

My People

*A project exploring the experiences of Gay,
Lesbian, Bisexual, Transgender and Intersex
seniors in aged-care services*

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Co-ordinated by Matrix Guild Victoria Inc
in conjunction with
Vintage Men Inc

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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 and emotional 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.

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).

Out: The disclosure of sexual/gender identity.

Senior: A person 65 years or older.

Sexual identity: A person's identity, an established mental picture of self, with a specific and fixed sexual identity e.g., heterosexual, homosexual, lesbian or bisexual.

Transgender: A man or woman whose gender identity is at odds with their biological sex.

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

Executive summary

Background

Many gay, lesbian, bisexual, transgender and intersex (GLBTI) seniors do not feel safe disclosing their sexual or gender identity. This is particularly true of those who are utilising the services of the aged-care sector. 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, perpetuate 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 stage of the Program, which concludes with the publication of this report, explored the experiences of GLBTI seniors in aged-care services in order to provide a catalyst for change. The additional Program stages aim to seek input from aged-care service-providers and support the development of GLBTI friendly services.

Methodology

Stage one of the Program, conducted in 2007, included two phases. The first phase involved in-depth interviews which explored the experiences of GLBTI seniors receiving aged-care services. A checklist of items to be covered was developed. 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.

The second phase involved identifying three participants who were willing to take part in further interviews to inform the construction of case study narratives. These participants were also invited to nominate 'significant others', including carers and family members, for interview, in order to contribute to their stories.

Participants' characteristics

Interviews were conducted with 25 participants. Twenty-three of the interviews investigated the stories of 19 aged-care recipients, three of which were chosen as case studies. While the study sought to interview the aged-care recipients, it became apparent that some GLBTI seniors were unable to share their stories because they were disempowered, or deceased. Therefore, as well as interviews with aged-care

recipients (14), stories were also shared by partners (2), a friend (1) and aged-care service-providers (2). Similarly, case-study narratives were complemented by interviews with carers (2) and family or friends (2). The stories recounted experiences regarding a range of aged-care services, including: home care (9), nursing homes (7), hostels (20), a psycho-geriatric residential care facility (1) and day-care centres (2). The aged-care recipients had an average age of 72 years (56 to 87 years) and included seven females who identified as lesbian, eight males who identified as gay or queer, two bisexual males and one transgender woman. Most participants lived in the Melbourne area (13) and almost half had a current partner.

Project advertisements also identified a number of willing interviewees who were not receiving aged-care services. One such interview was conducted with a 47-year-old transsexual lesbian who provided valuable insights into the challenges she encountered working in aged care as a woman who did not always pass as a woman. A number of aged-care service-providers made contact with the researcher to share their experiences regarding the barriers and enablers to creating GLBTI-friendly aged-care services. One interview was conducted and will be reported on in stage two of the program.

Findings

The key findings from the study are drawn from a number of themes which emerged in relation to the experiences of GLBTI seniors. Additionally, strategies to address the discrimination experienced by some GLBTI seniors in aged-care services were identified. The eight core issues identified as relating to the experiences and special needs of GLBTI seniors are presented next.

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:

- 1.1. Have never experienced a time when they have felt safe disclosing their sexual/gender identity
- 1.2. Revisit past discriminatory experiences when encountering discrimination and consequently feel upset, anxious and depressed
- 1.3. Have learned that they need to be assertive to prevent discrimination
- 1.4. Often have a network of 'chosen' family or friends rather than genetic family ties, while 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 because:

- 2.1. They are aware that discrimination occurs, as they have:
 - 2.1.1. Experienced discrimination in aged-care services
 - 2.1.2. Heard reports about discrimination in these and related services
 - 2.1.3. Witnessed discriminatory responses from aged-care service-providers to GLBTI people profiled in the media
- 2.2. They fear a diminished standard of care or deterioration in their relationships with their carers
- 2.3. They fear the resignation of valued home carers
- 2.4. They believe that aged-care service-providers do not expect them to be sexual or GLBTI
- 2.5. They believe that many aged-care service-providers do not understand what GLBTI or GBLTI culture means and therefore how to meet the needs of GLBTI seniors.

3. The impact of identity concealment

GLBTI seniors who feel unable to disclose their sexual/gender identity may:

- 3.1. Feel unable to be themselves and feel devalued or depressed.
- 3.2. Experience stress and pressure from maintaining a façade of heterosexuality
- 3.3. Have unmet care needs
- 3.4. 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:

- 4.1. Transsexuals who do not pass as a man or a woman
- 4.2. Cross-dressers who do not have the opportunity to cross-dress in privacy
- 4.3. Those who have a demonstrative relationship with their same-sex partner
- 4.4. Men who are HIV positive and are therefore expected to be gay
- 4.5. 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:

- 5.1. 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
- 5.2. To have their relationships recognised by aged-care service-providers, other clients and families
- 5.3. To be protected from discrimination by co-clients with dementia
- 5.4. To be supported to provide informed consent relating to sexual expression
- 5.5. 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 and may involve:

- 6.1. Physical touch such as holding hands, hugging, kissing
- 6.2. Contact with partners and private time together
- 6.3. 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.
- 6.4. Dressing in clothing that expresses their sexuality/gender
- 6.5. Sexual intercourse, masturbation, sex toys and sexually explicit material such as magazines, DVDs and books.

7. Inadequate standards of care

Some aged-care services discriminate against GLBTI seniors by failing to create GLBTI-friendly services, including:

- 7.1. Staff being unaware of their legal responsibilities regarding discrimination
- 7.2. Staff not being held to account if discrimination occurs
- 7.3. A lack of staff guidance in the form of organisational policies, education and leadership around the care of GLBT seniors
- 7.4. The provision of a diminished standard of care to GLBTI seniors
- 7.5. Staff failing to protect GLBTI seniors from discrimination by co-clients and visitors in shared services
- 7.6. Restricting opportunities for sexual expression
- 7.7. Allowing the values and beliefs of aged-care service-providers to govern the care delivered to GLBTI seniors
- 7.8. 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 by aged-care services:

- 8.1. Creating GLBTI-friendly aged-care services
- 8.2. Affirming the legitimacy of GLBTI seniors' sexual/gender identity
- 8.3. Creating opportunities for dialogue with GLBTI seniors around their care needs
- 8.4. Understanding the importance of sexual expression and providing GLBTI seniors with opportunities for sexual expression to occur
- 8.5. Valuing the intimate relationships and friendships of GLBTI seniors.

These issues reflect the experiences of the GLBTI seniors interviewed for this study. The interviewees also provided a number of suggestions for the development of aged-care services to ensure that consumers are safe from discrimination and that their needs are met.

Moving forward

The research participants identified two key strategies to address the many concerns expressed by GLBTI seniors, as are highlighted in this report. Firstly, support for GLBTI-specific aged-care services was expressed. Secondly, the need for education related to the needs of GLBTI seniors was also identified.

GLBTI-specific aged-care services

Most participants articulated support for GLBTI-specific aged-care services. Such services were viewed as pivotal to the protection of seniors from discrimination by staff and co-clients. These participants felt that in such a facility their care needs would be met, sexual expression would be permitted and partners would be welcomed. They also felt that they would be able to relate to co-clients in shared services. To date there are no GLBTI-specific aged-care facilities in Victoria.

GLBTI-specific services were considered to be one strategy to prevent discrimination and meet the needs of GLBTI seniors. A second strategy was the education of aged-care service-providers.

Education

The need for the education of aged-care service-providers was explicitly described by some participants. The opportunities for education were also implied in the stories shared. One particular area where education is required relates to the specific equal opportunity legislation. Some aged-care service-providers do not appear to understand their responsibilities under this legislation. It may also be useful to share with aged-care service-providers the characteristics of care that were valued by GLBTI seniors.

‘My People’

Most participants referred to their valued relationships as ‘My People’. 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.

Understanding and empathy

The importance of understanding and empathy was highlighted with an emphasis on the value of service-providers understanding and responding to the needs of GLBTI seniors. Some participants thought that GLBTI service-providers were better able to understand their needs and have empathy. Empathy was seen as an act of understanding, and it was noted that some aged-care service-providers did not empathise, as they did not understand what it meant to be GLBTI. Many participants indicated that aged-care service-providers needed to understand the needs of GLBTI seniors before the GLBTI service consumers could feel safe disclosing their sexual/gender identity. This included the need for service-providers to understand the following:

1. The fact that seniors are sexual
2. The fact that some seniors are GLBTI
3. What cultural and sexual expression means to GLBTI seniors, what it encompasses and how opportunities for expression can be provided
4. The historical experiences of the current generation of GLBTI seniors and the implications for their care
5. Strategies to develop GLBTI-friendly aged-care services
6. Positive responses to the disclosure of sexual/gender identity by GLBTI seniors
7. Negative consequences for GLBTI seniors who feel that they have to re-enter a closet when they receive aged-care services
8. The impact of staff values and beliefs of service-providers on the care that they deliver
9. The potential vulnerability of GLBTI seniors who are unable to conceal their identity
10. Staff responsibility to protect GLBTI seniors from discrimination
11. Universal infection-control guidelines, and how the fear of HIV/AIDS relates to the care of gay men
12. The special needs of GLBTI seniors with dementia.

These understandings could be conveyed to aged-care service-providers through access to the stories presented in this report. It is hoped that these stories can also generate understanding and empathy among staff, which in turn may serve to assist GLBTI seniors to feel that they can trust their carers.

Trust

Several participants described the importance of trusting relationships with family, friends and aged-care service-providers. This is not surprising, given their historical experiences of discrimination upon disclosure. To foster trust in their relationships with aged-care service-providers, some participants described allowing carers to know them as a person before disclosing their sexual identity. Most participants felt that they needed to trust their carers, particularly if they were dependent on the aged-care service provided. However, a sense of mistrust and fear was apparent in many stories and several participants identified the need for aged-care service-providers to understand and have empathy with GLBTI seniors before they could be considered trustworthy.

Advocacy

Significantly, 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 were generally people who understood GLBTI seniors, had 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 was also identified. Such a notion of 'leadership' in relation to legal protection could be seen to be provided in the legislation which prohibits discrimination on the grounds of sexual/gender identity. However, the practical implementation of such legislative requirements has sometimes fallen short in some aged-care services. In some services, the development of organisational policies to support diversity was apparent through the employment of GLBTI staff and an investment in staff education in diversity.

To create GLBTI-friendly aged-care services, it would be useful to invite service-providers to themselves play a role in determining how change can occur. However, while education and GLBTI-specific facilities are considered important elements of a development process, some GLBTI seniors currently continue to experience discrimination. Strategies for the protection of these seniors need to be clarified.

Partnerships with aged-care services

It could be argued that as the community is generally unaware that seniors are sexual and the some seniors are GLBTI, it is not surprising that aged-care service-providers hold the same beliefs. Furthermore, few aged-care service-providers have been provided with education around sexual expression and ageing. However, given the reliance of seniors on aged-care services, service-providers need to understand the importance of sexual expression and GLBTI identities.

Aged-care services will increasingly find themselves caring for GLBTI seniors. The opportunity exists to work with aged-care services to create GLBTI-friendly services. The achievement of such an outcome would ideally involve the engagement of service-providers and other stakeholders in the exploration of their own experiences, the provision of feedback on this report and the determination of strategies for creating GLBTI-friendly aged-care services. It is hoped that the publication of this report provides evidence which can serve as a basis for such a process to take place. In this way, the process of the development of genuinely culturally appropriate aged-care services can begin.

I don't get on with any of the buggers here.
They're not my kind of people
(Nancy, 79 years, transsexual woman)

Background to the study

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, 2002a). While there are no accurate figures on the percentage of seniors who are gay, lesbian, bisexual, transgender or intersex (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, 2004a). 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.

The phenomenon of disclosing sexual/gender identity in aged-care services is complex and can vary in different social or health-care contexts. On one hand it is

reasonable to expect that a decision not to disclose sexual/gender identity is the prerogative of each individual. On the other hand, there is increasing concern that GLBTI seniors have little choice but to conceal their sexual identity, given the reports that aged-care services are not GLBTI-friendly and have discriminated against some seniors who have disclosed. Furthermore, there is concern that a discriminatory response may have negative affects on the sense of self-worth of GLBTI seniors.

The need to improve Australian aged-care services for GLBTI seniors has been extensively explored by Harrison (2002a, 2002b, 2004a, 2004c, 2005a, 2005b, 2005c, 2006a, 2006b, 2006c) and these publications are available at (<http://www.rainbowvisions.org.au>) [Go to Resources – Ageing]. In particular, Harrison (2001, 2004b) has identified a cycle of invisibility involving GLBTI seniors in aged-care services. This cycle involves an assumption of heterosexuality by providers in aged care and a failure to create a climate in which GLBTI seniors are prepared to disclose their identity, life history or care needs. Consequently, aged-care service-providers are unaware of or deny the existence of GLBTI clients and their particular needs. These concerns have also been identified by Dr Mark Hughes from the University of New South Wales, who has interviewed GLBTI seniors and proposes that the failure to provide GLBTI-friendly aged-care services is an indirect form of discrimination (Hughes, 2006; Hughes, 2007).

The effects of discrimination on GLBTI seniors are significant. Discrimination can result in a lack of social connectedness (McNair et al., 2001) and render GLBTI seniors silent, invisible and isolated (Age Concern, 2002; Callan, 2006; Leonard, 2003). Isolation is viewed as one of the primary risk factors for elder abuse and neglect (Cook-Daniels, 1997; Wolf, 1996).

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.

In considering aged-care reforms, it is useful to remember that the attitudes and practices in aged-care services tend to reflect those of society generally (Osborne et al., 2002). Therefore, reforms to aged care need to take into consideration the attitudes of our society regarding whether seniors are acknowledged as sexual beings, or sexually diverse people. Challenging the cycle of GLBTI seniors' invisibility could involve encouraging seniors to disclose their sexual/gender identity and educating aged-care service-providers, and the community at large, about their needs. However, anecdotal reports of discrimination in aged-care services indicate that it may not be safe for GLBTI seniors to disclose. Rather, it may be more appropriate to afford aged-care service-providers with the support required to create GLBTI-friendly aged-care services in which seniors feel safe disclosing their sexual/gender identity.

Certainly, there has been a lack of attention to GLBTI concerns within Australian gerontology literature (Harrison, 2004). However, the focus is slowly shifting. GLBTI ageing issues have been raised in every state which has hosted public hearings of the National Human Rights and Equal Opportunity Commission Inquiry into Discrimination and Same Sex Relationships (http://www.humanrights.gov.au/human_rights/samesex/index.html) (Harrison, 2006c, 2006d). Additionally, the Ministerial Advisory Committee on Gay and Lesbian Health has advised the Victorian Government that it needs to understand the issues relevant to discrimination and invisibility and work to achieve the necessary changes (Department of Human Services Victoria, 2007).

Others involved in promoting reforms include The ALSO Foundation, which commissioned a study into the needs of GLBTI seniors (Chamberlain and Robinson, 2002). The study involved interviews with 52 GLBTI seniors to identify their needs. In response to the findings, the ALSO Foundation established a Seniors Project

Advisory Committee, which has overseen the development of a seniors information service brochure, physical and social activities and plans to advocate for culturally competent standards of aged care (Birch, 2004b). Another group involved in supporting change is *InterSection Melbourne* (De Saxe and Lovett, 2008), an activist group with a web-based presence (<http://www.zipworld.com.au/~josken/ageing.htm#ageing>), 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.

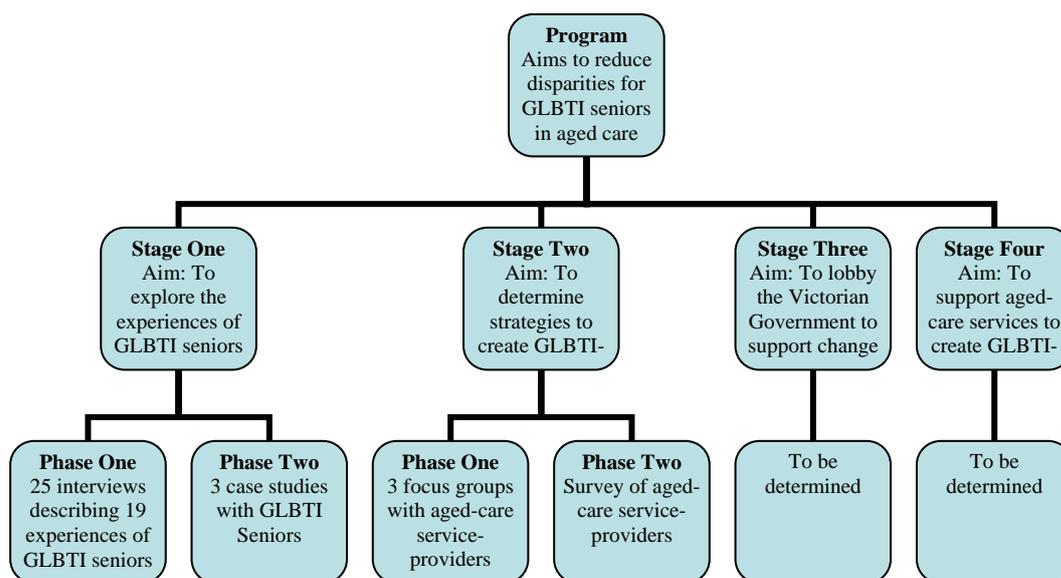
The challenge of aged-care reforms has also been supported by Matrix Guild Victoria Inc, a group founded to promote appropriate caring support for older lesbians, combat ageism and advocate on behalf of older lesbians. Matrix Guild provides a home-based service run by lesbians for older lesbians who want to stay in their home. It has also collaborated on a number of small studies regarding the needs of older lesbians (Bryer, 2004; Testro Gladys, 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 to challenge the invisibility of GLBTI seniors.

Program outline

Matrix Guild was concerned about the anecdotal reports of discrimination affecting GLBTI seniors in aged-care services. In particular, Matrix Guild identified the need to support change by gathering first-hand accounts of aged-care experiences which could serve as a catalyst for change. The Guild worked in partnership 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 Program aims to support the well-being of GLBTI seniors in Victoria by creating GLBTI-friendly aged-care services. Such services could assist GLBTI seniors to feel safe disclosing their sexual/gender identity and ensure that their needs are met. To achieve this aim four stages were identified and are illustrated in Figure 1 (below). The first stage, which is the subject of this report, sought to gather evidence of the experiences of GLBTI seniors in aged-care services in order to support the call for reform. The second stage aims 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 or government departments with influence, such as the Council on the Ageing, the Department of Health and Aged Care and the Office of Senior Victorians to support the required changes which are the focus of stage four.

Figure 1: Program Concept



All stages of the Program are designed to create new understandings and generate responsive action (Carr and Kemmis, 1986). The critical methodology is concerned with the identification and eradication of injustice (Kemmis and McTaggart, 2000) and favours excluded, silenced or subordinated voices over dominant voices to guide change (Hadfield and Haw, 2001). In this respect, the research project serves to reinforce the importance of hearing the voices of GLBTI seniors.

To achieve the aim of reducing disparities for GLBTI seniors, the Program 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., 2005a) 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., 2005b). 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 one are described in the following section.

Exploring the experiences of GLBTI seniors

Stage one sought to gather evidence of the experiences of GLBTI seniors receiving aged-care services. The project involved two phases; the first phase included in-depth interviews with GLBTI seniors to determine whether some interviewees might prove appropriate for case-study follow-up. The second phase involved descriptive case studies with three of the GLBTI seniors interviewed in phase one. Descriptive case studies provide a complete description of a phenomenon within its context (Yin, 2003). The ‘case’ was defined as the aged-care recipient and the study sought to record narratives related to their experiences, rather than the aged-care service itself. The use of multiple studies provided a small amount of comparative data to analyse findings (Yin, 2004) and enabled exploration of the experiences of a gay man, a lesbian and a transsexual woman.

Data collection and participant involvement

The primary data-collection technique involved in-depth interviews with GLBTI seniors. A target of 20 interviews was set, with three interviews being extended to case studies. To strengthen the data, interviews with ‘significant others’, family members and care-givers were undertaken. (Yin, 2003) Documentary evidence, such as legislation and relevant reports was also gathered.

Participants were sought through the Steering Committee's networks and paid advertisements. A project flier was also developed (see Attachment 1) and distributed through networks including GLBTI organisations and aged-care services. Advertisements were placed in the GLBTI press and seniors' publications with an estimated circulation of four million people. The project was also promoted through interviews on JOY FM (gay and lesbian radio) and the ALSO Foundation Health and Wellbeing Festival. The language chosen for the project flier and paid advertisement was carefully considered. Acronyms such as GLBTI might not be used by seniors (Cook-Daniels, 1997; Harrison, 2004d; Quam, 1993) and therefore the term 'non-heterosexual' was used in an attempt to ensure that most GLBTI seniors understood that the project related to them. Despite these efforts a number of challenges were encountered identifying willing participants.

The challenge of identifying participants

The process of achieving the target number of participants to meet the study criteria (see protocol on following page) was challenging and time-consuming. While most participants were recruited through 'word of mouth', this required repeated calls for participants. Contact was made by a number of GLBTI staff working in aged care. They reported that there were potential participants who were unable to be involved because they feared negative repercussions. Furthermore, a number of aged-care service-providers expressed reluctance to distribute project fliers. They believed GLBTI seniors who were in the closet might be distressed if heterosexual clients responded in a homophobic manner to the fliers.

The study sought to interview intersex seniors. Intersex people are reported to experience unique physical and psychological issues as they age (McFall Sullivan, 2008). However, no intersex seniors were identified through the advertising processes.

Another challenge related to identifying lesbian participants. The apparent reluctance of lesbians to volunteer was discussed with a number of participants. These women speculated that older lesbians were more closeted than gay men. One lesbian receiving home services suggested that:

They are being protective. I think gay men have come out so far, they have carried the banner as it were. I don't mean that the women haven't. I think once the gay men came out they really came out. After all those years of persecution and being jailed they must have just wanted to be free of this whole discrimination thing. Even when I was in my twenties you could spot a gay man a mile off because they were limp-wristed and mincey. People would joke about them and point at them and laugh at them, there was nothing hidden. I'm not backward in coming forward. I could imagine that some older women would be terrified of talking to someone about themselves and even more terrified of tape-recording or being written up. Terrified of coming out really even if it was just to you. They might be utterly and completely closeted (Susan, 77 years, lesbian).

While these differences between older gay men and lesbians are not well explored in the literature, other researchers have reported difficulty identifying GLBTI seniors who are willing to participate in research studies (Quam, 1993). In response to this challenge researchers have found it necessary to involve middle-aged participants and ask them to envisage the challenges they might face as they age (Quam and Whitford, 1992). However, given that the study reported here sought to explore the experiences of aged-care services, considerable effort was required and employed to identify participants.

Study protocol

The study protocol described the need to recruit a group of participants who were willing to share both positive and discriminatory experiences in aged-care services, and were able to provide a balance of sexual/gender identities and a range of aged-care service experiences. To achieve these criteria, 14 interviews were conducted with aged-care recipients and a further five interviews were conducted with partners and friends of aged-care service recipients, as well as aged care service-providers. Those five interviewees recounted stories of discrimination incurred by aged-care recipients who were either deceased or not empowered to tell their stories themselves. It was anticipated that allowing others to tell stories on behalf of aged-care recipients would give a voice to GLBTI seniors who had been silenced.

Interviews were digitally recorded, transcribed and the notes provided to participants for verification and de-identification. Interviews were semi-structured and allowed participants to tell their story at their own pace and within their comfort levels. A

checklist of items to be covered over the course of interviews was developed. It invited each person to describe:

- Their perceptions and/or experiences of being GLBTI in the twentieth century
- Their needs as a GLBTI senior
- Their experiences of disclosing their sexual/gender identity
- Any positive experiences of aged-care services
- Any discriminatory experiences of aged-care services
- The impacts of aged-care services on their lives
- Any changes required to make seniors feel safe disclosing their sexual/gender identity.

Case-study participants were involved in a number of interviews (three to four) and identified 'significant others' such as family or carers who were willing to be interviewed to share their insights into the story.

Participant characteristics

Interviews were conducted with 25 participants. The interviews investigated the stories of 19 aged-care recipients (see Table 1). In addition to stories told by the aged-care recipients (14) themselves, stories were shared by partners (2), a friend (1) and aged-care service-providers (2). Case-study interviews were complemented by interviews with significant others including carers (2) and family/friends (2). The stories recounted experiences in aged-care services including: home care (9), nursing homes (7), hostels (2), a psycho-geriatric residential facility (1) and day-care centres (2).

The aged-care recipients had an average age of 72 years (56–87 years) and included seven women as lesbian (7), and eight males who identified as gay or queer (8), two bisexual males (2) and one transgendered woman. Most participants lived in the Melbourne area (13) and almost half had a current partner. Project advertisements also identified a number of willing interviewees who were not receiving aged-care services. One such interview was conducted with a 47-year-old transsexual lesbian,

who provided valuable insights into challenges encountered working with residents with dementia. A number of aged-care service-providers made contact with the researcher to share their experiences regarding the barriers and enablers to creating GLBTI-friendly aged-care services. One interview was conducted and will be reported on in stage two of the program.

Table 1: Characteristics of Stage One GLBTI consumers of aged-care services

No	Name	Age	Identifies as	Aged-care service	Interviewees
1	Anne	77	Lesbian	Home care	Anne
2	Sara	63	Lesbian	Home care	Sara
3	Janet	58	Lesbian	Home care then nursing home	Janet
4	Joseph	61	Queer	Home care	Joseph
5	Robert	75	Gay	Home care	Robert
6	James	64	Gay	Hostel	James
7	David	87	Sexual	Home care	David
8	Keith	84	Gay	Hostel	Keith
9	Margaret	56	Lesbian	Day-care centre	Margaret
10	Ian	73	Gay	Nursing home	Roger: partner
11	Susan	77	Lesbian	Home care	Susan
12	Elizabeth	72	Lesbian	Home care & day care	Elizabeth
13	Bill	71	Gay	Home care & nursing home	Steven: partner
14	Doug	68	Gay	Psycho-geriatric residential care	Tim: partner
15	Anthony	84	Bisexual	Nursing home	Paul: aged-care nurse
16	Charles	84	Bisexual	Nursing home	William: aged-care chaplain
17	Tom	64	Gay	Nursing home	Tom, Kathleen: mother, Lizzi: Community Liaison Officer
18	Thelma	67	Lesbian	Palliative care	Maureen: partner, Jean: friend
19	Nancy	79	Transsexual woman	Residential aged care	Nancy, Maggie: nurse

Data analysis

The data from case-study interviews was analysed to construct narratives which were reviewed by participants. Each case study was analysed as an independent case and then returned to the participants for verification. Next, findings which were replicated or contrasted across the cases were identified (Yin, 2004) and presented to participants for feedback.

The remaining interviews were subjected to thematic analysis using the five stages of 'Framework': familiarisation; application of a framework; indexing; mapping and interpretation (Ritchie and Spencer, 1994). These stages involved:

1. **Familiarisation**: listening to each interview in order to become familiar with it and transcribe notes for participant verification.
2. **Indexing**: sorting each interview into themes.
3. **Application of study framework**: Sorting the themes from individual interviews into a report structured around the study themes or questions and identifying new themes not covered by the study questions.
4. **Mapping**: Reviewing the report to make connections between the themes and identify shared or differing experiences.
5. **Interpretation**: Considering the structure of the report, contrasting with the research literature and reporting a summary of the issues.

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 the genuine voices of GLBTI seniors, participants were provided with interview notes for verification and case-study participants were given the opportunity to verify the reflections on their stories. Increasing the trustworthiness of the study by making the study practices visible (Sandelowski, 1993) was achieved by developing an audit trail, or list of project records providing a picture of what occurred (Kemmis and McTaggart, 1982).

In case-study research, attention to validity and reliability is required to increase the robustness of findings (Yin, 2003). This was achieved by gathering multiple sources of evidence, undertaking participant verification of narratives, documenting a case-study protocol and pattern-matching between the study findings and the predicted pattern of non-disclosure and unmet needs (Yin, 2003).

Ethical considerations

A study protocol highlighting the ethical considerations was developed and reviewed by the Steering Committee. The document 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 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, such as the potential distress for participants when recalling discriminatory experiences. All participants signed a consent form before interviews were conducted. Ethical considerations included the need to protect confidentiality and the possible vulnerability of participants who were providing the critique of a service on which they were dependent. Copies of the information sheet and consent form are provided in Appendix Two.

Strategies employed to protect participant confidentiality included inviting participants to review interview notes and case-study reports to de-identify their service and themselves. To protect their identity, most participants also chose a pseudonym. A smaller number requested that their preferred name was used, as they were confident that this would not have negative consequences for them.

Four participants reported emotional upset at recounting painful experiences such as the loss of a partner, shock therapy, discrimination or sexual abuse. The upset was articulated by Elizabeth, who recounted experiences of discrimination and reported:

I found it difficult after the interview and reading the notes. It raised things for me that have been dormant for a long time. I found myself withdrawing from people again. I think that because it was an affable interview it raised things that have been squashed and I realised afresh things from my past (Elizabeth, 72 years, lesbian).

Elizabeth and other participants were provided with the opportunity to withdraw from the project and given information for external counselling and support. However, in each case participants expressed the desire to continue. A number expressed the desire to tell their stories so that others could learn from their experiences.

Conclusion

In the following sections the findings are presented, beginning with a summary of the thematic analysis, which is followed by the presentation of the case studies. Given that few studies have gathered first-hand accounts of the experiences of GLBTI seniors in aged care, this study provides new and useful insights. The qualitative findings represent the experiences of a small number of GLBTI seniors. In this respect, the research does not claim to be reflective of all GLBTI senior experiences. The intent of the study was not to make generalisations about this larger population. Indeed, the aim of the exploration reported in this document was to present the voices of 19 aged-care recipients in the hope that this stimulates debate and provides an urgently required motivation for change and further research.

Findings from interviews

The key findings from the study are drawn from a number of themes which emerged in relation to the experiences of GLBTI seniors. Six themes or core issues were identified:

1. The impact of historical experiences of discrimination
2. Invisibility as an impact of current discrimination
3. The impact of identity concealment
4. The impact of inadvertent visibility
5. The impact of dementia
6. Enabling sexual and cultural expression.

These themes are briefly outlined in the following section and explored in greater depth in the case studies. A further two themes regarding inadequate standards of care and achieving a safe environment will be described at the end of the report.

1. *The impact of historical experiences of discrimination: 'Cop it sweet and shut up'*

Most interviewees shared disturbing stories of the experiences of coming of age in the early twentieth century. These stories provide an important context for their expectations and experiences of aged-care services. In particular, having experienced discrimination, many participants expected that it was not safe to disclose their sexual/gender identity. One such example was provided by Joseph, a former police officer, who recounted:

I have seen discrimination the few places where I was doing active police work. They'd raid a toilet or the beach. They only prosecuted single men. It was just blatant discrimination, they were picking on what they thought was a soft target – gay men. The police thought 'God only knows what they are getting up to in the tea trees'. Their actions weren't going to be criticised if they just stuck to victimising those chaps because the gay community wasn't quite as outspoken. This was before 1988. You'd cop it sweet and shut up (Joseph, 61 years, queer).

This experience left Joseph with no doubt that discrimination occurred. and as a consequence he felt that it would be safer not to disclose his sexual identity to his carers. Furthermore, despite recounting a number of stories indicating that his carer was homophobic, he continued to live by the adage, 'cop it sweet and shut up'.

Other participants described how their sexuality was considered to be illness. Susan, a 63-year-old lesbian, described how a friend of hers who was a student nurse received 'jump start' or shock therapy in the late 1950s after telling her nursing tutor that she was attracted to females. Susan recalled her friend saying: *It was meant to teach me how to be straight, but all it taught me was to keep my mouth shut.* Similarly, James described his experience of being given 'shock therapy' after he identified to his parents that he was sexually attracted to men. James remembers:

I ended up in a psych[iatric] ward. I was in and out for months and I didn't know why I was attracted to men so I had to go to a psychiatrist. He told me he thought I was gay. They gave me shock treatment because I was stressed out and panicking and I didn't know what I was. They reckoned homosexuality was a sickness. But I don't believe it's a sickness. Because you love the same sex doesn't mean it's a sickness (James, 64 years, gay).

While both gay men and lesbians reported discrimination, their accounts differed. A number of lesbians reported the pressure to be 'nice' or not attract 'unfavourable attention' by being a lesbian. For example, Anne explained:

How women were taught to be self-effacing. A lot of older women try not to attract unfavourable attention, and once it was noticed that you were a lesbian it perhaps went against them. They became very good at keeping quiet, some of them (Anne, 77 years, lesbian).

Pressure to deny same-sexual/gender difference was also encountered from the church and from families. Elizabeth, a 72-year-old lesbian, described how she learned from her church that being same-sex attracted was an 'anathema' and felt devalued as a consequence. Similarly, James, who identified as gay, told his mother in the 1960s that he was going to have gender reassignment surgery and describes that she responded by saying, *I gave birth to a boy, not some Sheila, some girl. If you [have the gender reassignment surgery] I'll disown you altogether* (James, 64 years, gay).

These historical experiences highlight the discrimination the current GLBTI seniors experienced from the police, the medical profession, the community, the church and their own families. It is not surprising that these experiences created the understanding for some GLBTI seniors that their sexual/gender identity was not valued.

2. Invisibility as an impact of current discrimination

In describing the challenges growing up in the early twentieth century, a small number of participants explained their efforts to challenge discrimination. One such participant was James who recounted how a resident in his hostel called him a ‘poofster cunt!’ In response James rebuked the resident and reported him to the hostel manager. When asked whether he felt hurt by the resident’s abuse James replied: *I didn’t feel hurt, because I spoke up. If I didn’t speak up it would have hurt my feelings something awful* (James, 64 years, gay). Similarly, Anne challenged discrimination when it occurred and suggested that:

To quite an extent these days, how you are received and accepted depends quite a lot on the image of yourself that you put forward. If you come across as confident and matter of fact: ‘Yes, that’s right I am [a lesbian], got any problems?’ People either don’t say anything or it’s generally something positive (Anne, 77 years, lesbian).

More frequently participants described responding to discrimination with the reinforced belief that their sexual/gender identity was not valued. This was described by Robert as internalised homophobia, or: *an insidious process stemming back from childhood and learning to hate oneself because of external homophobia. John Howard [ex prime minister] alone is enough to give it to you* (Robert, 75 years, gay). Similarly, Elizabeth grew up understanding that her sexuality identity was an ‘anathema’ to the Christian church she was part of and reflected that:

The problem is that part of you believes that you are an anathema. It affects your self-esteem and things like that. The effects are insidious. The thing that I have worked out is that if you know something and can work it out intellectually it has less power. But the problem is that a lot of this is so insidious you can’t work it out and so there it still retains its power and that’s the problem (Elizabeth, 72 years, lesbian).

Some participants also described more contemporary experiences of discrimination which affected their sense of self-worth. Paula, a 47-year-old transsexual lesbian, described recent gender reassignment surgery and her brother's response that she:

... shouldn't tell his children I was having the surgery. So I didn't see them for five years. The way I see it prejudices are built into people. My niece was about 11 years old when I transitioned. My brother said they were too young to know - they might have got hassled at school (Paula, 47 years, transsexual lesbian).

While participants reported that they had witnessed enormous changes over their life time, a number were aware that discrimination still existed. This understanding was a factor in the reluctance of most seniors to disclose their sexual/gender identity to aged-care service-providers.

Disclosure to aged-care service-providers

A small number of participants chose to disclose their sexual/gender identity to service-providers. Anne described how she would disclose if she was questioned about her sexuality. However, she added, *I neither avoid it nor push it forward. It's just a fact about me. Like the fact that my hair is going grey and I've lost a lot of weight recently* (Anne, 77 years, lesbian).

By contrast, most participants believed that they needed to hide their sexual/gender identity to avoid discrimination. For example, Keith reported that he would not tell staff in his hostel that he was gay because, *it would be a surprise for people to know I was gay. Disappointment would be a better word. They would be disappointed; they would think less of me* (Keith, 84 years, gay). For Keith, part of the cost of maintaining a heterosexual façade was that he was unable to access his much-loved sex toys, gay DVDs and magazines.

Other participants reported receiving the message that homosexuality was unacceptable. Joseph described how his home carer saw him watching a movie starring gay actor Rock Hudson and said, *Oh, what a waste!* On another occasion when Joseph made reference to the carer about his need for a bath, he said:

‘I would rather people think I was homosexual than dirty’. And she [the carer] said, ‘Oh, you would not want them thinking you’re one of those would you?’ I don’t know what she’d think if she opened one of the bedside tables and found *Transsexual Climax* magazines there or something. Struth! (Joseph, 61 years, queer).

Two participants reported more direct discrimination when they disclosed their sexual identity. For example, Roger described how his friend Ian was treated with ‘contempt’ by carers who did not value his sexuality:

The personal assistants were homophobic in my view. There were about three other gay residents; [and] they just treated those guys with contempt. If Ian pressed the buzzer they’d say, ‘Yeah! In a minute’. They were sort of staying away from him; because he was gay, because they might catch it. There was ignorance and intolerance and [inability] to actually see a person for a person, not as a sexual identity. If Ian had been a barrister or something like that I imagine they would have given him a different treatment. If he’d been [married and] his wife died two years ago. I am almost sure he would have got a bit of different reaction (Roger for Ian, 73 years, gay).

Roger reported that Ian experienced a homophobic response from most of his carers, but predominantly when staff had, *come in with different cultural values, particularly in countries where sexual diversity is more frowned upon* (Roger for Ian, 73 years, gay). Similarly, Janet experienced the discrimination when she was approached by the Director of Nursing in her nursing home who told her that, *The Muslim girls who worked there objected to the lesbian porn videos that I had* (Janet, 58 years, lesbian). Janet was perplexed at this feedback, as she didn’t have any pornographic videos and could only speculate that a staff member had seen her watching a television series called *Queer as Folk*. The challenge experienced by Janet and others highlighted the need for staff training to ensure that providers understand the legal and ethical responsibilities they have in relation to GLBTI seniors.

3. The impact of identity concealment

The pressure of being identified as GLBTI for those who were closeted was a significant burden. For example, Joseph described his fear that he would be outed if his carer found some of his sexually explicit magazines. While he believed he should

not have to hide his sexuality in his own home, he also felt that unless he did he would be unable to retain his carer.

The pressure of concealment was intensified for participants in shared services such as day centres, nursing home and hostels, who needed to consider disclosure to other residents as well as staff. This was highlighted by Margaret, who made the decision to disclose to other residents in her day-care centre. In response Margaret reported that co-clients ridiculed her because she was a lesbian: *I get called a 'fucking thing' in here and everything, and 'a poor excuse for a bloody woman'* (Margaret, 63 years, lesbian).

Other participants described how being closeted meant that they could not be themselves. Elizabeth explained how she attended her local day care centre four times a week and how, *In none of those sessions I feel I can be who I am* (Elizabeth, 72 years, lesbian). For her there was a sense of loss and devaluating at having to hide an important part of herself. Conversely, three participants described how important it was for them to disclose their sexual/gender identity so that they could be themselves. To protect themselves from discrimination, each waited until carers got to know them as people before they disclosed. As Janet described of her home carers, *I usually built up a relationship first. I was scared of rejection I think. I wanted them to relate to me as a person first. It's a bit stupid* (Janet, 58 years, lesbian). For Janet and others, being accepted as a person correlated with having their needs understood and met. However, not all participants were able to make carefully considered decisions about whether or when to disclose.

4. Longing for touch: exploitation and vulnerability

The importance of understanding the issues around GLBTI ageing were highlighted in a story shared by William, a chaplain working in a nursing home. William recalled the story of Charles, an 84-year-old man who was admitted to the nursing home with his wife. William described Charles as, *not in any way severely demented, but there were some cognitive losses there, and emotionally he was so alive*. William added that for Charles, after the death of his wife, *the issue of his own sexual identity surfaced*.

William felt that Charles was attracted to men and as a consequence a male staff member:

... allowed a sexual encounter to happen between them. This personal-care attendant would have attended to his showering, so would have been with him when he was naked. The old man probably welcomed any sort of physical contact and then there was this incident where the young man allowed himself to be touched (William, for Charles, 84 years).

The sexual encounter was observed by a staff member, then reported, and the male staff member was sacked. In his role of chaplain William was asked to provide Charles with support. When they met William felt that Charles was grieving over the staff member who had left and when asked about what happened Charles said, *It was so lovely*. Over a number of support meetings William assessed that Charles had:

... a deep and desperate longing for human touch and particularly contact with another man. Simply this deep longing, I think, to gain some expression of what was within him. People of his vintage didn't really have the words, they just had the feelings and they weren't sure what to do with them (William, for Charles, 84 years).

However, William also noted that while Charles was happy that there was, *A vulnerability around being a gay man in aged care and they can be taken advantage of, particularly when there is longing for touch and attention*. This vulnerability was exacerbated by the fact that staff in the nursing home could not conceive that Charles was sexual, let alone gay. Perhaps as a consequence staff could not conceive that a male resident would need to be protected from a sexual encounter with other males.

5. The impact of inadvertent visibility

A number of participants encountered discrimination when their identity was exposed to aged-care service-providers. In particular, being HIV positive or transgender, having a same-sex partner or having dementia were factors which exposed participants' sexual/gender identity.

HIV positive

Case study two is the story of Tom, a gay man with HIV/AIDS living in a nursing home. While Tom decided to hide his sexual identity, his carers made an assumption that he was gay because he was HIV positive. Similarly, it became apparent from other interviews that some aged-care service-providers consider that being gay and HIV positive were mutually inclusive. This is of particular concern, because it meant increased levels of discrimination from staff who were worried that they could contract HIV by touching a gay man. Steven described how a home carer was showering his partner Bill and became aware that they were gay:

The carer wouldn't really shower Bill after that. Bill was blind, deaf, full of arthritis and needed all the help going. I think the carer was concerned that we were gay. The guy thought, 'He's gay and has he got something else wrong with him?' He was worried about HIV/AIDS. That's what I think. I phoned the council and told them. They were very good. I told them I didn't want him back (Steven, for Bill, 71 years, gay).

Similar staff ignorance was communicated by Paul, a nurse working at a hostel. He described the response of a personal-care attendant when she realised that a resident was gay:

She threw her hand in the air and started shaking it and going, 'Ooh! Ooh! I shook his hand this morning'. She was implying that she felt filthy because she touched a gay man. She said, 'I just don't know where his hands have been' (Paul, 40 years, nurse).

These stories highlight the challenges encountered by some gay seniors when aged-care service-providers make the assumption that all gay men have HIV/AIDS and that the virus can be spread by touching them.

Transgender visibility

Transgender participants described the visible nature of their gender identity and the subsequent exposure to discrimination. This was particularly apparent in the story told by James, a 64-year-old gay man living in a hostel. Dressing as a woman was critically important for James's mental health, and so he had an assortment of dresses, wigs and make-up in his hostel room. While James chose to share his cross-dressing

with his carers, it would have been impossible for him to cross-dress without their knowledge, given his lack of privacy. Indeed in a previous special accommodation unit, James was told that he was not allowed to cross-dress.

Having a partner

Three participants described the presence of their same-sex partner as making their sexual identity apparent to carers. Two of these participants, who were receiving services in their own home, felt that it was important to disclose their sexual identity to carers because it was so apparent. Steven shared his efforts to convince his partner Bill to disclose:

Well people have got to know. They are going to be in our environment, so let's tell them now. They have to know, they are going to be in our home. Bang! Wherever they look there will be photos of you and I together. No grandchildren, no wife, no nothing. I just felt it was getting to that stage where I had to (Steven, for Bill, 71 years, gay).

Steven disclosed to carers and generally received a positive reaction. However, one carer would not touch Bill after realising that he was gay. In response Steven rang the local council and requested that this staff member not return. For participants in residential aged care, this choice was not available. Consequently, some continued to receive care from staff who obviously disapproved of their sexual/gender identity. In a similar manner, participants with dementia faced unique issues.

6. The impact of dementia

The challenge of living with dementia was highlighted in a number of interviews. One particularly powerful story was shared by Tim who gave an account of the grief associated with having to move his partner Doug to a psycho-geriatric residential facility. Having lived together for 45 years, Tim described the difficulty he faced leaving Doug who pleaded to be taken home:

[I would say to him], 'It's not because I don't love you. You know I love you with all my heart but I have to try and do what's best for you'. It was very difficult, very heartbreaking. Someone that you've lived with all those years and you know that they are not going to go home with you.

That's difficult especially when you go in and see him. Having to leave him there is very, very difficult. You feel that you want to pick him up and take him home. But you know you can't because you know he needs 24-hour care (Tim, for Doug, 68 years, gay).

For Tim it was important that the staff caring for Doug understood the challenge that both he and Doug were experiencing. Tim explained that staff needed to understand that his emotional pain was no different from a heterosexual person's pain. He argued that:

Staff training is needed just to understand that a person might be gay. You know that a gay person is going through the same trauma as a heterosexual couple would be if their husband or wife got dementia. They go through the same grieving side of things. Their partner is not the same person that they met and feel in love with and they are never going to come home. I think it's important to understand that gay people go through the same pain. They're a gentle, loving, kind person who loves their partner like I do with Doug. I'm going through the same pain. I think staff need to be told dementia just doesn't categorise, it doesn't say I'm just hitting the gay community, it just hits anyone. It goes across all people, heterosexual, bisexual or gay people and everyone is going through the same pain with their partner (Tim, for Doug, 68 years, gay).

The nature of Tim and Doug's relationship was questioned at the time of Doug's admission by the activities co-ordinator. Tim reported that it took time for staff to get to know him and understand that his relationship with Doug was as important, and their challenges were as difficult as for a heterosexual couple. However, Tim also noted that he received a particularly positive response from a gay nurse:

[He would come up to me] and put his arms around me, sometimes gives me a kiss on the cheek and say, 'How are you, darling?' That's good; it's nice that that is there. [None of the other staff do that] but they always say hello how are you? (Tim, for Doug, 68 years, gay)

Tim reported that he was able to achieve understanding and support from this gay carer and that other carers and families provided him with support once they got to know him and understand him. A further challenge encountered by Doug and other interview participants was the dis-inhibited behaviour of other clients with dementia.

Co-residents with dementia

A number of participants described the challenge of sharing services with homophobic residents who had dementia. Tim recalled:

One [resident], when I was giving Doug a kiss goodbye, just went, 'Ugh!' Then one said, 'Are you a fag?' And I said, 'Well yes'. But then she's got problems here [in the head]. She seems to be OK now, she's only ever said it the once. I think they have got used to me coming in all the time (Tim, for Doug, 68 years, gay).

Such dis-inhibited responses from seniors with dementia were also reported by James who was frequently called a 'poofster cunt' by a co-resident. James recalled that the abuse continued despite staff's intervention, because the resident had dementia and as James articulated, *You can't tell mental people what to say* (James, 64 years, gay).

For both Tim and James the support of staff in managing homophobia from other residents was important. This advocacy role was highlighted powerfully in Nancy's case study, in which her carer intervened to prevent transphobic abuse. However, other participants described the reluctance of homo/transphobic staff to protect them from discrimination. Furthermore, Janet described the response from a homophobic aged-care service-provider to the challenges she experienced living with residents with dementia:

I am intruded on day and night by other residents on a daily basis repeatedly. They take no notice when I complain. They are supposed to give you privacy but I haven't had it. And it is absolutely driving me mad and making me very depressed and I have never been as depressed as I have been since I have been here, for a lot of reasons. Why should I have to put up with it? They think it's funny sometimes. The carers, they are called carers, they are untrained workers and there is nothing caring about most of them. It is very much a misnomer. One day, there's a little guy here, a resident, and he was a real pest at entering the rooms. He came in here and masturbated during my dinner one night. I buzzed and no one came for 20 minutes. When they came they thought it was really funny. He was at the door another day trying to come in. The nurse was outside the door; she said in a loud voice, 'Oh, don't go in there, she doesn't like men'. I thought that was quite homophobic actually, and that is not the case anyway. I didn't respond to it at all. It was obviously said in such a loud voice that I would hear. If I had responded I would have had got into strife with her and there would have been a lot of bitching (Janet, 58 years, lesbian).

The challenge of being GLBTI and having dementia or sharing services with co-clients with dementia placed participants at greater risk of discrimination. This highlights the importance of engaging aged-care service-providers in understanding the needs of GLBTI seniors and advocating on their behalf.

7. Enabling cultural and sexual expression

The importance of cultural and sexual expression was raised by a number of participants, particularly those who had a partner and those recently separated. Anne reflected on her relationship and its importance: *We think we are very lucky to have each other. It is just very supportive and reassuring to have somebody like her and she says somebody like me to back up to* (Anne, 77 years, lesbian). The importance of relationships and touch was described by Steven, who recalled how his partner Bill was admitted to a nursing home:

[He] was blind, couldn't hear and touch was important. He needed me. So I would give him a kiss him on the forehead, get my arms around under the wheelchair and hug him and we would sit just holding hands, I have got to look after my friend; he's in a bad way. I have got to be there for him as much as I can (Steven, for Bill, 71 years, gay).

In Steven's interview it was apparent that touch was a way for him to connect with Bill, to comfort him. Similarly, James described how he felt when his partner of 47 years was admitted to a nursing home and they had less contact: *If I am not touched I don't feel loved. I need to be touched. I miss that.* James missed his partner's touch so much that he said, *I was going to drink poison to kill myself* (James, 64 years, gay). Separation from a partner limited the capacity for sexual expression and it was considered important that staff understood and supported such sexual expression.

Privacy

Participants who were more dependent appeared to have less privacy and opportunities for sexual expression. The challenge of limited privacy was particularly noted in hostels and nursing homes, where residents' rooms could be accessed by staff and co-residents. Consequently, participants recounted the impossibility of keeping GLBTI-related materials such as community newspapers in their rooms without

expecting to be outed. This resulted in limited opportunities for sexual expression and a sense of disconnection from the GLBTI community. Keith reported that he was able to watch some gay TV in his hostel room at night if he had his hand on the remote control, ready to turn it off if staff entered the room. Keith also reported that when he entered the hostel he had to leave his sex toys at home because he knew that he would not have enough privacy. When asked whether it was possible to lock his door Keith replied, *That's a dangerous thing because the staff would want to know why you were locking the door. I really had to say, 'None of that'* (Keith, 84 years, gay). While Keith said 'none of that' he took great delight during our interviews sharing images of the gay men he had inserted into pages of a *National Geographic* magazine.

Available resources

Participants with physical disabilities often lamented their limitations and the compromises they presented in terms of requiring aged-care services. Several interviewees noted that if they had available funds their life would change because they could access the care they desired, rather than the care that they could afford. Roger described scouting for a suitable nursing home for his friend Ian. He observed that there were homes where, *the atmosphere and the people in the place seemed enthusiastic and it was effortless for them to, not only to deal with their clients, but to deal with the people who were coming and observing what they were doing*. However, without sufficient finances Ian was forced to accept a facility where he was unable to express his sexuality.

Service-provider control and resident autonomy

One of the key factors influencing opportunities for sexual and gender expression was the extent to which aged-care service-providers maintained control over residents. For example, Keith compared his hostel room to his home and speculated:

If I was at home I would have my porno photos out, stuck up on the wall. I have brought some with me; I keep them in the drawer. I didn't put them up because I would cause a sensation. The staff would say: 'Get that down.' It would change the way I was cared for, for the worse. It's the sort of thing that you just wouldn't put up in a place like this. In your own

private home, yes, but not semi-public place like this (Keith, 84 years, gay).

The potential for staff disapproval and a reduced standard of care reduced Keith's capacity for sexual expression. While this censorship was implied, others illustrated more explicit forms of censorship. Paul, a nurse working in aged care, described his visit to a hostel over a twelve-month period and observed the care provided to two transgender residents:

There were two guys who were cross-dressing. One was full make-up and frock, frilly knickers and bras, the whole lot and wigs. When I worked there recently both of them had stopped. These guys had lived on the streets and in rooming-houses and had a really, really tough life and they have managed to continue to cross-dress throughout their whole lives. They go into an aged-care facility run by [names the Catholic institution] and it's just stamped out. People laughed about it; it was a bit of a joke. It was whispered about, it wasn't spoken about as a matter-of-fact sort of thing. I am certain you wouldn't find it in their care plan (Paul, 40 years, gay nurse).

The capacity of workers to provide understanding and to support the need to cross-dress was highlighted by James. At the time of the interview, James reported that staff allowed him to cross-dress and that: *The staff could have said to me I can't dress up in drag but they didn't say that. They said it's all right. I did a concert here in drag. The staff said, 'Don't get high-heeled shoes because you might fall'* (James, 64 years, gay). In a contrasting experience James described how staff in a special accommodation unit prohibited him from cross-dressing and recalled:

Dressing as a woman is lovely. It makes you feel good. When you're a woman, you *are* a woman. When you're a man you feel depressed. Your mind is trapped. I have got more female hormones that I've got male hormones. You feel like you're a woman trapped in a man's body. When I dress as a woman I feel on top of the world, you know that there is nothing missing about me. If you think there is something missing you are very depressed. In the special accommodation they wouldn't have you dress as a woman. I felt a bit unwanted. I thought there was something missing. I was starting to get depressed and feel suicidal. Not being allowed to dress as a woman, I reckon it's discrimination (James, 64 years, gay).

The story told by James portrays the importance of sexual expression and suggests the capacity of aged-care service-providers to enhance the lives of GLBTI seniors by supporting such expression.

Family control

Opportunities for sexual expression were sometimes controlled by families. A number of participants who required nursing home or hostel care relied on families to advocate for them with the aged-care service. However, it appeared that some family members took advantage of this dependency and the opportunity to control sexual expression through a number of means, including preventing access to participants' partners.

One poignant example of the capacity of staff to facilitate sexual expression was told by Paul, a nurse working in aged care. He shared the story of Anthony, an 84-year-old man who was admitted to a nursing home. On the admission assessment the Activities Officer was told by Anthony's wife that his hobby was making pornographic videos of young boys. Anthony's wife then recounted her experience of discovering Anthony in their home filming a sexual encounter with a male escort. As a wealthy man Anthony had the resources to remain at home with carers. However, after witnessing this sexual encounter, Anthony's wife refused to continue supporting his home care and Anthony was admitted to a nursing home. Paul observed that most staff were aware of the circumstances of Anthony's admission and while Anthony was *a pretty likeable guy, no-one seemed to particularly like him*. Certainly staff disapproved of his use of the male escort. When he attempted to book an escort to visit the nursing home the nurse-in-charge intercepted the call and cancelled the escort. In reflecting on this, Paul suggested:

Anthony must have noticed it was cancelled but didn't say anything because he probably thought he was breaking the rules, which of course he wasn't. Maybe he was ashamed. For the rest of his life he is not allowed to have sex, even though he is clearly sexual (Paul, 40 years, nurse).

Anthony's story highlights the potential of both families and staff to control opportunities for sexual expression. It also highlights the blurred boundaries that exist when staff do not appear to understand the needs of GLBTI seniors, nor the rights that residents have to maintain a degree of autonomy.

Seniors' Stories

Phase two of the study involved exploring the experiences of GLBTI seniors in greater depth through three in-depth stories (case studies) from a gay man, a lesbian and a transgender woman. The stories begin with an introduction. The participants then speak for themselves, with expletives and colloquialisms retained.

Story 1: 'Why not take all of me?' Living with HIV/AIDS in a nursing home

I miss the intimacy of male company. I'm in a nursing home, it's not my real home, there's no privacy and there are rules. I'm not able to live a gay man's life in a nursing home. I would prefer to be living in my own home with carers and with the gay community at my fingertips. I see the gay magazines when I go out to pubs but I couldn't bring them back here (Tom, 64 years old, gay man).

Written by Catherine Barrett and Lizzi Craig

Tom's story

Tom was a 64-year-old gay man with HIV/AIDS living in a public nursing home. Kathleen, his 85-year-old mother, and Lizzi, his Community Support Officer from the Victorian AIDS Council, were also interviewed. As a relatively young and cognitively intact man, Tom was already out of place. The majority of people in residential aged care are older than 75 years and have dementia (Australian Institute of Health and Welfare, 2002a). These differences exacerbated the strangeness Tom felt as a gay man with HIV/AIDS living in a nursing home.

If asked to care for someone like Tom, many aged-care service-providers would have few resources to guide their practice. Documents which govern aged care require that staff ensure that residents' *individual interests, customs, beliefs and cultural and ethnic backgrounds are valued and fostered* (The Aged Care Standards and Accreditation Agency Ltd, 2006). However, this guideline is very broad and is more

likely to be interpreted as making reference to the needs of a resident not born in Australia rather than the cultural needs of a gay man. The need for specific information to inform practice is imperative, because people with HIV/AIDS are living longer and will increasingly require aged care (Sellers and Angerame, 2002).

Given the deficit of knowledge in this area, Tom's story provides valuable insights. Indeed, the case study highlights the difficulty Tom's carers had in understanding his cultural needs and the isolation and loneliness that resulted. This loneliness exacerbated the sense of loss Tom experienced in not having contact with his family because they disapproved of him being gay and HIV positive. The alienation Tom felt was reinforced during his first interview, when he sang a song by Seymour Symons: *All of me, why not take all of me; can't you see I'm nothing without you?* The song reflected Tom's experiences of rejection because he was gay and HIV positive.

Tom's story begins with Tom, Kathleen and Lizzi introducing themselves before exploring Tom's premature ageing and admission to a nursing home. The story first describes the effects of the nursing home on Tom's quality of life and capacity to express his sexual identity. Then it examines the provision of HIV supports by a gay-friendly service, exploring how these supports allowed Tom to express his sexual identity and stimulated some staff interest in Tom's sexual identity.

Introducing Tom, Kathleen and Lizzi

Introducing Tom

My name is Tom, I'm 64 years old and I've been living in a nursing home for four years. I am here because I've got HIV and I had a stroke. I've got two brothers, one sister and my mother is 85 years old. I never knew my biological father, never knew him. He just disappeared. So I stayed at a children's home. It was a tough experience to start off with. It was a religious institution; religion rammed down our throat. Church twice a day; three times on Sunday and prayer in between. Then Mum met John, our saviour. He gave us his name and got us out of the home, John did. Although John was a good man, he wasn't exactly a father.

I first knew I was gay when I was eighteen years old. I didn't choose to be gay; a person didn't come along and say, 'Listen, do you want to be gay or straight?' I had no choice in the matter. I didn't want to be gay. It just happened that some gene come along and made me that way. You have to make the best with what you've got. That's it; we are what we are. You don't always get what you want. Be nice if you could, but very hard to come by.

When I realised I was gay I had to adjust to the fact that I could never have children and that it would be a lonely life when I get older. No wife to love me; no children to love me; no-one to look after me. It wasn't what I wanted. I wanted to be like everyone else. But I had that gene in me. I don't know where it came from. You can't always get what you want. Because I am gay I'm looking towards a lonely life. It would make a difference; if you love someone, if you meet someone and fall in love with them. Oscar Wilde said: 'One friend in a lifetime much; two many; three hardly possible'.

In 1983 the doctor rang me at work to tell me I had HIV. I said, 'I'm sorry to hear that'. I kept it to myself. I didn't tell anyone I had HIV. Eventually they put two and two together and got four.

Introducing Kathleen

When I realised Tom was gay it was a bit of a shock. Not too much of a shock because I knew he had a funny sort of a life, you know. Tom didn't tell me he was gay. I never knew exactly what was going on. Tom went to live in Melbourne and when I visited him he was living with this *man* and it still didn't dawn on me that he was gay. I was as green as anything, I had no idea what gay was then. Then I realised later on he must be gay. Well, he was stopping with this man. I thought it was queer and I thought, 'Oh well, perhaps it's cheaper living in the same place and sharing the rent'.

It wasn't too much of a shock. I suppose I was partly expecting it. The thing is you hear it said that they become like that, they become a gay person. *But* I don't think he *became* a gay person. It was already here; it was born in him. It was there. He wasn't

like the others; he never played outside with the kids. He was always playing with his soldiers on the table. He never mixed with children, with the others. He was quite different to the others. I knew he was different in that way.

I suppose we all wish our children were normal, most people would wish that. But you have got to expect the unexpected. It's all lovely when they are children and then they grow up. When I was little people used to say about some boys, 'He's a Nancy'. We thought that meant they were being a sissy. We didn't know about the other part, that a man would have sex with a man. We were green in those days, absolutely green. I must have been 40 before I found out what gay people really were. I knew about Oscar Wilde being gay. They used to put jokes about being gay on the TV. I heard about gay through the media and when HIV came around that opened our eyes. There was all this gay bashing and then HIV, so you would have to be blind to think it wasn't going on. People are starting to accept being gay; I think that's a good thing.

Introducing Lizzi

I first met Tom about eight years ago when I was working as a district nurse and he was managing at home with quite intensive support. Last year I was appointed Tom's Community Support Officer. He has had so much adversity in his life and I wonder in awe how he has survived and where he gets his strength to still go on. For Tom: his childhood; the orphanage; identifying as a gay man; and being diagnosed with HIV/AIDS at a time when most people died; that's a lot in one life. I guess Tom lived life to the full in those days as life was so short. I think he was a drinker and a smoker and suffered with high cholesterol, which is also a side-effect of some anti-retroviral treatments. I would think that all of these were contributing factors to him suffering a stroke and needing nursing-home care at 61 years of age.

Stories of challenge and staff education

Premature ageing and nursing-home care

Tom: Being in a nursing home makes me feel old. Being surrounded by people who are so old here makes me feel old.

Lizzi: In the days when Tom was diagnosed, HIV/AIDS was a death sentence. Tom was told that he only had months to live. At the time many of his friends were dying of HIV/AIDS and since then Tom has experienced the death of a lot of friends who were diagnosed in the 1980s before anti-retroviral therapy. He has experienced the loss of his own health and had to face his own mortality. He has had loss of identity, loss of income, loss of sexuality and loss of family. But the greatest loss was the loss of his long-term partner. Along with this he has faced poverty, stigma, discrimination and rejection.

When I first met Tom he looked to be a man in his seventies and I was surprised to learn that he was only in his mid 50s. He says that he has had a good life and has lived a good life. Now this was someone who was 57 at that stage. I said to him: ‘You’re only young!’ But for Tom he has lived his life.

Loneliness and isolation

Tom: In the nursing home I’ve got no-one to talk to. The other residents here are all asleep. They have their tea and go to bed, same old routine next day. Up the next day, same process, breakfast in their room, come down and have lunch, sleepies in the afternoon and then beddie-byes. They can’t help that. They’re not living, they’re just existing. Lying there all day, poor devils. Just lying there asleep waiting for meals or beddies and start all over next day, same old story, it doesn’t change. That’s their lot. It’s my lot too.

I have no-one to talk to, really hard to adapt to it too. But I’ve realised this is my lot. I’ve got no conversation; it’s depressing. I can’t converse with them. For a few years I railed against it, and then I got depressed and succumbed to it. I realised I was stumped and that this was my lot, I’m in a nursing home. I need to get out and have a few beers or latte. 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. Lucky I’ve got my own room though. I’m very lucky. I’m very lucky I’ve got me own TV. It makes the time go.

I have got no-one in my life now that loves me. Except the old girl, she loves me. When mum goes I'm done. I've got brothers and sisters, but we don't talk, because I'm gay. Primarily that's the reason, because I'm not married with children. If I was a straight man I would be much more acceptable to them. Being gay to them is foreign; we were brought up in a religious institution. It's sad. I'm lonely because I don't have any contact with them.

Going out for lunch today made me feel alive again. Someone to talk to; someone I can converse with. Oscar Wilde said, 'City life, millions of people living lonesome together'. Right, now let's be positive.

Fractured family supports

Kathleen: Tom used to come at Christmas time every year, and then all of a sudden he stopped. He distanced himself away from the family. So it wasn't really the family's fault entirely. He decided he didn't want to have his family around because of the way he was living, because of his lifestyle. Because people in that position, being gay, know they are not doing the right thing, so he wiped us out. He was very, very angry when he was young. I used to be scared of him; he used to frighten the life out of me. One time when he was really angry my husband told him, 'You better go; you've upset your mother'. So he left and we didn't see him for seven years. Well, we didn't worry too much about it because he knew where to come; he knew where we were. He'd got his own life.

If he wanted us we were here. *If* he wanted us! If he didn't want us, that's it. So when he got himself sick, then he wanted us. That happens, doesn't it? When they get sick they want the parents. I have a better relationship with Tom since he became sick. I wasn't frightened to go up there and stay with him. We kept in touch. Actually, funny enough, I am more close to Tom than I am to any of the others. Since he has been sick we can talk about things, we get conversation together. Queer, in'it? I have had a better relationship with him since he became sick.

Lizzi: I have spoken to one of Tom's sisters and she said to me, 'He's been bloody near death a few times and we all prepare for his death and he bloody well lives. How

much longer can we take this?' With HIV/AIDS, people can be at the palliative stage and you would not think they would be there tomorrow, and then do this resurrection. I think Tom's sister may feel some resentment watching her elderly mother going to Tom's bedside, doing the vigils, sitting there with him and everyone is prepared for his death and then he doesn't die. This happens time and time again. Tom's sister drops Kathleen off at the nursing home but doesn't go to visit him. Tom's brother doesn't come to visit because he says his partner will leave him if she knows that he has a brother with HIV/AIDS. He hasn't told his partner that his brother has HIV/AIDS.

Repression of sexual expression and identity

Tom: I miss the intimacy of male company. I'm in a nursing home, it's not my real home, there's no privacy and there are rules. I'm not able to live a gay man's life in a nursing home. I would prefer to be living in my own home with carers and with the gay community at my fingertips. I see the gay magazines when I go out to pubs but I couldn't bring them back here.

I've had good times. I used to go to Steam-Works, the Peel Hotel and have oogie boogies before I came into the nursing home. Now the libido has gone; it's zilch. I've been in the nursing home four years. That dampens your libido, of course. It wasn't to start with, then I adapted to the place, I realised there was nothing here. I had to forget about any sexual relationship with a male, forget about sex generally. It can't happen now, it's impossible. As far as sex is concerned, as far as relationships are concerned, it's impossible.

Lizzi: How does a gay man in a nursing home like Tom who is still a sexual being express his sexuality? He can't. He can't talk to the nursing home staff about that because he is fearful that he might receive lesser care. A lot of people think that a man having anal sex with another man is quite disgusting. Because the staff can't talk about his sexuality openly and comfortably, they are not meeting Tom's needs and he is living a shadow of a life. He will say to me, 'I haven't had sex for many years now'. I say to him, 'Well, is there any lead in the pencil?' He says, 'If the right man came along there would be plenty of lead in the pencil', and laughs. He is able to talk

to me about his sexuality, especially touch and intimacy. He needs to express where he's at and what he needs.

Tom told me he likes to go out for coffee or a drive so that he can get away for a while and feel normal again. He talks about the constraints of being openly gay in the nursing home and that he is fearful of discrimination. When I reminded him that the staff knew he was gay he said, 'Yes, but you know Lizzi, I can't tell the jokes I would tell the other gay boys, and I have to be careful of how I act or commenting on cute men, so my mind is constantly saying I can't *say* those things'.

Tom often comments how much he misses the culture of gay people and his community, and that it is really lovely having me come to visit him because he doesn't have to be guarded with me, as I understand and am part of the gay community. I often wonder about the energy it takes him to maintain this persona of being guarded about his sexual identity. What effect does that have on his health, not being able to be who he is? That must shorten your life span: living and breathing an existence that is so far from what he knows. He puts a lot of energy into making the nursing home work for him.

Dependency, control and a good patient

Tom: If I had a magic wand first of all I would walk all right, and if I had money I would buy a little flat for myself. I would have some nice stuff around and live a normal life with interesting people and sit back and have people visit me. Money doesn't necessarily bring happiness, but it gives you choices and independence.

Lizzi: Tom always praises and hardly ever complains about his care. He always says that he is very lucky to be looked after by lovely people. I think he is concerned that if he doesn't comply with the staff he may be discriminated against, so he has settled for his lot. He feels that there is no hope for him of ever getting out of this institution and that he has to make the best of that. Tom has learned to keep his mouth shut and not make waves.

The nursing home takes most of Tom's pension. So there is little spending money for him to go out to lunch. If he had more money he could go out more. He has to ask the staff for cigarettes and feels that his independence has been taken away. The nursing home dishes out his cigarettes, for God's sake! It's about control. It wasn't Tom's idea; he has been told he is only allowed so many a day. He needs to be able to choose whether or not he has a cigarette. Tom states that he feels compromised at times and controlled, as he has to ask for money and cigarettes and doesn't have any autonomy with his finances.

'My People' – understanding gay culture

Tom: When I came to the nursing home I told them I was married. Then they started asking where the pictures were. If you're married you have pictures of the wife and children. I didn't tell them at first I had HIV, but they were giving out my medications. They worked out I was gay. I have had HIV for 24 years.

Lizzi: Tom didn't have a choice about telling the nursing home that he had HIV/AIDS. He is on anti-retroviral medications, so any nurse giving those out would know that he had HIV/AIDS. Tom has the double whammy of being a gay man and HIV positive.

Tom has a great package of care for his HIV/AIDS. There is a HIV/AIDS consultancy service that provided education for staff before Tom was admitted and continues to provide ongoing education. The consultancy service has given the staff guidelines for what to look for, what is reportable and given them phone numbers of who to ring straight away and they visit the home every month to review his care. He has a psychiatric liaison nurse goes in to see him and a general practitioner with expertise in HIV/AIDS. He has respite in an infectious diseases unit for two weeks six times a year, and my services. There is nowhere else that I could imagine that he would be looked after as well as he is. And yet it still doesn't meet his needs and he is quite unhappy and tells me that he lives from meals to meals and sleeps in between. This state of mind and lived existence is detrimental to his health and longevity.

Stimulating staff understanding and empathy

Tom: The respite is very good and the staff are very good about my HIV. They are better at looking after someone with HIV than the staff here, they are more professional. We need a gay nursing home. It's about understanding, having someone who understands. The staff in a gay facility would be more understanding.

Lizzi: I think the staff are honestly trying to reach out to Tom, but they don't understand. I have spoken to some of the staff after he had a night out at a drag show. They said it was great for Tom to be out and about with his own peers and what a difference it had made to Tom's well-being. Apparently he talked of nothing else for days and was happy singing songs from the show. One nurse said that Tom had told her that he couldn't wait until he goes again. I asked her if she had ever been to a drag show or a gay venue and she said, 'No, but I would like to'. I asked her if she would like to go with Tom next time and she said that she would love to. She also said that it would benefit Tom if she understood more about his culture and community. I think that this was a very positive step for her to take and to be able to identify that she needed to learn more about Tom's life.

How can you expect the majority of people who identify as heterosexual to understand gay culture? The supports that Tom has have raised more of awareness that people who are positive and are gay do have a community outside the nursing home that are prepared to do something about his care.

ReMEMBERing and 'My People'

Lizzi: I noticed when Tom had his respite he met other clients that he had known for a long time, who were also part of the gay community and his whole persona changed. They would laugh, joke and come alive. One of the men, who was a fantastic drag queen, would redo his routine. It was out of sync and sometimes you don't know whether to laugh or cry when you are watching him. But to me it was very moving, because in his eyes I could see that he was back on that stage and Tom was there in that bar watching him. It didn't matter how out of kilter it was, the memories were there for them both. They'd swap stories and talk about the drag queens and the clubs and say, 'Remember when?' There was a lot of remembering. Similarly, people that

have been victims of holocausts survived by forming groups and reMEMBERing their lived experience, sharing stories and keeping their memories alive. I think that is really powerful. They get together so they are re-members of a new group and they are reMEMBERing their experiences. This is what I saw Tom and his group doing during his respite. They were reMEMBERing and keeping their memories alive in light of adversity.

Tom: 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?

Story 2: ‘Don’t be too polite, girls, show a little fight’: The story of lesbians providing palliative care at home

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 in their last years. If you don’t talk up you die very lonely. If the worst comes to the worst, well you are not a murderer, you are not a thief, just a very great lesbian who loves women (Maureen, 74 years, lesbian).

Background to Thelma’s story

This is the story of a community of lesbians who negotiated a partnership with district nursing and palliative care services to provide care for Thelma, a 67-year-old lesbian, feminist and political activist who died at home in 2003. The provision of care in the home is highlighted in the story and, while aged care is often thought to comprise residential aged care (nursing homes and hostels) most aged-care services are received at home.

Thelma’s story highlights the importance of seniors accessing services in their own home, rather than relocating to a hostel or nursing home. Indeed, home-based services, such as the Home and Community Care Program, were provided to over 142,000 senior Victorians in 2003–04 (Department of Human Services Victoria, 2008). This compares with the 37,445 seniors who required nursing home or hostel care (Department of Human Services Victoria, 2004). Given the importance of home-based services, this case study presented the opportunity to explore how these services can meet the needs of GLBTI seniors.

Thelma’s story involved home services such as the district nurse and palliative care services. While neither service is exclusively aged care, they represent some of the services accessed by GLBTI seniors living at home.

Thelma’s story was told by Maureen, her partner of 19 years and Jean, a friend who cared for Thelma as she died. Three phone interviews were conducted with Maureen and two with Jean. Interviews with the district nurses and palliative care staff were

not undertaken, as they could not be located. Maureen was passionate about sharing Thelma's story and sent a package of obituaries from newspapers and lesbian publications with a note saying, *I am so happy you will know my Thelma*. The obituaries described Thelma's social, political and feminist activism including her contributions as a founding member of organisations supporting women and lesbians in particular. Some of her activism included participation in a 1980s 'kiss-in' protest outside the Australia Hotel after two gay men were arrested for kissing in public. Others involved challenges to the male-only rule in the front bars of hotels and a successful campaign to enable women to get bank loans without a male guarantor.

In one interview Maureen sang one of Thelma's favourite songs, written by Glen Tomasetti to support the case for equal pay for women in the 1960s. The lyrics include: *Don't be too polite, girls, don't be too polite, Show a little fight, girls, show a little fight. Don't be fearful of offending in case you get the sack. Just recognise your value and we won't look back*. The song was selected as the title for this story because it represents the connection between Thelma's passion for lesbian visibility and her experience of home-based care services.

The story begins with Maureen and Jean introducing themselves and sharing their experiences of support in the lesbian community. The women describe the disclosure of their sexual identity to carers, their guidance on how to care for older lesbians and the response that they received. The insights provided are enhanced by Maureen's reflections on the importance of being visible and Jean's experiences as a lesbian working in aged-care services. Given that so few GLBTI seniors disclose their sexual identity in aged-care services, this story provides a unique opportunity to explore disclosure and its consequences. The conclusion embodies the aims of the study, to recognise GLBTI seniors, by sharing Maureen's tribute to Thelma.

Introducing Maureen, Thelma and Jean

Maureen and Thelma

Maureen: I am 74 years of age and I came here from South Africa when I was 39 years old. I missed my family; I had no family in Australia. You know who was my

family? My friends the lesbians are my family. I have a few straight friends and I find it very hard, because I wouldn't say that the straight friends are my family. They are on a different planet; they don't feel what I feel.

I became a lesbian at the age of 18 years old and I told my mother and my father. They didn't understand, but my mother just took it in her stride. In those days people didn't shout from the roof tops that they were a lesbian. My partner Ally always wanted to be in the closet. She didn't like that word 'lesbian'; she didn't want to do anything political or nothing, 'no marches, no nothing'.

When Ally left me I did meet this wonderful woman, Thelma. Thelma was born in 1936 and we were together 19 years. Thelma kept things from her own family. Her mother was Italian and Italians don't look very kindly on being a lesbian. She went in all the marches and once on International Women's Day, she spoke on the steps of Parliament House. On the 31st October 1969, Thelma and two women chained themselves across the doors of the Arbitration Commission to protest about the inadequate pay rates for women as well as all sexist discrimination faced by women in society at that time.

Thelma was sick in August 2002 and she died in February 2003. She had cancer of the kidney, then the liver.

Introducing Jean

Jean: I have been a friend of Maureen and Thelma's for the past ten years. I helped to care for Thelma when she was dying. I wanted to provide Thelma with the best care she could possibly receive. I am very conscious of the need for lesbians and gay men to access good care because I work in health care, as the Director of Nursing in an aged-care facility, and so I am aware that discrimination can occur. I am out at work and sometimes I think there might be discrimination with the CEO because it is a Christian organisation. I have cared for lesbians and gay men and they are very much closeted. My last experience was with a gay man, he was very much out. Initially, the nurses questioned HIV/AIDS and they wanted to know if they should get him tested. It wasn't a concern at all and I asked them what they were going on about. The staff

were OK about it after education. I think a lot of it was ignorance, really. I wonder whether a director of nursing who is not a lesbian would jump in at the deep end and have all these tests done and have the staff start to wear gloves? I wonder!

I have nursed closeted older lesbians and I just sense that they are a lesbian. I talk to them privately, tell them I am a lesbian and say, 'You're in safe hands'. If they have a photo of their partner I will say, 'That's a nice photograph; is that someone who is special to you?' I don't ask if they are a lesbian – no, no, no, not to someone who I feel has been closeted. I feel my confidences are much appreciated, I can tell by their facial expression. They feel that we share something, it's a conversation that we have together.

If I had the choice I would prefer to be cared for by lesbians, someone who could understand me better as myself. If I go to a health professional I always say I would rather have a woman and if it's a lesbian even better. I feel sometimes if it's a heterosexual I need to hide something of myself, they might not understand. So, because of my experiences in aged care and my own needs as a lesbian I understood the importance of the care that Thelma received.

Stories of visibility and partnership

A chain of lesbian support

Maureen: Lesbians do better than straight people with support because 99% of lesbians love one another and are committed to one another. There is a whole chain of lesbians and you don't break the chain because when you need somebody it's there. I have people talking to me at 11 or 12 o'clock at night, just to talk. They got a few problems, they're alone, and I listen to them. They at least know that at the end of the line there is someone who understands. They don't want to talk to Life-line; they want to talk to a *lesbian*. If I don't help these people out, the chain is gonna be broken. We need to stick together, there's too few of us around.

The 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. Very, very important. If I felt a bit sick now I could phone somebody and I would get someone over here quick smart. I keep in touch. You gotta keep in touch, you do get lonely you know.

The chain allowed Thelma to be cared for at home and also enabled me to survive after her death. I got a lot of support. People phoning, people visiting and they still do. If you don't keep in touch you'll be lost. We are all getting older and if you can you need to make friends with the young dykes, because most young dykes are not ageist and they can look after us when we need someone.

Jean: I know that as a group we wanted to give Thelma the best death that she could have had. We would do that with any of our friends, we would do that for each other. We joke at times and say who is going to be there when we are dying? We are getting older too, that's the thing. We joke and say we need to befriend some of these younger lesbians; easier said than done.

Trusted carers

Maureen: When Thelma died we had women come in the last month, they were our lesbian friends. These friends who looked after Thelma, they understood who she was and also had a medical background. There was also Jean T. and Pat R. who came. You have to mention their names, they did so much. They understood who Thelma was and they understood me as well. We also had a lesbian cleaner who was very considerate and careful when she wanted to clean around where Thelma was sitting. I would take Thelma to the bedroom and then she would clean. This woman was very, very caring and I don't think we would have got this consideration from a straight woman. She was more caring.

Jean: Thelma and Maureen trusted us. That trust was very important to Thelma. We were the ones who were asked to come and care for her. There was trust in the sense that we were friends and we were lesbians. We had that knowledge or that healing and

caring aspect to us that Thelma trusted, especially for intimate things like washing and toileting that professional people do, that Thelma trusted to us to do for her.

It was extremely important to Thelma that we were feminist lesbians because she was such an activist and a very strong lesbian. She was always out and in her dying process she was out too. We did have the outside services, the district nurses and the Palliative Care Service, but we were always present when they were there with Thelma in the last weeks of her life.

A Process of love

Jean: There were three of us who had nursing experience that provided 24-hour care for Thelma for the last days of her life. We would be there in the morning to care for her and then we would take it in turns to sleep in the room with her. It worked out really well and we ourselves were good friends. It was so smooth. It was a process of love. I am a nurse. The caring aspect you do professionally, but to be with a close friend who is dying and a supportive community was different. At work I am around people who are dying all the time and sometimes people die alone, whereas with Thelma there was always a community present. There would always be one of us with her. Sometimes we come together very well as a community when someone is dying.

Thelma was out there fighting for social justice and I believe if someone gives that to the lesbian community you want to give back to them. I often thank Thelma for inviting me to be there to care for her. It was such an honour, such an intense time and such a time of love.

Healing for the lesbian community

Jean: There were friends of Thelma and Maureen who didn't have a nursing role but provided us with care. Sometimes you could hear the giggling of the community in the garden and we just knew that they were there. They would bring us scones or a nice meal and they were there if we needed to talk to them. One friend had a beautiful vegetable garden and she would make lovely pasta sauces for us. Another friend, Sally, came from Tasmania and cooked for us and loved us all through food. Cuddles

were provided for me, and a bed was made for me on the floor so I could give all my energy to Thelma. That was really important because then I could give 24-hour care to Thelma without being interrupted.

It was a healing time for us, because as lesbians and friends we ourselves were being nurtured. It was an emotional time for us and it was a spiritual time because we were caring for someone very close to us who was dying. That in itself is healing: healing for you and healing for the lesbian community.

Speaking out

Maureen: 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. If Michael Kirby, the Chief Justice of Australia, is out, surely you as an ordinary person can be out? OK! So you might have got some flak 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, just a very great lesbian who loves women.

Home-based support services

Maureen: I got some help from a Palliative Care Service and the District Nursing Service, and they were marvellous and they knew we were lesbians. The district nurse had to come in every day, because she had to oversee things and if you needed them you just buzzed them and they would come. The case manager from the Palliative Care Service would come three or four times a week.

Disclosure and respect

Maureen: Thelma was recognised as a lesbian by the services that came into the house when she was sick. The district nurse and Palliative Care Service knew we were lesbians and they respected it. I told them straight when they came. 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 only time a male came was the doctor from the Palliative Care Service and he also knew we were lesbians. He took me aside and said, 'Maureen you got to be very strong because unfortunately Thelma hasn't got very long'. He was caring.

They all knew we were lesbians. Thelma's doctor knew, the lawyer knew, the funeral people knew, everybody knew because we told them all. You've got to be honest. If I ever go into an old age home I'll be bloody telling them, love. What you see is what you get. You go up to the matron or the CEO and say, 'Well look, I am a lesbian. I don't want special treatment; I only want to be respected for my lifestyle and my ideas'.

I had the case manager here and she was a wonderful young woman. She used to sit out the back and have a yarn with us. She knew we were lesbians and she told me afterwards that she knew immediately she came in, because there was this beautiful way I looked at Thelma and way that Thelma looked at me. She knew but she said that she appreciated me coming out to her. She would come and say, 'Hi Thelma', and kiss Thelma on the top of the head. That was really nice. I think she liked the atmosphere here.

Shared care

Jean: The Palliative Care Service was there for advice and support. 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. They were very supportive of us as a community. We were very surprised. They said to us that they had never come across this kind of support before. They kept saying, 'This is amazing'. I felt very comfortable with them if I had any questions to phone them and talk to them. They were very happy to share her care. They didn't take the back seat as such, but they realised that we were the carers looking after Thelma and they were there to assist us.

The rainbow fairy

Maureen: On Christmas Day this one nurse from the Palliative Care Service came along dressed as a fairy, which was amazing. She had all the rainbow colours; she was an amazing young woman. It made a difference because, from the word go, she knew we were lesbians.

Jean: When Thelma died the Palliative Care Service was there within an hour and they bought a counsellor along for us if we needed counselling. Later the case manager asked was there anything else that they could have done for us as a community. They used the word 'community' and 'your community'. The case manager and other palliative care staff were all very accepting of us as a community.

I met the rainbow fairy three years after Thelma died and we had a lovely conversation. The fairy was saying how she was amazed at the support provided by the lesbian community and this was three years later! Even three years later the lesbian community was still recognised!

The importance of home

Maureen: Caring for Thelma at home was the greatest blessing for both of us. She wanted to die at home and it was just an amazing series of events. Every day was a new day for us. We were happy and I was happy that she could live and die at home. She did not want to die in a hospital. In a hospital I would be running back and forwards. When she died here and when she was sick here, 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. It was really important to me. The whole episode of sickness, the caring and dying could only be put in one word: inexplicable. The service we got from the authorities and from the lesbians was just great.

Jean: If Thelma needed to go into care I believe that she wouldn't have been happy. Thelma was very much sensitive to her environment and would not have been happy anywhere but home. She was in her home and it was very much Thelma's home and she died in her chair. The chair was a recliner that the palliative service gave us. A

hospice or aged-care service would just be a foreign environment and I don't know if as a lesbian community we would be welcome to the same extent, or whether we would have felt relaxed. Many of us felt very much at home in Thelma's house where she had entertained us so well, fed us for years and supported us. It was very much a lesbian household. Because it was her house her lesbian friends were very much welcome. You look around the bookshelves in her sitting room where she was dying and see a lot of feminist titles, lesbian artwork, beautiful lesbian portraits and her four cats. She would not have been able to have her cats in a hospice. She loved her cats, and her cat Matilda sat on her arm-rest while she was dying.

A tribute to the love of my life

Maureen: When Thelma died I was so overcome. My friends washed her and dressed her and she looked absolutely beautiful. She stayed with me for six hours after she died and whatever people I could get hold of, they came to pay their last respects. I started phoning people and they came along. She looked beautiful and then we clapped her out of the house. Before the funeral people took her away I kissed her.

Thelma was my partner and she was quite a remarkable woman. She loved animals, she loved women and she loved debating. She was a great woman and I was honoured to have her in my life. I would like to have another 20 years with her but I can't be greedy, can I? Thelma was, is, and always will be the love of my life.

Story 3: 'She is who she says she is': The story of a transwoman living in a Catholic supported accommodation service

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. One bludger says he's going to flatten me. He says it's because of what I am, a transsexual. He doesn't understand it. He puts his fists up like he's going to punch me. I don't get on with any of the buggers here. They're not my kind of people (Nancy, 79 years, transsexual).

Background to Nancy's story

This is the story of a transsexual woman living in a Catholic supported accommodation service. While numerous terms are used to describe transsexuals (Couch et al., 2007), the terms used in this story will reflect those Nancy uses to refer to herself. Nancy was born male and had partial gender-changing surgery when she was 31 years old. Nancy moved into the supported accommodation service when she was 64 years old. In Victoria, services such as this provide housing and support for people with a range of disabilities, most of whom are older than 70 years of age (Department of Human Services Victoria, 2003).

The opportunity to meet Nancy came through Maggie, a nurse who had been caring for Nancy for 15 years. Nancy agreed to be interviewed but was preoccupied with threats from a co-resident. Her room contained no personal affects. She claimed that the two suitcases lined against her bedroom wall were packed, ready for her to move to a place where she could be happier and free from harassment. Nancy's story provided insights into issues of discrimination and the authority and influence that staff have in the provision of culturally appropriate care for residents.

The story presents four vignettes outlining episodes of discrimination and acts of advocacy. The discrimination involved breaches of the principles of the *Health Services Act 1988* which protects the basic human rights of people living in supported accommodation services, nursing homes and hostels (Department of Human Services

Victoria, 1988). In particular, the vignettes concern Section 10 of the Act, which includes principles stating that:

- Residents should be treated with dignity and respect
- Residents are entitled to choose and pursue friendships and relationships with members of either sex
- Residents should be provided with shelter in a home-like environment
- Services should be provided in a safe environment.

The case study also explores the power of organisational leadership in the celebration of diversity. It finishes with Maggie's reflections on her relationship with Nancy and the importance of carers understanding that Nancy 'is who she says she is'.

Introducing Nancy and Maggie

Nancy: Me name is Nancy and I was born in 1928. I was born a boy and so me parents called me Brian. Mum was all right, but Dad used to belt the shit out of me and me brother; he was on the grog all the time. I worked as a female impersonator, part of Les Girls [an all-male revue]. I met Carlotta, one of Les Girls in Kings Cross in Sydney. I was known as Bridget then. It was good fun; I enjoyed meself. When I got dressed up as a woman, guys would want to be with me. It was a lot of fun.

I was in the navy during the Second World War. Those were the days. When I came out of the navy I worked with a horse trainer and I worked in the mines and I was a boxer. I was in jail once for vagrancy, five years in Long Bay Jail breakin' rocks. I know how to look after meself. No-one else can do it as good as I can. There's nothin' I can't do. I can do anything and I know it too.

In 1959, when I was 31, I had the operation [breast implants]. I wanted to have it done. I don't regret having it done. I don't regret it. I couldn't have the bottom done [my penis inverted] because I was too old for that. Then I had me name changed, from Brian to Nancy. Life changed when I had breasts. I felt I was what I wanted to be. I don't regret having it done, I'm happy. It would have been different if I'd had the penis done, I could have had been pierced by a man. It would have been nice. I

wouldn't have been able to have any children, but I would have had sex with me husband if I'd had that done. It was pretty important to have breasts. I could probably go and have sex with another woman, but I wouldn't. I'm not a heterosexual; I'm a transsexual.

I wear a wig. I've got three wigs. Me hair has never grown, it's long but very thin and it's me male hair. I still take female hormones. I have had to take them since I had the operation. I have been on them for nearly 50 years. It's the female tablet, I've got to have it seeing as I'm not a pure male any more. I'm a trans, both, fifty-fifty. I'm happy with what I am.

I got married when I left the navy and then me daughter was born. I haven't heard from me daughter for a while. I divorced me wife. I've been married twice, once to a man and once to a woman. That's enough for me. I don't regret having the surgery done. I don't regret it. That's how I got attached to me husband. I lived with him for 10 years. He was a lovely guy. He died 10 years ago. I still miss him. He was just spot on.

I would like to meet someone else. But I don't think I'm going to get tied up again, bugger it! You would have to find a partner who was broad-minded. That's a very hard thing to find. You can't always find a thing like that again. They'd have to be broad-minded to understand me. Me having both organs, breasts and a penis, they would have to be broad-minded to love me. That's going to be very hard, I know that. I won't get no-one now. It'd be impossible.

Maggie: When I first met Nancy in 1992 she was living in a special accommodation service with Frank, but Nancy was Brian as well. She *was* Brian. We didn't realise that she didn't have the complete sex-change operation. We had other gay couples in the building and it was like walking into, 'Oh! This-is-a-bit-different'. I hadn't come across gay men and transsexuals before. It was funny, because you'd walk past the toilet and Nancy would be standing up urinating and you'd think, 'What is she doing?', and then you'd go, 'Oh, that's right!'. When I found out that Nancy only had the breast implants and the hormone treatment my heart went out to her. She has had to live like that for so long, in purgatory basically, because she was not one and she

was not the other. My heart just went out to Nancy. To me Nancy was Nancy. So if you walked past the toilet and she forgot to shut the door you would sort of go, 'Oh, that's right'. All the staff were like that, everyone accepted her as a woman. Both the brother and her daughter refer to Nancy as 'He'. Her brother gets embarrassed. That's why the staff are so great, we are all very protective of her.

Stories of discrimination and advocacy

Promoting dignity, respect and femininity

Maggie: Nancy dressed very inappropriately when I first went to work in the special accom. The staff there used to think it was funny when Nancy walked out in her bikini with half her genitals falling out the bottom of her bikini pants. She would put eye make-up on and had eyeliner up past her eyebrows. The staff wouldn't sit down and *show her* how to apply make-up without going overboard, without looking like a painted doll with big red cheeks. They thought it was funny to watch her get around like that. I didn't like that. I fired the lot of them.

When I took over management of the service with a new team, we started to teach Nancy how to actually tone it down: don't wear a bikini outside; don't wear tight legging and midriff tops; if you're going to be feminine, be feminine. We were teaching her how to be feminine and she blossomed. We helped her out when she went buying wigs. Her hair used to grow out from underneath the wig and we would get Nancy in the bath and shampoo what hair she had left and trim it so it would fit under the wig properly. We'd do her feet and her nails. We used to do Nancy's wigs, her nails and go op-shopping and buy her nice dresses. I bought her all these sarongs and she put them on with a fur coat. It was like forty degrees. It took me a while to click it was the tattoos; she didn't want anyone to see her tattoos. So I went and got her a nice little bolero long-sleeved cardigan, she was rapt.

Modelling recognition of the right to choose relationships

Maggie: Frank was Nancy's partner for 18 years and their families wouldn't have a bar of it. The staff and myself were very mindful that Nancy and Frank had a very

boisterous sex life. We had to learn to knock on their door and then wait for permission to enter the room. We walked into some pretty interesting situations. Nothing was ever said, 'Isn't that unreal at her age?' It really floored me! It shocked quite a few of the staff. They were a couple in every sense of the word.

A lot of people didn't agree with the way they lived, but Frank was sick and he didn't have long to go, so why interfere? Just leave them alone, make sure they are OK and Nancy is happy. In 1997 Frank had to go to hospital; they told Nancy he might not last. Next morning Nancy rang his sister and was told that she could not go to see him because only family could visit. 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'. So I took her to the hospital and marched her in and they said, 'It's family only.' So I said, 'This is his partner'. She stayed there for about an hour, she was so happy. The charge nurse rang later that night to say he died. That was so cold, because his sister wouldn't even ring. I went downstairs and got a valium and some water and came into Nancy's bedroom. I said, 'Have this Nancy, I've got something to tell you'. Then I said, 'He's gone'. She started crying. And she lay down on the bed and I just cuddled her, and we both cried until she fell asleep. The next day we waited to hear from the family again and heard nothing. So I rang the sister about the funeral and she said, 'I'll get back to you about that'. Three or four days went past and I was thinking, 'We should have heard by now'. So I rang them. They had buried him two days earlier. How could they do that? I didn't know how to tell Nancy.

I was at home the day after Frank died and one of my staff rang me. 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 drive there. I went flying up the stairs and into the bedroom and I said: 'Who are you and what are you doing?' He said that he was collecting Frank's belongings. But Frank had nothing. 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'. So he left and the police came. He called them. How we got through that I'll never know. The family wouldn't tell us where Frank's grave was. It took us about a year to track that down so that Nancy could visit his grave.

Responding to transphobic abuse and providing a homelike environment

Nancy: The other bludgers that live here give me a hard time. Discrimination against transsexuals is everywhere. Everywhere is the same; you can't get away from it. I don't like it here, too many bludgers. That's why I keep away from the buggers. That's why I mention about me leaving here and going to live in Adelaide. There are certain ones in here I don't get on well with. 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. I don't want to fuckin' eat. Can't you see I'm trying to die? Me life's too fuckin hard. I'm sick of it.

I only leave me room if I feel like a meal. Other than that I stay here. That's me life. I don't associate with anyone. They're not my kind of people, they're not sociable people. I don't go anywhere near them, only at mealtimes. They don't interest me. I am up here all the time, away from everyone else, bugger them!

One bludger says he's going to flatten me. He says it's because of what I am, a transsexual. He doesn't understand it. That's why I am anxious to go and leave here. Had I been a normal sex it would have been a different story then. He puts his fists up like he's going to punch me. He's only a little bastard. That's one reason I want to get away from this place. I'm scared, that's why I stay in my room. I don't get lonely; I've got me television. It's been that long now on me own it doesn't worry me. I haven't seen him for a while, but if I did he would have another go at me again. That's why I want to get away from here. That's why I have got me cases packed. I would be better off away from here. He's the only one that's had a go at me, but I keep away from everyone.

Maggie: We've got rules about harassment and threatening behaviour that the residents have to stick by. If a resident breaks the rules, we 'breach' them by putting in a formal complaint which goes to community housing. If they get three breaches it goes to a tribunal hearing to determine whether they can continue to live in the building. I have breached the resident that has been harassing Nancy and if we see it happening the staff intervene.

Not all the residents here know Nancy is a transsexual. I think that some of them just think she is a very strange-looking lady. Some of the guys treat her with a lot of respect. It's hard for a lot of people to live together like this, so you are going to have your arguments and fights. Sometimes it gets very loud. When an argument starts, Nancy resorts back to being Brian. She puts her fists up and starts swearing. One of the residents said, 'It's not a lady, it's a man, and if she punches me I'll punch him back'. So they don't look at her as a female, they look at her as a man. There was an incident about a week ago in the dining-room when Nancy was arguing with another resident who was drunk and she picked a chair up and threw it at him.

Recognising vulnerability and providing a safe environment

Maggie: Nancy would like another boyfriend. She had a boyfriend here at one stage and he was just after her money. She was going to go and live with him. She wants so much to be liked. I told her to go and live with him for the weekend, so that if anything happened she could come back. But she packed her bags and she moved in with him. Came to pension day he took her pension and kicked her out. She so wants to be loved. She so wants to be somebody's partner.

The staff are so great, we are all very protective of her. Nancy would talk to anybody; she would just talk to anyone and everybody. She is very vulnerable, especially now [that her cognitive function has declined]. About a month ago Nancy was outside the building talking to the people who sit there and smoke. There was a guy there, a schizophrenic who lives in the tram stop, who had been hanging around for a couple of days. When Nancy came inside he followed her up to her room and then started touching her and masturbating. Nancy left the room and when she returned to her room he was gone. I took her to a sexual assault counsellor.

Nancy told me she had let this man into the building because he was talking to her. That's the thing about Nancy. He talked to her, and she is lonely and wants company, and because he talked to her she trusted him. I called the police and they asked me whether I thought she was making it up or fantasising. I showed them the video tapes from the surveillance cameras of him following her into her room. She is so lonely

she will talk to anyone. I think that's why they want to send her to a hostel, so she will be safer.

I wonder at times if maybe Nancy and I have got that bit of an affinity because, from day one, I have never questioned her gender identity. I wonder if that stays in her head. The staff here were told from day one about who Nancy is and they treat her like any other resident. We treat everyone equally regardless of their sexuality or gender identity. We are familiar faces, we are her family. 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.

Implications for aged-care services

This report has presented the experiences of 19 GLBTI seniors receiving aged-care services in Victoria. While the findings cannot necessarily be generalised to the larger population, they provide evidence of the challenges facing some GLBTI seniors accessing aged-care services. This report stimulates debate regarding the disparities experienced by GLBTI seniors and the need to develop GLBTI-friendly aged-care services. In this last section of the report the implications of the research findings for aged-care services will be explored. To provide a context for these implications, it is useful to reiterate the eight core issues identified as relating to the experiences and special needs of GLBTI seniors.

Core issues in relation to GLBTI seniors

1. The impact of historical experiences of discrimination

The current generation of GLBTI seniors were 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:

- 1.1. Have never experienced a time when they have felt safe disclosing their sexual/gender identity
- 1.2. Revisit past discriminatory experiences when encountering discrimination and consequently feel upset, anxious and depressed
- 1.3. Have learned that they need to be assertive to prevent discrimination
- 1.4. Often have a network of ‘chosen’ family or friends rather than genetic family ties, while 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 because:

- 2.1. They are aware that discrimination occurs as they have:

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- 2.1.1. Experienced discrimination in aged-care services
 - 2.1.2. Heard reports about discrimination in these and related services
 - 2.1.3. Witnessed discriminatory responses from aged-care service-providers to GLBTI people profiled in the media
 - 2.2. They fear a diminished standard of care or deterioration in their relationships with their carers
 - 2.3. They fear the resignation of valued home carers
 - 2.4. They believe that aged-care service-providers do not expect them to be sexual or GLBTI
 - 2.5. They believe that many aged-care service-providers do not understand what GLBTI or GLBTI culture means and therefore how to meet the needs of GLBTI seniors.

3. The impact of identity concealment

GLBTI seniors who feel unable to disclose their sexual/gender identity may:

- 3.1. Feel unable to be themselves and feel devalued or depressed.
- 3.2. Experience stress and pressure from maintaining a façade of heterosexuality
- 3.3. Have unmet care needs
- 3.4. 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:

- 4.1. Transsexuals who do not pass as a man or a woman
- 4.2. Cross-dressers who do not have the opportunity to cross dress in privacy
- 4.3. Those who have a demonstrative relationship with their same-sex partner
- 4.4. Men who are HIV positive and are therefore expected to be gay
- 4.5. 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:

- 5.1. 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
- 5.2. To have their relationships recognised by aged-care service-providers, other clients and families
- 5.3. To be protected from discrimination by co-clients with dementia
- 5.4. To be supported to provide informed consent relating to sexual expression
- 5.5. To be cared 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 and may involve:

- 6.1. Physical touch such as holding hands, hugging, kissing
- 6.2. Contact with partners and private time together
- 6.3. 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.
- 6.4. Dressing in clothing that expresses their sexuality/gender
- 6.5. Sexual intercourse, masturbation, sex toys and sexually explicit material such as magazines, DVDs and books.

7. Inadequate standards of care

Some aged-care services discriminate against GLBTI seniors by failing to create GLBTI-friendly services, including:

- 7.1. Staff being unaware of their legal responsibilities regarding discrimination
- 7.2. Staff not being held to account if discrimination occurs
- 7.3. A lack of staff guidance in the form of organisational policies, education and leadership around the care of GLBT seniors
- 7.4. The provision of a diminished standard of care to GLBTI seniors
- 7.5. Staff failing to protect GLBTI seniors from discrimination by co-clients and visitors in shared services

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- 7.6.Restricting opportunities for sexual expression
 - 7.7.Allowing the values and beliefs of aged-care service-providers to govern the care delivered to GLBTI seniors
 - 7.8.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 by aged-care services:

- 8.1.Creating GLBTI-friendly aged-care services
- 8.2.Affirming the legitimacy of GLBTI seniors' sexual/gender identity
- 8.3.Creating opportunities for dialogue with GLBTI seniors around their care needs
- 8.4.Understanding the importance of sexual expression and providing GLBTI seniors with opportunities for sexual expression to occur
- 8.5.Valuing the intimate relationships and friendships of GLBTI seniors.

These issues reflect the experiences of the 19 GLBTI seniors interviewed for this study. The interviewees also provided a number of suggestions for the development of aged-care services to ensure that consumers are safe from discrimination and that their needs are met.

Moving forward

This 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'. This was articulated by Steven, a 71-year-old gay man who reflected on the care received by his partner Bill in a nursing home. Steven reported that for a gay man, being admitted to a nursing home was landing: *smack bang into the middle of heterosexuality*. While he was able to support Bill, he reflected that as he aged:

There is no-one there to protect me as I could with Bill. There must be hundreds or thousands of guys around Australia who are in a similar situation or getting to that. They have got no-one if they go to a nursing home. They probably want to sit there and just pass away as soon as possible, because they can't be themselves because they are in a straight nursing home. Imagine a lesbian who's been in a loving relationship with a partner and suddenly thrust into the blue-rinse set. It's not her scene whatsoever. It would be so frightening. What is there for them? There's nothing. Just to sit there in this nursing home and be part of a culture that they really never wanted to be a part of. They get their meals; they get a shower or there might be a bus that takes them out once a week. But there is nothing there in conversation that would be interesting to them. They could discuss things on telly, but it's not like being with one of your own group. You would have to be very guarded and that puts a strain on a person. 'Why didn't you ever marry?' 'Haven't you got grandchildren?' The old questions. You are in a group of people who have still not grown up with the outing of gay and lesbians. People who want to know 'why'? It could be very, very difficult (Steven, for Bill, 71 years, gay).

The support for GLBTI specific services was also articulated by Anne, a 77-year-old lesbian who was receiving home services. Anne expressed concerns about the possibility of being separated from her partner and noted:

I have been meeting lately, a lot of older lesbians who have been saying: 'I am the only child, I have no children. Eventually, when I want care and I am willing to pay for it, like sell my house ... is there anything going like that old dykes' home?'... The facility would allow partners to stay together. Very few hostel-type accommodations would accept a pair of old dykes because there would be uproar from the residents; there is enough uproar having married couples living together. There is a Lodge in the city with double rooms. Lesbian couples wouldn't be accepted; it's very upmarket, a square broadminded place. If lesbians wanted to go into an aged-care facility as a couple you would be very lucky to find one that would accept you as such. You would even be lucky to find one that would give you adjoining rooms. Although it is illegal to discriminate,

there is always a way out. If we wanted to go into hostel accommodation as a couple, I think we would find it almost impossible. The idea of the old dykes' home is great (Anne, 77 years, lesbian).

Anne's need to have her relationship recognised by aged-care service-providers and co-client was shared by others. Joseph, a 61-year-old queer man receiving home services, described the need for services in which he would not be discriminated against because of his sexuality:

If you can go to a place where you're not in the least bit embarrassed about your sexuality or your sexuality, preferences or activities then the rest is a doddle. You're not likely to become the subject of discussion if you're interested in model railways. But your sexuality, particularly homosexuality, defines how a lot of people respond to you (Joseph, 61 years, queer).

The fear that his sexuality would define how his carers responded to him prevented Joseph from disclosing his sexual identity. The wisdom of this decision was consolidated for Joseph in the homophobic remarks made by his carer in response to gay men profiled in the media. The solution preferred by Joseph was GLBTI-specific facilities which valued sexual/gender diversity. Joseph suggested that:

If you're in a gay and lesbian aged-care facility and they had doctors and people coming in, they would know they are going to this sort of place. They can't say they were confronted because this old chap wanted to talk about anal activity. You'd say: 'Well look pal, what did you expect?' So you're going to get people that are coming in there that you can reasonably assume 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).

Like Joseph, many participants reported diminished opportunities for sexual expression in care. There appeared to be a correlation between dependence on service and opportunities for sexual expression; with those who were more dependent and had less privacy and fewer opportunities for sexual expression. The importance of sexual expression being supported by staff, and being made safe, was explored by Joseph:

I think it's a good thing to continue on in sexual activity as long as you can. I want to do that in a place where there is no odium attached to it. People understand. You're not just another dirty old poof. If you wanted

to hire someone to come in and have sexual activity with you, you're in a place where it's relatively safe. You're not just another vulnerable old poof out there in the suburbs at the mercy of some bloody homicidal young bloke who's decided he's going to kill you and rob you (Joseph, 61 years, queer).

These comments highlight the fear felt by many participants that generated support for GLBTI-specific aged-care services. On the other hand, most participants also described the importance of staff education to prevent discrimination and ensure that staff understood their needs. In the next section the suggestions for the education of staff are described.

Education

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. Perhaps the most pressing need for education relates to the legal responsibilities of aged-care service-providers in relation to discrimination. As cited previously, 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), the *Equal Opportunity Act* (1995) and the *Statute Law Amendment (Relationships) Act* (2001) clarify the right to equality.

It may be important to ensure that aged-care service-providers are aware of their responsibilities under this legislation. Furthermore, it is necessary to further explore how such legislation intersects with legislation governing aged-care services. Other opportunities for the education of aged-care service-providers are highlighted in this report. In particular the phenomenon of 'My People' and the associated service characteristics that enabled participants to feel valued and cared for are explored next.

'My People'

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.

Understanding and empathy

The importance of understanding and empathy were highlighted when valued service-providers respond with understanding to the needs of GLBTI seniors. Some participants thought that GLBTI service-providers were better able to understand their needs and have empathy. Empathy was seen as an act of understanding, and it was noted that some aged-care service-providers did not empathise, as they did not understand what it meant to be GLBTI. 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. Some of the particular issues which arose related to the need for staff to understand the following:

1. The fact that seniors are sexual
2. The fact that some seniors are GLBTI
3. What cultural and sexual expression means to GLBTI seniors, what it encompasses and how opportunities for sexual expression can be provided
4. The historical experiences of the current generation of GLBTI seniors and the implications for their aged care
5. Strategies to develop GLBTI-friendly aged-care services
6. Positive responses to disclosure of sexual/gender identity by GLBTI seniors
7. Negative consequences for GLBTI seniors who feel that they have to re-enter a closet when they receive aged-care services
8. The impact of staff values and beliefs on the care that they deliver
9. The potential vulnerability of GLBTI seniors who are unable to conceal their identity
10. Their responsibility to protect GLBTI seniors from discrimination
11. Universal infection-control guidelines, and how the fear of HIV/AIDS relates to the care of gay men
12. The special needs of GLBTI seniors with dementia.

These understandings could be conveyed to aged-care service-providers through access to the stories presented in this report. These stories could also assist in generating understanding and empathy and enable GLBTI seniors to feel that they can trust their carers.

Trust

Several participants described the importance of trust in their relationships with family, friends and aged-care service-providers. This is not surprising given the historical experiences of discrimination upon disclosure. To foster trust in their relationships with aged-care service-providers, some participants described allowing carers to know them as a person before disclosing their sexual identity. 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 and participants identified the need for aged-care service-providers to understand and have empathy with GLBTI seniors before being considered trustworthy.

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 and in other cases it was an aged-care service-provider. Advocates were generally people who understood GLBTI seniors, had 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 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 sometimes fallen short in some aged-care services. In some services, the development of organisational policies to support diversity was

apparent through the employment of GLBTI staff and an investment in staff education in diversity.

To create GLBTI-friendly aged-care services, the stories from GLBTI seniors in this study could be used as a basis for service review and policy development. It could also be valuable for staff to determine strategies for creating GLBTI-friendly aged-care services.

While responses to this report seek to address the needs of GLBTI seniors in aged-care services, discrimination will continue to occur. Interim strategies to provide advocacy for GLBTI seniors and support for aged-care service-providers need to be considered as a process of developmental change in the sector.

Partnerships with aged-care services

The general community is often unaware that seniors are sexual and the some seniors are GLBTI. Therefore, it is not surprising that aged-care service-providers hold the same beliefs. Furthermore, few aged-care service-providers have been provided with education about the issue of sexual expression and ageing. However, given the reliance of seniors on aged-care services, service-providers need to understand the importance of sexual expression and GLBTI identities.

Aged-care services will increasingly find themselves caring for GLBTI seniors. The opportunity now exists to work with aged-care services to create GLBTI-friendly services. To achieve this important goal it is necessary and important to engage service-providers and other stakeholders in the process. By exploring their experiences and seeking feedback on this report, the determination of strategies for creating GLBTI-friendly aged-care services can only be enhanced.

Attachment 1: Advertising

The Experiences of Older Non-Heterosexuals - Services and Support for Older People

The Matrix Guild and Vintage Men are conducting a study exploring the experiences of older non-heterosexual people as recipients of services and support for older people. This could include services in nursing homes, hostels, in their own homes and in many other locations, such as a community or day care centre or medical service. If you are gay, lesbian or bisexual and a current or past recipient of such services or other supports and you would like to tell us about your experiences (or if you know someone who would) please contact Catherine: Project Researcher on 0448011394 or cchange@netspace.net.au before July 31st 2007.



This Project is proudly supported by the Matrix Guild of Victoria, Vintage Men Inc, The Reichstein Foundation, The Brotherhood of St Laurence, Victorian Gay and Lesbian Rights Lobby, Gay and Lesbian Health Victoria, The Also Foundation, Women's Health East, Women's Health in the South East, Women's Health West, The Australian Lesbian Medical Association, The School of Health Sciences: The University of South Australia, The Victorian Council on the Ageing and Victorian Equal Opportunity & Human Rights Commission.

Attachment 2: Participant Information & Consent



Version 2: Dated 10th May, 2007

Full Project Title: Exploring the Experiences of Non-Heterosexuals in Aged Care.

Project Researcher: Catherine Barrett

This Participant Information and Consent Form is six pages long. Please make sure you have all the pages.

1. Your Consent

This Participant Information and Consent Form contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in the Project before you decide whether or not to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may wish to discuss the Project with a relative or friend.

Once you understand what the Project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

The Project is being undertaken by Matrix Guild Victoria and the Vintage Men.

Matrix Guild: Provides services for lesbians over 40 years of age and is committed to the support of appropriate care, accommodation choices and alternative lifestyle options. Matrix Guild also provides information and training for government, service-providers, consumers and the general public.

Vintage Men: Is a social and support group for mature gay and bisexual men and their friends.

The aim of the Project is to identify the needs of older non-heterosexual people. This will enable challenges to policy and legislative officers at all levels of government where unmet needs exist.

To identify these needs, the Project Researcher will interview 20 individuals about their experiences of aged care. These interviews will explore positive stories of aged care, as well as stories of negative experiences, which may include discrimination. To understand these experiences in more detail, a number of participants will be invited to take part in more in-depth interviews and may or may not choose to nominate two 'significant others', such as a partner or an aged-care service-provider, to be interviewed. Nomination of such significant others is entirely the choice of participants, who may opt not to do so but still wish to be interviewed.

The Project is being monitored by a steering committee with representation from a number of community groups which support the gay, lesbian, bisexual, transgender and intersex community. The Steering Committee will support the Project and any changes which are initiated in response to the Project. The Committee includes representation from the following organisations:

Matrix Guild Victoria Inc.	Vintage Men Inc.
The Carlton Clinic	The Brotherhood of St Laurence
Victorian Gay and Lesbian Rights Lobby	Gay and Lesbian Health Victoria
The Also Foundation	Women's Health East
Women's Social Health Advocate	Women's Health West
Australian Lesbian Medical Association	
School of Health Sciences, The University of South Australia	

The Project has also received in-kind support from the Victorian Council on the Ageing; Equal Opportunities Commission Victoria and Women's Health Victoria. In addition, funding has been received from the Reichstein Foundation.

3. Procedures

After you have spoken to the Project Researcher on the phone, you will be sent this information form, inviting you to participate in an interview. The interview will take between 30 and 60 minutes and can be conducted over the phone or in person. In the interview you will be invited to describe your experiences of aged care. You will also be asked how the aged care you have received has affected you and your relationships.

To understand the experiences of participants further, a small number of interviewees will be invited to nominate other people, with an influence on their experience of aged care, to be interviewed. For example, this may include a partner or aged-care staff. In an interview, the Project Researcher will invite this person to describe his or her experiences of aged care for non-heterosexuals. The Project Researcher will discuss with you whether your identity needs to be protected from this person and, if so, how this can occur.

All the interviews will be taped and later transcribed for analysis. You will be invited to review a copy of the notes taken from your interview and make any necessary changes before it is included in the project report.

4. Possible Benefits

Your participation in the interviews is not expected to benefit you directly. However, your participation may help to positively change the type of aged-care services provided in the future, and the manner in which aged-care services are provided.

5. Possible Risks

The possible risks from participation in the Project are minimal. The Researcher will discuss with you what strategies will assist in protecting your identity. You will also be invited to check information before it goes into the Project report to de-identify any aspects of your story.

If you nominate 'significant others' to participate in interviews, the Researcher will invite you to clarify whether your identity needs to be protected and, if so, how this can be achieved. Strategies to protect your identity will include de-identification of your story as it appears in the project report, before it is available to these 'significant others'.

6. Alternatives to Participation

You do not have to participate in an interview to receive the care you require. If you do not wish to take part you are not obliged to.

7. Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this Project and that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law.

We will maximise confidentiality and protection of privacy during reporting. In any publication relating to the Project, information will be provided in a way to prevent you from being identified.

Only Project staff will have access to the information collected from your interview. In accordance with Australian Privacy laws you have the right to access the information collected and stored by the Project Researcher about you. You also have the right to request that any information with which you disagree may be corrected. Please contact the Researcher if you would like to access your information.

Records of interviews will be stored securely in a locked filing cabinet. This data will not identify you. Following completion of the study, research records will be stored securely and retained for a period of five years after publication in Gay and Lesbian Health Victoria archives and then destroyed.

8. Results of the Project

Results of the Project will be presented back to the Project Steering Committee. If you would like a copy of the summary of the results of the Project, please notify the Project Researcher.

9. Further Information or Any Problems

If you require further information or if you have any problems concerning this Project you can contact: The Project Researcher, Catherine Barrett, on 0448 011 394

10. Other Issues

If you have any complaints about any aspect of the Project, the way it is being conducted or any questions about your rights as a participant, then you may contact Jane Kent, Community Development Worker, Matrix Guild on 0438 411 441.

11. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the Project at any stage.

Before you make your decision, the Researcher will be available to answer any questions you have about the Project. You can ask for any information you want. Please sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw your participation after you have signed the consent form, please notify the Researcher before you withdraw. This notice will allow the Researcher to provide you with a *Revocation of Consent Form*.

12. Ethical Guidelines

This Project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical guidelines for this Project are monitored by the Project Steering Committee.

Participant Interview Consent Form – Aged-Care Recipient

Version 2: Dated 10th May, 2007

Full Project Title: Exploring the Experiences of Non-Heterosexuals in Aged Care

I have read and I understand the Participant Information, Version 2, 10th May 2007.
I freely agree to participate in this Project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep
The Researcher has agreed not to reveal my identity and personal details if information about this Project is published or presented in any public form.

Participant's Name (printed)
Signature _____ Date _____

Researcher's Name (printed)
Signature _____ Date _____

Note: All parties signing the Consent Form must date their own signature.

Participant Interview: Revocation of Consent Form – Aged-Care Recipient

Full Project Title: Exploring the Experiences of Non-Heterosexuals in Aged Care

I hereby wish to WITHDRAW my consent to participate in the Project described above and understand that such withdrawal WILL NOT jeopardise my care or my relationship with my carers.

Participant's Name (printed)

Signature

Date

Resources

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.

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.

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.

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

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>>.

Inter/Section 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>).

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>).

The 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/>).

Matrix Guild Victoria Inc. (0438 411 441): 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>).

The 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 (9776 8667): A social and support group for mature gay and bisexual men and their friends. (www.geocities.com/vintagemen).

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).

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