



# 'We don't have any of those people here ...'

By Jude Comfort, Rita Freijah, Barbara Horner, Alexandra McManus, Graham Lovelock and Michelle Hunter

Most people ageing with HIV in Australia are, and will continue to be, gay men. For those who avoided disclosing their sexuality throughout their lives or who have limited disclosure to a small circle, the prospect of dealing with aged-care services can be daunting.

For many older gay men diagnosed with HIV in the eighties or nineties, the concerns around disclosing sexuality are compounded by past experiences of stigma and discrimination due to their sexuality, with additional fears around disclosure of their HIV-positive status.

The GRAI research outlined in this article raises important issues that must be addressed in planning for the diversity of the Australian population – planning that needs to acknowledge the issues faced by the Australian cohort of gay men ageing with HIV. (Eds.)

## Introduction

GRAI (Gay, lesbian, bisexual, trans and intersex Retirement Association Inc.)<sup>1</sup> recently released the findings of a 12-month research project conducted in Western Australia (WA), looking at the accommodation and service needs of older non-heterosexual people. The research was supported through a Lotterywest Social Research Grant and involved collaboration between Curtin University, through the WA Centre for Health Promotion Research, the Centre for Research on Ageing, Curtin Health Innovation Research Institute and GRAI.

The project came about from formative research conducted by GRAI and researchers at Curtin University in 2006/07, confirming that older and ageing gay, lesbian, bisexual, transgender, intersex (GLBTI) individuals accessing retirement and residential aged-care services in WA

experienced unmet needs and fears of discrimination.<sup>2</sup> This was in line with other national and international research indicating that older GLBTI people were likely to be disadvantaged in the aged-care sector due to their minority sexuality. The research was used to develop best practice guidelines to assist providers to deliver more GLBTI inclusive services and help in addressing challenges faced by members of the GLBTI community.<sup>3</sup> This article discusses the background to the research and presents the best practice guidelines.

## Background

In addition to the usual issues facing older adults, such as loneliness, isolation, loss of autonomy and increasing dependence, older GLBTI individuals may experience further stressors.<sup>4</sup> These are usually associated with sexual orientation, disclosure of sexual orientation and/or gender identity to health care providers, discrimination, lack of legal recognition, little, if any, protection of lifetime partnerships, and limited opportunities to meet other older GLBTI people.<sup>5,6</sup>

Furthermore, the heteronormativity (presumption and preferences of heterosexuality) of retirement and residential aged-care facilities is a concern for many older GLBTI people. Heterosexual assumptions coupled with the notion of older people being asexual, can make GLBTI people feel that their same-sex relationships are not valued or understood and that partners will be excluded in care planning and decision-making.<sup>7</sup> Additionally Addis reports some older GLBTI people fear a lack of recognition and support of their 'families of choice' from service providers.<sup>8</sup>

Older GLBTI Australians grew up during a time where homosexuality was illegal, and those found to be engaging in homosexual activities were prosecuted. The negative attitudes of society in general towards homosexuality led to persecution, condemnation, hatred and discrimination, with homosexuality commonly viewed as a 'sickness, sin and disgrace'.<sup>9</sup> Consequently the GLBTI

population was concealed from the general population with few people disclosing their sexual orientation for fear of reprisal and/or prosecution.<sup>10</sup>

As a result, getting older for many GLBTI people can mean increased fear of being 'outed' after a lifetime of avoiding disclosure of their sexuality, or fear of lack of understanding and support as they seek assisted care. Concealment of identity renders older GLBTI people invisible and may result in service providers unintentionally failing to address their needs beyond the physical.

There is a growing body of research around GLBTI gerontology within Australia and internationally. Although there may be context specific considerations, recurrent key themes identified are:

- historical experiences of homophobia/discrimination
- current experiences of homophobia/discrimination
- concealment of identity – invisibility
- ageism within the GLBTI and wider communities
- impact of homophobia/discrimination on the quality of care delivered
- heteronormativity, and
- social isolation.

## Research methodology

The research outlined in this paper is unique in Australia as it sought to examine experiences and attitudes of service providers around GLBTI client issues. Organisational data were collected through a self administered Chief Executive Officers (CEOs) Survey and a separate Facility Survey to facility managers. Forty CEOs of retirement and residential aged-care organisations in WA with multiple facilities completed the CEOs Survey, with a response rate of 32.5% (n=13). The CEO Survey was also sent to single entity organisations and a 14.5% (n=23) response rate was achieved. Operational data were collected through a statewide *Facility Survey* sent to 320 retirement and residential aged-care providers in WA, with a response rate of 26% (n=83)

for this group. Qualitative data was collected through two focus groups.

## Results

The full findings in the final report are available at [www.grai.org.au](http://www.grai.org.au). A brief summary of some of the key findings are presented in this section. 86% of *Facility Survey* respondents were unaware of any GLBTI residents or supporting families currently or previously accommodated within their facility. Only 30% of respondents agreed that their facility recognises that GLBTI residents have specific needs. The majority of *Facility Survey* respondents (79%) agreed, or strongly agreed, that a resident's sexuality was not their concern, however over half (88%) indicated that a resident's beliefs and personal diversity were promoted within their facility's policies and procedures. The majority of *Facility Survey* respondents (66%) felt that they provided a GLBTI-friendly and trusting environment which 'treated everyone the same'.

Table 1 (on the following page) summarises the attitudes of facilities to GLBTI issues. The majority of facilities did not provide any training on GLBTI issues, and their policies did not address GLBTI issues.

## Best practice guidelines

An important outcome of the project was the development of best practice guidelines for retirement and residential aged-care providers in Western Australia which seek to encourage management and staff to adopt practices that create an inclusive environment, accepting and welcoming of all groups, including GLBTI people. The guidelines are also designed to provide an operational context whereby providers of retirement and residential aged-care are better able to recognise, understand and meet the specific needs of GLBTI people.

*continued overleaf*

**Table 1** Facility attitudes with regards to GLBTI issues (n=83)

	Strongly disagree n (%)	Disagree n (%)	Unsure n (%)	Agree n (%)	Strongly agree n (%)
Your Facility recognises that GLBTI residents have specific needs	4 (5)	18 (23)	33 (42)	19 (25)	4 (5)
Same-sex partners of a resident have the opportunity to be involved in that person's care	0 (0)	0 (0)	13 (10)	30 (38)	40 (50)
Your Facility provides a GLBTI-friendly environment	0 (0)	3 (4)	24 (30)	32 (40)	21 (26)
Non-judgemental language is used and promoted within your Facility's printed policy and procedure documents	1 (1)	1 (1)	14 (17)	32 (40)	33 (41)
All residents' beliefs and personal diversity (e.g. religious, cultural, sexual) are promoted within your Facility's policies and procedures	0 (0)	2 (3)	7 (9)	24 (30)	46 (58)
A resident's sexuality is not of concern to your Facility	2 (3)	7 (9)	8 (10)	29 (36)	34 (43)
Staff treat residents as individuals (not defined by their cultural/political/sexual identity) at your Facility	0 (0)	0 (0)	4 (5)	21 (26)	55 (69)
Your Facility provides a trusting environment where residents feel safe enough to disclose their sexual orientation	0 (0)	1 (1)	14 (17)	33 (41)	33 (41)
GLBTI issues are not important to your Facility	5 (6)	29 (37)	17 (22)	17 (22)	10 (13)
GLBTI residents' needs are openly discussed at your Facility	2 (3)	20 (26)	25 (45)	14 (18)	6 (8)
Other residents are encouraged to support a GLBTI-friendly environment	3 (4)	12 (16)	44 (57)	14 (18)	4 (5)

To achieve best practice for accommodating older GLBTI people five principles were identified:

1. inclusive and safe environment
2. open communication
3. GLBTI sensitive practices
4. staff education and training, and
5. GLBTI inclusive organisational policies and procedures.

### Implications for service providers

The findings of this research have a number of implications for providers of retirement and residential aged-care if they are to adequately meet the unique needs of older GLBTI people. It should be acknowledged that while a response rate of 26% of facilities (n=83) is not optimal, this rate is what can be expected when surveying such organisations.<sup>11</sup> Respondents included a variety of facilities across location (metropolitan – 53%, rural – 40%, remote – 7%), size (61% with staffing levels of 25 full-time equivalents or less) and ownership (55.6% not-for-profit).

It is clear that older GLBTI people currently accessing retirement and residential aged-care are a hidden population. Older GLBTI people in general do not feel safe to disclose their sexual or gender identity to

aged-care providers as a result of their past experiences of discrimination.<sup>12</sup> Additionally, concerns are raised regarding the fact that a large number of residential facilities are run by faith-based agencies.<sup>13</sup> Although some of these facilities may be accommodating to all seniors, others exclude potential residents (including GLBTI people) who do not adhere to their particular religious conventions.

Heteronormativity and homophobia exist within the broader community and they are also likely to exist in retirement and residential aged-care facilities.<sup>14,15</sup> It is essential that agencies provide inclusivity training for their staff at an organisational and facility level. Findings from this research indicate that few agencies currently make such training available for their staff, or have GLBTI-inclusive organisational policies and procedures that would assist in supporting long term change in attitudes and practices.

### The future

While these best practice guidelines were developed based on research completed in Western Australia, they have national merit. The nation-wide adoption of the guidelines developed as part of this research would provide a

starting point for fundamental national reform at an organisational level, and would lay the foundation for positive changes in retirement and residential aged-care facilities.

Although HIV does not exclusively affect gay men, issues around planning for aged-care have particular resonance for older gay men living with HIV. Some people living with HIV may require access to retirement and residential aged-care services at an earlier age than would generally be expected. Naturally occurring age-related conditions such as cardiovascular disease, diabetes, osteoporosis, some cancers and dementia are presenting at an earlier age for some people living with HIV, causing early onset of ageing.<sup>16</sup> This has implications for service providers, as the need to accommodate much younger people with complex and unique care requirements increases.

Further research is required to explore the implications of HIV-related early ageing for providers of residential aged-care; and the social dimensions of accommodating people living with HIV.

The implications of HIV on ageing also need serious community engagement. It is hoped the work of GRAI and the output from this research will provide an impetus for action on the part of both the retirement and residential aged-care sector and the GLBTI community.

The culture that exists within the aged-care sector results in a lack of understanding of the social history of GLBTI clients and unique needs of this group. The SwanCare group in Western Australia is the first aged-care provider to commit to adopting the best practice guidelines. Many other aged-care providers appear open and willing to consider how to be more inclusive of GLBTI clients, however they lack the skills to do so. It is time to push forward with quality education and training for this sector.

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UNAIDS Executive Director Michel Sidibé visited China and commended China's response, saying, 'This scale of transformation gives me and many others hope that China can make breathtaking strides in other areas of universal access, if the will is there. And I believe it is.'<sup>17</sup>

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