End of Life Forum Submission

from
Gay and Lesbian Equality Network

February 2009

SUMMARY

Lesbian, Gay and Bisexual (LGB) people have experienced important changes in advancing equality in Ireland in the past twenty years. Equality legislation established a number of key protections against discrimination and the Government has also committed to addressing a key outstanding legal issue: providing for legal recognition of same-sex couples. As Bertie Ahern stated in April 2006 when he was Taoiseach

> *"Our sexual orientation is not an incidental attribute. It is an essential part of who and what we are. All citizens, regardless of sexual orientation, stand equal in the eyes of our laws. Sexual orientation cannot, and must not, be the basis of a second class citizenship."*

Many LGB people are increasingly open about their sexual orientation with support from their family, friends, communities and in their workplaces. Many LGB people are in lifelong relationships and a significant number are raising children..

There have also been a number of significant initiatives, by Government and agencies across a range of service areas designed to proactively identify the needs of and inequalities experienced by LGB people and to address these through policy change and service development.

However, despite the progress being made, significant challenges remain in advancing equality and in ensuring that services are accessible to LGB people and responsive to their particular needs.

The current opportunities for health providers, especially at end of life, include:

- Recognising LGB sexual orientation and same-sex relationships, at times in situations where it is not being declared openly
- Creating an atmosphere of openness and inclusion that unequivocally welcomes LGB people and their relationships
- Addressing negative attitudes among other older service users which may cause distress or fear among LGB sharing the facility or service
- Avoiding the assumption that people using or providing the service are all heterosexual.

GLEN welcomes this opportunity to contribute to the End of Life Forum. The issues affecting LGB people at end of life present a number of opportunities for service providers and policy makers to ensure that facing death and bereavement is enhanced by a commitment to inclusiveness and meeting the needs of diverse populations in Ireland.

1. Introduction

Considerable progress has been made over the past decade in promoting equality and inclusion for LGB people, including the Equality legislation that prohibits discrimination on the basis of nine protected grounds, one of which is sexual orientation. The scope of the Equality legislation covers discrimination in employment and in the provision of services.

In recent years, a number of national policies (Department of Health and Children, 2000 and 2006; Equality Authority, 2002; Health Service Executive 2005; National Economic and Social Forum 2005) have highlighted the need for LGB people's health needs to be considered by health professionals and for health care providers to be inclusive of this patient group in their practice. By understanding the specific health needs of LGB patients and the barriers they may face in meeting their health needs, service providers can ensure they are providing an appropriate and accessible service to this patient group.

There has also been positive and productive engagement between LGB organisations and professional bodies on LGB health issues. The HSE has also been working with GLEN and other LGB organisations to map out health needs and gaps in health service provision for LGBT (lesbian, gay, bisexual and transgender) people with a view to developing a national strategy to make services more responsive to the particular needs identified.

A critical issue has always been the recognition and support of LGB relationships and families. Many lesbians and gay men have been in lifelong relationships unsupported by the state. In the last number of years there has been significant progress on this issues, with all political parties, the programme for government and continuous public opinion surveys favouring the introduction of civil partnership for lesbian and gay couples. The Governments Colley group recommended two options for same-sex couples; access to civil marriage, which would underpin a wider equality for LGB people or the introduction of full civil partnership, which would provide the protections and obligations of marriage for same sex couples.

The Government has committed to introducing legislation that will give legal recognition to same-sex partnerships. The Heads of Bill were published in 2008 and legislation is expected in 2009 which will confer the equal protections to same-sex couples as currently accorded to opposite-sex married couples.

A key area of concern for GLEN is that the proposed registered civil partnership scheme in the published Heads of Bill largely treats civil partners as a self-contained unit with limited reference to, or provision for any children that reside with and are dependent upon them. This has the potential to disadvantage children living in these situations, and create difficulties in areas such as health care provision and decision making.

There is a significant legacy of exclusion from supports – family, service provision and legislative protection for lesbian and gay people. It is just 15 years since decriminalisation of homosexuality, and despite the very significant progress since then, there are profound consequences for many LGB people not least among these is the invisibility of their relationships.

This legacy also places a particular responsibility on service providers to reach out to that previously excluded group and to make their services accessible and appropriate for LGB people.

Very many older LGB people, in particular gay men, have had profound experiences of death and end of life through the HIV and Aids epidemic, which until the mid-1990s resulted in a high level of death and for some, the wiping out of much of their friendship networks.

2. The Health-Related Circumstances of LGB people

Although there are no conclusive figures on the size of the LGB population in Ireland it is generally accepted that between five and seven percent[1] of the general population is lesbian, gay or bisexual. Based on the Irish census figures for 2006 this suggests a population of 254,500 LGB people in Ireland.

It is important too, to remember that within the palliative care setting LGB people are not only represented among service users, and their families and friends but also among the staff cohort of service providers.

Four recent studies identify key issues for LGB people and healthcare in Ireland that are significantly relevant to the End of Life Forum.

Supporting LGBT Lives (Mayock et al 2008)

A study of 1,110 LGB people in Ireland, which examined amongst other things LGBT people's experience of using healthcare services, found that:

- Healthcare providers were only aware of respondents LGBT identity in 44% of cases
- 76.9% felt healthcare providers need to have more knowledge and sensitivity to LGBT issues
- Only 40% felt respected as an LGBT person by their healthcare provider

This indicates that a significant number of LGB respondents perceived that healthcare providers don't have the knowledge and understanding necessary to provide a service appropriate to their needs. In addition to this, healthcare providers typically presumed that their patients were heterosexual, leading to reluctance on the part of these patients to disclose their sexual orientation and associated health issues or concerns. Lesbian patients were more likely than gay men to report a history of difficulties with healthcare providers.

The effects of stigma, marginalisation, discrimination and harassment on mental health of minorities, including LGBT people can increase LGBT people's vulnerability to developing mental health problems. Lower degrees of inclusion, equality and support may result in increased risk of minority stress which may result in risks to mental health

---

[1] Based on the UK Government estimates in the National Survey of Sexual Attitudes and Lifestyles (NATSAL 1990 and 2000)

The study also found that the majority (81%) of LGBT people are *now* comfortable with their identity, with over two thirds of respondents disclosing their identity (coming out) to all their immediate families

LGBT West Needs Analysis (Gleeson and McCallion 2008)

A needs analysis of LGBT people in Galway, Roscommon and Mayo reported that 69% of survey respondents had experienced some form of discrimination because of their sexual orientation. 50% of participants were presumed heterosexual in health care settings. Participants described the need for creating more visibility and providing information and leaflets in waiting rooms.

Recognising LGB Sexual Identities in Health Services (Gibbons et al 2008)

Many respondents, in this study commissioned by the Equality Authority and the Health Service Executive raised concerns about the status of same-sex partners and implications for next-of-kin in relation to health service provision. The issue most raised was the importance of the recognition of same-sex partnerships, especially when an LGB person is hospitalised.

The *grief experience of same-sex couples within an Irish context (Higgins 2008)*

If health care professionals are not aware, or willing, to openly acknowledge people's sexual identity, it is unlikely that they will provide holistic care or create the space where the grief and loss associated with the death of a sexual partner can be explored.

Health care professionals need to display visible evidence of an open, non-judgemental environment; such evidence might include questions that do not presume heterosexuality; the visibility of gay and lesbian literature on bereavement and information on gay and lesbian bereavement support groups.

While end-of-life care is not restricted to older people, research in other countries allows us to compare older lesbians, gay men and bisexuals with their heterosexual counterparts, and highlight some key differences that have profound implications for service providers.

In research conducted by the Brookdale Center on Aging (sic) (Cross P and Brookdale Center 1999) in New York, for example, it was found that older lesbians, gay men and bisexuals have significantly diminished support networks when compared to the general older population. Brookdale found that:

- up to 75% of older lesbians, gay men and bisexuals live alone (compared to less than 33% in the general older population)
- 90% do not have children (compared to less than 20% in the general older population)
- 80% age as single people, without a life partner or 'significant other' (compared to less than 40% in the general older population)

When compared to their heterosexual counterparts, therefore, older lesbians, gay men and bisexuals are:

- 2½ times as likely to live alone

- twice as likely to age without a partner or 'significant other'
- 4½ times as likely to have no children to call upon in times of need

This translates into a lack of traditional support networks that may not be replaced by the strength of other close friendships or the size of informal support networks within the lesbian, gay or bisexual community, with the result that:

- 20% of older lesbians, gay men and bisexuals indicate they have no one to call on in a time of crisis or difficulty – a rate up to ten times higher than that seen in the general older population

This means that older lesbians, gay men and bisexuals are much more reliant on and have a much greater need for professional services and formal support systems in old age than is the case with their heterosexual counterparts. However, other studies in the US have shown that older lesbians, gay men and bisexuals do not access the programmes and services they need. In fact:

- older lesbians, gay men and bisexuals are five time less likely to access services for older people than is the case in the general older population, because they fear discrimination, homophobia and ignorance and that they will have to hide their sexuality

Other studies have pointed to the ways in which many older LGB people have in fact created supportive networks, often as necessary substitutes for family. These kin-substitutes may however be rendered invisible by assumptions that the older LGB person has no family based on lack of contact with blood-relatives.

A recent Australian study of older LGB people in aged-care services (Barrett 2008) identifies core issues relating to the experiences and specific needs of older LGB people:

- The impact of historical experiences of discrimination
- Invisibility as an impact of current discrimination
- The impact of identity concealment
- Enabling sexual and cultural expression
- Inadequate standards of care
- Achieving a safe environment

The impact of historical experiences of discrimination on the current population of LGB older people, many of whom may have lived the bulk of their lives before the development of strong LGB communities and legal protections is also identified as a key factor for health and social service providers in a Canadian study (Brotman etc al 2002). They may have feared prosecution, being labelled as criminals or attempts by the medical establishment to cure them. Many older LGB people have had life-long experiences of hiding their sexual orientation and being distrustful of health, social welfare and other institutions.

These findings are reiterated in a publication by Age Concern England *The whole of me A resource pack for professionals (Knocker 2006).*

> "Remember, we started out life as being 'criminals'. Homosexuality was illegal till 1967 so many of us lived in fear of being caught, losing our jobs and even our

families. Though I think mum always knew deep down, it was never talked about and that's how we all just got on with life"

3. Barriers to accessing appropriate and accessible services

There is now a growing body of research evidence that LGB people in general face particular and specific barriers to accessing medical and health service appropriate to their needs (see for example report of the Equality Authority, 2002). These barriers may also be present in accessing end-of-life care. For example:

3.1The presumption of heterosexuality and fear of discrimination on the basis of sexual orientation.

- Many LGB people can postpone or decline seeking medical care due to fear of negative reaction should their sexuality become known to medical practitioners. Research by AGE Concern in the UK has shown that older LGB people can be particularly reluctant to seek the health care services they need due to heightened fear arising from past experience of severe prejudice, including criminalisation.
- The Canadian study (Brotman) indicates that older LGB people who experienced the pervasive social stigma prior to the advent of the social and political change on LGB issues maintain a sense of extreme caution with respect to whether societal attitudes have really changed. They are often reluctant to place trust in social systems (i.e. health care) they perceive as having persecuted them.
- When LGB people do access health services, fear of negative reaction can also lead to reluctance to reveal personal information to medical professionals, even when this information is critical to their well-being. Examples include a reluctance to talk about sexual behaviour relevant to sexual health or to refer to the death or illness of a partner that might be linked to stress or depression.
- LGB people can also be reluctant to access medical services as they are unclear and uncertain about the confidentiality of their discussions with their GP or other medical practitioner. Concerns about confidentiality can be especially significant in relation to discussing issues such as HIV, where there are serious social and economic implications, for example impact on life insurance etc.
- The recent Australian study (Barrett) documents how previously "out" LGB people may feel they no other option but to hide their sexual orientation because of living in residential homes and facing harassment and negativity from other residents and the professionals working there.

3.2 *Lack of understanding of LGB issues*

- *There is a need for further education among health care professionals on gay and lesbian issues and communication skills such as sensitive enquiry, reading cues, active listening, acknowledging the sexual nature of relationships and responding appropriately or affirmatively to LGB people and their needs.*

3.3 Anti-gay bias among professionals

Anti-gay bias among professionals results in LGB patients receiving sub-optimal care and experiencing direct or indirect discrimination or exclusion when they use health

services. According to the Group for Advancement of Psychiatry[9] the characteristics of professional anti-gay bias are:

- Presuming patients are heterosexual
- Pathologising, stereotyping and stigmatising LGB patients
- Failing to empathise with or recognise LGB patients' health concerns
- Failing to appreciate any non-heterosexual form of behaviour, identity, relationship, family or community
- Making unsolicited attempts to change a patient's sexual orientation

Any of the above forms of anti-gay bias can result in inadequate care. Best practice implies that health care practitioners are aware of potential anti-gay biases and how these can impact on patients.

3.4 Lack of recognition of same-sex relationships

Although progress has been made in recognising the significance of same-sex partnerships, many LGB people are still concerned that their partner will not be given the same recognition as next of kin that is afforded to a spouse.

The Equality Authority report (2000) notes that it is not clear how the IMO guide on the provision of information to relatives or input into treatment decisions when a patent is not able to communicate would be applied with respect to same-sex partners. It is unclear, they note, whether doctors in these situations would respect the wishes of a same-sex partner above those of relatives, even in situations where the same-sex partner has been nominated by the patient as the person with whom their condition is to be discussed. This concern is echoed in the Gibbons et al 2007 study.

There are also same-sex couples who do not disclose their sexual orientation and are, therefore, not explicit about the nature of their relationship.

The Higgins study, (Higgins 2008) demonstrates the impact of professionals colluding with the tacit nature of the relationship and failing to address the support needs of the bereaved partner resulting in an experience of "disenfranchised grief." An example of this is contained in the following:

> " Although society recognised that the person had lost someone significant in their life, it was not given the recognition that would have been offered to a widow or widower in the heterosexual community"

4. Inclusive Service Provision

Much of the research referred to earlier in this submission clearly shows that LGB people may be reluctant to disclose or discuss their sexual orientation because of previous negative experiences, fear of rejection or embarrassment, or a perception that health care providers do not have the knowledge or understanding to provide a service appropriate to their needs. The assumption by many health care providers that the patient is heterosexual can compound the patient's reluctance to disclose their sexual orientation.

All health care providers, and in this context, end of life services should address this lack of disclosure so they gain the confidence of service users. Clearly enunciated policies,

clearly visible statements of welcome and inclusion in hospitals, hospices and health centres will ensure that LGB people will not simply remain silent.

The development of inclusive services can address many of these types of issues. Inclusive services follow both the developments in equality legislation and a desire on the part of health care providers to provide appropriately accessible services to a diverse population. Inclusive practice applies to all forms of diversity, including sexual orientation and it means that healthcare providers:

- Recognise diversity among their patient population and respect this diversity
- Understand the issues facing diverse patient groups (such as LGB patients) and are able to respond to their specific health needs
- Provide an accessible and appropriate service within their scope of practice and refer patients on to specialist or other services where necessary

By understanding the specific health issues that may affect LGB patients and knowing how to provide an accessible and appropriate service to them, general practitioners can be confident that they are practicing inclusively and delivering a professional service to all patients regardless of their sexual orientation.

In the context of end-of-life services, there are a number of recommendations to improve service provision to ensure that it is appropriate and sensitive to the needs of LGB people.

5. Recommendations

GLEN makes the following recommendations for making end of life services more appropriate and sensitive to the needs of lesbian, gay and bisexual people in Ireland.

5.1 *Develop positive statements of welcome and other ways of demonstrating that the service is inclusive of LGB people.*
Positive and clearly visible statements of welcome and inclusion serve to re-assure many LGB people that they do not have to hide their sexual orientation when using a service. Such statements may also encourage LGB people to address harassment from other people using the service.

The inclusion of LGB people in information about the service and the display of posters/leaflets reinforce the commitment to provide an appropriate service to LGB people

5.2 Ensure that practitioners do not assume heterosexuality of service users, colleagues or family and friends.
Using open and inclusive language facilitates disclosure and discussion. Using appropriate language and open questions indicates to LGB people that a healthcare practitioner is not making an assumption that they are heterosexual. For example asking if someone has a partner is more inclusive than asking if they are married.

5.3 Health care professionals should be aware of anti-gay bias
Good practice implies that health care professionals are aware of the potential for anti-gay bias and how this can impact on the LGB service user. Often such bias is due to a lack of awareness of contemporary research on sexuality and sexual orientation or from a lack of familiarity with LGB issues. Inclusive practice is one where professionals challenge any anti-gay bias they may have or encounter. Even the most subtle or

indirect expressions of anti-gay bias may have an adverse effect on the professional relationship and the LGB person's willingness to disclose relevant personal information and health concerns to the care provider.

5.4 Develop a code of good practice to reflect the needs of LGB people

The development of a code of practice with commitments to inclusive service delivery for LGB people makes a clear and unambiguous statement that LGB people are welcome and valued as part of the community using the service.

5.5 Ensure that pastoral care provision is appropriate and sensitive to the needs of LGB people.

Many LGB people have had negative and deeply hurtful experiences of church at both institutional and inter-personal levels. They may, therefore, be anxious that end of life service provision automatically entails pastoral care.

While pastoral care may be welcomed by some LGB people it is also possible that many LGB people would prefer not to engage with it though some may have difficulties in expressing this.

Pastoral care should be available in such a way that a person who does not want it should be able to refuse it easily. When pastoral care is being accessed by LGB people is very important that it does not reinforce negative experiences of church and/or spirituality. Pastors will require a degree of awareness of, and sensitivity to, the variations of family and alternative kin networks that often play a significant role in the lives of LGB people.

5.6 *Consult specifically with the LGB population.*

We would suggest that the Forum conduct a specific strand of consultation with LGB people. GLEN would welcome the opportunity to work with the Forum on developing and implementing a national consultation with lesbian, gay and bisexual people ein Ireland

GLEN - the Gay and Lesbian Equality Network - is a Policy and Strategy focused NGO which aims to deliver ambitious and positive change for lesbian, gay and bisexual people (LGB) in Ireland, ensuring full equality, inclusion and protection from all forms of discrimination.

References

Cross P and Brookdale Center on Aging of Hunter College (1999). Housing for Elderly Gays and Lesbians in New York City. New York: Services and Advocacy for Gay lesbian, bisexual and transgender Elders (SAGE)

Department of Health & Children (2000). The National Health Promotion Strategy 2000-2005. Dublin: Department of Health & Children.

Department of Health & Children (2006). A Vision for Change - Report of the Expert Group on Mental Health Policy. Dublin: Department of Health & Children.

The Equality Authority (2000). Partnership Rights of Same-Sex Couples. Dublin: Equality Authority.

Equality Authority (2002). Implementing Equality for Lesbians, Gays and Bisexuals, Dublin: Equality Authority.

Gibbons et al (2008). Recognising LGB Sexual Identities in Health Services; The Experiences of Lesbian, Gay and Bisexual People with Health Services in North West Ireland. Dublin: Equality Authority, Health Service Executive.

Gleeson and McCallion (2008). A Needs Analysis of the Lesbian, Gay, Bisexual and Transgender Population in Galway, Mayo and Roscommon. Dublin: Gay and Lesbian Equality Network (GLEN).

Health Service Executive, (2005). Reach out: National Strategy for Action on Suicide Prevention. Dublin: Health Service Executive.

Higgins et al (2008). The grief experience of same-sex couples within an Irish context: tacit acknowledgement. *International Journal of Palliative Nursing 2008 vol 14 no 6 pp 297-302*

Knocker S. (2006) The whole of me; meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing. London: Age Concern England.

Mayock et al (2008). *Supporting LGBT Lives: A study of the Mental Health and Well-Being of Lesbian, Gay, Bisexual and Transgender People*. Dublin: Trinity College Dublin Children's Research Centre.

National Economic & Social Forum, (2003). Equality policies for lesbian, gay and bisexual people: implementation issues. Dublin: National Economic & Social Forum