



Productivity Commission Inquiry into 'Caring for Older Australians'

July, 2010

Caring for Older Australians Productivity Commission GPO Box 1428 Canberra City ACT 2601

Submitted by email to: agedcare@pc.gov.au

Dear Inquiry Secretary,

Please find below a joint submission by Matrix Guild (Vic) Inc (Matrix) and Coalition of Activist Lesbians – Australia (COAL) to the Productivity Commission's Inquiry into *Caring for Older Australians*. Matrix and COAL thank the Productivity Commission for the opportunity to make this submission.

Matrix and COAL also support the submission to this Inquiry of Dr Jo Harrison from the University of South Australia

About Matrix Guild Victoria Inc (Matrix)

In 1992 Matrix Guild Victoria Inc. was founded by, and for the benefit of, Lesbians over forty years of age. Matrix is committed to the support of appropriate care and accommodation choices for older Lesbians in Victoria. The vision and aims of the founding Lesbians were to raise money to assist Lesbians who are marginalised, at risk, disabled/frail, and to enhance their wellbeing and quality of life. We do this through provision of information on care and support services, whilst at the same time promoting and liaising with government agencies and service providers to develop more appropriate Lesbian-friendly services. Matrix combats ageism and opposes discrimination against older Lesbians; challenges lesbophobia; promotes social contact and support among older Lesbians; supports accommodation choices that cater to the needs of ageing Lesbians; conducts research; and advocates on behalf of older Lesbians to governments and other relevant bodies.

As the result of a bequest by a deceased member of Matrix, three social housing flats - for lesbians of reduced means - are currently under construction in Brunswick, Melbourne.

About Coalition of Activist Lesbians - Australia

The Coalition of Activist Lesbians - Australia (COAL) is the only United Nations-accredited lesbian non-government organisation (NGO). COAL was formed in 1994 to work towards ending discrimination against lesbians. We are a national community-based organisation that advocates on behalf of Australian lesbians to all levels of government.

In this role, COAL lobbied at the UN 4th World Conference on Women, Beijing, 1995, and co-hosted the first international lesbian-space tent at the 1995 NGO Forum. COAL networks widely with national and international women's, and lesbian and gay, organisations. Among a number of other organisations, COAL successfully lobbied for the Australian Government to sign the Optional Protocol to the Convention for the Elimination of All Forms of Discrimination Against Women (CEDAW).

COAL produces research papers about lesbian health; violence against lesbians; lesbophobia; and lesbian domestic violence. We have convened the Lesbian Health Advisory Group (LHAG) in NSW to promote best practice lesbian health care. COAL produces training manuals on cultural competence for service providers, in order to improve lesbians' access to these services. In addition, we produce trainer training manuals for those running groups for new and emerging lesbians.

As Australia's peak body on lesbian-specific human rights COAL is well-placed to offer a complementary perspective to that of Matrix on *Caring for Older Australians*.

Indigenous Aged

As a sign of respect, and in acknowledgement of the specific health needs of indigenous Australian community and aged care facility residents, Matrix Guild (Vic) Inc and COAL - Australia support the calls of the indigenous Australians who make submissions to this Inquiry for affirmative action to be taken in pursuing equitable, as distinct from equal, health outcomes for First Australian people in community and residential aged care.

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5. Examine the future workforce requirements of the aged care sector, with regard to Lesbian-specific needs, 'to ensure that the sector has access to a sufficient and appropriately trained workforce'

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Introduction

In this submission, Matrix and COAL:

- 1. Examine social, clinical and institutional barriers to Lesbian access to culturally competent residential and community aged care in Australia, outlining how the mainstream service system has failed, and is still failing, to meet the needs of Lesbians as a specific group;
- 2. Provide evidence of Lesbians' relative financial disadvantage in relation to gay males and heterosexual women which may affect their access to aged care;
- 3. Outline research and policy initiatives which work counter to Lesbian independence, social participation and social inclusion;
- 4. Examine policy, services and infrastructure that could support older Lesbians to remain in their own homes for longer, participate in the community, and reduce pressure on the aged care system;
- 5. Consider 'technical and allocative efficiency issues, recognising that aged care is an integral part of the health system and that changes in the aged care system have the potential to adversely or positively impact upon demand for other care modalities'
- 6. Suggest mechanisms which would minimize the complexity of the aged care system for clients, their families-of-origin and families-of-choice, and providers and provide appropriate financial protections and quality assurance for consumers
- 7. Consider what might 'allow smooth transitions for Lesbian consumers between different types and levels of aged care, and between aged, primary, acute, sub-acute, disability services and palliative care services, as need determines'
- 8. Examine the future workforce requirements of the aged care sector, with regard to Lesbian-specific needs, 'to ensure that the sector has access to a sufficient and appropriately trained workforce'

We do not, at this stage, intend to address points 4 to 6 of the Terms of Reference concerning fiscal implications of, or mechanisms for, transitioning from the current physical infrastructure or regulatory arrangements to a new system. Instead, Matrix and COAL will concentrate on our own, and other, research on Lesbians in residential and community aged care. WE feel that is important that the voices of Lesbian residents, community care consumers, and aged care workers be heard. Matrix's research can be found at http://www.matrixguildvic.org.au/ Subsequently a study on aged care conducted in Western Australia (GRAI, 2010) has confirmed many of Matrix's findings.

We note that, point 2 of the Productivity Commission's Terms of Reference enumerates a number of marginalised aged care communities, namely those 'living in rural and remote locations, Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, and veterans'. While there are Lesbian members of all these marginalised groups, the Terms of Reference do not make it explicit whether Lesbians are to be included in 'culturally diverse communities'. If not, they are invisible.

It is a strange paradox that, whereas it has been estimated that 8-11% of the Australian population belong to sexual minorities (Australian Medical Association, Online, 2002), none of these people, *purportedly*, end up in community or residential aged care (GRAI, 2010; Matrix Guild 2009, 2008) because service providers are mostly unaware that they have Lesbian residents or community clients.

In all my years of working in health I've never had someone ever say to me I'm a lesbian female... within the patients or residents, or whoever... So I don't know how staff would respond in that situation (Respondent low care facility) (GRAI, 2010:56)

One result of this invisibility is many aged care facilities' failure to regard Lesbians as a group with special needs, or to give any priority to writing policies and procedures that protect Lesbian residents and consumers, or correcting heterosexist practices among staff and co-residents (Matrix Guild, 2009, 2008). How would aged care accreditation bodies react to facilities which said they were not going to take the needs of CALD or indigenous seniors, or aged care consumers with disabilities into account?

The Australian Medical Association's *Position Statement on Sexual Diversity and Gender Identity* states that:

'Australia's Aged Care policies make no reference to the specific needs of GLBTI older people, particularly in relation to institutional care. There is a need to recognise sexual and gender diversity within the aged care sector as this lack of recognition means that the health needs of many older people are not being adequately addressed with culturally appropriate care' (AMA Online, 2002)

The term 'LGBTI' refers to 'lesbian, gay, bisexual, transgender, and intersex' people. Recent evidence (Chamberlain and Robinson, 2002) recognises that, as a result of their experiences of discrimination, LGBTI seniors do indeed have special needs (Matrix Guild Vic Inc, 2009:15). LGBTI aged care recipients constitute not only one vulnerable population - but, in fact, a number of populations - all with specific 'special needs'. For instance, Matrix's research included a case of staff not wanting to touch a gay male senior who was HIV+. And another case of a male who needed assistance from staff with cross-dressing. Lesbians' needs differ from these, but also, often, from the needs of heterosexual women in aged care.

The Productivity Commission's Terms of Reference do not explicitly mention, or define, the term 'a resident-centred approach', although this is implied in Terms of Reference 1 and 2, in that the needs of specific marginalised groups are to be taken into consideration. Matrix and COAL assume that this is the equivalent of 'patient-centred care' in hospitals whereby, ideally, residents' needs are taken as the starting-point and institutional aged care resources and personnel are organised around them, rather than vice versa (Stewart 2001, 1995; Stewart et al, 2000). The 'community expects aged care service providers to understand and respond to the needs of seniors who are dependent on them' (Matrix Guild Vic Inc, 2009:51). This is no less true for Lesbians than for other residents or community care recipients.

This submission argues that Lesbians belong to a specific culture - which is different from that of other sexual minorities - and that Lesbians' care needs, in the context of community and residential aged care are largely unmet, which often results in suboptimal care outcomes.

It is not only within the wider community, but also within the LGBTI (lesbian, gay, bisexual, transgender, intersex) communities themselves, that gender differences between Lesbians and gay men are poorly understood. Dyson states that there is a 'tendency to focus on a specific target group as if it is gender neutral, such as homosexual people... This ignores the fact that women and men in the population in general, as well as in marginalised and smaller communities, experience differences that stem from the effects of sex role stereotyping' (Dyson, 2001:12). This is corroborated by section 2.3 of the Australian Medical Association's *Position Statement on Sexual Diversity and Gender Identity* (2002 Online); the United Nations General Assembly *Declaration on Sexual Orientation and Gender Identity* (18 December, 2008); and *The Yogyakarta Principles on the Application of International Human Rights Law in Relation to Sexual Orientation and Gender Identity* (March, 2007, Online). That is why it is necessary to treat Lesbians as a separate, and autonomous, group from gay men when considering their aged care needs.

Similarly, compounding the lack of understanding outlined above is the inability, of many, to grasp that intra-gender differences - and hence differential needs for protection from discrimination - exist between heterosexual and Lesbian women. As women, Lesbians are vulnerable to sexist discrimination, but Szymanski's research has shown that, unlike heterosexual women, 'lesbians may face oppression based on both their sexual orientation and their gender' (2005:355). Thus, it is necessary to take these two interlocking forms of discrimination into consideration when considering Lesbians' - as opposed to heterosexual women's - aged care needs. Again, Lesbians must be treated as a separate, and autonomous, group vis a vis 'women' if their care needs are to be adequately addressed.

As the longest-standing peak community bodies (18-16 years) representing Victorian - and Australian - Lesbians Matrix Guild (Vic) Inc and Coalition of Activist Lesbians – Australia are in a unique position to offer this Inquiry a Lesbian-specific perspective on residential and community aged care. This submission mainly only covers the 'L', or Lesbian, part of the LGBTI community/ies, providing Lesbian-specific evidence where this is available.

No previous Australian studies, before the Matrix research (2009, 2008), have sought feedback both from aged care service providers and residents or community care recipients to develop an action plan to create LGBTI-friendly aged care services.

This Inquiry is particularly timely. Matrix's own research reveals - in some residential and community aged care - a lack of cultural competence regarding Lesbians. This means that these residents and community members often have ongoing unmet needs which significantly negatively affect their quality of life. Indeed, some LGBTI seniors have been reported, in clinical interactions, to prefer 'death rather than go into a nursing home' (The Senate Community Affairs Reference Committee, June, 2010; Matrix Guild Vic Inc, 2009:48).

The importance of the April, 2010, revision of the Victorian *Equal Opportunity Act 1995*, and its exceptions and exemptions (which are echoed in most states' legislation) cannot be overestimated with regard to its impact on caring for older Lesbian Australians.

Definition of Terms

HETEROSEXISM, also sometimes known as **HERERONORMATIVITY**, may be defined as 'the complex social and psychological processes underpinning violence and discrimination against...lesbians....a social system that privileges heterosexuality at the expense of non-heteronormative sexual orientations and gender identities (Fish, 2006; Herek, 1990; Leonard, 2005). Heterosexism

assumes that sex, gender and the relationship between the two are fixed at birth... According to this heterosexist presumption, society is built on the primal division and attraction between male and female. Those who challenge this presumption are subject to differing degrees of discrimination and abuse. (Heterosexism is a) coordinated system for punishing those who in different ways pose a threat to heterosexist privilege and authority' (Leonard et al, 2008:4). Heterosexism also implies 'that alternative sexualities pose a threat to society' (Clause 2.1, AMA, Online, 2002).

The **ASSUMPTION OF HETEROSEXUALITY** (Brown, 2000; McNair, 2000) is one of the most common manifestations of heterosexism and heteronormativity.

There has been a growing body of evidence concerning the *MINORITY STRESS* experienced by lesbian and gay people (Balsam and Szymanski, 2005; Meyer, 2003, 1995; Brooks, 1981). Meyer has defined 'minority stress' as 'the excess stress to which individuals from stigmatized social categories are exposed as a result of their social, often a minority, position' (Meyer, 2003:675). One study of lesbians and gays showed that 'There are numerous decisions and choices (large and small) that they make, and numerous ways in which they modify their behaviour, in an effort to reduce the likelihood of abuse' (Attorney-General's Department of NSW and Urbis, Keys, Young, 2003:6). Minority stress theorists describe the ongoing tension of trying to decide whether a Lesbian is safe to come out or not and the conscious decision to expose themselves to the possibility of discrimination (Balsam and Mohr, 2007; Lewis, Derlerga et al, 2003; Link and Phelan, 2001). This would apply both to Lesbian residents and to aged care service staff members.

HOMOPHOBIA/LESBPOPHOBIA

Homophobia is defined as 'The fear and hatred of gay and lesbian people and of their sexual desires and practices' (Leonard, 2002:9). O'Hanlan et al argue that 'the practice of homophobia – the socialization of heterosexuals against homosexuals and concomitant conditioning of...lesbians ...against themselves – must be recognized by healthcare providers as a legitimate and potent health hazard' (1994, Online). For the purposes of this submission, the word 'lesbophobia' will be substituted for the more widely used 'homophobia'.

To the extent that a lesbian takes these derogatory societal values into herself, she will experience *INTERNALISED LESBOPHOBIA* (Balsam and Szymanski, 2005; Szymanski, 2008, 2005; Szymanski and Chung, 2003). This internalised stigma may prevent her from, amongst other things, accessing healthcare or reporting heterosexist violence (Leonard et al, 2008; McNair, 2003, 2000; McNair, Anderson et al, 2003; McNair and Dyson, 1999).

FAMILY-OF-ORIGIN is the family into which one is born, **FAMILY-OF-CHOICE** is the family, who are not necessarily related by blood, with which some Lesbians, especially those who suffer some degree of estrangement from their families-of-origin, surround themselves for support.

We will now address some of the specific Terms of Reference.

Terms of Reference

1. Examine social, clinical and institutional barriers to Lesbian access to culturally competent residential and community aged care in Australia, outlining how the mainstream service system has failed, and is still failing, to meet the needs of Lesbians as a specific group

It is not possible to gain a proper understanding of the implications for care of why Lesbian residents and community consumers of aged care services might be reluctant to disclose their sexual orientation - to their own cost - without an understanding of the **impact of historical experiences of discrimination** (Matrix Guild, 2009:9). Why should this matter? Of what relevance to current aged care provision could it be if both individual and institutionalised violence, abuse, ignorance, and discrimination against Lesbians are endemic? It matters because, unless aged carers are aware of their consumers' needs, it is unlikely that these needs can be met. And if they remain unaware that they have Lesbian consumers, due to many Lesbians' refusal to disclose their sexuality, they will not be in a position to address those needs.

A. Medical and Mental Health Settings

If aged care is seen as an extension of the healthcare system, in general, then treatment of Lesbians in clinical settings – and their responses to that treatment – may be seen as acting as predictors of their involvement, and participation, in the Australian aged care system

Approximately one-third (27.4%) of Victorian Lesbians (n=355) have experienced active discrimination in medical settings because of their same-sex relationships (McNair and Thomacos, 2005). This figure is consistent with the 23% (n=447) of Lesbians in a survey conducted five years previously, who had experienced discrimination in medical settings against themselves as individuals (VGLRL, 2000). There is no reason to believe, given the vulnerability and dependence of Lesbians in residential aged care, that the figure in those settings would be significantly lower. Further research is required on this subject.

One in eight lesbians - more in rural areas - had their medical confidentiality breached in a five- year period (McNair and Thomacos, 2005). It has been shown that confidentiality is an issue in rural areas, in general (Gottschalk, 2007). Participants in Green and Gregory's study of rural welfare practice highlighted the management of confidentiality as a major issue in the general community, including how to work in 'non-stigmatising ways and how to offer services that did not "label" individuals' (2004: 249). While medical failure to protect Lesbian patients' confidentiality - by members of a respected and supposedly ethical profession - does not equate to physical violence, it is an important issue because of the potentially great negative impact it can have on Lesbians' lives. It is likely to contribute to Lesbians' perceptions of lack of safety and respect in health settings. (Concrete examples of how this manifests in aged care will be explored in another section of this submission).

Discrimination in healthcare is important because it can lead to Lesbians choosing not to seek healthcare, or avoiding doing so until their ill-health is far-advanced which, Wilkinson and Pickett (2009) would argue, increase the burden of ill-health of the entire population. A survey of lesbian patients at the Carlton Clinic in Victoria (n=160) revealed that 47% have not come out to their GP and that 31% did not have a regular GP (McNair and Dyson, 1999). More research shows that some lesbians delay their attendance at

primary care providers for as long as possible (Bowers, Plummer et al, 2006; McNair, 2003, 2000). In their national survey of 791 New Zealand lesbians, Saphira and Glover (1999) showed that lesbians delay seeking both alternative and mainstream healthcare: 33% use self-care and 53% wait before presenting, while Neville and Henrickson's survey - undertaken seven years after that - showed that some lesbians were choosing not to access primary healthcare services at all because of their sexual orientation (2006). A Sydney survey of sexual minority women (n=440) revealed that 16% had never had a Pap screening (Richters, Song et al, 2004). Some respondents in the Melbourne Royal Women's Hospital survey said that they had been denied Pap tests because they were lesbians (Brown, 2000). Others indicated that lesbians wanted to disclose – but were afraid to do so (Brown, 2000). Medical assumptions of heterosexuality can endanger the lives of Lesbians because it is assumed that they have never had sex with men and that STIs like HPV, the precursor to cervical cancercannot be spread between women.

In a survey of staff at the Royal Women's Hospital (n=80) clinicians were either unaware of the need to ask patients if they were Lesbians, or afraid of offending if they did; over 80% saw no reason to ask; and 57% believed that Lesbians do not have different health issues from other women, or were unsure (Brown, 2000. See also National Women's Health Policy, 1989). It is possible to interpret 'fear of offending' as a projected manifestation of what is happening in the mind of a practitioner (Gelso, Fassinger et al, 1995), who is embarrassed by the whole topic of sexuality, rather than that of his/her patient. This phenomenon was actually made explicit in Hinchliff, Gott, and Galena's (2005) article *I Daresay I Might Find it Embarrassing* and covered in Tideman et al's (2004) article outlining how even sexual health specialists find it challenging to discuss their patients' sexual histories. (See also Khan, Plummer et al, 2008,2007). While discussing Lesbians' sexual history is an important aspect of their healthcare needs, it must be understood that discrimination affects Lesbians' whole-of-life health.

Neville and Henrickson's empirical study on lesbians' perceptions of healthcare services asserts that 'Fear of homophobic reactions through actual previous negative experiences, including mildly judgemental interactions, with healthcare professionals influences LGB people's decisions as to whether they will disclose' (2006:409). Article 6.3 of the Australian Medical Association's position statement on sexual orientation 'acknowledges that a doctor's use of language that assumes an individual to be heterosexual makes it harder for a person to disclose their sexuality' (2002 Online). Lesbians have sometimes been blamed for their failure to seek professional care, and they are sometimes criticised for their choice not to disclose or, often, disclosure is regarded as irrelevant to their care (Khan, Plummer et al, 2008; Neville and Henrickson, 2006; McNair, 2000).

If they are over 37 years old, Lesbians' formative years will have been spent in a socio-historical context in which homosexuality was clinically defined as a mental illness (See previous editions of the American Psychiatric Association's *Diagnostic and Statistical Manual* and *International Classification of Disorders*).

Some of Matrix Guild's recent aged care research participants know what having one's sexuality defined as mental illness entails. Having shock therapy

'was meant to teach me how to be straight. All it taught me was to keep my mouth shut' (Matrix Guild, 2008:36).

Other Lesbians, who are currently in or entering aged care, have also suffered from social stigmatisation, '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' (Matrix Guild Vic Inc, 2009:9). Evidence exists of Lesbians who have needed to seek support from outside agencies, rather than families-of-origin, from

whom they were estranged (Clarke, 2004). This estrangement from potential family supports might render Lesbians who were entering aged care more vulnerable to discrimination than women who were surrounded by protective and supportive families-of-origin.

Some counsellors, psychiatrists, and physicians offer exemplary care to their lesbian clients (Mulligan and Heath, 2007; Stevens, 1996; Garnets and Hancock, 1991). However, regardless of the removal of homosexuality as a mental disorder from the *Diagnostic and Statistical Manual* in 1973 (and *ICD-10*, its British and European equivalent, in 1992) homosexuality and lesbianism are still deemed by some psychoanalysts to equate to treatable psychopathology (Singer, 2008, 2005; Welch, Collings et al, 2000), which needs to be 'repaired'. Singer states that 'these sentiments still exist within our profession, but are kept out of print...Homophobic sensibilities continue to find a voice in training institutes and psychoanalytic doctoral programs' (2008:181. See also Rothblum, 1994, who stated the need for differentiation in research between lesbians' and gay men's mental health). Later in this submission it can be seen that geriatricians working in aged care are not immune from lesbophobic discrimination.

Confirmation of the above views is presented in articles by Bowers, Plummer et al (2006) and Daley (2003) regarding resistance to gender diversity training in public hospitals and the difficulty in changing their ingrained lesbophobic cultures and practices. Neville and Henrickson suggest that the situation is not much different across the Tasman, 'Despite an apparent acceptance of LGB people in recent times, there is a continuing and underlying stigma associated with living a non-heterosexual lifestyle' (2006:408). Earlier research, for example the findings of Tonkins' psychological sciences thesis, suggested that, 'While (131 heterosexual Melbourne trainee mental health) professionals may advocate for the legal and civil rights of ...lesbians, their affective responses and moral judgements... (are) considerably less positive and accepting' (Tonkin, 1997:56). Although he does not mention lesbophobia explicitly, Croskerry's research on patient safety in hospitals argues persuasively that diagnostic derailing and even total failure can be occasioned by emergency diagnosticians' 'affective influences' (2005).

Some Lesbians choose to attend Lesbian-specific medical clinics in order to avoid the potential of lesbophobic, or ignorant, healthcare. For instance, in the international context, a Lesbian sexual health service was set up in Glasgow (Carr, Scoular et al, 1999) and was immediately well-patronised. In Australia, some clinics have developed reputations for being more, or less, Lesbian-friendly.

Knowledge of their Lesbian patients' and residents' sexual orientation is *not* irrelevant to clinical practitioners and aged care providers' ability to offer patient-centred or resident-centred, culturally competent care. Unless they can reflect upon their own attitudes to sexuality and sexual orientation, and feel comfortable to discuss these issues with patients they will not be able to understand the effects of stigma and discrimination and ongoing minority stress upon their residents' and patients' mental and other health.

Invisibility, or sub-standard treatment, of Lesbians in healthcare in general may, as Matrix's and GRAI's research shows, flow through into their similar treatment in aged care. Birch suggests that '...there is no reason to ask anyone if they are gay, lesbian, bisexual or transgender if there is no acknowledgement of this status, or if there is no relevant or inclusive service or program to benefit that person. If there is no gay-friendly symbol on the door, no staff trained in sensitivity to GLBT needs, nor even a basic program in place – why would GLBT seniors make use of your service or declare themselves to be GLBT if they do choose to use the service?' (Birch, 2004:17)

B. Community Settings

Lack of safety, in every setting, follows Lesbians throughout their lives and can result in stress, anxiety and an unwillingness to trust people who - and institutions which - have not previously demonstrated their trustworthiness. There is abundant evidence of heterosexist violence, discrimination and abuse in Lesbians' homes, schools, workplaces, geographic locations, same-sex relationships, mainstream organisations, legal settings, medical settings, and on the street (Berman and Robinson, 2010; Corboz, Dowsett et al, 2008; Leonard et al, 2008; Gottschalk, 2007; Hillier et al, 2005; McNair and Thomacos, 2005; Attorney-General's Department of NSW and Urbis, Keys, Young, 2003; McNair, 2003; Daley, 2003; Dyson et al, 2003; Gottschalk and Newton, 2003; Brown, 2000; O'Hanlan, 1994).

Studies in the three eastern states of Australia have consistently demonstrated high levels of violence against Lesbian and gay people, combined with a reluctance to report this violence to authorities. Research on 1,100 GLBT people in Queensland, released in June 2010, has found that 72% of those living in Brisbane have been victimized in the past 2 years due to their sexual orientation or gender identity. Of female participants, 6% have been physically assaulted with a weapon, 15% assaulted without a weapon, 69% verbally abused, and 75% of this violence and abuse has gone unreported (Berman and Robinson, 2010). These figures are consistent with earlier Victorian findings, in which 70% of heterosexist violence goes unreported, despite 19% of anti-lesbian violence requiring medical treatment (Leonard, Mitchell et al, 2008). This violence and abuse have remained stable over time, for instance 71% of lesbians in a 2005 study were verbally abused, 10% physically assaulted, 1.5% sexually assaulted (McNair and Thomacos, 2005). Disturbingly, 41% of Victorian lesbians are in, or have been in, violent and abusive same-sex relationships (Leonard, Mitchell et al, 2008), which has gone unacknowledged by the national anti-violence strategy. Some of this lack of reporting may be the result of internalised lesbophobia, which leads Lesbians to expect not to be taken seriously, but some of it is also based on past negative experiences (Leonard, Mitchell et al, 2008). In one NSW study, 'over half took the view that gay men and lesbians were generally safer if they hid their sexual orientation' (Attorney-General's Department of NSW and Urbis, Keys, Young, 2003:7), or 'just lock your door' as one respondent to the Leonard et al survey had been advised to do by a policeperson to whom they were reporting heterosexist violence (2008:1).

In 2005 77.9% of Victorian lesbians and gays felt unsafe to hold their partner's hand in public (McNair and Thomacos, 2005:56). According to Leonard et al, 'GLBT people perceive public space as inherently unsafe' (2008:22), with good reason it seems. In Leonard et al's survey, 'Nearly 85 per cent of GLBT respondents have been subject to heterosexist violence or harassment in their lifetimes' (2008:4). This is consistent with the overall findings of an earlier survey in NSW, in which 'Eighty-five per cent had at some time experienced (homophobic) abuse, harassment or violence... A total of 69% of survey respondents felt vulnerable to violence or harassment from strangers (74% in inner Sydney, 63% outside Sydney). Additionally, 19% felt vulnerable to violence or harassment from people they knew' (Attorney-General's Department of NSW and Urbis, Keys, Young, 2003:2). According to the NSW Attorney-General, 'The social problem of hate related violence towards gay men and lesbians has been formally recognised by Governments in New South Wales for some 20 years' (Attorney-General's Department of NSW and Urbis, Keys, Young, 2003:ii). It is not a new one. In a NSW survey conducted in 1995 'gay men and lesbians were between four and six times more likely to be assaulted in a 12 month period than other Sydney men and women' (Attorney-General's Department of NSW and Urbis, Keys, Young, 2003:ii).

Lesbians are stigmatised in at least two different ways, with the interlocking discriminations of sexism and heterosexism, and more if they happen to belong to other minority groups. For instance, 'Middle-Eastern background participants said that homophobic abuse from family or community could take such forms as exclusion, verbal abuse, assault, stalking, threats of violence and even death threats. "Honour killings" as a possible response would be the most extreme expression of a family's feelings of shame about a daughter who did not conform to family and community expectations' (Attorney-General's Department of NSW and Urbis, Keys, Young, 2003:5).

There are very few, if any, settings, including aged care, where Lesbians do not feel vulnerable, wary and self-protective.

C. Legislative Settings

There is no Federal legislation that protects Lesbians from discrimination on the grounds of sexual orientation. (This will be discussed further in Point 2). Sections 5(1) and 88EA of the *Marriage Act 1961*, revised in 2004, deny marriage, or recognition of a previous overseas marriage, to Lesbians (Commonwealth of Australia, 2004, Online), singling them out from the general population for discrimination.

In April, 2010, on advice from the Scrutiny of Acts and Regulations Committee, the Victorian *Equal Opportunity Act 1995* (Parliament of Victoria, 28 April, 2010) was changed so that religiously-run organisations can no longer discriminate against people on the basis of race, age, disability, and physical features. Sections 75-77 of the *Equal Opportunity Act 1995* remained unchanged, thereby allowing religiously-run organisations to continue discriminating against people on the basis of their sexual orientation (Parliament of Victoria, 28 April, 2010; Fyfe, 2009). This has immense implications for Lesbians who are in, or seeking, aged care services. It means that Lesbians have no legal redress if they are discriminated against in residential or community aged care service run by religious organisations. It also greatly affects Lesbians' ability to feel safe in accessing healthcare and aged care. For instance, a Lesbian could not feel safe from potential discrimination or abuse in accessing any of the 75 hospitals and 550 aged care services run by Catholic Health Australia (2010, Online), nor aged care facilities run by other religious denominations. Most other Australian states have similar religious exceptions and exemptions to their *Equal Opportunity Acts*.

The Federal government argued that the changes to Centrelink entitlement to benefits were 'equal' because gay and Lesbian couples now have to disclose their relationship status, just like heterosexual couples do, and receive a lesser 'couples' benefit. But this does not take the impact of historical discrimination into account. The effects of this legislation will be discussed more fully under Terms of Reference point 2 of this submission.

D. Family-of-Origin

Under normal circumstances, a person might expect that her family would support her when she was going through difficulties, such as making the decision to enter, or entering, aged care. It can be particularly shocking for a Lesbian to discover that this support is conditional upon her adopting her

expected role in society. The punishment for refusing to do so can be quite pronounced social exclusion. Gottschalk and Newton found that families-of-origin often expressed a conditional, and 'limited form of acceptance coupled with restrictions placed on public display of a homosexual relationship in family and local community contexts' (2003:5). It would be useful to know what psychological effects these mixed messages have on Lesbians, both in residential and community aged care if, for example, the family-of-origin visits them in a facility. Further research is required on this subject.\

E. Rural Settings

The situation of Lesbian seniors in rural aged care facilities can be particularly vulnerable and isolated because there are a 'hell of a lot of people who are bigoted because they don't encounter sexual diversity ('Lisa', team leader, home and community care)' (Matrix Guild Vic Inc, 2009:33). Older rural lesbians whose partners die can often face exclusion because they are invisible:

'In rural Victoria a lot of lesbians are not out. Some of them have been living together for many years but haven't come out to work or to their family. So, when their partner dies they are devastated because they can't tell anyone' ('Vanessa', manager, community care).

(Matrix Guild, 2009:33)

Although it was not specifically related to aged care, only 45.5% of LGBT research participants in Gottschalk's research on rural-dwellers believed that Lesbian or gay sexual orientations 'reflect a natural expression of human sexuality' (Gottschalk, 2007: 11), as suggested by the Australian Medical Association (Online, 2002). Hearing generalised negative comments about LGBT people, and seeing the negative effects on the lives of other Lesbians in a country town, made it harder for some of the Lesbians in Gottschalk and Newton's (2003) study to come out, themselves. Gottschalk and Newton's research showed that, amongst their rural participants, 'Eighty-nine percent of lesbians...indicated that they had heard negative comments made about homosexuals. Seventy-eight percent...were aware of homosexuals being abused or bashed and 81.8% of lesbians...were aware that homosexuals were actively discriminated against' (2003: 89).

The above situation potentially makes accessing services and support a scary process for rural lesbians. 'Maggie' said, 'I was too frightened to come out in Ballarat because I often heard a lot of negative comments made about lesbians and I'd seen the way a lesbian couple lost all of their friends when people found out they were gay' (Gottschalk and Newton, 2003: 89-90). Knowing everybody in a small country town, and having them know you - with a concomitant lack of anonymity and confidentiality - was a common theme in much research on Lesbians living in rural settings. Edwards conducted in-depth interviews with eight South Australian women, who were found to experience 'lack of visible role models' (Edwards, 2005:4), lack of nearby social support networks, 'conservative and homophobic communities' (Edwards, 2005:5) where everyone knows everyone's business.

Because people often know each other in small country towns, it would seem particularly important for professionals to maintain their clients' confidentiality. However, it was found that 13% of lesbians (and a greater percentage in rural areas) had had their medical confidentiality breached in the past 5 years (VGLRL, 2000). Therefore, lesbians living in rural, regional and remote areas live with well-founded fear of being 'outed', or having their sexuality disclosed by other people without their consent. This can have drastic consequences for their education, employment, and overall wellbeing – and also, presumably for their experiences in aged care, although these have not yet been thoroughly researched. Evidence exists of lesbians being driven out of the rural communities where they live (Gottschalk, 2007). When she asked

Lesbian research participants whether discrimination by family, friends, neighbours and the general community, or fear of such discrimination, had caused them to leave their rural/regional community, Gottschalk (2007) found that these factors had caused 38% of lesbians to re-locate, sometimes forcibly. 'Kate' explained, 'The rural community I was living in held a town meeting where it was decided to "get rid of the undesirables" (Gottschalk and Newton, 2003: 96).

Resilience in rural Lesbians would be promoted by being surrounded by supportive connections with their families-of-origin and peers in the broader community. Since these are, unfortunately, often not available, it is essential - especially in rural areas – for them to have access to mental healthcare providers who can offer them non-judgemental attitudes and competence in identifying their unique needs and providing positive input in addressing them (Suicide Prevention Resource Center, 2009 Online). Again, cultural competence in addressing lesbians' specific issues is often lacking, partly due to funding and partly due to lack of professional development in staff (Gottschalk and Newton, 2003). Although evidence is lacking concerning the situation in rural aged care, there is no reason to believe that attitudes among rural aged care service providers would differ significantly from the rural community in general. Further research is required in this area.

F. Residential Aged Care – 'In the Closet' or Disclosure?

Some care providers are aware of the effects of stigma and discrimination on Lesbians' health (Garnets, Hancock et al, 1991) and offer them culturally competent care. However, the vast preponderance of research findings indicate that many aged care service providers display their ignorance or heterosexism by being unaware that they have Lesbian aged care residents (GRAI, 2010, Matrix Guild, 2009, 2008; Harrison, 2006, 2001; Hughes, 2004, 2004a), or treat Lesbian patients (Newnham, 2001; Brown 2000; McNair, 2000; Stevens and Hall, 1998, 1991). They simply assume that all of their female patients are heterosexual (Neville and Henrickson, 2006; Brown, 2000) and also assume that, by 'treating everyone equally', they are demonstrating a lack of prejudice (GRAI, 2010; Matrix Guild, 2009, 2008; Brown, 2000)

...that particular facility just got on and treated everybody exactly the same (Respondent low/high care facility) (GRAI, 2010:57)

However, as Dyson (2001) points out, there is a difference between equality and equity. Equality only takes 'inputs' of resources into account, whereas equity demands that people's specific needs and outcomes be taken into account. If people have 'special needs' they are likely to require different amounts of different types of resources, in order to gain satisfactory care outcomes. Matrix's research has found that 'Sexual and cultural expression is important for the mental health of GLBTI seniors in many respects' (Matrix Guild, 2009:9-10), yet often efforts in aged care facilities are focused on stamping this expression out.

i. Sexuality and Intimacy

Ageism seems to affect many seniors in aged care in that neither heterosexual nor sexual minority people are expected to be sexual beings by aged care service providers, nor even to have a need for intimacy.

'As soon as you mention sexuality people think that you are talking about sex. There is not enough distinction made between sex and intimacy. There is very little discussion about intimacy and how we relate to a person in an intimate way. I think that we have to be very

careful not to proscribe this in a narrow way' (Focus Group 3: community support and advocacy groups) (Matrix Guild, 2009:34-35)

It never came across my desk as an issue. Lots of sexual issues between staff, between clients and family and all sorts of things, but never non-heterosexual issues
(Respondent independent living) (GRAI, 2010:56)

Heterosexist discrimination, like other forms of discrimination, is often the result of fear and ignorance:

At the base of a lot of homophobia is a fear of a different sexuality. There isn't an understanding of how a person can have a different sexuality, also that a woman could be a lesbian but might also be straight for some of her life. Some women deny their sexuality because they don't want to deal with the oppression that they might find. ('Elizabeth', coordinator, GLBTI support and advocacy group) (Matrix Guild Vic Inc, 2009:36).

In some aged care services the only staff discussions surrounding sexuality and gender identity amounted to 'gossipy stuff; people would whisper and talk ('Penny', nurse, high care) or, laugh and snicker ('Hazel', nurse, high care) amongst themselves. If it was thought about at all, it was assumed that sexual minorities' lives were defined only by sex. This situation perpetuated heterosexist discrimination, which often went unreported.

General agreement was expressed that 'the community did not value seniors nor consider them to be sexual or sexually diverse' (Matrix Guild, 2009:31). As one man put it:

'That is part of the social conscience, that older people should not be seen or heard. If an older person is gay they stand out more and society says: How dare you do this!' ('Patrick', coordinator, GLBTI support and advocacy group) (Matrix Guild, 2009:32).

As happens in the wider community, often staff in aged care services misunderstand sexual orientation and identity as only concerning a person's choice of sexual partners. They, therefore, have problems in comprehending the 'cultural isolation' (Matrix Guild, 2009:36) that may be experienced by Lesbian residents who have been used to living their younger lives embedded within (a particular part of) the Lesbian community.

Even when there is managerial knowledge of legislation prohibiting discrimination against LGBTI people, Matrix found that 'the practical implementation of such legislative requirements has fallen short in some aged care services' (2009:27). Despite the legislation, there is evidence - provided both by residents and by service providers - of ongoing discrimination within residential aged care services.

These are some quotes from LGBTI aged care residents:

'You cop it sweet and shut up.

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

Some older women would be terrified of talking.

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

I keep my mouth shut. I have to be careful what I say. I have no conversation. I can't talk to the staff in here' (Matrix Guild Vic Inc, 2009:14)

"... 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 (sic) were a lesbian it perhaps went against them. They became very good at keeping quiet, some of them (Anne, 77 years, lesbian) (Matrix Guild Vic Inc, 2008:36)

'Elizabeth' is 72 years old now. The fact that she grew up knowing that her sexuality was 'anathema' to the Christian church in which she was raised reverberates in her interactions with other people to this day:

'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) (Matrix Guild Vic Inc, 2008:37).

And some from aged care providers:

'There is a silence.

Some of the staff whisper and snigger.

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

We need to acknowledge our discomfort.

It requires constantly working with staff to say that it is OK to talk about it (sexuality)' (Matrix Guild Vic Inc, 2009:14).

It also requires education of heterosexual co-residents, if LGBTI residents are to be in a safe environment in aged care services.

'One of the things that worries me with support is that we need to educate not just staff but other residents who are homophobic as well' (Focus group 3: community support and advocacy groups) (Matrix Guild Vic Inc, 2009:42)

Discriminatory attitudes held by heterosexual aged care co-residents are not always, but can sometimes be, expressed directly and openly. Moral dilemmas may be experienced by service managers, such as the one who 'reported being approached by a resident who had seen a television report on a lesbian marriage and said, "it's disgusting and you should see them; one of them looks like my father" (Focus Group 2: residential aged care managers) (Matrix Guild Vic Inc, 2009:33). Expression of heterosexist discrimination by some residents, and/or staff, can be problematic for services that are legally responsible for providing a safe environment for all their residents. This situation may, inadvertently, be exacerbated if service management are unaware of Lesbian residents who have chosen not to disclose their sexuality but actually witness that discrimination. In exploring the specific needs of LGBTI residents, 'some staff © Matrix Guild (Vic) Inc and Coalition of Activist Lesbians – Australia

reported that there was a need for, awareness and sensitivity to any discrimination from other residents or staff that may occur (Focus Group 1)' (Matrix Guild Vic Inc, 2009:39).

Ageism is also apparent within the group 'Lesbian', in that younger Lesbians do not want to support seniors' activism, but expect equitable treatment to be afforded them when they get to the age of going into aged care:

'Younger lesbians want older lesbians as role models but they wonder how much the issues for older lesbians are of concern to them. They think that by the time they are our age we will have paved the way' ('Elizabeth', coordinator, GLBTI support and advocacy group). (Matrix Guild, 2009:32).

Consensus was reached by one focus group of aged care service providers that a LGBTI senior would have 'to be very brave to disclose in aged care' (Matrix Guild, 2009:33) due to potential sexuality discrimination by those who are charged with Lesbians' care.

There is also a need clearly to define the linkage between LGBTI issues and culture, and the silencing of Lesbians by repressive attitudes:

'GLBTI activism is often seen to be only about sex rather than also being about a range of issues related to our sexualities. GLBTI activism and sexualities are defined as just about sex... We need to be able to say this is what it is like to be a lesbian; this is what our sex is like. ... It has been taboo to speak about this for long enough. ... We need to celebrate what we do and talk openly about our sex and female sexuality generally' ('Elizabeth'; coordinator, GLBTI support and advocacy group). (Matrix Guild, 2009:35)

As one aged care nurse explained, some staff are

'a bit funny about residents having sex, a bit prudish, a bit sniggery, a bit conservative. They don't expect older people to have sex. It just doesn't happen here' ('Hazel', nurse, nursing home). (Matrix Guild, 2009:35)

The normal reaction, in some aged care facilities, when sexual expression occurred 'was often a response aimed at eradication' (Matrix Guild, 2009:35):

'Geriatricians are not good at acknowledging sexuality. There is increased awareness when there are issues but it is addressed from a medical rather than psycho-social perspective. Some geriatricians are positive about sexuality; others struggle and are homophobic' ('Aviva', geriatrician, hospital/community care and education) (Matrix Guild, 2009:35).

Unsurprisingly, based on the above evidence, many participants in the initial *My People* survey of aged care residents (Matrix Guild Vic Inc, 2008) referred explicitly to the need to be surrounded by 'my people', or non-judgemental partners, friends, family-of-origin, and aged care providers with whom they could be open about themselves, and comfortable, and safe. This need was based on historical experiences of discrimination and social stigmatization. However, the decision to hide one's sexual/gender identity in aged care services is also reinforced by either deliberate, or inadvertent, current discrimination. Some examples affecting Lesbians uncovered in the *My People* report include:

- Lesbian residents who are too afraid to come out, or disclose their sexuality, to aged care staff for fear of discrimination
- Service providers' refusal to allow expressions of intimacy between visiting partners and residents
- Institutional prudishness concerning the sexuality of all aged residents, both LGBTI and heterosexual (Matrix Guild, 2008).

Partly due to the decision of many Lesbian residents not to disclose their sexuality, some 'aged care service providers are unaware of GLBTI clients and their particular needs. This invisibility, and the lack of evidence regarding the experiences of GLBTI seniors, perpetuates the status quo in which discrimination often goes unchallenged' (Matrix Guild Vic Inc, 2009:68). It was found that 'A sense of mistrust and fear was apparent in many stories' (Matrix Guild, 2009:27) not only as a result of past discrimination, but it was also 'reinforced by recent anecdotal reports of discrimination when disclosure occurs' (Matrix Guild Vic Inc, 2009:7. See also Matrix Guild Vic Inc, 2008). The impact of identity concealment is that Lesbian 'seniors who feel unable to disclose their sexual/gender identity may: feel unable to be themselves and therefore feel devalued or depressed; experience stress and pressure from maintaining a façade of heterosexuality; have unmet care needs; and have limited opportunities for sexual expression. (Matrix Guild Vic Inc, 2009:9-10).

Even should the aged care staff be aware of residents' sexual orientation, this is often not discussed openly, but 'talked around', which some staff feel might compromise resident care:

'I looked after an old lesbian who would have been older than 70 and her partner Beryl used to visit. We would talk with her around their relationship. We couldn't say the word lesbian because they never told us that they were. But we knew that Beryl was the person who took home the clothes to wash and she was the one who was recorded as the next of kin in the medical records' ('Penny', nurse, high care) (Matrix Guild, 2009:38).

Some aged care service providers felt it was inappropriate to ask a resident about their sexual orientation, thus leading to a 'dance' between some clients who want to disclose, but are afraid to do so, and some staff who suspect the answer, but are reluctant to ask. Harrison (2001) reported a clinical interaction in which one man's life was completely changed (for the better) by two words: a staff member asked him if his partner was female *or male*. That lack of assumption on the part of the staff member gave him the courage to come out, and receive, thenceforth, culturally competent care.

Some residential aged care service providers argue that a person's sexuality is a private matter (Hughes, 2004a) and their own business (Harrison, 2001), but this can, in some instances, be used as an excuse for not pursuing cultural competence with Lesbian residents. 'There are many facets to the question of privacy and if sexual and gender identity are rendered "private" then GLBTI seniors remain invisible' (Matrix Guild Vic Inc, 2009:39).

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

(Matrix Guild, 2009:40).

This is all very well, but it may have significant implications for their standard of care. The choice of many LGBTI residents not to disclose their sexuality to aged care service providers and assessors - and of the latter not to inquire too closely - can perpetuate residents' invisibility, and lack of provision for their unmet needs. The following quote could be interpreted as this assessor's failure to acknowledge the obvious:

'In all the years that I have been doing this work I have not come across an older person who was gay.... I can think of a couple of women that we visited. They described themselves as really good friends. They said that they used to work together and they lived together. I just accepted that because I'm pretty stupid. I can think of a couple of older school teachers, librarians and nurses who used to live together. There was nothing to say that they were sexual but they may have been lesbians' ('Marg', acting manager, aged care assessment service) (Matrix Guild, 2009:40-41).

Sexual diversity needs to be accorded the same respect as any other form of cultural diversity, but Matrix found that

'Sexuality was understood to be about sex and seniors were not expected to be sexual or sexually diverse...A recurrent theme was the lack of permission to speak about sexuality... Many aged care service providers did not understand the needs of GLBTI seniors. There was a common perception that being GLBTI was about "who you had sex with" and seniors were not expected to have sex. Consequently, seniors that were GLBTI were not considered to have special care needs' (Matrix Guild, 2008:11).

Matrix's research found there to be some issues with culturally competent care for Lesbians whose partners suffered from dementia, for instance they need staff to understand that the grief and loss involved in having a same-sex partner with dementia is no less than that experienced by a heterosexual couple(Matrix Guild Vic Inc, 2009:9-10).

It appears that there is quite a need for mainstream aged care service providers to be trained in cultural competence with Lesbian residents and community aged care recipients.

ii. Cultural Expression

Hughes quotes Wilcocks (1987) who characterises living in aged care as the 'negotiation of private lives in public spaces' Hughes (2004: 389). It needs to be understood that, before they have a need to go into aged care, many Lesbians have chosen to live - to greater or lesser extents - exclusively within their chosen part of the lesbian community/ies. Lesbians have their own culture, and sub-cultures. They have their own community groups, e-lists, websites, cafes, books, films, fashions, symbols, dance venues, publications, preferred lesbian-friendly clinicians and alternative healthcare practitioners, health conferences, theatre productions, tradeswomen, land, recreational and tour groups. Some choose not to be in the company of men - no matter whether these men are gay or straight. So, for them, to even enter a mixed-sex aged care facility - no matter how 'friendly' this institution might be - is already taking them massively outside their cultural comfort zone.

One example uncovered in Matrix's research in relation discrimination against a resident's right to enjoy her Lesbian culture was the report that the Director of Nursing in her nursing home approached her, saying that 'The Muslim girls who worked there objected to the lesbian porn videos that (she) had'

('Janet', 58 years, lesbian) (Matrix Guild Vic Inc, 2008:39). Puzzled by this statement, since she did not have any pornographic videos, 'Janet' could only conclude that they had seen her watching the TV series *Queer as Folk* (Matrix Guild Vic Inc, 2008:39). Irregardless of what she was watching in her own room, it is debatable whether a) the staff have a right to complain to management; and b) whether it is management's proper role to take a resident to task over what she is watching. Hughes argues that 'privacy strategies should not simply require the hiding of the self' (2004:389) and, in the case of residential aged care, especially in one's own room, which has 'the value of a personal refuge' (2004:387). This is particularly essential for Lesbians, for whom all public space is inherently unsafe, as shown in point B above.

This vignette illustrates the need for aged care service providers to ensure that all of their their staff are fully trained concerning their ethical and legal responsibilities towards residents in their care. Additionally, there needs to be an aged care facility policy which clearly spells out the residents' rights to privacy and to participating in, and expressing, their own culture.

Then again, 'the impact of inadvertent visibility' (Matrix Guild, 2009:9-10), due to the way in which some Lesbians express their culture, for instance in their manner of dress, exposes them 'to discrimination from staff, co-clients and visitors because they are unable to hide their sexual/gender identity' (Matrix Guild, 2009:9-10).

G. Aged Care Residents in Day Care Centres

Visits to aged care day care centres, along with heterosexual co-residents, can be fraught with difficulties for Lesbians, regardless of whether they have disclosed or not. One Lesbian, who has chosen not to come out to the day care centre where she spends four days a week, reports that 'In none of those sessions I (sic) feel I can be who I am' ('Elizabeth, 72 years, lesbian) (Matrix Guild Vic Inc, 2008:40). But, if a resident does come out, she may experience discrimination: 'I get called a "fucking thing" in here and everything, and "a poor excuse for a bloody woman" (Matrix Guild Vic Inc, 2008:40). So it is in all settings in aged care takes place where professional development needs to occur. What can be done about co-residents' discriminatory behaviour is an altogether different, but no less important, issue.

H. Community Care in the Home

The 'value of a personal refuge' (2004:387) takes on a whole new meaning when it comes to Lesbians having community aged care providers enter their own homes. This renders them exceptionally vulnerable, should the community aged care worker hold negative attitudes and values towards Lesbians. Often there is no choice given to community care recipients as to which workers will care for them. What is a Lesbian who receives home care to do? Should she 'de-lesbianise' her home before a worker visits in order to protect herself? Must she remove all her lesbian books from her bookshelves, hide her DVD collection, remove all Lesbian artwork from her walls and Lesbian crafts and insignia from her sitting room and bedroom? This was amusingly portrayed in a play in which a raunchy poster of Madonna was turned around to reveal a poster of a high-up figure in the church when the parents or home help came to visit. But its message was a serious one about society's values and the way in which lesbophobic

discrimination can be internalised, as well as being institutionalised, causing tension about being an inauthentic person in some people's company.

There is heterosexist discrimination in the wider community, as evidenced in a vignette provided by 'Vanessa', the manager of a community care service. She detailed how a female home care provider was not able to work with a particular Lesbian client because 'her husband would not allow it' (Matrix Guild, 2009:32). The cultural backgrounds of aged care workers is an important issue for Lesbians. This will be covered in more detail in point 8 of this submission.

Another aged care provider argued that what happened in the community at large was mirrored in the microcosm of aged care. She argued that society is

'extremely discriminatory towards GLBTI people and what happens in aged care is another symptom of that' ('Angela', team leader, home and community care) (Matrix Guild, 2009:31).

I. Pessimism About Change

There appears to be some degree of pessimism, on the part of potential Lesbian consumers of aged care as to whether the system can be changed, within the foreseeable future, to allow Lesbian and other GLBT seniors to be themselves in aged care settings.

I don't believe you will affect society that much that I can slap a big kiss on my partner's lips. (Participant Focus Group 2) (GRAI, 2010:60)

We thought if we couldn't find care we're going to have to take care of ourselves. I mean we've got nurses and doctors [as friends] so we're a group of professionals and we thought that we could build a little community ourselves and take care of ourselves

(Participant Focus Group 2) (GRAI, 2010:59)

It is quite an indictment on society that the only way in which Lesbian and other GLBT taxpayers can envisage themselves as being treated properly in aged care settings, having their human rights respected, is to provide that aged care for themselves.

2. Provide evidence of Lesbians' relative financial disadvantage in relation to gay males and heterosexual women which may affect their access to aged care

Lesbian seniors' ability to pay for aged care, if that is a requirement, is likely to be affected by the cumulative, legally-sanctioned financial discrimination they have faced for most of their lives. The older a Lesbian is, the greater time, and financial amount, she has been penalised for her sexual orientation.

The Australian government conceded that 85 Federal laws discriminated against Lesbians financially, in the spheres of health care and medications, aged care, employment, workers' compensation, taxation, social security, veterans' entitlements, carers' leave, family law, superannuation, and migration, based on

the findings of the Human Rights and Equal Opportunity Commission (2007). Similarly, in Victoria in 2001, the Victorian government had changed 114 laws that discriminated against Lesbians – often financially – with the *Statute Law Amendment (Relationships) Act* and the *Statute Law Further Amendment (Relationships) Act* (Victoria Legal Aid, Victorian Gay and Lesbian Rights Lobby, and Law Institute of Victoria, 2007). That's 199 discriminatory laws that adversely affected Lesbians.

The Australian government claimed to have fixed the above inequities with the passage of several pieces of legislation, including the *Same Sex Relationships (Equal Treatment in Commonwealth Laws - General Law Reform) Act.* However, even when the State and Australian governments did change those laws, they *did not undo the decades of accumulated comparative Lesbian financial disadvantage and discrimination.* If Australian women 'accumulate poverty' (Australian Human Rights Commission, 2009), Australian Lesbians accumulate poverty at a far greater rate than their heterosexual sisters.

Lesbians have also been discriminated against, compared to heterosexual women and other recipients of Federal government allowances, in being offered no transitional arrangements, as has been customary with large legislative change (e.g. 23 year transition in aged care pension), with the enactment of the *Same Sex Relationships (Equal Treatment in Commonwealth Laws - General Law Reform) Act.* The impact is: forced disclosure of lesbians' sexual orientation (unnecessary with heterosexual people) to a government department if one member of a Lesbian couple is receiving government benefits; psychological trauma to those Lesbians who have needed to protect themselves by living in hiding; but the worst impact of all is that the law will discriminate most against the oldest, most vulnerable, Lesbians who have already experienced the longest and most pronounced effects of 199 discriminatory laws. They have no legal means by which to seek redress for their cumulative relative financial disadvantage, which will adversely affect their ability to pay for public services like healthcare and aged care.

Article 23 of the *Universal Declaration of Human Rights*, declares that 'Everyone, without discrimination, has the right to equal pay for equal work' (United Nations, 1948, Online). Australian women, as a group, are paid less than men. It is generally, however, more difficult for two women to live on the pay of one woman - as the revised Centrelink legislation demands if one Lesbian partner is working and the other is on a benefit - than for a woman and a man to live on the pay of one man, because of the persisting gap in gender pay rates, or the salaries of two gay men. Evidence exists of Lesbians being better educated than women, and people, in general (Leonard, Marshall et al, 2010; Banwell and Bammer, 2005; VGLRL, 2005), but Hyman has presented evidence of better-educated Lesbians receiving lower rates of pay than men and women in general (2001).

Further research is required on just how Lesbians' comparative financial disadvantage may translate into their access to aged care.

3. Outline research and policy initiatives which work counter to Lesbian independence, social participation and social inclusion

There is an almost universal assumption that lesbians' health needs are the same as those of heterosexual women (Ministerial Advisory Committee on Gay, Lesbian, Bisexual, Transgender and Intersex Health and Wellbeing, 2009; National Women's Health Policy, 1989). Thus, healthcare for women who face discrimination on the basis of sexual orientation and gender identity is invisible, just as the specific health needs of women used to be invisible.

Ongoing failure to ask a question on sexual orientation of the older cohort of the Australian Longitudinal Study on Women's Health - on the grounds that asking this question would destroy the cohort and that, anyway, sexual orientation has nothing to do with health (Lees personal communication 2008, 2004) - means that national probability-sample evidence is not being collected on the health of the older Lesbian population. This 'lack of evidence' - or purported 'lack of demonstrated need' as it was characterised in Horsley and Tremellen's (1996) research, translates into lack of funding for research, which affects policy, which affects clinical practice, which turns into a vicious cycle which keeps Lesbian health off the mainstream agenda. It was only philanthropic funding which allowed Matrix Guild to undertake its research on discrimination in aged care.

Controversy currently surrounds beyondblue's, the national depression body's, failure to give priority to GLBT people's mental ill-health due to discrimination. One example of this is evidence, uncovered in an international literature review in 2008, that found lesbian and gay communities' youngest *and oldest* community members to be the most vulnerable to depression and suicide as a result of discrimination (Corboz, Dowsett et al, 2008. See also Dyson et al, 2003; Quinn, 2003). Yet beyondblue's exclusive focus is on young GLBT people's circumstances, thereby disenfranchising depression and suicide studies on the older segments of the LGBT community/ies. This may have significant ramifications for aged care policy and for Lesbians' social inclusion, or isolation, as the case may be. Birch argues that there is a 'need for specific action to address an increasing problem of loneliness and social isolation for some GLBT seniors' (Birch, 2004:6).

Aged care accreditation and complaints procedures have been demonstrated, in the recent Federal Department of Health and Ageing's Review (Walton, 2009), to work counter to Lesbian independence, social participation and social inclusion. For instance, Walton found there to be a need for

'availability of anonymous complaints, particularly as a safety mechanism to support complainants where there is genuine fear of retribution. This was specifically raised in

relation to gay lesbian bisexual transgender and intersex care recipients or carers because of the fear of homophobic/ transphobic retribution. Some care recipients have been threatened with 'outing' by providers if they raise a complaint about service standards' (Walton, 2009:40).

Participants in Matrix's research felt that lip service was paid to LGBT people's needs but that, in reality, the system was being manipulated and nothing was being done by most aged care facilities to ensure that their needs were being met.

'Care planning is geared for a particular purpose, around funding. The best we do after the assessment is ask (the resident questions). ... culture is paid lip service. We have the Standards and Guidelines for Residential Aged Care Services and there is a formula to follow. If you follow the formula and the Aged Care Standards and Accreditation Agency comes in and if you meet that formula you will be accredited. But if you scratch below the surface you realise that nothing is happening. (The cultural needs of residents are) ... given lip service. The aged care standards are good, (but the problem is) ... how they are interpreted.

The staff (doing assessments and care planning) ask residents questions that fit in with their idea of a good resident in a good facility. We need to ask residents the question: What does that mean to you?' (Focus group 3; community support and advocacy groups) (Matrix Guild Vic Inc, 2009:40).

Aged care recipients were very aware of this fact, and 'Rather than giving lip service to the notion (of resident centred care), participants wanted to see service providers demonstrate genuine commitment to ensuring their safety and understanding of their needs' (Matrix Guild, 2009:27). Sadly, the existing accreditation system appears to be incapable of delivering this objective. Accreditation assessors need to be aware of power relations between management of aged care services - whose major aim is to (re)gain accreditation - and the potential for conflict between their interests and those of populations of residents with special needs.

GRAI's research bears out Matrix's findings and suggests that, until aged care facility management are financially penalized, and forced to comply with quality assurance legislation, nothing will be done.

People are not, you know are aware [sic] and they may not agree with it, they may think it's a whole lot of crap but because they're going to get hurt by it [lose their accreditation] or could do, then they have to comply, they comply so I think [it's] ... got to be codified and it's got to be spelled out (Participant Focus Group 2) (GRAI, 2010:60)

It's not on the ACME assessment in terms of doing an assessment on how you get your funding. So it doesn't, it's not captured anywhere.....So there may well be a lot of people within our facilities who have all sorts of different backgrounds that we just don't know about (Respondent low/high care facility) (GRAI, 2010:57)

The comments of 'Marg', the manager of an aged care assessment service, are worrying, since they indicate a certain degree of political naiveté and inertia, even after she had read the Executive Summary of *My People*:

'It was interesting reading but I don't really know if we would do anything. We don't really have enough numbers of (GLBTI) clients... We see about 5000 clients a year. With everything else going on this would not be a priority unless we had the clients' ('Marg', acting manager, aged care assessment service) (Matrix Guild Vic Inc, 2008)

Examine policy, services and infrastructure that could support older Lesbians to remain in their own homes for longer, participate in the community, and reduce pressure on the aged care system

Partly as a result of the endemic heterosexist discrimination in the mainstream Australian aged care system, of which the Matrix Guild and GRAI research (2010, 2009, 2008), detailed above, can give but a small example, many Lesbians would prefer not to go into aged care, but to have support to stay in their own homes (Matrix Guild, 1997).

There are already some good gay- and Lesbian-specific community-based initiatives regarding older members of their communities, aimed at assisting them to stay in their own homes for longer and to counter the social isolation felt by some Lesbian and gay seniors. But these are mainly the result of grassroots activism and individual philanthropy.

For instance Matrix Guild:

- a) already offers community-based care to older Lesbian members in need, although their funding to do this has all been raised almost solely from their own fundraising efforts.
- b) is currently having three social housing apartments built for Lesbians of reduced means.

That there is a pent-up need for these initiatives is demonstrated by the fact that, before the apartments have even been built, they are over-subscribed, with inquiries concerning renting them far outnumbering their availability.

There is a significant unmet need for GLBT retirement homes. A gay philanthropist is tapping into this need by building a retirement village for his community in Ballan, about an hour to the north of Melbourne. In the month following the launch of Linton Estate, a \$26-million development of 120 5-6 star units, in July 2008, and before any of the units had been completed or advertised, there were inquiries from 24 countries (*Melton Moorabool Leader*, 19-8-2008, p403), including Australia. To our knowledge, no similar development is envisaged - other than a pipe dream - for older Australian Lesbians.

It is the recommendation of this submission that all government policies, at all levels, need to include consideration of the specific needs of the different components of the GLBTI community/ies. Moreover there should be 'nothing about us, without us' i.e. Lesbians and gay men from all grassroots community-based organisations must be meaningfully involved in decisions that affect them concerning aged care. Funding for Lesbian-supplied Home and Community Care - for Lesbians - would likely resolve the problem of high workforce turnover of carers who come from countries and cultures where Lesbianism is even less accepted than in Australia.

Consider what might 'allow smooth transitions for Lesbian consumers between different types and levels of aged care, and between aged, primary, acute, sub-acute, disability services and palliative care services, as need determines'

If there can be indigenous-run health and aged care facilities (such as Aboriginal Community Elder Services in Melbourne) for older indigenous people, when their percentage of the overall population is less than a quarter the size of the LGBT community/ies, one is prompted to ask why there is no similar, government-funded Lesbian-specific organisation. This submission has already demonstrated that Lesbians have special needs, which are distinct from those of other members of the LGBT community/ies.

One participant in Matrix Guild's research asserted that it had taken *twelve years* to train organisations fully to comprehend cultural diversity and to be culturally inclusive of, and competent with, sexual minorities (Matrix Guild Vic Inc, 2009:44). Ideally all mainstream aged care services and facilities would have this cultural competence, but this submission has shown that there is a long way to go, yet, in this regard. Until a society-wide campaign has been successful in eradicating lesbophobic discrimination in all

phases of aged care, it might be more productive - for the smooth transition of Lesbian elders through the different stages of aged care, if Lesbian-run facilities were established and run by, and for, Lesbians themselves.

Lesbians are already undertaking palliative care for Lesbians. They have even found it necessary to publish a book about the subject, entitled *Willing up and Keeling Over* (Long Breast Press, 2007), since Lesbians' experiences with families-of-origin and mainstream religious, or funeral, organisations have often been found to leave a lot to be desired. The great need for this type of resource – and Lesbians' hunger for Lesbian-specific information - has been demonstrated by the book's subsequent publication in the United States.

Examine the future workforce requirements of the aged care sector, with regard to Lesbianspecific needs, 'to ensure that the sector has access to a sufficient and appropriately trained workforce'

Birch (2004) proposes that Aged Care Worker Certificate III/IV courses should recognize GLBT people as a group with special needs. However, there seems to be some resistance to this concept, as demonstrated by GRAI's research in Western Australia:

I think given the range and the level of training that currently aged care facilities have to do as a requirement I'd be honest and say I think that [GLBTI training] would be quite low down on the list of priorities (Respondent independent living) (GRAI, 2010:58)

Like at the moment because we've got immigration from the sub-continent just pouring through the door their cultural caring for them [residents] is different...So I think that's going to impact on gay people or whatever their orientation is and whatever their expectations are because those different sexual orientations are not as accepted as [sic] much (Participant Focus Group 2) (GRAI, 2010:60)

The problem with offering Lesbians non-discriminatory aged care is that all staff in all residential aged care have to be taught cultural competence with sexual minorities. Continually changing numbers of community care workers all need to be briefed on what is expected of them, in Australian society, regarding LGBT customers. And, perhaps most importantly of all, co-residents need to have anti-lesbophobia instilled in them. This is a service-wide ongoing task.

Conclusion

Matrix Guild's research in Victoria and GRAI's research in Western Australia demonstrate that, either through ignorance, or personal attitudes towards non-heterosexual people, or the perceived pressures on and priorities of Australian aged care service providers, the needs of Lesbian residential and community aged care consumers are not being met. Dr Jo Harrison's research in South Australia (2006, 2001, 1999) tends to confirm these findings, as does Dr Mark Hughes' work in New South Wales (2004, 2004a).

Permission to Speak (Matrix Guild Vic Inc, 2009) offers a pathway towards the provision of culturally competent care for Lesbians in residential and community aged care. Advocates, such as Matrix Guild and COAL – Australia can assist both aged care consumers and service providers on this journey via:

- 1. 'The enormous potential of aged care service providers to make a difference to the lives of GLBTI seniors
- 2. The power of empathy and modelling respectful care
- 3. The importance of building trust in relationships with GLBTI seniors
- 4. The negative impacts of discrimination
- 5. The significance of history in planning care for GLBTI seniors
- 6. The impact of aged care service providers values and beliefs on care
- 7. The time and resourcing required for change
- 8. The need to provide permission for clients to speak about their sexuality
- 9. The need to provide staff with permission to discuss sexuality' (Matrix Guild Vic Inc, 2009:45)

This submission argues that Lesbians belong to a specific culture - which is different from that of other sexual minorities – and that Lesbians' care needs, in the context of residential aged care are largely unmet, which often results in suboptimal care outcomes.

'Understanding a person's sexuality should really start before they enter the service so that as they navigate the service system ... at every step their needs are understood and they will not slip the out of the net. We have to be careful that a promised service is delivered' ('Vanessa', manager, community care) (Matrix Guild Vic Inc, 2009:40).

Based on Matrix's research, with regard to Lesbian seniors, it is clear that this promise has not always been fulfilled. It could be argued that unknown care needs equated to 'unmet care needs (and that) without education and dialogue, aged care service providers did not understand what it was that they needed to do' (Matrix Guild Vic Inc, 2009:39), including their obligation to fulfil their existing legal responsibilities.

Matrix Guild (Vic) Inc and Coalition of Activist Lesbians – Australia thank the Productivity Commission for the opportunity to make this submission. Both organisations would be grateful for the opportunity to give input to any further consultations and inquiries held by the Productivity Commission on the subject of aged care.

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