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Re: Inquiry into Palliative Care in Australia

I am grateful to the committee for the opportunity to provide input into the inquiry examining palliative care in Australia. I am able to provide further information or clarification should the committee request this.

The information contained in this submission relates to palliative care issues as they impact on gay, lesbian, bisexual, transgender and intersex (GLBTI) Australians, their carers, significant others and advocates. I am particularly concerned that the terms of reference of the inquiry did not explicitly state that GLBTI related matters were to be examined and would strongly recommend that these specific issues be given dedicated attention in a specific section of the inquiry report, should that prove possible.

The recent Productivity Commission report into aged care *Caring for Older Australians* included GLBTI matters in its final report in a dedicated section referring to the needs of this specific group. In many respects, the needs of GLBTI people in relation to palliative care and end-of-life experiences, as well as in relation to aged care itself, warrant specific attention and explicit recommendations given their unique nature.

The issues raised here relate primarily to terms of reference:

a)iii: people from culturally and linguistically diverse backgrounds;

a)iv: people with disabilities;

c): efficient use of palliative, health and aged care resources;

e): the composition of the palliative care workforce;

e)ii: the adequacy of workforce education and training arrangements;

g)i: avenues for individuals and carers to communicate with healthcare professionals about end-of-life care.

I am grateful for the opportunity to provide information to assist the inquiry in its deliberations regarding palliative care. End-of-life matters are given scant attention when issues impacting on the health of older people are discussed and this is particularly the case in relation to GLBTI people.

Across Australia GLBTI older people are living in fear of abuse, neglect, forcible outing, denial of service, homophobic vilification, eviction and isolation as they confront or consider the reality of confronting the current aged care sector and rely on that sector for support in the midst of increasing physical or cognitive dependency. In this respect, GLBTI older people, particularly those over 70 years of age, form a uniquely vulnerable cohort within the sex, sexuality and gender diverse community, and have received very limited attention and action in relation to protection of their rights. [1] [2] This reality is seriously compounded amidst the vulnerability and frailty that accompanies the need for palliative care services.

There is a rapidly growing body of evidence regarding the situation and needs of GLBTI elderly people, and the prospects for baby boomers who are GLBTI in relation to a future interfacing with the aged care and palliative care sectors about which many express grave fears.

While the Federal government has enacted measures to protect the rights of consumers in respect to certain areas of aged care over the past two decades, including the provision of aged care advocacy services across Australia, these measures have not been explicitly and legislatively extended to protection of the rights of GLBTI consumers, which renders older GLBTI people seriously vulnerable to potential abuse and denial of appropriate care and services, including at the end of life. Consumers who are GLBTI remain largely invisible and are therefore assumed by service providers to not exist.

As my Doctoral research into GLBTI aged care in the USA and Australia identified, this cycle of invisibility entrenches fear of discrimination and a tendency for GLBTI consumer to not approach services for support. They are not reassured that services are inclusive and safe, and that their relationships will be respected and recognised, both on formal documentation and at the level of provider-recipient communication. As consumers and their significant others remain hidden from providers of care, including providers of palliative care, quality and likelihood of delivery of service is compromised and may even

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[1] Harrison, J (2004) 'Discrimination and older gays: surviving aged care' in Equal Time Anti-Discrimination Board of New South Wales, No 61, August pp. 1-3 http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/vwFiles/ET%20Aug%2004%20.pdf/$file/ET%20Aug%2004%20.pdf

[2] NSW Anti Discrimination Board (2005) New South Wales Anti Discrimination Board Working Paper on Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) Ageing and Discrimination http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/pages/adb_glbti_consultation

lead to neglect. GLBTI older people require support from service providers who are fully trained in the provision of culturally appropriate services to people of diverse sex, sexuality and gender identities.

This needs to include training at VET level, through relevant TAFE and RTO courses in community services, health, aged care and related subjects, as well as tertiary education and on-site delivery. All level of training, including regular updates are needed, particularly given high turnover of staff. It is imperative that protections which serve to address and eradicate this fear and invisibility are operating at the strongest possible level, so that all organisations providing palliative care services are bound by clearly outlined regulations regarding sex, sexuality and gender diversity to the fullest possible extent. Unless this is the case, GLBTI elderly people and others requiring palliative care, including those living with HIV / AIDS remain vulnerable and unprotected. GLBTI people with dementia and their significant others will also experience a range of special needs which must be taken into account (Birch, 2009).

The paper that I co-authored with the Australian Coalition for Equality, (Harrison and Irlam, 2010) available at http://www.coalitionforequality.org.au/LGBTI-AgedCareDiscussionPaper.pdf provides further detail regarding this situation, and outlines the implications for the aged care sector of the 2008 Federal reforms removing discrimination against same-sex couples. The paper has provided a basis for discussion with government about measures which need to be taken to ensure that legislative and service provision as well as program reforms impact on consumers and the sector in an effective manner.

Many of the issues in the paper, although focused on aged care, related directly to palliative care contexts. The appropriate use of terminology on documentation and in face-to-face communication; the need for formal recognition of same sex partners and their full inclusion in decision making processes; the need for families of choice, formed by GLBTI people who may have been rejected by biological family, to be fully recognised as carers and support people on a par with 'family'; the significance of training and education; the need for further research; and the importance of recognition of GLBTI issues in all standards and policies are all matters that pertain directly to end-of-life situations.

It is vitally important that GLBTI consumers, their representatives, people they nominate as their 'person responsible' or 'next of kin' as well as their significant others and family of choice are fully aware of the documentation that will prove crucial when end-of-life decisions are made. Power of Attorney documents, advanced care directives, enduring or other guardianship documents, and other documentation that could be termed 'living wills' need to be strongly promoted and publicised through legal services and advocacy services as well as government agencies and GLBTI organisations, so that GLBTI people are aware of the significance of these documents and able to ensure they are in place at minimal or no financial expense. The work of Cartwright (2011) in the development of GLBTI appropriate documents and a kit targeted to the GLBTI community in this respect, currently applicable to NSW and Queensland, provides a basis for the development of a national kit which could be of considerable value.

Indeed, the recently released Federal guidelines for palliative care for aged care in the community (Department of Health and Ageing, 2011) setting do include GLBTI matters and this is to be commended.
http://www.health.gov.au/internet/main/publishing.nsf/Content/400BE269B92A6D73CA2578BF00010BB0/$File/COMPAC-30Jun11.pdf

The guidelines provide a useful starting point for discussion of palliative care issues as they impact on GLBTI people and their significant others at a broader level, including in residential and hospital care. In some respects the guidelines could be strengthened in the extent to which they emphasise the importance and unique nature of the needs of GLBTI consumers.

However,the lack of reference to Australian research and developmental work in the area in the guidelines is a serious concern, as the reliance on overseas references could be taken to imply a complete lack of local academic and service attention to GLBTI palliative care issues. Clearly, given the work of Cartwright and others, this is not the case. It would be beneficial to see the guidelines used as a basis for the development of more comprehensive document related to GLBTI palliative care which is couched in an Australian context.

The impending transfer of all responsibility for aged care to the Federal government under the Health and Hospitals Reform Commission and COAG reforms, and the outcomes of the inquiry into aged care conducted by the Productivity Commission, now under consideration by the Federal government, give greater impetus to the need for the strongest possible anti-discrimination protection at Federal level for GLBTI consumers of palliative care and aged care services, as well as their partners, significant others and representatives. All providers, including faith-based, religious and charitable organisations in the aged care sector, need to be bound by anti-discrimination regulations and there should be no provision for exemptions from this.

The presence of faith-based residential and palliative care providers is a significant consideration given the history of GLBTI relationships with church organisations. While it is not the case that all faith-based organisations will necessarily discriminate or provide poor quality care, unless organisations declare their commitment to the promotion of diversity, consumers do not know this. Formal policy statements and service charters are required. Some providers in aged care have already enacted such policies. Until consumers have absolute certainty, they will delay seeking services and support, and fear retribution or neglect.

http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/AgedCareReformInvitation

http://www.pc.gov.au/projects/inquiry/aged-care

The work of Professor Cartwright (Cartwright, 2010; 2011, Leinert et al 2010) and her colleagues is of critical importance in this respect. The matter of consistency of documentation systems, particularly related to Advanced Care Directives, is problematic and needs attention, so that systems across Australia do not dramatically differ.
http://aslarc.scu.edu.au/downloads.html

Indeed, the transition process taking place towards Federal responsibility for aged care provides a significant window of opportunity for the Federal government to ensure maximum protection from discrimination and well targeted education around certainty and safety for GLBTI aged care consumers, including consumers of palliative care services. It is imperative that targeted education and information programs that impact on service providers and consumers, as well as their representatives and advocates take place.

As has been expressed to the Federal Minister for Ageing, Mark Butler, by GLBTI community elders and carers as well as GLBTI organisations and experts at his recent national round of conversations regarding the Productivity Commission report, the aged care and palliative care sectors are particularly important and somewhat unique in relation to the matter of exemptions, given the 'hidden' and 'invisible' nature of the client group that may be experiencing discrimination. GLBTI elders have lived lives of persecution and discrimination and this seriously impacts on their vulnerability in relation to the aged care sector.

The Summary Document from the National LGBTI Ageing Roundtable held in Sydney in October 2011, available at http://www.lgbthealth.org.au/sites/default/files/Summary-Report-22Nov11.pdf includes reference to the session at the Roundtable at which discussion between the LGBTI representatives, including elders, and the Minister for Ageing, Mark Butler, took place. The matter of the lack of aged care related anti-discrimination protections and the importance of there being no exemptions applied in relation to aged care were raised with the Minister. Palliative care related matters were also raised in the context of the need for culturally appropriate services. Matters related to the importance of ensuring that the definition of a 'protected person' in relation to the family home did not put GLBTI elders in a situation of stress or financial hardship, including having to sell the home, should a compulsory reverse mortgage scheme be established. This matter was raised by myself at the Roundtable and has been outlined in a submission to the Consolidation of Anti-Discrimination Legislation Inquiry currently being undertaken by the Attorney General (Clarke, 2012). Such socio-economic matters can have a significant impact on quality of life and negatively impact on the end-of-life experience, if stress and hardship are experienced amidst serious or terminal illness.

The Roundtable, in similar fashion to GLBTI participants at the Minister's many recent national conversations on aged care, reinforced the need to recognise that faith-based providers in both residential and community based care organisations are expressing a strong desire to be understood and seen to be actively not discriminating on the grounds of sexual orientation and sex and / or gender identity. Such organisations are actively participating in Federally funded GLBTI cultural awareness in aged care training, and are recipients of Federal funding for GLBTI targeted aged care packages to provide services to people living at home. This is a positive development that could be directly transferable to palliative care contexts.

Exemptions from anti-discrimination requirements on any basis, including religious grounds, will only serve to further increase GLBTI invisibility and compound the vulnerability and fear that currently exist for consumers and their carers. I am aware of instances where elderly GLBTI aged care consumers, particularly in residential care facilities, establish a trusting confidential relationship with one member of staff who is openly GLBTI or GLBTI-friendly in approach. Often this provides a lifeline from complete isolation, withdrawal and depression. It can also prove to be critically important when end-of-life situations arise.

Allowing exemptions that may enable faith based organisations to exclude GLBTI people from employment by their organisations would seriously compromise the safety and well-being of consumers of palliative care support, as well as GLBTI aged care staff themselves. Discrimination that creates a heteronormative environment in an aged care setting leaves an already vulnerable group of consumers in a seriously grave situation which is exacerbated when they require palliative care intervention. It is strongly recommended that no exemptions apply in relation to aged care or other services that provide palliative care, and the special nature of the need to protect an invisible population be recognised.

Preferably, no exemptions should be provided under any circumstances. Even in circumstances where a provider organisation were to be granted an exemption that provider must be legally obliged to publish the detail of the exemption in all their publications, documents and public information, as well as in all recruitment and human resources documents. The exemption information also needs to be published on the Aged Care Standards and Accreditation Agency web site and in all Agency reports.

It is vital that any protections contribute to ensuring that consumer rights are protected while not seeking to force GLBTI elders out of the closet. Certainly, this fear of being forced out of the closet was one of the most emphatic fears expressed by GLBTI elders and their representatives in relation to the Centrelink reforms which resulted from the Federal reforms in relation to same-sex couples.
http://www.acon.org.au/advocacy/news/centrelink-changes-update

The Federal government needs to consider the means by which this 'outing' will not be imposed on GLBTI elderly people or others requiring palliative care, but rights will be protected and understood by all those involved in an end-of-life situation. In this way, the needs of GLBTI people requiring palliative care support, along with their significant others will be met in a way which places the onus on the provider, rather than the recipient of care, with respect to ensuring culturally appropriate care in a safe and inclusive environment.

Further Background Information related to GLBTI aged care

The doctoral research which I conducted investigated the lack of recognition of gay, lesbian, bisexual, transgender and intersex (GLBTI) issues in all areas of gerontology, including government policy and programs in Australia and the USA. The research revealed a serious lack of attention to concerns related to sexuality and gender identity in the Australian context. In the US context, a history of recognition of GLBTI concerns at all levels of aged care was apparent. The thesis is available online at
http://arrow.unisa.edu.au:8081/1959.8/24955

The deficit in Australian gerontology is reflected in an almost complete lack of mention of GLBTI elderly people in aged care policy, education and training, research priorities, program guidelines and consumer related initiatives, including advocacy. This absence of mention of or attention to the special needs of GLBTI elders and their carers and advocates reinforces invisibility and avoids the need to address whether standards of care are culturally appropriate to GLBTI needs. This reinforces fear of discrimination for consumers and a lack of awareness of obligations and responsibilities for providers.

As a gerontologist with thirty years experience in direct care, policy development, research, training and advocacy, I am acutely aware of the strong history of recognition of special needs groups which has underpinned Australian aged care policy. As founder of a remote area aged care advocacy service, I am cognisant of the Federal government's commendable role in the recognition of residents' rights, particularly those of Indigenous residents of residential aged care facilities. The development of the Aboriginal and Torres Strait Islander Aged Care Strategy was evidence of this commitment to ensuring that Indigenous people receive special consideration and culturally appropriate intervention, care, and service provision. A similar national strategy or plan in relation to GLBTI aged care is urgently needed.

The continuing almost complete lack of mention of GLBTI aged care in government documents and procedures at Federal level stands in stark contrast to the commitment to Indigenous aged care, and requires urgent attention and redress. GLBTI consumers remain almost completely invisible within aged care services and across the aged care sector. This invisibility, due to lifetimes of fear of persecution and discrimination, is itself reflected in the absence of GBLTI issues in Federal aged care policy and ongoing programs.

The lack of attention runs counter to the rapidly increasing recognition of GLBTI aged care concerns across Australian gerontology and the GLBTI community, including representative organisations. Research, policy development, advocacy and other initiatives are occurring across Australia in relation to GLBTI ageing, and this is reflected in gerontology and in GLBTI organisations' platforms, strategic plans, managerial structures, investigative projects, publications, internal discussions, research processes and information dissemination.

Submissions to the Federal reviews of the Aged Care Complaints Investigation Scheme and Aged Care Accreditation Processes, the latter which has yet to release its report, highlight matters connected to GLBTI aged care and the process of compliance and quality improvement. In particular, submissions from the LGBTI Health Alliance, ACON, The GLBTI Retirement Association, Associate Professor Mark Hughes, Matrix Guild Victoria and the Victorian Gay and Lesbian Rights Lobby, Lesbian and Gay Solidarity Melbourne and myself highlight these concerns. Professor Walton highlighted privacy and sensitivity matters related to GLBTI concerns in her final report regarding the Complaints Investigation Scheme. I would urge the inquiry to access the GLBTI related submissions and the final reports where possible given that they raise serious matters connected to a vulnerable special needs group which has received almost no attention in past deliberations around consumer rights.

I would highlight the relevance of the Senate Community Affairs References Committee report *The Hidden Toll: Suicide in Australia*, which makes particular mention of the matter of depression, anxiety and suicide as they impact on older GLBTI Australians who fear or experience discrimination. These fears may well be compounded in a palliative care situation and the factors which result in attempted or completed suicides may well be exacerbated in such circumstances.
http://www.aph.gov.au/senate/committee/clac_ctte/suicide/report/index.htm

There is evidence that GLBTI people postpone seeking help and approaching service providers due to fear of discrimination and persecution, both in the area of mental health and in relation to health and aged care matters generally. This includes a fear of needing palliative care and being particularly dependent on service providers who may be homophobic, transphobic or unaware of the special needs of intersex people.

Two reports from a four stage Foundation funded GLBTI aged care project conducted by the Matrix Guild Victoria, investigated and revealed discrimination and abuse on the basis of sexuality and sex or gender identity. The reports are also available online at http://www.matrixguildvic.org.au/project.html

As baby boomers who are out (open regarding sex, sexuality and gender identity) begin to access aged services, including residential facilities, the aged and palliative care sectors will increasingly need to take GLBTI concerns into account. Ideally, the process of incorporating GLBTI needs into legislative and policy and in-service protections will take place prior to this future scenario.

References and Resources in relation to the comments made in this paper

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NSW Anti Discrimination Board (2005) New South Wales Anti Discrimination Board Working Paper on Gay, Lesbian, Bisexual, Transgender and Intersex (GLBTI) Ageing and Discrimination (includes Harrison keynote presentation delivered on February 15th)
http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/pages/adb_glbti_consultation

Rainbow Visions Ageing Resources Online
http://www.rainbowvisions.org.au/resourcesAgeing.html

The National Gay and Lesbian Task Force – Outing Age - Aging Issues (2009)
http://www.thetaskforce.org/issues/aging
http://www.thetaskforce.org/downloads/reports/reports/OutingAge.pdf

Additional relevant reports and publications are available at the following sites:

http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/pages/adb_glbti_consultation
[NSW Anti-Discrimination Board report on GLBTI aged care discrimination]

http://www.rainbowvisions.org.au/resourcesAgeing.html
[Links to full text documents on GLBTI ageing in Australia]

http://www.acon.org.au/about-acon/Strategies/ageing
[Ageing Strategy; ACON (AIDS Council of NSW)]

http://www.acon.org.au/womens-health/ageing/lesbians
[ACON Lesbians and ageing information]

http://www.acon.org.au/about-acon/Strategies/ACON-Strategic-Plan-09
[ACON organisational plan with ageing as a priority area]

http://www.qahc.org.au/seniors
[Queensland LGBT Ageing Action Group]

http://glhv.org.au/node/557#attachments
[Birch, Heather - Alzheimer's Australia publication on dementia and gay men and lesbians]

http://glhv.org.au/taxonomy/term/40
[Gay and Lesbian Health Vic. Resources on ageing]

http://www.grai.org.au
[GLBTI Retirement Association Inc – including recent research into residential provider attitudes and the development of practice guidelines]

http://www.lgbthealth.org.au
[National LGBT Health Alliance – ageing as a priority]

The recent Federal decision to provide a one-off grant to a pilot project to provide education around GLBTI issues to residential aged care staff in specific sites in NSW is a welcome development:

http://www.smh.com.au/national/back-into-the-closet-gays-find-few-friendsin-aged-care-20100416-skgc.html

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