibiscus Heights). Being comfortable caring for a gay man enabled them to challenge the homophobic views of colleagues. For example, one of Edward's primary carers recalled how a colleague stated that homosexuality was ‘affronting’ and ‘repulsive.’ In response, the primary carer reported that, *I told her that my son is gay and we have to accept that, so she has started to change the way she thinks.* (Focus Group 1: Hibiscus Heights).

Aged care service providers were positively influenced to understand GLBTI seniors when they had a constructive relationship with a GLBTI person. These benefits were enhanced further when the GLBTI person was a line manager. One example shared involved a lesbian couple who were the director of nursing and chief executive officer of a nursing home. The women were open with staff and residents about their relationship:

It is not unknown that we are a couple. We don't hide it. ..We have started modelling ourselves. We don't set gay and lesbian aside as something different to be tackled. .. Knowing the industry as well as we do, (we know) there is a profound educational profile. It starts at the top in terms of management role modelling. Staff learn from us that we are everywhere. They also learn that other than the fact that we are in a same sex relationship, we do everything like the others do. We are not standing up with pink strips, we are normal people. (Focus Group 2: residential aged care managers).

Some cautioned that the reliance on change champions to create GLBTI-friendly services could leave GLBTI seniors vulnerable if the champion left after the senior disclosed.

One of our gay residents chose our nursing home because I'm gay. ... It worries me that we have got no policies or procedures around sexuality and I am not going to be there forever. I worry that he came under false pretences. What happens when I leave? He thinks that he has come into a gay friendly nursing home. (Focus Group 2: residential aged care managers).

Other change 'champions' involved entire team and organisations. For instance, the City of Port Phillip and The Carlton Clinic were described as organisations that had a significant number of GLBTI employees, understood the needs of GLBTI seniors and demonstrated leadership in acceptance of diversity.

There is an opportunity to empower older people to empower themselves and their families we have got gay workers. ... I have been talking about cultural diversity, it takes a long time to get other people to be your advocates, it just took about 12 years to get people to understand it, it is far better for them to be saying it than me. But the work on empowering older people and their families is great (in the) interim... will change practice quickly. (Focus group 3: community support and advocacy groups)

While many change champions were GLBTI or had contact with the GLBTI community, others were simply motivated by empathy. The *My People* report documented the story of Nancy, a transsexual woman and Maggie her carer who advocates for her across a range of discriminatory encounters (pp. 73-80). Another powerful story of empathy was told by

Penelope, a director of nursing caring for a cross dresser. The story is summarised in Table 7 (see following pages). The story encapsulates much of what was shared by GLBTI seniors and aged care service providers including:

1. The enormous potential of aged care service providers to make a difference to the lives of GLBTI seniors
2. The power of empathy and modelling respectful care
3. The importance of building trust in relationships with GLBTI seniors
4. The negative impacts of discrimination
5. The significance of history in planning care for GLBTI seniors
6. The impact of aged care service providers values and beliefs on care
7. The time and resourcing required for change
8. The need to provide permission for clients to speak about their sexuality
9. The need to provide staff with permission to discuss sexuality

Table 6: One change champion's story

**It started with a smile:
Caring for a cross dresser in a nursing home**

My name is Penelope. A couple of years ago I was the Director of Nursing (DON) of a high level care facility. We had a gentleman, Dennis, who was in his mid seventies who had a stroke. Dennis was a burly man who worked as a truck driver. When I took over the role as DON in that facility I heard staff giggling about the fact that Dennis liked to dress in women's clothing.

Having empathy and building trust

The staff used to ridicule Dennis because he liked to wear women's clothing. I think that people fear what they don't understand. They don't have to agree with what Dennis was doing but if they can understand then they can support him. When I met Dennis I felt sorrow for him; I felt that this was him as a person, a man who likes to wear women's clothing. I felt sad that he could not be the person that he was. I felt that if this is what he wanted to achieve then I would help him. I didn't want him to have to live a false life.

The staff used to catch him wearing women's clothing and they found that quite funny. I struck a rapport with Dennis and once I had his trust I asked him about dressing in women's clothing. I developed a rapport starting with a smile. He had difficulty speaking because of his stroke. After a while he would be there at the front door waiting for me to arrive at work in the morning. When I walked in he would always give me a high five. It grew from there. We would chat about general things and after about 2-3 months we were talking about his life and he told me that he used to be married and had a couple of young kids. When he mentioned that his marriage broke down I asked him was there any particular reason why? He said no. Then I said: Do you like to dress in women's clothing? He went silent and a bit funny. I said that if he wanted to dress in women's clothing he was able to. He said: No! No! Then I said that if he wanted we could talk more and I would be there to help.

Culturally appropriate assessment and care planning

Days went on as normal and one day he came into my office and we had a big talk about it. Dennis told me that it started when he was quite young. Every time he was found wearing women's clothes there were negative repercussions. When his mum found out she kicked him out of home. When his wife found out their marriage fell apart and he was not allowed to see his children. When the staff found out they laughed at him. When I first took over at the facility he just had small items like stockings. When the staff admitted him they found stockings in his things. They thought it was funny. They were not educated and didn't understand.

Dennis was really embarrassed when I asked him about dressing in women's clothing. I asked him if he would like to wear the women's clothing more often. I asked him what he liked to wear. He liked to wear dresses and stockings. He was reluctant to accept the offer of wearing the women's clothing more often. I said to him that he could do that and the staff would not have to see. I invited him to have a certain time of the day when he could wear the women's clothing and I would make sure that no-one went into his room; no-one could see him. He had private time between two and four o'clock in the afternoons when he would get dressed. There were certain days that he wouldn't do it. That was because the staff that disapproved were working. The facility was in a low socio economic area and the staff could be a little rough around the edges. I think that there were some staff that when management went home they could be inappropriate. You can't be there all the time and unfortunately some staff took advantage of that. Dennis told me that there were some lewd comments made to him by these staff. He wouldn't tell me what was said or who said it, he was worried about retribution. I asked him if he wanted to be able to wear women's clothing every day and outside his room. He said that he didn't. I think that he had had such a bad experience with the staff.

Table 6 continued

The other residents were not aware that he sometimes wore women's clothing. He didn't tell them because he felt like he didn't fit in with most of the other residents. We had some very vocal residents who would have ridiculed him; we could not change their minds, being that generation and cognitively impaired. He used to put the women's dresses at the end of his wardrobe so that the staff would not see them. It was easier to work with him than it was to work with the staff. The staff were the most difficult, they did not see that it was about him as a person.

Staff Education and cultural competence

The biggest thing that we needed was to try to educate the staff. Dennis needed assistance to get dressed; he needed to have some staff on board. I got his permission to talk to staff. We ran a session on the Standards and Guidelines for Residential Aged Care. If you run a session on sexuality people won't turn up. We started with a session on resident's rights, then confidentiality and then sexuality. We ran sessions on sexuality over about six weeks. It was such a big thing; we really opened up can of worms. We talked about the resident's right to have their life in the facility reflect their life at home as closely as possible. We started with that, and then we talked about sexuality in general. We talked about what would happen if a heterosexual resident wanted a sexual relationship and their right to do that. Next, we broached the subject about homosexuals and how the staff would feel if they were caring for someone who was homosexual and wanted a sexual relationship. Some staff were horrified.

We had a gay staff member and that was great. He encouraged a lot of other staff to understand. He was a driving force in that sense because at the education sessions he talked about what it was like for him to be gay. He talked about his experiences and how difficult it was for him, then he talked about how difficult it would be for a resident. After that one of the staff said: Do you know that we have a resident who likes to dress in women's clothes? I asked the staff how they felt about that. Some of the staff said that it was wrong and that we should not even be discussing it. I said that it was Dennis' right to do this and this is his sexuality and this is who he is. I told the staff that we are his advocates and we needed to help him. We discussed it openly and I encouraged them to think about how Dennis would feel. I asked them to think about what it would be like if it was you? That's how we finished the session. Some of them went away and did a lot of thinking and then came back with a slightly different attitude. This was over a period of time, it took a while. Having such open discussion was a new thing and for the staff it was a 'no-no'; they did not want to discuss sexuality; they just wanted to look at washing and dressing. We had quite a large group of staff who were Christian Fundamentalists. They were horrified and said that this was wrong. They were the minority, but I could never get them to accept who he was. In the end most of them left.

After the education session I had two staff that were willing to accept and help Dennis. I told Dennis, some of the staff are aware and would really like to help you. I asked Dennis to think about whether he would like them to help him. He thought about it for a while and said that he would give it a go. These staff provided him with the physical assistance to dress in women's clothing and did it without ridicule. Once Dennis was comfortable with these staff members he began to allow them to help him. We started with two staff and then we had another one on board, and then another. It took us nine months from the time I built a rapport with Dennis to the time we got staff on board. It took him time to accept that staff wanted to help. It was Dennis' first experience of being accepted wearing women's clothing. I put in a big effort to educate staff and I felt that for the first time he was with some people who accepted him for who he was.

Leadership

When I first met Dennis he only had small items of women's clothing like gloves and stockings and he was quite withdrawn and depressed. We took him shopping for dresses. He had make up and he started to wear lippie outside the room as he got more confident and as we got more staff on board. He was grateful to me, he would always say thank-you. When he was allowed to dress as a woman it was like a huge weight had been lifted off him. He became more social and got involved in groups. It made a difference to his mental health.

6. Gay men and the fear of HIV/AIDS

The stories in the stage one *My People* report raised concerns with participants in stage two about the level of education around HIV/AIDS. Participants were asked to comment on the care of a gay man with HIV/AIDS. Penny's reaction typified many of the responses when she said that, *people would over-glove; there are always staff who go too far; I don't think staff have nursed enough HIV, so they would freak out* (Penny, nurse, high care). Others like Hazel suggested that, *some staff might steer away* (from this resident), *not go near him, and avoid nursing him. They need the facts of how HIV is transmitted and whether there going to be any dangers for them* (Hazel: nurse, high care).

At Hibiscus Heights the staff reflected on Edward's care thus: *...we don't have the information on whether he has AIDS. I feel sorry for the poor personal care attendants that go in there and don't wear gloves to protect themselves. If they get AIDS who are they going to sue?* (Focus Group 1: Hibiscus Heights). While these fears have the potential to damage Edward's care they were easily eliminated through the provision of staff education.

Gay seniors are aware of the stigma surrounding their sexual identity. James shared the story of a 70 year old HIV positive gay man who was told that he required nursing home placement. In response:

He decided that he didn't want that; so he went off his antiretrovirals. He chose death rather than go into a nursing home. Powerful isn't it? He was a very proud and independent man. Again issues of sexuality, ageing and HIV/AIDS coming to an intersection. He chose death rather than go into a nursing home (James: health services manager, GLBTI care/advocacy).

As people with HIV/AIDS live longer many more will require aged care services. Consequently, to prevent discrimination education needs to be provided about the care needs of people with HIV/AIDS. There were many references to education by participants in the stage two study.

The training around sexuality should makes sure that people understand that sexuality is only one part of a person's life and does not represent the person as a whole. Sexuality is one aspect, a large aspect and should be

incorporated into culturally appropriate training that workers should get. Not just sexuality, but a whole package. It all comes back to respect. (Vanessa: health services manager).

This education also needs to explore the fears held by aged care service providers. Focus Group 2 referred to education specifically in the area of HIV and that consideration could also be given to establishing a residential care facility specifically for people with HIV/AIDS.

I have had people come to me and they are really concerned because their son is working with someone with HIV and they are really worried that they are going to catch it. A lot of personal care attendants left school early in a third world country so giving them education is going to be tough. As people living with HIV... (are living longer it is now becoming a question as to) ...whether they look at opening a HIV specific facility. A lot of people with HIV dementia are going to be hitting nursing homes. People would do a lot better to have one here and one there, you might be able to train your staff but you are always going to have your agency staff who are going to refuse to wash them. (Focus Group 2: residential aged care managers).

In such a facility staff could be educated around the need particular to the physical and psycho-social needs of seniors with HIV/AIDS.

7. 'People like that' – fear of the unknown

Discriminatory views were particularly evident in the stage one report, *My People*, around the needs of transgender seniors. In considering a vignette on the care needs of a transsexual woman from *My People* a number of stage two participants reported that aged care service providers would not welcome her. Penny described how her colleagues would:

... make a drama of it. There would be that talking at the desk; stuff that's really cruel. Staff would be passing judgements. You would hope that her care would not suffer. The staff would not be outwardly cruel but they would ignore her. If they decided that she was a woman, the whiskers would be off, but the penis would throw them. She would be in the 'too hard' basket. (Hazel: nurse, high care).

Similarly Penny talked about how staff would be challenged because, in her small town, *there just aren't people like that* (Penny: nurse, high care).

I think people would be a little bit not quite sure how to cope with Nancy (case study in stage one report, *My People*) in the beginning but I think, especially if she's got dementia, they would try to be a little more understanding. The staff might be uncomfortable when they were showering her because she's got a penis, but they would get used to it. There just aren't people like that here. There are no transsexuals here. I think her shaving, well there would be people who would laugh or snicker behind her back and there would be people who would help her to shave. The other residents can be very intolerant with each other. Some would alienate themselves from her and others wouldn't care. (Penny: nurse, high care).

Similarly, discriminatory responses were evident amongst clients in shared services, as James suggested:

Transgender people are between a rock and a hard place. We had a client who was male-to-female who ended up in a facility for HIV positive women. The other women there rejected her because they considered her to be a man so she was sent to the male facility. The clients in the male facility considered her to be a woman and rejected her. Our members pick on transgender clients (James: health services manager, GLBTI care/advocacy).

Several participants expressed their concern that aged care service providers would have difficulty meeting the needs of transgender seniors because they did not expect clients to be transgender. In contrast, staff working in residential services reportedly expected that their clients were diverse and understood their care needs. Lisa suggested that it was important to have conversations with staff about how they feel because, *people often look at transsexuals and don't take them seriously. We need staff education so that we could link them with the appropriate services.* (Lisa, team leader, home and community care)

All my staff have worked with people with frail aged, intellectual disabilities and mental illness and when you are with such a range of people you have to learn to be flexible and respond to a range of needs. (Lisa, team leader, home and community care).

These stories underscore the importance of context in considering strategies to create GLBTI-friendly aged care services.

The significance of context

The context in which aged care services are provided exerts influence upon the care provided to GLBTI seniors. The themes highlight that the challenge of creating GLBTI-friendly aged care services cannot simply be conceptualised as the interface between heterosexist service providers and GLBTI seniors. Rather, the attitudes and beliefs of aged care service providers are considered to be a microcosm of the ageist and homo/transphobic views of the general community.

It could be argued that aged care service providers are no more enlightened than the rest of the community. Seniors are not expected to be sexual or have diverse sexual and gender identities and therefore aged care service providers have not received training in this area. However, the community expects aged care service providers to understand and respond to the needs of seniors who are dependent on them.

Perhaps the most pervasive factor in these discussions was the failure of aged care service providers to discuss the sexual and gender identities of older people. In the absence of accurate information being GLBTI was considered to be about 'who you had sex with' and seniors were not expected to be having sex and therefore not expected to be GLBTI. Consequently, management strategies, including libido suppressants, were informed by a desire to stop sexual expression. Indeed, conversations about sexual diversity and gender identity need to occur for change to take place.

Aged care service providers have the opportunity to demonstrate leadership in the care of GLBTI seniors and protect them from discrimination perpetrated by other service providers, families, co-clients and the community. This was evident in the story told by Penelope, the director of nursing who worked through numerous obstacles in her efforts to support a male resident who wanted to cross dress (see table 7). In the following section, the strategies identified by Penelope and other participants are explored.

Strategies to create GLBTI-friendly aged care services

The previous sections of this report and the stage one report *My People* explored the experiences of GLBTI seniors and aged care service providers to support the development of GLBTI-friendly aged care services in Victoria. The following section presents a summary of the strategies recommended by participants to create such services. The strategies relate to eight core themes identified by aged care service providers:

- 1 The importance of powerful allies
- 2 The immediate need for advocacy and support
- 3 The need to educate aged care service providers
- 4 The role of change champions
- 5 The opportunity to educate the community
- 6 The opportunity to empower GLBTI seniors and their advocates
- 7 The value of GLBTI-specific aged care services
- 8 The significance of research
- 9 The importance of legislation

Each of these themes is explored by presenting corroborating or disparate views of aged care service providers. Next, from each theme strategies to create GLBTI-friendly aged care services are identified.

1. The importance of powerful allies

Aged care service providers suggested that the scope and complexity of the change required necessitated a coalition of allies to ensure its success. These allies need to include those with the mandate to lead change, including the aged care industry and government bodies. This high level support could enhance the strategic nature of change processes and involve service providers who would not support change unless they were given a directive to do so.

The importance of receiving support from government to translate evidence from research such as that contained in the *My people* report and to make changes to policy and practice was highlighted in the recent release of a mental health paper by the Victorian Government Department of Human Services (2008). Several aged care service providers noted that the paper, failed to address the evidence concerning mental health issues in the GLBTI community.

We need to think about awareness raising. I was surprised that the mental health paper (*Because Mental Health Matters: A new focus for mental health and wellbeing in Victoria*) that has been developed by the Victorian Department of Human Services has ignored the GLBTI community. All the work that has been done around suicide and mental illness in the GLBTI community that has been funded by DHS! We also have a gender dysphoria clinic that is DHS funded. But the mental health paper has ignored the knowledge and evidence around GLBTI people and mental health.
(Jean, lesbian, academic and health care professional).

The importance of powerful allies was also described by those GLBTI seniors reported in the stage one report, *My People*, who were concerned that some aged care service providers could 'recite a mantra' around acceptance of diversity whilst discriminating against clients. There was general agreement that unless discrimination was monitored and change was supported by government agencies, change would not be achieved.

There is not enough monitoring of practices. We are expected to produce good outcomes but there are individual interpretations of what a good outcome is. If you ask the right question you will get the right answer. As auditors we see what we want to see.

(Focus group 3: community support and advocacy groups).

Aged care service providers recommended that a lobby group of powerful allies be established to support the process of determination of strategies which arise from the outcomes of this report.

Out of this we need a lobby group because they have a lot of power. A lobby group would have the ability to enact change in government, in funding bodies, Aged and Community Care Victoria, the ALSO Foundation, Council on the Ageing, the National GLBTI Health Alliance, Carers Victoria...

You've got the federal government who has got the HREOC (Human Rights and Equal Opportunity Commission) Report which includes aged care. Maybe it's a good time to be raising awareness of GLBTI issues.
(Focus group 3: community support and advocacy groups)

Group members could also include Matrix Guild Victoria and Vintage Men. The lobby group could assist in gathering the momentum for change. Certainly, the stories from GLBTI seniors and service providers highlight the need for strategies to address the immediate needs of those who are being discriminated against.

2. The immediate need for advocacy and support

The immediate need for advocacy and support services for GLBTI seniors was identified by aged care service providers and GLBTI seniors in *My People*. Both groups expressed concern that strategies for change would not assist those who are already in services where discrimination occurred. Furthermore, data from participants in stages one and two revealed that those seniors who had positive experiences of aged care services and those who were able to negotiate positive outcomes in response to discrimination were those who had advocates.

Collaboration between existing advocacy and support services would assist with the need to educate those within the aged care industry around the needs of GLBTI seniors. This could provide some avenues towards immediate resolution for those currently experiencing discrimination in aged care services. Advocacy and support groups which could be involved include: Seniors Rights Victoria; The Community Visitors Program; The Aged Care Standards and Accreditation Agency; Matrix Guild Victoria; Vintage Men; and The ALSO Foundation. (see resource list at attachment 2). Engaging with these groups about the historical experiences of GLBTI seniors and their existing care needs could support their services to meet the needs of GLBTI seniors. This could provide pivotal support for GLBTI seniors receiving aged care services while a broader program of education is developed and implemented.

Indeed, one of the participants suggested that GLBTI support and advocacy groups need a higher profile.

At a larger picture level it is necessary for older lesbians to know about community organisations that can provide them with support and knowledge of their rights. They need to have knowledge about where they can turn for personal, cultural and legal support.

(Elizabeth; coordinator, GLBTI support and advocacy group).

Another participant suggested a simple strategic approach through which organisations could be better linked: that there be created a *list of organisations that people can access*, which could be made available across the sector.

(Vanessa: health services manager).

3 The need to educate aged care service providers

Participants across both stages of the program highlighted the importance of education in creating GLBTI-friendly aged care services. Concern was expressed that sexual and gender diversity education is not currently part of training for aged care service providers because sexuality was not considered to be important to seniors. The provision of education that includes information about a diversity of sexualities and gender identities, as well as issues relating to GLBTI cultures and ageing could provide the opportunity to impart new knowledge and skills, challenge homo/transphobic values and beliefs and give staff permission to speak about sexual and gender identity.

Several participants expressed concern about the lack of training accessed by aged care service providers. Patrick commented that aged care service providers could be, *driving trucks one day and caring for people the next* (Patrick; coordinator, GLBTI support and advocacy group). Others suggested that, *the more education you have the more likely you are to see your own homophobia and try to correct it; at least in a work situation* (Angela, team leader, home and community care). Education was required to ensure that staff understood what was required of them. However, as Jean and others articulated, it was *a cop out (for service providers) to say that they didn't understand, given there is a diversity framework in the Department of Human Services that highlights the importance of culture. We need to make that link for GLBTI service providers* (Jean: academic, health professional, GLBTI care/advocacy). For service providers, making that link involves understanding legislative requirements and coming to recognise sexual and gender diversity as culture.

Many participants mentioned training alongside the need for education of service providers, as comments from one focus group demonstrate:

Education needs to be targeted to senior management because they are the ones that drive change or not. They need someone to tell them about professional responsibility to say what is ok and it is ok to be different. We need people who model at a management level. We need little stories which give us hypothetical(s). We need to start chipping away at the edges. We tell stories. The majority of people that are not educated don't learn with words they learn with hypotheticals.

We need compulsory education because it is always going to be a handful of people who will take it up. They need to be educated about the legislation.

Need education for tertiary institutes and to create the opportunity to talk. (There could be) set up replays and scenarios and workshops to confront people.
(Focus Group 2: residential aged care managers).

Conceptualising sexuality and sexual and gender diversity as culture

A number of GLBTI seniors in the stage one study articulated that aged care service providers did not understand what gay was. This proposition was evidenced in their own stories and the focus group and interview data from aged care service providers. Being GLBTI was often conceptualised as ‘who you had sex with’ and people in same sex relationships were considered by some to be, *sexual deviants* (Angela, team leader, home and community care). Others agreed that it was necessary to define sexuality because, *as soon as you mention sexuality people think that you are talking about sex; there is very little discussion about intimacy and how we relate to a person in an intimate way* (Focus Group 3: community support and advocacy groups). The need to focus broadly on sexuality and sexual and gender identity as culture was also emphasised by Jean who suggested that:

It is a classic error to label GLBTI seniors by their behaviour only. They have multiple identities and different cultural perspectives. We all have to exist to some extent in the heteronormative culture. For GLBTI seniors who have lived most of their lives closeted, the majority of their culture is heterosexual but a part of them is gay. This is an innate part of people that is important to them and when they have to suppress it they can feel silenced and not truly themselves. Health professionals need to see GLBTI issues as about cultures, which is what the *My People* report is about, different social networks, belief systems and values. This group, whether closeted or not, at least part of their culture is GLBTI. It is not just about their behaviour, most are not behaving in a gay way.
(Jean: academic, health professional, GLBTI care/advocacy).

The concept of culture is familiar to aged care service providers. However, frameworks for cultural competency are often interpreted as relating to ethnicity.

The education that is currently provided around discrimination is more focused on culturally and linguistically diverse (CALD) than sexuality. That hasn't happened with us as a culture.
(Angela: team Leader, social worker).

We need culturally appropriate services. We have culturally appropriate services for CALD people but not for GLBTI people. We don't know what being GLBTI means for aged care. We don't even have language for it. We talk about GLBTI friendly aged care but we don't know what that means. (Vanessa: health services manager).

Culture is paid lip service. .. If you follow the formula and the Aged Care Standards and Accreditation Agency comes in and if you meet that formula you will be accredited. ... Some people think that meeting cultural needs is having a culture care kit on their shelf. (Focus group 3: community support and advocacy groups)

Vanessa clearly explained how this problem can be addressed for the recipient of aged care services.

Education needs to start with those who are doing the assessment of the older person's needs. .. If there is an issue missed, if they don't identify it then the client is not tapped into the supports, the mentoring and they miss an important level of service. Their needs have to be identified at the level of the Aged Care Assessment Service. ... I know lots of people that would not disclose. It's the way that it is asked. You don't ask straight out: Are you GLBTI? You say to a person: The reason that I am asking is because we would like to see you receiving the services that you require. I would like your permission to give this information to the people who are caring for you. You need to do this so that they don't have to tell people themselves when they front up to the service. The next step is the full on assessment. This is done in their own home, before they get services. (Vanessa: health services manager)

This issue was also aptly pointed out by Jenny, an educator teaching aged care workers using the 'Community Services Training Package: Working effectively with culturally diverse clients and co-workers' (Community Service and Health Industry Skills Council, 2002). This package articulates that students must be made aware of *culture as a factor in all human behaviour (and have) respect for cultural diversity (including) work practices (which) may relate to persons of diverse sexual preference* (p.641). However, Jenny's efforts to include GLBTI seniors in student learning were dismissed by her managers as inappropriate. Jenny lamented that the impact on students was that they graduated, *believing that sexual orientation is not a legitimate, or relevant or valid subject and has no bearing on anything except what people do in their bedroom. It's very dismissive* (Jenny: educator, community care).

Many stage two participants were interested in addressing the problems they have experienced with the lack of a conceptualisation of sexual and gender identity as culture.

Education needs to come back to culture. Can aged care service providers be educated to think of sexuality as culture, not just what people do or don't do? There are communities built around it. I think it is a cop out not understanding it well enough. Given there is a diversity framework in DHS that highlights the importance of culture we need to make that link for GLBTI service providers. Sometimes the different parts of the system don't talk to each other very well. (Jean: academic health professional).

While conceptualising sexuality as culture was intended to enable a broad definition, some aged care service providers suggested definitions that were broader still. In particular, suggestion was made that, *there is complexity around what we have to deal with; there are a range of permutations of GBLTI. I really think that we need to deal with is individuality* (Focus Group 3: community support and advocacy groups).

Our members pick on transgender clients. ... They are not large in number but they have specific challenges and needs. We do have positive transgendered people who are discriminated against. There is a bit of a pecking order (with) HIV. It is one thing to have HIV/AIDS but if you have Hepatitis C you don't own up to it. The clients are more fearful of finding out that they are Hepatitis C positive because they are generally regarded as injecting drug users and have a lower social status. Assumptions are made. They are a marginalised group within a marginalised group. (James: health services manager).

It is a classic error to label GLBTI seniors by their behaviour only. They have multiple identities, different identities and different cultural perspectives. We all have to exist to some extent in the heteronormative culture. (Jean: academic health professional)

Aged care is so mono-cultural or one minded. Diversity is not considered the norm. There is the bigger picture that everything is geared to a mono-cultural world. There is a mantra around the need to treat everyone the same (Focus group 3: community support and advocacy groups)

People think that GLBTI community is homogenous but it is not. What we need is respect for culture. We don't have that sense of respect for people's culture. It is not about empathy; it's not about tolerance; it's about respect. (Vanessa: health services manager)

In addition to these suggestions for the content of education provided to aged care service providers, a number of suggestions were made about the delivery of education.

We need education. We need to persevere with educating people...If people are going to discriminate and are going to be honest about it, if they had the balls to come out and talk about being a homophobe ,they can be given further education. We could have a gay bloke talking to them about their experiences and they can develop a feel for what it is like for a gay person...We need to ask carers for anonymous feedback or ask them one-on-one about what they want about these issues. We need education provided by someone with qualifications in the area, rather than the straight team leader.

(Interview)

Methods for delivering staff education need to take into account relevant factors such as the high turnover of staff, low literacy, limited exposure to GLBTI seniors and the impact of individual providers' values and beliefs on the care that they provide. Suggestions for accommodating these needs included: stories that captured the voices of GLBTI seniors; workshops with experiential and interactive learning activities; and practical strategies for care. Systems for education were considered important and could include staff orientation programs and other mandatory training. These processes of education were considered to give staff permission to speak about GLBTI seniors. Participants reported that these processes were accelerated by the presence of change champions. Education by GLBTI seniors themselves could also prove to be an important model.

4. The role of change champions

In many of the stories shared by GLBTI seniors and aged care service providers mention was made of positive outcomes being achieved by change champions. In many cases the champion was a GLBTI aged care service provider.

I think that there is probably a lot less homophobia where I work because everyone knows that I am gay. (Focus group 2).

When I worked as a manager in residential aged care staff knew that I was a lesbian and all the gay and lesbian staff came out. I was the talk for a long time. Even personally it's all about education and I would put it [my sexuality] in their face. I got people on board. If I say I am lesbian it helps people to come out. (Focus group 3).

GLBTI staff often raised awareness in colleagues of the normalcy of being GLBTI and provided support for colleagues to understand the challenges a GLBTI senior might encounter. Others were actively involved in advocating for the rights of clients.

I think that the main issue is cultural isolation. On an immediate level our organisation is involved in advocacy and lobbying governments for changes to policy and services. On an everyday level working with seniors the main thing that we confront is cultural isolation. (Interview Elizabeth).

The opportunities for improving care through the provision of GLBTI staff were noted by Aviva who suggested, *I would like to see enough gay workers to create gay friendly aged care. We are not going to be able to convert workers into sympathetic people overnight* (Aviva: geriatrician, hospital/community care and education).

Champions of change were not only GLBTI carers. There are a number of stories that described the powerful advocacy work of heterosexual carers. These champions included Maggie (see table 4), Penelope (see table 7), and the staff from Hibiscus Heights. These women shared a willingness to learn about the needs of their GLBTI clients.

There is also a need for senior GLBTI support and advocacy groups to have a higher profile. We need support from government so that we can have a higher profile in society, and so that we can monitor abuse and offer alternatives to heterosexuality. (Interview Elizabeth).

Such change could provide immediate improvements in the care of GLBTI seniors while more long term strategies, such as education across the whole aged care sector, the provision of broad based formal advocacy to GLBTI seniors and the development of GLBTI-specific aged care facilities, take effect. However, supporting change champions is not a substitute for systemic change. This was emphasised by a service manager who described a gay resident choosing his facility after recognising that the manager was gay. While this meant that the resident was well looked after, the manager was concerned that if he left, the organisation had no policies on sexuality, and the resident could find himself out in a homophobic facility. He commented: *It worries me that we have got no policies or procedures around sexuality and I am not going to be there forever. I worry that he came under false pretences. What happens when I leave?*

He thinks that he has come into a gay friendly nursing home (Focus Group 2: residential aged care managers).

While the opportunity to support change champions is certainly one way to move forward, it does not replace the need for change in other areas such as generic education of aged care service providers and the community generally.

5. The opportunity to educate the community

A number of aged care service providers identified that their colleagues were a *microcosm* of the general community and reflected the homo/transphobic views of the general community. Consequently, it was felt, *until society says that we are not going to tolerate homophobia, it won't change... It will only change by the gay community being strong enough to get society's support; like we have done with gay marriage.* (Patrick; coordinator, GLBTI support and advocacy group).

One stark example of the need for community education was the home carer whose husband banned her from visiting the home of a lesbian client to provide care. This situation highlighted the need to see discrimination in aged care services in the context of community perceptions.

It was beyond the scope of this research to seek suggestions regarding ways to accomplish the significant task of educating the community. The enormity of the task was highlighted by Patrick who cautioned, *we are kidding ourselves if we think that we can do a few reports and think that everything will change* (Patrick; coordinator, GLBTI support and advocacy group). While there is no suggestion that this report will prompt significant change, there is some evidence that the project itself has already raised community awareness and garnered a significant level of media interest (see media interest register, attachment 2).

6. The opportunity to empower GLBTI seniors and their advocates

A small number of stories shared by GLBTI seniors in the report from stage one *My People* described the capacity of empowered individuals to ensure that their care needs

were met. Some aged care service providers expressed concern that such stories should not be held as an example for others regarding the means by which they could assert their own needs. Particular concern was expressed that individuals have differing experiences and responses and could not be expected to replicate the techniques used by others. However, there was a general consensus amongst aged care service providers that the opportunity existed to provide information and resources for GLBTI seniors and their family, thereby assisting GLBTI seniors to advocate for themselves. That particular residents were able to act in an empowered manner is indicative that once empowered, GLBTI seniors could become aware of and successfully claim their rights.

.. there was an openly gay, very assertive, lesbian woman; she was the type of person no one would dare mess with. I used to bring in the gay press for her each week. She was the type of person that no one would mess with: 'I am out and proud - deal with it. (focus group 2).

However, this needs to be countered by the fact that some residents such as those with dementia will require formal advocacy support so that they are not ostracised.

We had a female resident and some of the staff were not comfortable caring for her. She used to touch the staff on the breast, so they were worried that she was a lesbian. She had been married but that doesn't mean anything. She might have just been mucking around but some of the staff were worried that she was a lesbian. She used to grab staff on the breast and thighs and she used to do this thing with her tongue like an oral sex gesture. Maybe she was a lesbian and because she had dementia she didn't realise what she was doing. People used to talk about it and wrote about it in her notes. (Hibiscus focus group).

Empowerment was viewed as a useful strategy for all GLBTI seniors, with specific relevance for older lesbians. These women were thought to be particularly vulnerable and in need of educational support. Elizabeth suggested:

There is a need to educate our community. We have to encourage (older lesbians) that are over forty years of age to recognise that they are getting older and that this is natural part of life. It is not an easy thing to do. They fear getting older and being disabled. The fear is quite ingrained and deeply felt. They fear being vulnerable because of physical incapacity. The fear of death is deeper behind that. They fear their physicality. They fear dependence on other people. There is a fear of being old and a fear of elder abuse behind the fear of being old. Women fear being vulnerable to abuse from their families, their partner and aged care service providers. And

cultural isolation makes them feel vulnerable. (Elizabeth; coordinator, GLBTI support and advocacy group).

Elizabeth also shared stories of older lesbians in heterosexual marriages that they were unable to 'leave' until their husband died. Information and assistance could be offered to these woman and other GLBTI seniors to enable them to understand their choices and seek support. Such information, it was suggested, could also be provided to families and friends who may also be positioned to support GLBTI seniors.

It takes a long time to get staff on board to be your advocates. It has taken me 12 years to get people to understand the importance of cultural diversity. It is far better to have staff working in aged care services advocating for cultural diversity that to have me saying it. It takes a long time, but empowering older people and their families is a great interim strategy that will change practice quickly. (Focus group 3).

It was acknowledged that not all aged care service providers would welcome the idea of providing services to empower GLBTI seniors. Penny described how, *nurses hate patients who take control, they like to be in control. If you said 'feminist' they would all roll their eyes into their head. They prefer if you are vulnerable and pathetic* (Penny: nurse, high care). Many agreed that changing practice takes time, however, *empowering older people and their families is great interim strategy that will change practice quickly* (Focus Group 3: community support and advocacy groups).

Empowerment of GLBTI staff was also raised as a significant strategy for creating positive change.

There is an opportunity to empower older people to empower themselves and their families. We have got gay workers We need to support older people and GLBTI staff. (Focus group 3).

Myself there are lot of clients that I wouldn't out myself to. The home care office knows that I am a lesbian. I wouldn't tell a lot of clients because if I did they would say that they do not want me back. How about some research in that area? What about the challenges for us? We need to see whether there are backwards prejudices. We need people to accept us regardless of our sexuality. I would be concerned about not getting work if I told a homophobic client that I was a lesbian. I do feel that there is a part of me that I have to hide. When I go to a new client they always ask: Are you married? What did you do on the weekend? I would like to speak

more openly about what I do. I would like to tell them about my girlfriend. It's not that I have a need to share, but I wish I could do that a little bit more without fearing that I could upset someone. (Interview Dana).

We have got a staff member who has a lot of contact with the community. She doesn't try to hide her sexuality or who she is, for most people it would be clear that she is a lesbian. I have never had a staff member who is so loved by the community. At Christmas our office was full of gifts for her and most people would know that she was a lesbian. She doesn't have lesbian tattooed on her forehead but she has a stereotypical look. She doesn't wear makeup and high heels, neither do a lot of the other staff, but she is clearly a lesbian and she is definitely adored. (Interview Lisa)

7. The value of GLBTI-specific aged care services

Most GLBTI seniors who participated in stage one of the project discussed the notion of GLBTI specific services with much enthusiasm, believing that such services would enable them to be themselves. Aged care service providers were more cautious about this option. They expressed concerns about how such services would be staffed and whether they would receive support from the government and aged care service providers.

One of the gay residents at work - I am the only person that he has come out to. He meets his boyfriend outside the facility. He would make a beeline for a gay facility...he would do really well in a gay facility. It is so sad to see someone not able to hold their head up. (Focus group 2).

As people are living with HIV longer there is the question of whether they look at opening a HIV specific facility. A lot of people with HIV dementia are going to be hitting nursing homes. People would do a lot better to have one here and one there you might be able to train your staff but you are always going to have your agency staff who are going to refuse to wash them. You could have a gay orientated rather than specific facility. (Focus Group 2).

I think a there would be a difference in a gay and lesbian facility. They could focus in a different way than a larger generic facility could focus. My idealistic assumption is that there would be a high sense of ownership by the residents, a feeling of safety and security and acceptance. The other side of that coin is you got to have the staff; that is where I would anticipate a very great problem. What happens behind closed doors... you

are not always there to monitor what is happening, what they are actually saying. (Focus group 2).

However, others such as James did not see staffing as a potential problem.

We need a purpose built home for people who are gay to end some of these discriminatory practices. There would be so many gay and lesbian nurses who would staff it. (Interview James).

The development of GLBTI-specific options was not seen to ameliorate the need for education and standards across the mainstream aged care sector.

I still believe that there is a need for a gay and lesbian facility but that does not mean that the overall standards and tolerance level...(are not) raised and addressed across the entire industry. I don't think that one minority is so specific from another minority that generic education can't raise it to a level where all minorities are respected. Not just tolerated but respected. (Focus group 2).

However, aged care service providers acknowledged that, given the challenges for GLBTI seniors in existing aged care services, the enthusiasm for specific services was hardly surprising. A number of aged care service providers suggested that there was a need for more research around what GLBTI seniors wanted from these services.

I would like to see a survey that is broad based. We need to ask if people want a gay and lesbian facility or whether we are just kidding ourselves in terms of what we want to see. Does the community really want it? Do we really need it? Most people don't think about it and then they are desperate. We need to find out exactly what it is that they need and then we can ask the department for it. The qualitative work that you have done is very important. Governments want quantitative data. We want it, we to see it also. We want to see something in the area but we don't know what to do. We need more factual information.

I am not convinced. I still would love to. It has been our dream but I am not convinced.

I think it would be awful to work in a GLBTI facility, they would be really demanding.

What service is it that this community actually needs? It hasn't been articulated.

In terms of aged care, there has been talk but I am not hearing convincing answers why there is something needed for the gay and lesbian community.
(Focus Group 2).

8. The significance of research

The research reported here aimed to explore the experiences of aged care service providers in order to determine strategies to create GLBTI-friendly aged care services in Victoria. This report and the *My People* Report presented evidence that GLBTI seniors have special needs and are discriminated against in aged care services. As such these reports provide evidence that contributes to a momentum for change.

Certainly this research could be replicated across Australia. Further research could also be undertaken to explore the experiences of intersex seniors, GLBTI seniors in rural areas, homo/transphobic staff and their responses to GLBTI seniors. Further research could also explore the strengths and coping strategies of GLBTI seniors and evaluate interventions for change.

You can set up supports but whether a person takes them on or not is a different matter. For example you can have a GLBTI friendly facility and women still don't come. This is the more subversive work that we need to do; we need to change the attitudes of older lesbians as well as people in general, on that deeper individual level. We need more research and we need theoretical analysis of data to achieve this deeper level of change. On that really deep level there could be more subversive work done with wider policy ramifications. And of course as well there has to be campaigns and reforms on different levels.

I think that we need to do more research too on what younger lesbians want and on ageism in the GLBTI community. Often younger dykes say that they are not interested in coming to events involving older lesbians. This is a form of ageism. It doesn't appeal to them and they experience a feeling of vulnerability when they are confronted with their own ageing. Women say that the most difficult thing that they have to confront is their old age. People don't want to know and unless we confront them with lesbian issues that are involved with the ageing process then a group for senior GLBTI support and advocacy is just a voice crying in the wilderness.(Interview Elizabeth).

9. The significance of legislation

Most aged care service providers articulated the importance of providing education in relation to the legislation developed to protect GLBTI people from discrimination. An awareness of the legislation would reportedly, *go a long way to making a difference* (Focus Group 2: residential aged care managers). Others agreed that, *even though I can't change some of staff values, I can make them aware of the legislation* (Alan: chief executive officer, low care). Some participants thought that aged care service providers *don't understand how discrimination manifests in practice*. (Focus Group 2: residential aged care managers). Therefore, an understanding of the legislation could change practice by highlighting the responsibilities of aged care service providers to protect GLBTI seniors from discrimination. This 'bottom line' approach provides the foundation to conceptualise sexual and gender identity as culture.

The basic education for the personal care attendants means that they all know that they can't discriminate against a Muslim or a black person. Still, I get people say outrageously homophobic things to me about gay residents even though they know that I am openly gay. They just don't understand. They have no idea that there is legislation against what they are saying. No idea; they are totally oblivious to how inappropriate it is. (Focus group 2).

We need to report people who breach the law...we need to write incident reports when discrimination occurs. (Focus Group 3).

The biggest change to make improvements for residents is to clarify the regulations. We need good industry standards of care. We need to be proactive. (Interview Ray).

The whole issue needs to be hit really hard. We can't continue to skirt around the edges. We can take it right back to the law and say that it is illegal to discriminate against someone because of their sexuality and put it out there that it is illegal. We need to say: Do you know it is illegal to discriminate against someone because of their sexual identity? If you are not meeting the standards I am going to report you. We have to hit their achilles heel. We need to tell them that their funding is tied to the standards and if they discriminate we will report them. They will lose their funding. I am sick of skirting around the edges. It has gone on too long. I am a registered nurse and I do agency in lots and lots of places and I work at the director of nursing level. I am empowered to use the system and I know the chain of command and who to report to. Some people find that threatening and I don't care. If they are not meeting the

standards if they are not meeting the law I report them. I fill out an incident report and they have to address it. (Focus Group 3)

Conclusions regarding strategies for change

The strategies presented in this section represent feedback from aged care service providers. Participants in the stage one research also recommended similar strategies for change with differing emphasis. For example GLBTI seniors emphasised the importance of personal history or prejudice and persecution and the positive prospect of GLBTI-specific aged care services.

In the report *My People*, GLBTI seniors described the information that aged care service providers needed to understand to care for them effectively while in the context of this report of stage two, service providers have elaborated on the way in which the education of those in the aged care industry might proceed.

The complimentary perspectives of GLBTI seniors and aged care service providers provide a strong foundation for the future development of an action plan (see appendix 4) to create GLBTI-friendly aged care services that operate within an aged care industry which genuinely celebrates diversity.

Conclusion

The *My People* and *Permission to Speak* reports have presented the experiences of 19 GLBTI seniors receiving aged care services and 36 aged care services providers regarding GLBTI-friendly aged care services in Victoria. These participants provided rich descriptions of their experiences and their suggestions for change. Consequently, the reports do not seek to generalise about the entire population of aged care services. Rather, the intent of stages one and two of the project is to provide evidence of the experiences of GLBTI seniors in aged care services in Victoria and offer practical strategies for change.

No previous studies in Australia have sought feedback from service providers and recipients to provide information that might feed into the development of a plan to create GLBTI-friendly aged care services. The Matrix Guild Victoria Inc and Vintage Men Inc program has generated interest in the media, discussion in the community and debate amongst aged care service providers and within the GLBTI community. This level of attention has increased the visibility of GLBTI seniors and raised serious concerns about their experiences in aged care services.

We live in an ageist society in which seniors are unseen and unheard and considered to be asexual. Given that aged care service providers have not been educated around the needs of GLBTI seniors it is not surprising that their views reflect the ageism of society. The vulnerability of some GLBTI seniors and their dependency on aged care services demands that service providers must take a lead role in creating GLBTI-friendly spaces. This process needs to take place in collaboration with government, GLBTI and aged care organisations, GLBTI seniors themselves and other key stakeholders.

Many of the strategies for change described in this report will take years to achieve. In the interim GLBTI seniors and service providers have vividly described serious discrimination which is currently taking place. Consequently, there is an imperative to act quickly to create change.

Appendix 1: Core issues in relation to GLBTI seniors

1. **The impact of historical experiences of discrimination:** The current generation of GLBTI seniors was coming of age at a time when their sexual/gender identity could result in enforced medical 'cures', imprisonment or loss of family, employment and friends. Consequently, they have special needs which need to be understood by aged care service providers. In particular, some GLBTI seniors: have never experienced a time when they have felt safe disclosing their sexual/gender identity; revisit past discriminatory experiences when encountering discrimination and consequently feel upset, anxious and depressed; have learned that they need to be assertive to prevent discrimination; and often have a network of 'chosen' family or friends rather than genetic family ties, although some may have few social connections.
2. **Invisibility as an impact of current discrimination:** Some GLBTI seniors closet their sexual/gender identity in aged care services through fear of discrimination. They are aware of the risks because they have: experienced discrimination in aged care services; heard reports about discrimination in these and related services; witnessed discriminatory responses from aged care service providers to GLBTI people profiled in the media. Consequently they: fear a diminished standard of care or deterioration in their relationships with their carers; fear the resignation of valued home carers; believe that aged care service providers do not expect them to be sexual or GLBTI; and believe that many aged care service providers do not understand what GLBTI or GBLTI culture means and therefore cannot meet the needs of GLBTI seniors.
3. **The impact of identity concealment:** GLBTI seniors who feel unable to disclose their sexual/gender identity may: feel unable to be themselves and feel devalued or depressed; experience stress and pressure from maintaining a façade of heterosexuality; have unmet care needs; and have limited opportunities for sexual expression.
4. **The impact of inadvertent visibility:** Some GLBTI seniors are exposed to discrimination from staff, co-clients and visitors because they are unable to hide their sexual/gender identity. These seniors, who require protection in aged care services, may include: transsexuals who do not pass as a man or a woman; cross-dressers who do not have the opportunity to cross-dress in privacy; those who have a demonstrative relationship with their same-sex partner; men who are HIV positive and are therefore presumed to be gay; and seniors with dementia who have lost their capacity to assess when and where it is safe to disclose their sexual/gender identity.
5. **The impact of dementia:** Some GLBTI seniors have dementia and need: staff to understand that the grief and loss involved in having a same-sex partner with dementia is no less than that experienced by a heterosexual couple; to have their relationships recognised by aged care service providers, other clients and families; to be protected from discrimination by co-clients with dementia; to be supported to provide informed consent relating to sexual expression; and to be cued around gender/sexual identity if required.
6. **Enabling sexual and cultural expression:** Sexual and cultural expression is important for the mental health of GLBTI seniors. Sexual expression may involve: physical touch such as holding hands, hugging, kissing; contact with partners and private time together; sexual intercourse or masturbation; and use of sex toys and sexually explicit material such as magazines, DVDs and book. Cultural expression may involve: making connections with the GLBTI community, including being with other GLBTI people, reading GLBTI community magazines, watching GLBTI television programs, attending special festivals/meetings and events; and dressing in clothing that expresses their sexuality/gender.
7. **Inadequate standards of care:** Some aged care services discriminate against GLBTI seniors by failing to create GLBTI-friendly services. Characteristics of these services include: staff being unaware of their legal responsibilities regarding discrimination; staff not being held to account if discrimination occurs; a lack of staff guidance in the form of organisational policies, education and leadership around the care of GLBT seniors; the provision of a diminished standard of care to GLBTI seniors; staff failing to protect GLBTI seniors from discrimination by co-clients and visitors in shared services; restricting opportunities for sexual expression; allowing the values and beliefs of aged care service providers to govern the care delivered to GLBTI seniors; and withdrawing physical contact from gay men in the belief that HIV/AIDS will be contracted.
8. **Achieving a safe environment:** A positive response to the disclosure of sexual/gender identity can result in GLBTI seniors feeling understood, valued and safe. A positive response can be achieved when aged care services create GLBTI-friendly aged care services by: affirming the legitimacy of GLBTI seniors' sexual/gender identity; creating opportunities for dialogue with GLBTI seniors around their care needs; understanding the importance of sexual expression and providing GLBTI seniors with opportunities for sexual expression to occur; and valuing the intimate relationships and friendships of GLBTI seniors.

Appendix 2: Media interest register

Date	Type	Title	Details
30/08 /2007	JOY FM	Well well well	Gay & lesbian radio- HIV and men's health segment
29/05 /2008	Joy FM	Well well well	Gay & lesbian radio- HIV and men's health segment
14/03 /2008	The Age Newspaper	The cost of living: HIV/AIDS	Article by Julia Medew
3/05/ 2008	The Age Newspaper	A lifetime wait for change	Article by Carol Nader
31/07 /2008	BNEWS	Care for older gays	Article by Andie Noonan
	JOY FM	Been there done that	
15/8/ 2008	Media release-LaTrobe University	Gay seniors go back to the closet as age care providers shun their needs	Web based media release by Adrienne Jones
13/08 /2008	Pinke.biz (UK)		Web based article by Eleni Henderson
13/08 /2008	Sydney Star Observer	Senior gays 'missing out'	Newsprint by Andie Noonan
20/08 /2008	Lesbian Life (USA)	LGBT seniors in aged care services face discrimination	Web based article
20/08 /2008	Same Same	Report damms GLBTI aged care	Web based article
19/09 /2008	Science Alert Australia New Zealand	Gay seniors shunned by carers	Web based article
17/09 /2008	Accessibility	Gay Seniors Feel Impact Of Poor Aged Care Options	Web based article
24/09 /2008	MCV	GLIBT seniors face discrimination	Article by Rachael Cook
19/09 /2008	Iconocast (USA)	Gay seniors shunned by carers	Web based article
17/09 /2008	Australian Ageing Agenda	GLBTI discrimination remains a problem	Web based article
28/09 /2008	JOY FM	Allegro Non Troppo	Gay & lesbian radio- classical music segment
8/10/ 2008	Life Matters - ABC radio	ABC radio	Radio national interview with Richard Aedy
Octo ber	Burondoora Leader Newspaper		
1/10/ 2008	Aged care crisis.com	Gay seniors feel impact of poor aged care options	Sydney Star Observer - Ani Lamont
1/10/ 2008	Aged Care Guide	Gays claim discrimination in aged care services	Web based article
1/10/ 2008	Elder Abuse Spotlight	GLBTI seniors discriminated	Web based article by Travis de Jonk

Appendix 3: List of resources

Aged & Community Care Victoria: A peak body for aged care in Victoria which exists to promote, encourage and assist the health and care needs of the aged and community care clients and to provide leadership in the aged and community care sector. <http://www.accv.com.au/>

Aged Care Complaints Investigation Scheme (1800 550 552): Available to anyone who wishes to provide information or make a complaint about an Australian Government-subsidised aged care service, including nursing homes, hostels, community aged care packages and extended aged care at home.

Aged Care Standards and Accreditation Agency: The independent body responsible for managing the **accreditation** residential age care facilities to improve service quality. (<http://www.accreditation.org.au/>)

ALSO Foundation (9827 4999): Works to enhance the lives of Victoria's diverse GLBT communities to create and celebrate a diverse, strong, safe and inclusive GLBTIQ community that contributes to and is respected by broader communities. (<http://www.also.org.au/>).

Alzheimer's Australia Hotline (1800 100 500): The peak body providing support and advocacy for the Australians living with dementia.

Carers Victoria (1800 242 636): A state-wide voice for family carers, representing and providing support to carers in the community for information, advice, personal support, and to access counselling. <http://www.carersvic.org.au/index.htm>

Community Visitors Program (1800 136 829): A community visitor is a trained volunteer who visits a range of residential services (including aged care) to identify, monitor and resolve issues and protect the rights and interests of people with a disability. <http://www.publicadvocate.vic.gov.au/Services/Community-Visitors.html>

Council on The Ageing: An independent consumer organisation run by and for senior Australians to protect and promote the well-being of all seniors. <http://www.cota.org.au/>

Gay and Lesbian Health Victoria: A website and clearinghouse that provides news and information of particular interest to the health and well-being of GLBTI people in Victoria. <<http://www.glhv.org.au/search/node/ageing>>.

Gay and Lesbian Issues and Psychology Review: In 2006 this journal was the first peer-reviewed journal in Australian to focus on GLBTI Ageing. The issue was edited by Dr Jo Harrison and Dr Damien W Riggs and is available on the Rainbow Visions site, at: (http://www.rainbowvisions.org.au/GLIP_Review_Vol2_No2.pdf).

InterSection Melbourne (9471 4878): An activist group with a web-based presence which takes action in relation to GLT ageing including advocating policy change. It also acts towards the development of programs to make local governments aware of the issues in their communities, including the issues for older gay men and lesbians. (<http://www.zip.com.au/~josken/ageing.htm>).

Matrix Guild Victoria Inc. (9532 4030): Founded by and for the benefit of lesbians over forty years of age. The Guild is committed to the support of appropriate care and accommodation choices and alternative lifestyle options for older lesbians in Victoria. (<http://www.matrixguildvic.org.au>).

National Aged Care Advocacy Line (1800 700 600): A national program promoting the rights of older people receiving Australian Government-funded aged care services to the community. The advocacy line can provide advice about rights; assist seniors to exercise their rights and work with the aged care industry to encourage policies and practices which protect consumers.

National GLBT Health Alliance: Established by a number of organisations working in the area of GLBT health research, programs and services to advocate on behalf of GLBT communities at a national level, with politicians, researchers, funders, and in the media. (<http://glbthealth.org.au/>)

Rainbow Visions: A coalition of individuals and groups who initiate and support actions that contribute to making the Hunter region a healthier, more enjoyable, rewarding and culturally rich place for GLBTIQ people. (<http://www.rainbowvisions.org.au/index.html>).

Seniors Rights Victoria (1300 368 821): A free service that has been established to help prevent elder abuse and safeguard the rights, dignity and independence of older Victorians. The service provides telephone information and referral, advocacy and support, legal services, community and professional education.

Victorian AIDS Council/Gay Men's Health Centre (9865 6700): A community health service which aims to improve the health and social and emotional well-being of the Victorian HIV positive and Gay, Lesbian, Bisexual and Transgender communities. In particular, we are invested in bring the AIDS epidemic to an end. (<http://www.vicaids.asn.au/content/default.asp>).

Vintage Men (0419 341 547): A social and support group for mature gay and bisexual men and their friends. (www.geocities.com/vintagemen).

Appendix 4.

Draft Strategic options to encourage the development of GLBTI-friendly aged care services in Victoria

This report explored the experiences of GLBTI seniors and aged care service providers and their perspectives on strategies to create GLBTI-friendly aged care services. The following pages provide draft strategic options recommended by program participants. These recommendations relate to eight themes derived from the analysis of the two projects undertaken and include:

1. Establish a lobby group
2. Implement immediate advocacy and support
3. Educate aged care service providers
4. Support change champions
5. Educate the community
6. Empower GLBTI seniors and their advocates
7. Support the development of GLBTI-specific services
8. Conduct further research.

The goal of each recommendation is presented before listing the objective and tasks undertaken to achieve each goal.

1. Establish a lobby group

Aim: To ensure a successful response to the serious concerns voiced in this report by identifying powerful allies who can support the development of GLBTI-friendly aged care services. Actions could include:

1.1. Invite key stakeholders to participate in a lobby group

- 1.1.1. Identify key stakeholders
- 1.1.2. Prioritise a list of actions responding to this report
- 1.1.3. Implement actions

1.2. Increase government responsiveness to the needs of GLBTI seniors by liaising with government to:

- 1.2.1. Support strategies to create GLBTI-friendly aged care services
- 1.2.2. Include sexual and gender identity education and the needs of GLBTI seniors in the training of aged care service providers

- 1.2.3. Explicitly refer to sexual and gender identity and the needs of GLBTI seniors in the Standards and Guidelines for Residential Aged Care Services
 - 1.2.4. Identify processes to monitor compliance of aged care services with antidiscrimination legislation relating to GLBTI seniors
 - 1.2.5. Support strategies to educate the community
 - 1.2.6. Support strategies to empower GLBTI seniors and their advocates
 - 1.2.7. Fund further research relating to GLBTI seniors
 - 1.2.8. Provide support and education to mainstream organisations with the capacity to support GLBTI seniors including: Seniors Rights Victoria; The Community Visitors Program at the Office of the Public Advocate; and the Aged Care Standards and Accreditation Agency.
- 1.3. Further investigate options for the development of GLBTI-specific aged care services as one strategy to create GLBTI-friendly aged care services
 - 1.4. Lobby for research funding to gather further evidence about the needs of GLBTI seniors and the effectiveness of interventions to create GLBTI-friendly aged care services
 - 1.5. Support the development of policies and program guidelines specific to the needs of GLBTI seniors.

2. Develop processes for immediate advocacy and support

Aim: To provide immediate relief to GLBTI seniors experiencing discrimination in aged care services.

- 2.1. Identify existing mainstream advocacy and support organisations that are positioned to support GLBTI seniors in aged care services such as: Seniors Rights Victoria; The Community Visitors Program at the Office of the Public Advocate; and the Aged Care Standards and Accreditation Agency.
- 2.2. Provide these existing groups with education and support around the needs of GLBTI seniors
- 2.3. Support change champions (see point 4)

3. Educate aged care service providers

Aim: To create aged care services in which GLBTI seniors have permission to speak about their sexual or gender identity. This will be supported by providing education to aged care service providers which takes into account the low literacy and high turnover of staff in some services. Sharing GLBTI seniors' stories could be employed to assist aged care service providers to understand situations they may not have encountered. Education could also seek to provide aged care service providers with permission to speak about their values and beliefs

and acknowledge any discomfort around sexuality or intimacy. Educational content could include:

3.1. Give aged care service provider permission to discuss sexual and gender identity

- 3.1.1. Disseminate copies of this report and the *My people* report
- 3.1.2. Discuss traditional responses to sexual expression
- 3.1.3. Discuss values and beliefs around sexual expression
- 3.1.4. Clarify sexual boundaries between clients and staff
- 3.1.5. Explore beliefs around the use of libido suppressants

3.2. The importance of sexual and gender identity and ageing

- 3.2.1. What sexual and gender identity means
- 3.2.2. How sexual and gender identity changes with age

3.3. The legislative requirements/guidelines governing the care of GLBTI seniors:

- 3.3.1. Anti-discrimination legislation including:
 - 3.3.1.1. The Charter of Human Rights and Responsibilities (2006)
 - 3.3.1.2. The Equal Opportunity Act (1995)
 - 3.3.1.3. The Statute Law Amendment (Relationships) Act (2001)
- 3.3.2. The relationships between anti-discrimination legislation and aged care legislation including:
 - 3.3.2.1. The Aged Care Act (1997)
 - 3.3.2.2. The Guidelines for the Home and Community Care Program National Service Standards (2003)
 - 3.3.2.3. The Standards and Guidelines for Residential Aged Care Services (2006)
- 3.3.3. How discrimination might manifest in practice
- 3.3.4. The legal consequences of discrimination
- 3.3.5. The legal responsibility to protect GLBTI seniors from discrimination
- 3.3.6. The importance of guiding staff with organisational policies, education and leadership relating to the needs of GLBT seniors
- 3.3.7. The legislation relating to sexual encounters between staff and clients
- 3.3.8. The legislation regarding the use of chemical restraints such as Androcur

3.4. What sexual and gender identity means to GLBTI seniors

- 3.4.1. Beliefs and perceptions in the general community regarding GLBTI seniors
- 3.4.2. How sexual and gender identity is expressed by GLBTI seniors
- 3.4.3. How sexual and gender identity differs between heterosexual and GLBTI seniors
- 3.4.4. How to create dialogue between GLBTI seniors and staff

3.5. The concept of sexual and gender identity as culture for GLBTI seniors

- 3.5.1. Differentiation between sex and culture
- 3.5.2. The importance of cultural connections
- 3.5.3. The need for staff to demonstrate cultural competency and provide safety
- 3.5.4. The impact of cultural isolation

3.6. The importance of sexual and cultural expression for health

- 3.6.1. The need to provide opportunities for sexual and cultural expression
- 3.6.2. The value of intimacy and touch and friendships
- 3.6.3. The need for privacy in shared services and at home

- 3.6.4. The consequences of prohibiting sexual and cultural expression
- 3.6.5. The correlation between dependency on services/family and reduced opportunities for sexual and cultural expression
- 3.6.6. The negative impacts of identity concealment
- 3.6.7. The importance of intimacy and touch
- 3.6.8. The reasons why identity concealment occurs
- 3.6.9. The benefits of sexual and cultural expression

3.7. The historical experiences of GLBTI seniors and implications for care

- 3.7.1. The legal, medical and societal responses to GLBTI people in the early 20th century
- 3.7.2. How past experiences of discrimination might affect the perceptions GLBTI seniors have of themselves
- 3.7.3. The fears associated with disclosure
- 3.7.4. The importance of 'chosen' family or friends rather than genetic family ties

3.8. Strategies to develop GLBTI-friendly aged care services where seniors feel understood, valued and safe:

- 3.8.1. Affirm the legitimacy of GLBTI seniors' sexual or gender identity
- 3.8.2. Create opportunities for dialogue with GLBTI seniors around their care needs
- 3.8.3. Understand the importance of sexual and cultural expression and provide GLBTI seniors with opportunities for sexual expression to occur
- 3.8.4. Value the intimate relationships and friendships of GLBTI seniors
- 3.8.5. Establish organisational systems and policies to support GLBTI seniors rather than rely on individual staff members

3.9. Positive responses to the disclosure of sexual and gender identity

- 3.9.1. Ensure that GLBTI seniors play significant roles in decisions that impact on them, as far as is possible. Ensure that their voices are heard; they are visible and their preferences are sought
- 3.9.2. Responding to individuals rather than stereotypes

3.10. The impact of staff values and beliefs of service providers on GLBTI seniors

- 3.10.1. Education which enables staff to explore their own values and beliefs and the impacts of these on the care that they provide
- 3.10.2. The effects of community perceptions on aged care

3.11. The potential vulnerability of GLBTI seniors who are unable or choose not to conceal their identity and therefore require additional protection including:

- 3.11.1. Transsexuals who do not pass as a man or a woman
- 3.11.2. Cross-dressers who do not have the opportunity to cross dress in privacy
- 3.11.3. Those who have an open relationship with their same sex partner
- 3.11.4. Men who are HIV positive and are therefore assumed by staff to be gay
- 3.11.5. Seniors with dementia who have lost their capacity to assess when and where it is safe to disclose their sexual or gender identity.

3.12. The needs of GLBTI seniors with dementia who require:

- 3.12.1. Staff to understand that the grief and loss involved in having a same-sex partner with dementia is no less than that experienced by a heterosexual couple
- 3.12.2. To have their relationships recognised by aged care service providers, other clients and families
- 3.12.3. To be protected from discrimination by co-clients with dementia
- 3.12.4. To be supported to provide informed consent relating to sexual expression
- 3.12.5. To be supported to maintain their gender or sexual identity.

3.13. The needs of older gay men

- 3.13.1. Staff values, beliefs and stereotypes about being gay and being an older gay man
- 3.13.2. The use of universal infection control guidelines and the fear of HIV/AIDS
- 3.13.3. The need for physical touch and intimacy
- 3.13.4. Strategies to protect gay men in shared services
- 3.13.5. Understanding the effects of dementia on the lives of gay seniors

3.14. The needs of older lesbians

- 3.14.1. Staff values, beliefs and stereotypes about lesbians and older lesbians
- 3.14.2. The historical role of women and lesbians including lesbian feminism
- 3.14.3. The barriers to sexual and cultural expression for older lesbians
- 3.14.4. Strategies to protect lesbians in shared aged care services
- 3.14.5. The effects of dementia for older lesbians

3.15. The needs of transgender seniors

- 3.15.1. Staff values, beliefs and stereotypes about seniors transsexuals and cross dressers
- 3.15.2. The care needs of seniors who are male to female and female to male transsexuals
- 3.15.3. The impact of the difficulty accessing gender reassignment surgery in the early 20th century
- 3.15.4. The physical, emotional and psychological needs of seniors who are transgender and the consequences of limited access to gender reassignment surgery
- 3.15.5. Why some seniors cross dress and the consequences of prohibiting cross dressing
- 3.15.6. The potential difficulty maintaining gender roles with ageing
- 3.15.7. The potential isolation for transgender seniors and the vulnerability that this creates
- 3.15.8. Strategies to facilitate sexual and gender expression in shared services
- 3.15.9. The impact of dementia on the capacity to maintain gender identity

3.16. The needs of intersex seniors

- 3.16.1. Staff values, beliefs and stereotypes about who intersex seniors are
- 3.16.2. Understand the invisibility of intersex seniors and identify potential needs

4. Support change champions

Aim: To improve the care provided to GLBTI seniors by supporting change champions who seek to create GLBTI-friendly aged care services.

- 4.1.** Identify individual change champions including aged care service providers, GLBTI seniors, families and advocates of GLBTI seniors
- 4.2.** Identify teams and organisations that are change champions
- 4.3.** Assess support needs
- 4.4.** Provide support and resources
- 4.5.** Identify strategies to recognise the leadership of change champions
- 4.6.** Share change stories with other potential change champions

5. Educate the community

Aim: To reduce disparities for GLBTI seniors and increase their supports by providing community education around the experiences and needs of GLBTI seniors.

- 5.1.** Clarify community values, beliefs and stereotypes around GLBTI seniors
- 5.2.** Identify resources to support community education
- 5.3.** Develop and implement education
- 5.4.** Target education program in rural communities and amongst heterosexual seniors

6. Empower GLBTI seniors and their advocates

Aim: To enable GLBTI seniors and/or their advocates to understand and assert their rights in aged care services.

- 6.1.** Develop accessible information on the rights of GLBTI seniors including:
 - 6.1.1. Legislation relating to discrimination
 - 6.1.2. What to do if advocacy is required
 - 6.1.3. What to do if discrimination has occurred
 - 6.1.4. How to protect oneself from homo/transphobia
- 6.2.** Seek feedback from GLBTI seniors on the information they require and the action they have taken and ideas they have
- 6.3.** Provide educational information that could be given to service providers by GLBTI seniors (or others on behalf of a senior who wishes to remain anonymous)
- 6.4.** Ensure that the voices of GLBTI seniors are heard and are involved in decision-making which impacts on their lives, at all times.

7. Support the development of GLBTI-specific services

Aim: To ensure that a range of GLBTI-friendly aged care services are available to GLBTI seniors.

- 7.1. Clarify what GLBTI-specific aged care services will be supported by GLBTI seniors eg: residential aged care, community care, HIV/AIDS specific facility, advocacy service or other agency
- 7.2. Explore the symbolic significance of GLBTI-specific aged care services for GLBTI seniors
- 7.3. Where appropriate identify strategies to support GLBTI-specific aged care services

8. Conduct further research

Aim: To promote further research in order to build on the body of evidence regarding the needs of GLBTI seniors. New initiatives could include research relating to the:

- 8.1. Historical experiences of GLBTI seniors
- 8.2. Resilience and coping strategies developed by GLBTI seniors
- 8.3. Community perceptions of GLBTI seniors
- 8.4. Perceptions of aged care service providers
- 8.5. Experiences of intersex seniors
- 8.6. The experiences of change champions
- 8.7. Issues for GLBTI seniors living in rural areas
- 8.8. The content of training programs for aged care service providers related to sexual and gender identity
- 8.9. Use of medications to decrease libido in aged care services
- 8.10. Expanding the current program to include all Australian states and territories
- 8.11. Explore further the meaning of GLBTI-friendly aged care services

References

AGE CONCERN (2002) Policy Position Paper: Issues facing older lesbians, gay men and bisexuals. Access date: March 2008. Available at:

(<http://www.ageconcern.org.uk/AgeConcern/Documents/OLGMppp.pdf>)

AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (2002) Older Australia at a glance. Canberra, Australian Institute of Health and Welfare, Commonwealth Department of Health and Ageing

AUSTRALIAN MEDICAL ASSOCIATION (2002) Sexual diversity and gender identity. Access date: March 2008. Available at:

(<http://www.ama.com.au/web.nsf/doc/WEEN-5GA2YX>)

AUSTRALIAN PRESCRIPTION PRODUCTS GUIDE (2007) Androcur CMI. Access date: June 2008. Available at:

(http://www.appgonline.com.au/drug.asp?drug_id=00075134&t=cmi)

BARRETT, C., ANGEL, J., GILBERT, M., BOURAS, C., THOMPSON, K. & SINGLETON, E. (2005a) Systematic processes for sustainable practice development. *Practice Development in Health Care*, 4, 5-13.

BARRETT, C., BORTHWICK, A., BUGEJA, S., PARKER, A., VIS, R. & HURWORTH, R. (2005b) Emotional labour: Listening to the patient's story. *Practice Development in Health Care*, 4 213-223.

BAYER (2008) Control of libido in severe hypersexuality and/or sexual deviation in the adult male. *Electronic medicines compendium*. Access date: June 2008. Available at:

(<http://emc.medicines.org.uk/emc/assets/c/html/DisplayDoc.asp?DocumentID=1808>)

BIRCH, H. (2004a) What about us? Positive ageing is also a GLBTI issue! *AAG Conference*. Melbourne.

BIRCH, H. (2004b) *About Time!*: GLBT Seniors ALSO Matter. Melbourne, The ALSO Foundation

BOURAS, C. & BARRETT, C. (2007) Strategies to enhance patient-centred care in a cardiothoracic surgical unit. *Practice Development in Health Care*, 6, 150-164.

BRYER, L. (2004) Home-based services for older lesbians. A research report on behalf of Matrix Guild Victoria Inc examining types of non-discriminatory, lesbian-sensitive support services required by older, disadvantaged lesbians wishing to remain in their own homes.

CALLAN, M. (2006) Providing aged care services for the gay and lesbian community. *Australian Nursing Journal*, 14, 20.

CARR, W. & KEMMIS, S. (1986) *Becoming critical: Education, knowledge and action research*, Burwood, Deakin University Press.

CHAMBERLAIN, C. & ROBINSON, P. (2002) The Needs of Older Gay, Lesbian and Transgender People. Melbourne, RMIT University and the Centre for Applied Social Research

COMMUNITY SERVICE AND HEALTH INDUSTRY SKILLS COUNCIL (2002). *Community Services Training Package*. Access date: May 2008. Available at: (<http://www.ntis.gov.au/Default.aspx?/trainingpackage/CHC02/download>)

COOK-DANIELS, L. (1997) Lesbian, gay male, bisexual and transgendered elders: Elder abuse and neglect issues. *Journal of Elder Abuse and Neglect*, 9, 35-49.

COUCH, M., PITTS, M., MULCARE, H., CROY, S., MITCHELL, A. & PATEL, S. (2007) *Tranznation: A report on the health and wellbeing of transgendered people in Australia and New Zealand*. Melbourne, Gay and Lesbian Health Victoria, Australian Research Centre in Sex, Health and Society, La Trobe University

DE SAXE, M. & LOVETT, K. (2008) *Inter~Section Melbourne*. Access date: March 2008. Available at: (<http://www.zip.com.au/~josken/inters3.htm>)

DEPARTMENT OF HEALTH AND AGEING AUSTRALIA (1997) *Aged Care Act 1997: Quality of care principles*. Canberra, The Department of Health and Ageing Australia

DEPARTMENT OF HUMAN SERVICES VICTORIA (1988) *Health Services Act 1988*. Canberra, The Department of Human Services.

DEPARTMENT OF HUMAN SERVICES VICTORIA (2003) *Summary 2003 Supported Residential Services (SRS) Census: Resident snapshot*. Access date: March 2008. Available at: (http://www.health.vic.gov.au/srs/downloads/resident_snapshot.pdf)

DEPARTMENT OF HUMAN SERVICES VICTORIA (2004) *Public sector residential aged care policy: The Victorian Government's role in residential aged care services*. Melbourne, The Department of Human Services.

DEPARTMENT OF HUMAN SERVICES VICTORIA (2007) *Ministerial Advisory Committee on Gay and Lesbian Health. 2007*. Access date: March 2008. Available at: (<http://www.health.vic.gov.au/macglh/>)

DEPARTMENT OF HUMAN SERVICES VICTORIA (2008) *HACC Facts*. Access date: March 2008. Available at: (http://www.health.vic.gov.au/hacc/hacc_victoria/facts.htm)

DEPARTMENT OF HUMAN SERVICES (2008). *Because Mental Health Matters: A new focus for mental health and wellbeing in Victoria*. Access date: May 2008. Available at: (<http://www.health.vic.gov.au/mentalhealth/reformstrategy/mhmatters-rep08.pdf>)

HADFIELD, M. & HAW, K. (2001) 'Voice', young people and action research. *Educational Action Research*, 9, 485-502.

HARRISON, J. (1999) A lavender pink grey power: Gay and lesbian gerontology in Australia. *Australasian Journal on Ageing*, 18(1), 32-37.

HARRISON, J (2001) 'It's none of my business: Gay and lesbian invisibility in aged care' in Australian Occupational Therapy Journal Vol 48 pp142-145
Access date June 2008. Available at:
(<http://www.rainbowvisions.org.au/HarrisonAOTJournal48.pdf>)

HARRISON, J (2002a) 'What are you really afraid of? Gay, lesbian, bisexual, transgender and intersex ageing, ageism and activism' in Word is Out March, pp1-11
Access date June 2008. Available at:
(http://www.rainbowvisions.org.au/wordIsOut_by_JoHarrison.pdf)

HARRISON, J (2002b) 'LGBT Elders Gaining Ground in Australia' in OutWord. American Society on Aging. Vol 9 No 1 Summer. pp3-7

HARRISON, J. (2004a) 'Discrimination and older gays: Surviving aged care'. in Equal Time. NSW Anti-Discrimination Board. No 61 August.
Access date: March 2008. Available at:
([http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/vwFiles/ET%20Aug%2004%20.pdf/\\$file/ET%20Aug%2004%20.pdf](http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/vwFiles/ET%20Aug%2004%20.pdf/$file/ET%20Aug%2004%20.pdf))

HARRISON, J. (2004b) Towards the recognition of gay, lesbian, bisexual, transgender and intersex (GLBTI) ageing in Australian gerontology *Annual Conference of the Australian Lesbian Medical Association*. Leura, New South Wales.

HARRISON, J. (2004c) Towards the recognition of gay, lesbian, bisexual, transgender and intersex ageing in Australian gerontology. Ph D thesis. School of Health Sciences, Division of Health Sciences. The University of South Australia.
Access date: June 2008. Available at:
(<http://arrow.unisa.edu.au:8080/vital/access/manager/Repository/unisa:24955?query=Harrison%2c+J>)

HARRISON, J (2005a) 'Pink, lavender and grey: Gay, lesbian, bisexual, transgender and intersex ageing in Australian gerontology' in Gay and Lesbian Issues and Psychology Review. Vol 1, pp11-16. Access date: June 2008. Available at:
(<http://www.rainbowvisions.org.au/HarrisonGLIPReview.pdf>)

HARRISON, J. (2005b) Healthy ageing: What is it? *GLBT Health Ageing Forum ACON*.
Access date: June 2008. Available at:
(http://acon.org.au/community/index.cfm?doc_id=1737&cat_id=112)

HARRISON, J. (2005c) Working Paper on Gay, Lesbian, Bisexual, Transgender and Intersex Ageing and Discrimination Sydney, New South Wales Anti Discrimination Board. Access date: June 2008. Available at:
(http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/pages/adb_glbt_consultation)

HARRISON, J. (2006a) Coming out from the shadows and into the light: Gay, lesbian, bisexual, transgender and intersex ageing-Celebrating diversity and taking action. *Australian Association of Gerontology Conference*. Sydney.
Access date: June 2008 Available at: (<http://glhv.org.au/taxonomy/term/94>)

HARRISON, J. (2006b) Coming out ready or not! Gay, lesbian, bisexual, transgender and intersex ageing and aged care in Australia: Reflections, contemporary developments and the road ahead. *Gay and Lesbian Issues and Psychological Review*, 2, 44-54. Access date: June 2008. Available at:

(http://www.rainbowvisions.org.au/GLIP_Review_Vol2_No2.pdf)

HARRISON, J. (2006c) OutWord Online: Insider's perspective on LGBT aging issues in Australia. 2006. Access date: March 2008. Available at:

(http://www.asaging.org/networks/lain/outword_online/2006/nov.cfm)

HUGHES, M. (2006) Queer ageing. *Gay and Lesbian Issues and Psychological Review*, 2, 54-59.

HUGHES, M. (2007) Older lesbians and gays accessing health and aged-care services. *Australian Social Work*, 60, 197-209.

KEMMIS, S. & MCTAGGART, R. (2000) Participatory action research. In DENZIN, N. & LINCOLN, Y. (Eds.) *Handbook of qualitative research*. London, Sage Publications.

LEONARD, W. (2003) Health and sexual diversity: A health and well-being action plan for gay, lesbian, bisexual, transgender and intersex Victorians. Melbourne, Ministerial Advisory Committee on Gay and Lesbian Health

MENTAL HEALTH ACT COMMISSION (2003). *Placed amongst strangers: Tenth biennial report 2001-2003*. London. The Stationery Office.

MCFALL SULLIVAN, S. (2008) Five questions for David Cameron: An intersex elder's view of aging. LGBT Aging Issues Network, OUTWORD. Winter 2008. Access date: June 2008. Available at:

(<http://www.asaging.org/networks/LAIN/outword-143.cfm>)

MCNAIR, R., ANDERSON, S. & MITCHELL, S. (2001) Addressing health inequalities in Victorian lesbian, gay, bisexual and transgender communities. *Health Promotion Journal of Australia*, 11, 32-38.

NATIONAL HEALTH AND MEDICAL RESEARCH COUNCIL (2007) Australian Code for the Responsible Conduct of Research Canberra, Australian Government

OSBORNE, D., BARRETT, C., HETZEL, C., NANKERVIS, J. & SMITH, R. (2002) The wellness project: Promoting older peoples' sexual health. Melbourne, National Ageing Research Institute

PATTON, M. (2002) *Qualitative research and evaluation methods*, London, Sage.

PITTS, M., SMITH, A., MITCHELL, A. & PATEL, S. (2006) Private lives: A report on the health and wellbeing of GLBTI Australians. Melbourne, Gay and Lesbian Health Victoria, The Australian Research Centre in Sex, Health and Society

QUAM, J. (1993) Gay and Lesbian ageing. Access date: March 2008. Available at:

(<http://www.cyfc.umn.edu/seniors/resources/gayaging.html>)

QUAM, J. & WHITFORD, G. (1992) Adaptation and Age-Related Expectations of Older Gay and Lesbians Adults. *The Gerontologist*, 32, 367-374.

QUEENSLAND CORRECTIVE SERVICES (2006) Administration form - Androcur treatment consent/information. Access date: June 2008. Available at: (http://www.correctiveservices.qld.gov.au/Resources/Procedures/Support_Services/documents/spsfrmandrocurtreat.doc)

RITCHIE, J. & SPENCER, L. (1994) Qualitative data analysis for applied policy research. In ALAN, B. & ROBERT, B. (Eds.) *Analyzing qualitative data*. London, Routledge.

SANDELOWSKI, M. (1993) Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16, 1-8.

SELLERS, C. & ANGERAME, M. (2002) HIV/AIDS in older adults: A case study and discussion. *AACN Clinical Issues*, 13, 5-21.

TESTRO GLADYS, J. (1997) Lesbian Health, Independence & Well Being Resource. Melbourne, The Matrix Guild of Victoria

THE AGED CARE STANDARDS AND ACCREDITATION AGENCY LTD (2006) Results and processes in relation to the expected outcomes of the accreditation standards. Melbourne, The Aged Care Standards and Accreditation Agency Ltd. Access date: April 2008. Available at: (<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-manuals-sgr-sgrindex.htm> and [guidelines](#))

VICTORIAN EQUAL OPPORTUNITY AND HUMAN RIGHTS COMMISSION (2006) Your right to rights: The Victorian Charter of Human Rights and Responsibilities explained. Melbourne, Access date: April 2008 (<http://www.humanrightscommission.vic.gov.au/human%20rights/default.asp#humanrights>)
Equal Opportunity Act (1995). Access date: April 2008. Available at: (http://www.austlii.edu.au/au/legis/vic/consol_act/ea1995250/)
Statute Law Amendment (Relationships) Act (2001). Access date: April 2008. Available at: (<http://www.austlii.edu.au/au/legis/vic/bill/slab20002000395/>)

WINTER, R. (2002) Truth or fiction: Problems of validity and authenticity in narratives of action research. *Educational Action Research*, 10, 143-154.

WOLF, R. (1996) Understanding elder abuse and neglect. *Aging*, 367, 4-9.

YIN, R. (2003) *Case study research: Design and methods*, London, Sage.

YIN, R. (2004) Case study methods. COSMOS Corporation. Access date: March 2007. Available at (<http://www.cosmoscorp.com/Docs/AERAdraft.pdf>).