

# SEXUAL IDENTITY IN HEALTH & AGED CARE

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## NARRATIVE RESEARCH IN THE BLUE MOUNTAINS

### FOR INFORMATION:

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Research into the experiences and needs of older gay, lesbian, bisexual, transgender and intersex (GLBTI) people in Australia is still in the early stages of development. Australian gerontology research has tended to take heterosexuality as the norm and has only acknowledged diversity in the older population in relation to ethnicity, disability and location. Compounding the problem, Australian sex research samples typically exclude people aged 60 and over.

The research reported in this paper is just one of a growing number of projects on GLBTI ageing in Australia, these include studies by Waite (1995), Harrison (1999, 2004) and Chamberlain and Robinson (2002), as well as forthcoming

PhD studies by Peter Robinson and Charles Lo. The focus of this particular project was on gays and lesbians approaching older age and their experiences of and expectations for health and aged care. The project extended from issues raised in earlier papers (Hughes 2003, 2004). It was small-scale qualitative research conducted within a particular location: the Blue Mountains in NSW. The aim of the research was to facilitate narratives relating to sexual identity and how this identity should or should not be acknowledged in contact with health/aged care providers.

Fourteen people were involved in the research. They had the choice of a male or female interviewer and if they

were currently in a partnership if they wanted to be interviewed together or separately. Eleven interviews were conducted in total: 3 with gay male couples; 3 with gay male individuals; 5 with lesbian individuals. Two people in the study had migrated from Northern European countries and one person identified as being part Aboriginal.



## WHAT IS NARRATIVE RESEARCH?

Narrative research involves eliciting and interpreting stories, usually conveyed during qualitative research interviews. Typically people tell stories about specific past events, habitual behaviours and hypothetical or imagined situations. The point of narrative research is not so much to get at an absolute truth, but to

understand what's important for a particular person—their own personal 'truth'. Each narrative comprises different components, but will usually include an evaluative statement in which the 'narrator' explains the purpose of the story and how they want it understood. In this study these evaluative statements were

identified and grouped in themes. In addition to the narratives conveyed during the interviews, each interview can be seen to contain an overall narrative—a story of the interview encounter. Narrative research is particularly suited to understanding identities—how people see themselves and want others to see them.

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## EVAN (70) & JAMES (59): BEING UP FRONT & OPEN\*

Evan and James see themselves as different from others of their generation in that they have always tried to be open about being gay, this usually involves being open about their (35 year) relationship. Each has been involved in gay community activism and welfare services. However since moving up from Sydney they have not become involved in the Mountains gay community – for James because he feels burnt out from working in the HIV area and for Evan because he is too busy. Unlike

others they know they have had positive experiences with the local hospital and generally feel that hospital staff nowadays, especially the younger ones, are much more accepting of gays and lesbians than they used to be. They are unsure about gay-specific services although recognise the need for more emotional support, for example after having lost a partner (especially for those who have moved to the mountains from Sydney and are isolated from other supports). James is

concerned that underlying sexual tension with gay staff might be difficult to manage. In receiving personal care it would be very important to be up-front and open and be clear that this is a non-sexual situation.

\* Please note: all names and some further identifying information have been changed to protect privacy.



## DOROTHY (66): IMAGINING A LESBIAN CARE HOME

Dorothy feels that she was a lesbian from a very young age and was accepted as such within her family. She worked as a medical specialist and was not open about being a lesbian in work contexts, because she thought it would affect her career. Since retiring Dorothy has been more open about her sexuality and is now actively involved in a lesbian community group. As a specialist she believes she didn't have the sort of relationship with patients where either

party could appropriately disclose being lesbian or gay. She believes it is important to keep personal matters separate from professional interactions. However, looking back on her work she worries that she could have done some things differently. For example, she remembers a patient who was dying and who was admitted to hospital for the last time. Dorothy knew she had a female partner, but on her last admission she only saw family members visiting and was

concerned that her partner was being ignored. In terms of her own health and aged care, Dorothy would tell a doctor privately that she is a lesbian if it is relevant to her care, but would not want it recorded on a file, although she would put her partner down as 'next of kin'. Dorothy would be out to any care workers who came to her home because they are on her own territory. She is interested in the idea of a lesbian care home, especially if privately arranged by friends.

“People are what I’m about. And to have the people I like and love and laugh with, I mean it’d be the best way.”

- Dorothy

## IDENTITY DISCLOSURE

Most people in the research felt comfortable using the labels 'gay' or 'lesbian' to describe themselves. However, there was a range of views on whether or not they would identify openly as gay or lesbian when in contact with health or aged care services. While some said they would try to be 'out' in all circumstances, most said

that it would depend on the situation they were in and the relevance to the care being provided. Some people thought it was important information for a General Practitioner to have, others felt that people providing personal or body care should know about their sexuality. For others it would be essential to iden-

tify as gay or lesbian to avoid being assumed to be heterosexual. Those in same-sex partnerships identified the importance of their partner being the 'person to notify' or 'next of kin'. Generally people felt that service providers could do more to provide a lesbian- or gay-friendly environment to facilitate identity disclosure.



## ROSEMARY (64): ASK ME OUTRIGHT

When Rosemary was 19 she fell in love with a woman and became quite 'freaked out about it.' She later married because she was afraid of being a lesbian. Now, having been in a lesbian relationship for many years and having more lesbian friends, she has come to accept how she is and things are 'magic'. Rosemary doesn't disclose being a lesbian in all situations, only when she feels it is relevant and to ensure that she is not presumed to be straight. While in hospital with pneumonia

Rosemary did struggle with how open she should be about her sexuality. She felt uncomfortable when her partner visited and wondered how staff would view their relationship. There was something about being in a weakened state and feeling powerless that contributed to her feeling uneasy. While she thinks these feelings were more related to her own fears than any particular failings on the part of staff, she does believe the hospital could have made it easier for her to disclose

being a lesbian, for example by having it recorded on her file. In receiving aged care Rosemary would want to be acknowledged as a lesbian. If she needed residential care she would prefer to be with her 'own kind' or at least all-women setting. She believes strongly that service providers should ask direct questions about sexual identity rather than force clients to work out when and how to disclose. This would 'just take a load off your mind.'



## WILLIAM (70): MY PRIVATE IDENTITY

William acknowledges that he is gay but he sees this as a private identity and one that is not appropriate for discussion in non-sexual situations. For William being gay is about homosexual behaviour and he recalls vivid childhood sexual experiences and the difficulties he has faced forming relationships and having sex in later life, particularly since the end of his marriage (to a woman). Just as important for William is his identity as a rice queen, which followed from a

conscious rejection of his past discriminatory attitudes towards Asians and an accepting of the 'beauty and decency of Asian people'. William disapproves of people who parade their gayness and who 'wave their wrists around'. He chooses to remain in the closet (except with other gay people, usually based in Sydney) because he wants to remain safe, lead a quiet life and not be the subject of local gossip. He doesn't think that gay people should receive

special treatment and generally he wouldn't disclose being gay when in contact with health or aged care services, although at least on two occasions Sydney doctors knew he was gay when he went to them for sexual health services. At the moment his mother's care in a local nursing home is the most important thing in his life and once she goes and he has got his house in order for his sons 'they can throw me in a box'.

"It suits me to be like I am and I feel that there is safety in what I'm doing."

- William

## HARRY (62) & SID (58): FEELING LET DOWN

Harry and Sid are open about being gay in most aspects of their lives and they generally expect people to be able to deal it. They have been together for 24 years and feel less connected now to the gay scene than they used to. Both experienced very negative reactions from family members when they were younger. Harry was subjected to threats and intimidation and attempts to have him hospitalised as a

mental health patient, although now his sister is more supportive. Sid's family still do not accept his homosexuality and view Harry (who is older) as the person who corrupted him. Both men are open about being gay with their GPs and when they have been in hospital. When Sid had cancer and was in hospital the surgeon refused to acknowledge Harry's right to information about Sid's condition and

would only speak to Sid's parents. Sid's mother contacted the district nurse before she visited Sid and warned her that she could be at risk of violence from Harry. When Sid was recovering at home he felt let down by the local gay community, despite having helped other people out in the past, and felt more supported by people from his workplace and by his neighbours.



## SHIRLEY (64): DON'T ASSUME I'M STRAIGHT

Shirley came out as lesbian in most areas of her life, including at work and to her family, not long after her mother died. She was nervous about her children's and brother's reactions, but they were generally positive about it. Her teenage son said 'Mum, if you're happy, we're happy.' Shirley has had cancer and has had a number of hospital admissions. She didn't disclose being a lesbian while in hospital and thinks that they (including her specialist doctor) probably assumed she

was straight given the regular visits from her children. However, she does believe it is essential for her GP to know and she has actively sought out lesbian or lesbian-friendly GPs. Overall Shirley reports positive experiences with the health care system and feels she has never been discriminated against. However once she complained about a form used in a menopause clinic as being targeted solely at heterosexual women. She received assurances that the form would be changed and

she feels very positive about having taken this action. In thinking about any future aged care, Shirley wouldn't want to be assumed to be straight and would want her sexual identity to be recorded on her file so that 'homophobic types' would be discouraged. She believes that all aged care consumers should have the same rights, particularly the right to good quality care. She would like to see more training for GPs to enable them to help people feel comfortable and able to disclose being lesbian or gay.



## MARGARET (69): PRE-EMPTING QUESTIONS

Margaret migrated to Australia when she was in her 20s, partly due to a desire to distance herself from a family that was negative towards homosexuality and which, at least for those remaining in her country of birth, still treats it as a taboo topic. As a former health care worker Margaret has been affected by the labelling of homosexuality as a disorder; this meant that in her early career she spent considerable energy trying to hide her sexuality from others.

More recently in work situations she believes that she was discriminated against not because she is a lesbian but because she is older. However, Margaret reported a distressing incident in which a hospital doctor (who knew she is a lesbian) publicly humiliated her in front of a group of medical students during a gynaecological examination. Because of a particular gynaecological condition she needs to explain to doctors that she is a lesbian, usually to pre-

empt questions about never having given birth or if she is married. This is done for practical reasons rather than emotional support. Margaret feels that variations in the quality of care provided in the health and aged care system are more likely to be affected by whether a client/resident is friendly and accommodating than their sexuality. However she feels there will probably always be a small group of workers who find it difficult to relate to gay people.

"They were assuming that every woman that comes into this clinic is straight. And yet they are trying to encourage lesbians to have pap smears."

- Shirley

## REG (60): GROWING OLDER WITH HIV

Reg moved up from Sydney after he retired, looking for a healthy lifestyle as he is living with HIV. After moving he became involved in a gay community organisation as volunteer carer. Although Reg personally identifies as gay he sees himself as closeted because he likes to remain a private person. Reg's volunteer work is very important to him and his concerns about the withdrawal of HIV services

and funding from the mountains area partly motivated him to be involved in this study. He is concerned that HIV services are being more centrally located in Sydney and are not always appropriate or attractive to older people. A major concern for people with HIV as they get older will be how they can get around in the mountains due to inadequate public transport. Personally Reg chooses to use health care

services in Sydney, rather than local services, although he recognises that as he gets older travelling to Sydney will become more difficult. He feels that it is important for health and aged care staff to know if people are HIV+ but doesn't necessarily believe their sexual identity should be known, unless their relationships or sexual behaviour is relevant to the treatment or care.



## DAVE (69) & STEPHEN (72): NO TO GAY GHETTO

Dave and Stephen met when they were in their twenties and, while they no longer have a sexual relationship, they feel very strongly connected. When he was younger Dave felt little attachment to the gay scene, although more recently he has become involved in the gay community in the Mountains and appreciates having gay friends. Stephen is uninterested in gay culture and was only involved in the gay scene in order to access exciting encounters – ‘I don’t really regard mere homosexuality as

a great deal to have in common with people’. Stephen has in the past experienced homophobic violence and Dave lost a job offer because it became known he is gay. Dave and Stephen were motivated to take part in this research because they wanted to express their concern that some migrant health and aged care workers have come from more restrictive societies than Australia and may find it difficult to accept gay relationships among their clients or patients. When Stephen was

in hospital for a hip replacement a social worker, originally from India, assumed he was married and probably a grandfather. He found explaining his circumstances to be uncomfortable and stressful. Dave and Stephen choose to go to gay GPs in Sydney, as they are well able to handle sexual health issues. If they were to move to a retirement village they would prefer a mixed facility, arguing strongly that they wouldn’t want to be trapped in a ‘gay ghetto’.



## JANE (72): MY SEXUALITY IS NOBODY’S BUSINESS

Jane says that she doesn’t think about or choose to label her sexuality. As a young person she was interested in both boys and girls, although she feels her attachment was probably stronger to girls. However she never thought of this as related to her identity – it was merely a sexual preference. She doesn’t identify with a lesbian community although when she was younger she did hook up with people involved in the butch scene in Kings Cross. Jane says that

her family didn’t discuss sexuality as a matter of course. When she was young her family wouldn’t have even known that lesbians exist, although she used to bring girlfriends back to their house. In later years her family, including her five children, would have worked out she preferred women because she lived with a girlfriend in the house. Jane has lived in country towns with her girlfriend and eventually people have just had to accept the

situation. For Jane her sexuality is private and individual and she feels it is no one else’s business. She believes that it is irrelevant to any medical or hospital care she might receive and she doesn’t believe any carer who visited her house would be interested in her sexuality. In a residential situation she doesn’t think it’s anyone’s business if someone is a lesbian. Jane is enjoying the experience of growing older, nothing really bothers her anymore.

“I think your personal sexuality is a private matter ... and every individual on the face of this earth is entitled to that privacy.”

- Jane

## ARNOLD (66): PREFERRING GAY STAFF

Arnold is comfortable with his gay identity. In most situations he is happy disclosing this to others. Arnold worked as a nurse for many years and continues to volunteer to assist people living with HIV/AIDS. He has been an active member of gay community groups in both Sydney and the Blue Mountains. Due to his own personal experiences and witnessing the discrimination against other gay staff, he has

learned to be careful in disclosing being gay in work contexts. And when working with gay patients or nursing home residents he prefers not to disclose because it tends to blur the professional boundaries of the relationship and sexual tensions can emerge. When he worked at a particular nursing home he was aware of many gay male residents, some of whom would regularly have sex together.

He claims that the overall quality of care was poor at this facility. In terms of his own care as he gets older Arnold would be happy to disclose being gay to aged care services and would request gay staff. He maintains contact with an older gay GP in Sydney, who has really become a friend. He also has a network of older gay friends and loves hearing their stories about gay life in the 40s and 50s.



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## BLUE MOUNTAINS

The City of the Blue Mountains is located on the western fringe of the Sydney metropolitan area. The area comprises 143 000 hectares, 70% of which is World Heritage listed national park. There are 28 towns and villages located across a 100km east-west ridge, with a total population of around 75 000. In 2001 there were 3332 people who spoke a language other than English, most commonly German, and 863 people who identified as indigenous. The population in the lower mountains (towards the east) has higher levels of education, income, employment and better health than that of the upper mountains (towards the west and centred on Katoomba). In 2001 12.2% of the Blue Mountains population was aged 65 and over, slightly higher than for Sydney (11.8%) but lower than the 13.2% rate for all NSW. The upper mountains area has a larger proportion of older people than the lower mountains and is known to have been a location for lesbian and gay retirement migration (typically from Sydney).



## HEALTHY AGEING FOR OLDER GAYS & LESBIANS

While Australian Governments stress the importance of healthy ageing to reduce older people's reliance on hospital and residential care services (and thus buffer the effects of population ageing), rarely identified are the obstacles older lesbians and gays face in achieving a healthy older age. Further research is required into three key factors that appear to affect the healthy ageing of lesbians and gays. First, we need to better understand how past experiences of discrimination, fears of future discrimination and the failure to provide lesbian- or gay-friendly services may affect older lesbians' and gays' preparedness to access health and aged care services. Second,

lesbians and gays experience higher rates of particular illnesses than the general population and there is a need to develop and research targeted health prevention programs to promote healthy ageing. Gay men experience sexual health problems, including HIV/AIDS, at a higher rate than the general population and if undetected and untreated these have significant implications for healthy ageing. The impact of living with HIV across the lifespan also needs to be better understood. Lesbians have an increased risk of breast and gynaecological cancers compared to heterosexual women, mainly due to higher rates of obesity, smoking and alcohol con-

sumption. These differences in illness suggest the need to evaluate preventative health campaigns targeted at older gays and lesbians. Third, healthy ageing is promoted by participation in social networks and communities. In the past older lesbians and gays in Australia have expressed concerns about being isolated in older age, especially given that many lack the intergenerational supports (i.e. children) that heterosexuals commonly rely on in their older age. More research is needed into experiences and consequences of social isolation and how these three factors may combine to affect healthy ageing for older gays and lesbians in Australia.