

LGBT People & End of Life:

Presentation to Joint Oireachtas
Committee on Health and
Children Public Hearings on
End of Life

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1. Introduction

Thank you for inviting GLEN to make a presentation to you on End of Life issues for lesbian, gay, bisexual and transgender people. This is an important matter and GLEN welcomes your consideration of it. Throughout my presentation I'll use the acronym LGBT to refer to lesbian, gay, bisexual and transgender people. Today I will highlight how LGBT people's needs can be fully incorporated into end of life policy and service delivery in Ireland.

2. Older LGBT People in Ireland

End of life issues affect LGBT people of all ages, as well as their partners, families and friends. However, older LGBT people are the group most affected by and concerned about end of life issues. For this reason I'll mostly focus on older LGBT people but the recommendations I make are applicable to services being provided to LGBT people of all ages.

A recent Irish study called **Visible Lives: Identifying the Experiences and Needs of Older LGBT People** is the first study of its kind in Ireland. It was commissioned by GLEN, funded by Age and Opportunity and the HSE and published in 2011. Prof Agnes Higgins from Trinity College Dublin was the principal investigator in this study and she is here in the public gallery today. On behalf of GLEN I would like to take this opportunity to thank her and her research team for producing this excellent research report.

- The study surveyed 144 LGBT people aged between 55 and 80 from across the Republic of Ireland and 36 people were interviewed.
- We found that 46% were living alone, 43% were single and 31% were feeling lonelier as they age. One in four are either just about getting by or are struggling financially
- Only 11% said they had written a living will and just one in four had given someone power of attorney. 48% said they have discussed their

final wishes with someone and 62% had written a last will and testament.

- By far the most preferred option is to live their final years and die in their own homes. The least preferred option is to be a nursing home.
- Because of fears of being placed in a nursing home, some said they would prefer to live in an exclusively LGBT retirement community or an older age facility that is fully respectful of LGBT people.
- A major concern for participants in the study is that older age and end of life services will not recognise or respect their LGBT identity or their relationships and that they would have to in effect 'return to the closet' and conceal their LGBT identity in order to feel safe when using these services
- Almost one in four said they had received poor quality healthcare and 40% considered this to be related to being LGBT.
- Just one in three believed that healthcare professionals had sufficient knowledge about LGBT issues and only 40% felt respected as an LGBT person by their healthcare providers.

It is clear from the study that older LGBT people fear being discriminated against when using end of life services including nursing homes and this results in them being cautious about being open about their sexual orientation or gender identity and reluctant to engage with health and support services. However, given the increased incidence of being single, living alone and not having traditional family support structures, older LGBT people are most likely to need, and indeed benefit from, such services at end of life.

Transgender people also have concern that as they age services will not be responsive to their needs or respect their gender identity. There is good evidence from Irish research that healthcare practitioners can have serious gaps in their understanding of the healthcare needs of transgender people and how to provide appropriate supports to this group.

LGBT people may have reasons for not disclosing that they are in a loving close same-sex relationship and not being 'out' can have huge implications for gay and lesbian couples when one partner is seriously ill or dies. This can lead to exclusion of the surviving partner from end of life decision-making and funeral planning. Difficult experiences such as these can be further compounded when the grief of the surviving partner is unrecognised or unacknowledged. This is referred to as *disenfranchised grief* and has been evidenced in Irish research on bereaved gay and lesbian people (Glacken & Higgins, 2008).

3. LGBT People in End of Life Services

The findings of *Visible Lives* coupled with the difficult experiences older LGBT people had in the past can lead to a particular set of challenges for LGBT people at end of life and for those providing services to them.

This point is echoed in an excellent resource developed by the National Health Service in the UK called **The Route to Success in End of Life Care: Achieving Quality for Lesbian, Gay, Bisexual and Transgender People** (NHS, 2012). The authors of this report identify that end of life services need to actively encourage LGBT people to be confident in being open about their relationships and needs. They say this can be achieved in a number of ways:

- By recognising that sexual orientation and gender identity doesn't just refer to who a person has sex with but is about who a person is, who they fall in love with and who they are in a loving committed relationship with (or would like to be).
- By using appropriate and inclusive language to facilitate understanding and identification of who is important to the LGBT individual
- By ensuring a comfortable and safe environment for LGBT people and their families and carers to feel able to be open, and
- By having an LGBT friendly culture based on an inclusive practice model

The Psychological Society of Ireland (PSI, 2008) also advocates an inclusive model of practice and describe this as:

- Expecting diversity among your service users and respecting this diversity.
- Understanding the issues facing diverse groups such as LGBT people and being able to respond to their specific needs.
- Providing an accessible and appropriate service within your area of competence.

4. GLEN Recommendations

In summary I would like to say that GLEN advocates the following to ensure LGBT people's needs are met at end of life:

- End of life policy should be based on principles such as equality, diversity and a respect for individual autonomy, and name LGBT people as a population group with specific needs
- End of life service provision should be based on a model of inclusive practice that both recognises and responds to the needs of different groups such as LGBT people, and that fully respects LGBT people's identities, relationships and families.

Thank you for this opportunity and I am happy to answer any questions you may have.

GLEN – Gay and Lesbian Equality Network

GLEN is a policy and strategy focussed organisation which aims to deliver ambitious and positive change for lesbian, gay, bisexual and transgender people across a series of areas: legal recognition and support for relationships and families; mental health; education; immigration, sexual health; community safety and community development. GLEN was a winner of a People of the Year award in 2010.

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