

# “Over the Rainbow” Lesbian, Gay, Bisexual and Trans People and Dementia Project

## Summary Report

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### **Report on the LGBT people and dementia support and advocacy project**

February 2015

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# ‘Over the Rainbow’ Overview and Aim

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The *Over the Rainbow* project was in partnership with the University of Worcester Association for Dementia Studies, Birmingham LGBT Centre for Health and Wellbeing and PACE Health London. We know that LGBT people with dementia are especially marginalised communities, and that the issues impacting LGBT people with dementia are under-represented in general dementia groups and charities (Alzheimer’s Society, 2013; Westwood, 2014).

What has not been heard are the voices of LGBT people with dementia themselves. Therefore, the aim of the *Over the Rainbow* DEEP project was to develop a support and advocacy group for LGBTQ people with dementia (February 2014 - February 2015). It aimed to offer:

- 1) An opportunity for LGBT people with dementia and carers to come together in safe spaces;
- 2) The facilitation of intergenerational dialogue, support and advocacy;
- 3) The voices of LGBT people with dementia to be heard (through ongoing ‘dementia rainbow friends’ buddying, and online representation).

## Strategy and Participants

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The first phase of this work was to generate interest by facilitating two networking workshops. The first of these workshops was held at the Birmingham LGBT Health and Wellbeing Centre on 29 May 2014, and the second was held at PACE Health in London on 27 June 2014. These workshops were widely advertised through the gay press, the two community third sector organisations, through the DEEP network, via social media and a range of dementia and LGBT organisations (see Appendix).

The Birmingham workshop was attended by seven participants. These participants included one lesbian carer of a partner with younger onset dementia, one gay man caring for his mother with dementia, and another lesbian caring for a friend with dementia. The London workshop was attended by three participants including a representative from DEEP. These participants included a gay male ex-carer of a partner with dementia. A further interview was conducted with a gay male ex-carer (aged 76). Therefore, in total, 11 individuals participated in this project.

Despite extensive advertisement (including blog entries<sup>1</sup> and promotion through the Alzheimer's Society) unfortunately there were no individuals with dementia who identified as LGBTQ present at the phase 1 meetings, which meant that it was not viable to operationalize the second and third phases of the project as outlined in Involvement Fund application form. The lack of engagement from LGBT people with dementia underscores the challenges of accessing this very hard to access group. As one of the participants explained:

*'isolated, older people LGBT with or without dementia. How do you find them? And it's very well-known statistically that a lot of them have lost family connections, partner's may have died, or they've moved areas to get away from their family, so they haven't got any connections around here. They don't want to go to the noisy bars etc. ... as you get older very often life gets smaller anyway, because it's all too fast and expensive etc um, and the weather, so these all of these factors' (Jose, BFG).*

Another highlighted the significant challenge of needing to:

*'work really hard at finding LGBT people with dementia for all sorts of reasons – not least the fact that they are not out. Um, I mean the last single LGBT person I dealt with in this situation was about two years ago now. ... he went into residential care. Then immediately he went back, straight back into the closet.'* (Clive, LFG).

<sup>1</sup> See: <http://dementiaproject.net/blog/?p=143>  
<http://dementiaproject.net/blog/?p=177>  
<http://dementiaproject.net/blog/?p=179>  
<http://dementiaproject.net/blog/?p=169>  
<http://revaluingcare.net/applying-critical-psychology-or-starting-a-support-and-advocacy-group-for-people-with-dementia-who-are-lesbian-gay-bisexual-or-trans-by-professor-elizabeth-peel/>

Taken together, there was five hours of discussion about LGBT issues in the context of dementia. The report that follows is based on these discussions and informed by relevant literature in this area. Ethical approval was granted from the University of Worcester ethics committee and consent was gained to audio-record the discussion groups and the interview.

The overarching question that guided the discussions was: What are the particular issues for LGBT people with a dementia?

These data were transcribed verbatim and subject to thematic analysis (Braun and Clarke, 2006). All names and other identifying information have been changed.

## Summary of Findings: Beyond lip-service

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The findings of the 'Over the Rainbow' - not over the hill - discussions are grouped into four main themes. These are:

- 1) Personal reflections on experiences of LGBT people with dementia;
- 2) Identities of LGBT people with dementia;
- 3) Negative experiences with health and social care professionals; and
- 4) Provision of LGBT appropriate support and care home services.

The report ends with some suggestions for DEEP groups and for health and social care professionals based on the 'Over the Rainbow' discussions.

### **1) Reflections on experiences of LGBT people with dementia**

Current evidence suggests that LGBT people have a range of relationships and kinship forms which do not necessarily map onto typical heterosexual kinship patterns. For example, historically LGB and non-heterosexual Trans people have not had their relationships legally recognised, have tended to not have children, and – because of experiences of heterosexism

and homophobia – have formed families based on ‘choice’ rather than traditional biological kinship (Weston, 1991). This social and legal historical context impacts especially on older LGBT individuals and communities who will have lived most of their lives under oppressive and unequal conditions. Therefore links with, and the maintenance of links with, other LGB&T people and communities can be especially important in later life (e.g., Heaphy, Yip and Thompson, 2003; Price, 2012).

Farid, a Muslim gay man caring for his mother with dementia, reflected on the specific experience that an LGBT person with dementia may have if they have lived their lives in a fairly closeted way:

*‘I’ve noticed that a lot of the mental health and dementia issues are not addressed for the LGBT community as much as they should be.... a lot of the older LGBT people are probably still not out to the wider community but not as much out as much as the- and suddenly to get dementia, you know they might be kind of out in themselves without them realising and then the implication that has.’ (Farid, BFG)*

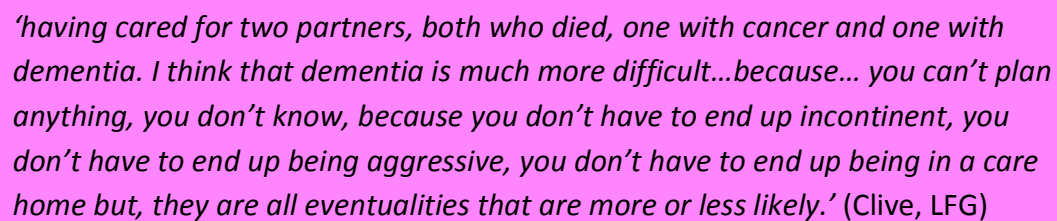
Intra- rather than inter-generational kinship networks may be especially significant for LGBT people as they age. In ‘Over the Rainbow’ was a friend of a gay man with alcohol-related dementia who was his primary informal care. As Arnold reflected:

*‘his dementia was very severe. And therefore, if they asked him, even a very general question he might have confabulated or he might have said nothing...And I was in a sense a keeper of his memory’ (Arnold, I)*

In Arnold’s case of caring for his longstanding friend with dementia he was, ultimately, excluded by the biological family and by the management of the care home his friend was resident in.

*‘It might have been different if I’d been a conventional, opposite sex partner.’ (Arnold, I)*

Lack of recognition of LGBT relationships (whether friendship or intimate relationships) have been well identified in the literature (e.g., Bond, Corner and Graham, 2004; Katsuno, 2005) and through accounts of experiences of people with dementia foregrounding examples of the shame, embarrassment and lack of recognition they have received. For those who were, or had cared for a loved one with dementia, there was a recognition – as in dementia studies and policy more generally – that dementia is a particularly difficult condition for those in a caring role (e.g., Peel & Harding, 2014). Clive, for example, was a white gay man who had cared for two partners:



*'having cared for two partners, both who died, one with cancer and one with dementia. I think that dementia is much more difficult...because... you can't plan anything, you don't know, because you don't have to end up incontinent, you don't have to end up being aggressive, you don't have to end up being in a care home but, they are all eventualities that are more or less likely.'* (Clive, LFG)

However, as well dementia being 'much more difficult' than other chronic and terminal conditions there are experiences of LGBT people with dementia and their carers which are more likely because their sexual and gender identity. For example, one gay male carer in Price (2008) noted how he and his partner had had their non-heterosexuality highlighted when his partner had to be Sectioned following a diagnosis of Alzheimer's. The service providers involved wanted to test the gay man with dementia for HIV as well, although it was not an AIDS-related dementia he had been diagnosed with.

There was reflection from some 'Over the Rainbow' participants on the skills, attributes and positive capabilities of loved ones living with dementia. Jill, who was caring for her civil partner Sally, who had been diagnosed with a rare form of younger onset dementia emphasised how 'amazing' she was, and how she has to work to support Sally's autonomy in the face of assumptions from others that she can no longer communicate for herself.

*'her outlook on things is just amazing. I'm not just saying that because she's my partner. She's a truly inspirational person.... She's just such an amazing person. And her personality shines through. And it doesn't matter how bad she is, she would never let, and that's the downside, because she will never let anybody know how ill she is. ... and she's still switched on. Like with, amazingly so, the computer. She's an absolute whizz on the computer, still. She's not lost that. ... this is what I find hurtful because we made so many plans to do so many things [...] 'Sally's in a wheelchair and when she first went into the wheelchair when we were out, they speak to me and say "'oh what's wrong with her?" and I say "well ask her?, she's there". (laughing). You know just say "Sally, you know would you mind telling me what's wrong with you?" She'll answer. And we had that so much and they still do that now.... "what's wrong with her?" and I say "why don't you ask her yourself?"' (Jill, BFG)*

## 2) Identities of LGBT people with dementia

LGBT people with dementia have multiple identities that intersect with age, gender, disability, social class, ethnicity and individual biographies and experiences. Farid emphasized the importance of LGBT people with dementia being 'seen as a person' first and foremost.

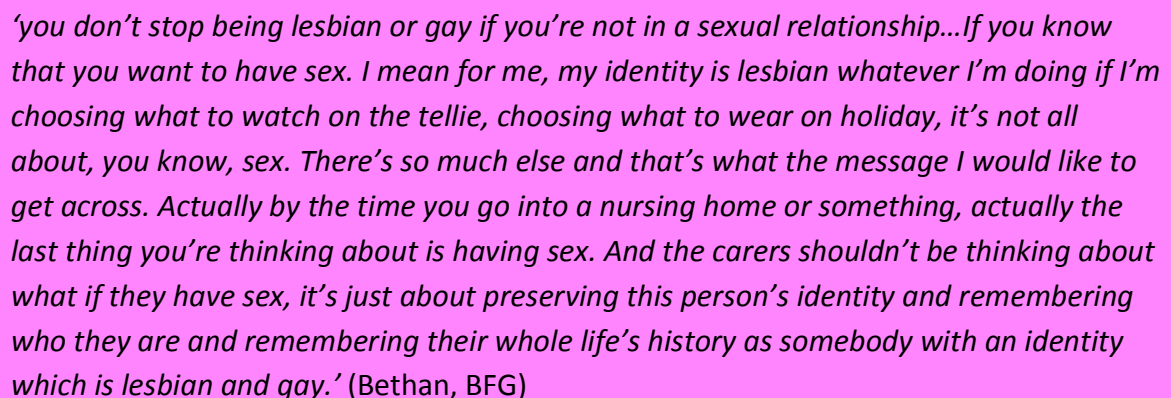
*'one thing that comes for LGBT people is that, we have to recognise that, first of all, is how to be ensured that in the dementia strategy, that they are seen as a person and then everything else. Because I think that what I get annoyed with is when you say to somebody you're gay, it's like everything about you is forgotten and nothing else matters just your sexuality. And people forget that you're an Uncle, you're a brother, you're a cousin, you're a friend, you want- you have aspirations, it's just like you that's all you are.'* (Farid, BFG)

This person-centred approach (Kitwood, 1997) is well embedded in dementia research, policy and practice, and should be equally applied in the context of LGBT people with dementia. However, in this context, this may mean moving away from liberal assumptions based on the core similarities between people and increasing awareness about the particular challenges that LGBT people with dementia may face or experience. This emphasis on the unique oppression and marginalization faced by older LGBT people in homophobic and ageist societies that often fail to acknowledge their existence is well emphasized in academic literature (e.g., Concannon, 2009; Westwood, 2014).



Concannon's (2009) study, for example, provides clear examples of the failure to recognize that being LGBT is more than about a person's sex life. Being LGBT shapes individual identity, and the ways in which LGBT people experience life. A 'culturally-sensitive' or culturally appropriate (Neville, Adams, Bellamy, Boyd & George, 2015) approach to person-centred dementia care may be needed to respond to the particular nuances in the experiences of LGBT people with dementia. One issue is connected to assumptions about sexual behaviour, or lack of sexual behaviour, in older age more broadly. Historically, asexuality in older age has often been assumed, but this assumption has been challenged in recent research (e.g., Gott, 2005; Rowntree, 2014).

There are a range of cultural stereotypes and assumptions that are associated with LGB individuals and communities (e.g., Peel, 2002, 2005) some of which conflate non-heterosexual identities with specific sexual practices, and others which link 'excessive' sexual practices and behaviours with gay male and bisexual identities. Regarding sexual identity and sexual behaviour for LGBT people with dementia, Bethan emphasized the importance of being LGB and/or T as a central identity, which needs to be remembered and preserved in care settings and by care workers (Birch, 2009).



*'you don't stop being lesbian or gay if you're not in a sexual relationship...If you know that you want to have sex. I mean for me, my identity is lesbian whatever I'm doing if I'm choosing what to watch on the telly, choosing what to wear on holiday, it's not all about, you know, sex. There's so much else and that's what the message I would like to get across. Actually by the time you go into a nursing home or something, actually the last thing you're thinking about is having sex. And the carers shouldn't be thinking about what if they have sex, it's just about preserving this person's identity and remembering who they are and remembering their whole life's history as somebody with an identity which is lesbian and gay.'* (Bethan, BFG)

Bethan echoes a participant in research conducted by Age Concern who commented: "I think sometimes people see it as all about sex! What you do in bed I mean. If I didn't have sex at all with a woman for the rest of my life, I would still be a lesbian. It's as integral to who I am as my identity as a mother, the job that I do and the beliefs I hold dear. It's not the whole of me but it

is a big part!” (Lishman, 2006, p.14).

It is well established that attitudes towards identity disclosure in later life are influenced by the perceived risks of disclosure, and earlier experiences of coming out (Hughes, 2007). As mentioned above, older LGBT people have experienced a less progressive social and legal climate in the UK, and existing literature highlights disclosing an LGBorT identities to service providers can be problematic for older people (e.g., Fenge and Hicks, 2011). For example: “Although I think it is important to be open about my sexuality, I still find it difficult. I do not like to have to make a public statement about an aspect of myself which is intensely personal.” (Gay and Grey in Dorset, 2006, p.20). In the context of an LGBorT identity and dementia, in the ‘Over the Rainbow’ project, concerns about disclosure – or the cognitive implications of dementia in revealing previously concealed identities were raised:

*‘if you’re bisexual, and you’ve hidden your bisexuality. A big secret from your bigger, wider family then you get dementia and you start preferring things earlier on in your life, how does that, that would cause problems within the family setting....So, it’s not as straight-forward, if you’re bisexual. That’s something you need to share with everyone. Because if suddenly you get dementia and you start to say things or start referring to your past or secrets in the past.’ (Farid, BFG)*

However, in line with previous research, there was a sense that dementia care settings need to value, acknowledge and support people’s LGBT identities. As Andy remarked:

*‘it’s been so much of a fight and a journey. And I’m not prepared to put that back away again. And for someone to take it away from me. And therefore, I want to maintain that. All the way through the rest of my life, you know, and as a result of that, I want a care system that will support me, because being gay is a significant part of me, it’s not the only part of me, it’s a significant part of me.’ (Andy, BFG)*

This echoes a quote in Price (2012, p. 518): “When I’m 75, should I need residential or nursing home care, I am not going back in the closet”. While it may be assumed, and some research evidence suggests, that older LGB&T people are less likely to disclose their sexuality (Traies,

2012), in this project some reported making the explicit decision to be open and clear about their relationship. Clive reports how, in being 'out' with all of the service providers involved in the care of his partner, they were able to challenge some of the liberal assumptions of sameness between LGBT and heterosexual people.

*'We decided to be out. ... all of the service providers that came in we said we are a gay couple ok, and all of them said, "it's ok we treat everybody the same" and so on, and we immediately said "that's not what we want". We don't want to be treated the same as everyone else but that gives you a common ground, we want to be treated as a gay couple.'* (Clive, LFG)

It is also important to recognize that sexual identities can change over time (e.g., Diamond, 2008; Kitinger & Wilkinson, 1995), particularly women's identities, and that dementia may impact on a person's sexual behaviour. As Bauer, Auliffe and Fetherstonhaugh (2016) suggest regarding residential care settings, 'sexual behaviour is all too frequently labelled 'inappropriate' or 'disruptive', especially when the resident has a diagnosis of dementia'. Jill, who was caring for her partner Sue talked of her 'thing about men's bottoms'.

*'I know it sounds really funny, but she's got this thing about men's bottoms. She does. She's in a wheelchair so if a man is standing up, "he's my type". If she sees a man she has to go and pinch his bottom. Which is fine, but not everybody sees the funny side to that.'* (Jill, BFG)

While Jill makes light of this change in her partner's behaviour, change in behaviours that are not congruent with a person with dementia's identity or current or previous relationships may be difficult for informal and formal carers.

## 2a) Trans identity and dementia

Trans<sup>2</sup> people with dementia may have different needs to cisgender LGB people with dementia. (Willis, Ward & Fish, 2011). For the trans focus group members in Willis et al.'s (2011) scoping research, gender transitioning and gender identity matters shaped how care was provided for members of the trans community. Trans participants provided accounts of how they had advocated for other trans individuals in medical environments, and provided community-based support (Hines, 2007). Research has also highlighted particular issues for trans people with dementia, as they may have complex social or bodily needs (Age UK, 2013). Trans and intersex people are also particularly vulnerable to discrimination in aged care settings, to the point where they may avoid seeking support altogether (Birch, 2008). Anecdotal evidence of denial of services has been identified, as well as forcibly preventing cross dressing and deliberate physical violence when people are revealed to be trans within a care home setting (Birch, 2008).

Due to both negative experiences with, and fear of judgment by health care providers, trans older adults may be hesitant to seek medical attention in the first place (Cahill, South, & Spade, 2000; Fredrikson-Goldsen, Cook-Daniels, Kim, Erosheva, Emler, et al., 2013; Witten, & Eyler, 2012). Furthermore, those who disclose their gender identity have been found to more likely experience discrimination in medical settings (Grant, Mottet, Tonis, Harrison, Herman, & Keisling, 2011). In the context of trans people with dementia, Emma, suggested that cognitive difficulties may cause particular challenges in maintaining gender identity:

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<sup>2</sup> Trans is used as an umbrella term to refer to all non-cisgender individuals including trans women, trans men, transgender, transsexual, gender fluid and non-binary gender people (Clarke et al., 2010).

*'with some people who are trans, what the dementia might end up doing is for them to regress and um, if you like, even forget that they have transitioned so, they um believe there in the um, the gender, the birth gender. And that in some cases, both of their sort of the carers and the health situation they're in and their own families may take advantage of that. ... somebody was buried as their birth gender and um their family kept all of their trans-support network away. And, um, there was another example, of where the er partner of the person, trans-person, who died, they were left with nothing, all the photos of them together had been destroyed by the family.... the caring services need to take into account...And actually not to collude with family or other people who are trying to put pressure on someone, you know, taking advantage of someone's, situation of dementia to make them into a person that they didn't want to be. (Emma, BFG)*

Trans people living with dementia may also have medical issues relating to their natal gender that emerge with ageing, such as osteoporosis or prostate cancer (Alzheimer's Society, 2013). Dementia may mean, for example, that a post-operative trans woman may forget that her external gender aspects have changed and may be confused and distressed about how to engage in aspects of self-care. Care staff may need to reassure and assist trans people, as with any confusion based on memory loss (Alzheimer's Society, 2013). Similarly, an awareness of daily issues that trans people face to maintain their body and their personal privacy needs, such as shaving, wearing a hair-piece and type of clothing when living with dementia are all important (Age UK, 2013). Bethan reflected on particular issues for trans people with dementia with regard to reminiscence therapy:

*'How do you do that positively? If you're doing sort of reminiscence or asking people to talk about when they were younger and they may have had much clearer memories. How you do that in a positive, supportive way? Do you talk about, I mean if they don't know then you they would say when you were a little girl, but you weren't you were a little boy. How you do that in a positive way, that's kind of reinforcing and recognising the journey and the transition, but that's not confusing to them and not confusing to the staff. I mean it's really quite a delicate thing that needs to be thought out really carefully doesn't it?' (Bethan, BFG)*

### 3) Negative experiences with health and social care professionals

Many LGBT carers encounter heterosexist responses and heteronormative assumptions from health and social care professionals to the point where partners face exclusion (e.g., Willis et al., 2011). One of Willis et al.'s (2011) focus group participants described at length their encounters with heterosexist responses from health care professionals. One member recalled the signs of ridicule between nursing staff about his partner and himself, whilst other participants recounted more subtle experiences of heterosexism in which health care staff failed to acknowledge their same-sex partners. A further study found that all members within the group commented on the lack of sensitivity and concern they had experienced by medical and human service personnel (Moore, 2002). One carer discussed how she “felt betrayed by the medical care system” as she had assumed that it would be compassionate and understanding of the needs and vulnerabilities of older people (Moore, 2002). Instead, after being referred to a University teaching hospital, the carer presented power of attorney and was spoken to in an ‘icy and accusatory’ tone by medical staff, in which they reiterated the need to speak to a family member.

Another group member in Moore (2002) recalled her experience when her partner was admitted to hospital after increased blood pressure and confusion and abdominal tenderness. The caregiver experienced prejudice and discrimination in which a nursing student referred to them as ‘a pair of old grey lesbians’ and she felt as if they were ‘the side show’ (Moore, 2002, p.31). In this project there were similar accounts of negative experiences with health and social care professionals.

*‘I’ve heard a care worker say “oh pray for them”, if they’re gay or refuse to touch their body. Because they might, if it’s gay men then they’ll get AIDS um if it’s gay women it might be taken wrong or want you to interfere with them, um, you know as if we’ve got not taste at all...but a lot of them actually hide their sexuality when the carer’s there. They literally change the room where the carer’s going to come into, taking photographs, the whole room, and put it all back out again afterwards.’ (Josie, BFG)*

Jill recounted an experience where Sally – her partner with dementia – had “*let slip or said about Jill as her partner*” and the speech therapist “*practically ran out of the door...and she never got the treatment*”. Jill reported these experiences in a very stoic way:

*‘awful for us because- but you know, you just shrug it off. You just get on with it, but you shouldn’t have to...You know we’ve had it in hospital as well. When she’s had some major operations and, um you know, as, um partner, civil partner and they like looked at me. And I said, “Is there a problem?” and they said, “no, no, no, no”. But they’ve been really funny with that. They’ve, well they’ve tried to be funny with me but they haven’t got very far. Because I won’t tolerate it. But we have been. I suppose it’s being like victimised, to a certain degree. (Jill, BFG)*

Care workers are often employed from other parts of the world where conservative religious views prevail, and therefore LGBT people with dementia may encounter negativity from staff (Knocker, 2012). Farid reflected on the potential challenge for migrant care workers and the different cultural context and belief systems that can present particular challenges for LGBT people in receipt of health and social care.

*‘what upsets me is that, like we talked about support workers who come from abroad, don’t have any qualifications ... someone who probably come from countries where [LGBT people] they face a criminal offence, punishment by death, come to a country where it’s very accepted but they go on a journey trying to get their head around it because they come from a country where they’re supposed to really, really hate people to a country where they accept gay people... But what really frustrates me is when I see professionals, speech therapists, nurses, social workers... they were saying things like, “oh I’m doing this course, I’ve qualified but I know one thing I don’t want to work with gay and lesbian people”’ (Farid, BFG)*

As highlighted by Clive earlier LGBT people, couples and networks do not necessarily want to be treated ‘the same’ as heterosexuals or in a heteronormative way. Here June reflects on the potential implications of this for person-centred care, and the need for health and social care professionals to move away from a heterosexual assumption.

*'I've got dementia so I shouldn't be ashamed of being gay and coming out and talking to somebody about it. And who's there to talk to, you know, the danger is that you set people up... a lot of people would say...but we deal with everyone in a person-centred way and we treat everybody as if they're equal. And that is good that we treat everybody the same but what I'm hearing...is actually we don't want to be treated the same because you're saying the same is assuming that we're heterosexual. And that's really- so actually I do want to be treated differently' (June, LGF)*

#### **4) Coming out to (dementia) care: provision of LGBT appropriate support and care home services**

Research focused specifically on LGBT people that are affected by dementia is lacking, although available research does highlight the failure of service providers to recognise sexual diversity in provision (Mackenzie, 2009; Price, 2008; Ward, 2000). Many of the challenges faced by LGBT people living with dementia, and their carers', partners, friends and relatives are no different to those of other's in a similar situation. However, it is important to recognise and understand the many extra issues and concerns they face when needing support and care home service provision (Ward, Pugh, & Price, 2010).

As discussed above, older gay men and lesbians have grown up in a time when there were laws that prohibited expression of their sexuality, with homosexuality classified as a mental illness until 1973 (DSM III). Their sense of identity and self-worth has been shaped in a context where homosexuality was considered "unnatural", therefore hiding their sexuality from a hostile world was an important survival and protective mechanism (Birch, 2008). Some lesbians and gay men may have entered into heterosexual relationships to "pass" as a heterosexual and therefore may have a previous different sex spouse and grown up children, who may not be aware of their sexuality, or if they are it may be an issue of contention (Birch, 2008).

Furthermore, lesbians and gay men may make decisions each day about whether they are "out" or in the "closet" by the simple use of a pronoun when referring to their partner, such as "my



friend, my partner or my sister/brother” depending upon their situation. However, many activities do not require people to state their sexuality and this can become an issue when a LGBT person is diagnosed with dementia and interacts with health services and support systems (Birch, 2008). The issue of LGBT identity being “eroded” in care settings was raised by Andy:

*‘one of the things that I’m quite concerned about ... what will happen if I end up with dementia as a gay men and I go to a care setting and somebody doesn’t remind me of what my sexual identity is and I can’t remember or something happens then there’s an erosion of that. How I will then be treated because what I don’t want to do is to go back in after coming out which is quite a dramatic process.’ (Andy, BFG)*

Many LGBT people have concerns about confidentiality and that support services will not be willing or able to meet and understand their specific needs (Alzheimer’s Society, 2013). With many LGBT people believing that they will become invisible and that they will experience prejudice and hostility, as they may have been discriminated against before (Alzheimer’s Society, 2013; Westwood, 2014). Older people with dementia are especially vulnerable and, as Andy discussed, if service provision is not LGBT-friendly there could be adverse impacts on social, cognitive and communicative functioning.

*‘older adults with dementia, who are frightened who are isolated who are unsure, if they haven’t got that kind of safe place to be themselves in terms of their own kind of sexual orientation and identity. I think there’s a real risk there for those individuals, and I wonder whether there’s the potential to actually exacerbate the dementia even further, because they’re retracting and withdraw from engaging.’ (Andy, BFG)*

Arnold also commented on the heteronormativity of care homes, and the importance of dementia care home provision as a key site ‘where attitudes have got to change’ in order for the diverse sexual orientation and gender needs of people living with dementia to be best met.

*'some have been out, before they've gone into a care home and they go back into the closet again [...]' 'a great tendency for um, care provision and social service generally to be organised for straight people. Which is the assumption that this is what we're dealing with... inevitably people with Alzheimer's, a significant number are going to end up in care homes with social workers. And that's where attitudes have got to change.'* [...] *'when I went to, to visit NAME in the care home, he would sometimes sort of treat me to a hug or a kiss or whatever it was. And often times not. I would leave it up to him. I think he was careful about sort of being discrete about his gayness to care home staff...who didn't technically know that he was gay.'* (Arnold, I)

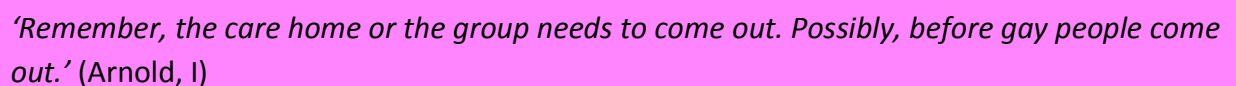
Clive, similarly, emphasized the compartmentalization and 'double existence' of 'many people of my age' with respect to a gay male friend with dementia who was in a residential care setting. People with dementia interacting in care home settings in ways which treat them as lacking permanency (e.g., hotels or lodgings) is not uncommon. But for this gay man with dementia his sexuality, age and dementia intersected in a way that impacted on his behaviour – 'shaking hands' rather than 'hugg[ing]' his friend when in the care home.

*'the way that his dementia explained what was happening to him was, that he was staying in a hotel and he didn't think he'd stay in this hotel very long. So he went back home...he really just packed his bags and said it's time for me to go home...but like so many people of my age, there was this double existence. I mean he was camp... and he had a huge gay um connection, but it was totally different from his other professional life. ... it was a compartment of his life....the sign of it was immediately was the fact that, when we used to meet at parties ... we always hugged each other – ... and it became shaking hands'* (Clive, LFG)

Qualitative research carried out by Price (2010) with twenty-one lesbian and gay carers further illustrates the complexities of managing disclosure of LGBT identities to health and social care professionals and organisations. She found that previous responses from health and social care professionals determine whether LGBT people decide to disclose their identity. Price (2010) found that carers mediated their disclosures in different ways: active disclosure; passive disclosure; active nondisclosure; or outed by their partner with dementia. She found that the responses the carers in her sample received to their disclosures was a critical issue. Service providers' reactions were found to range from a broad acceptance of lesbian and gay people's circumstances to a persistent disregard of their needs.

Brotman et al. (2007) identified the critical issue of respondents' fear of coming out to service providers or that of returning to the 'closet' and further supports research that suggests that experiences of discrimination and distrust in health care prevent LGBT people from accessing essential health and social care services. Moreover, the actual prospect of requiring health and social care services causes anxiety (Davies, Addis, MacBride & Shepherd, 2006; Heaphy & Yipp, 2003, 2006; Price, 2005).

Therefore, health and social care services and professionals need to come out, signal their LGBT friendliness and *actively work* to counter heteronormative assumptions in service provision and delivery in order to provide appropriate support and services to LGBT people living with dementia and their carers and supporters. Arnold succinctly summarized this:



*'Remember, the care home or the group needs to come out. Possibly, before gay people come out.'* (Arnold, I)

There were two key elements of this identified in the 'Over the Rainbow' project:

1) signaling safety; and 2) LGBT appropriate virtual and non-virtual support.

These aspects are now considered in turn.

#### **4a) Signaling safety**

It is important to provide spaces, practices, language and symbols that indicate a non-discriminatory environment (e.g., Harrison, 2001). LGBT service users, especially those who may be confused, or not able to express themselves coherently due to cognitive losses associated with dementia, will need particularly clear and explicit signals from service providers and health and social care professionals that the environment or the person is non-discriminatory.

In previous research an LGBT 'kite mark' as a visible, reassuring and effective sign within care contexts was highlighted as important: "My dream is to have a kite mark, so that LGBT people

can see, at once, if a service provider is LGBT friendly. A kite mark that would indicate that staff have been made aware of LGBT clients, and would indicate that prejudice of any kind would not be tolerated. That would be make me feel safe and confident.” (Price, 2012, p.519).

A visual signal of LGBT friendliness and safety was also highlighted by Arnold:

*‘in care homes I think as well. There’s got to be some signs around, that you know, people can pick up on, there could be pictures on the wall of same-sex people or whatever. I mean I would do very much more than that but I’m just thinking of what an up-hill battle it is with care homes.’ (Arnold, I)*

Participants also emphasized how verbal as well as environmental signals of safety were very important for LGBT people with dementia. Bethan talked about how important cueing in to gender neutral pronouns can be an important mechanism for then encouraging a person to disclose their non-heterosexuality.

*‘She was quite wary about coming out. And I could see the photo on the mantelpiece and she was talking about you know you- in- with no pronouns. ...So I had to kind of, open it up, and make it clear that it would be fine to say something’ (Bethan, BFG)*

As well as signaling safety in generic services and support. LGBT dementia specific support, both virtual and non-virtual was highlighted as important.

## **4b) Appropriate non-virtual and virtual support**

The importance of support groups for lesbian and gay carers of those living with dementia has been reflected in research into connecting lesbian and gay elder care providers through a telephone support group (Moore, 2002). In the ‘Over the Rainbow’ project social media was raised as a specific source of connection, and community:

*'people of my age are seen to be over the hill and if you have dementia, even more so. And of course one of the great things about, about the twitter community is that there is more and more people with dementia that are using it' [...] 'it's just a matter of feeling you're not alone'* (Clive, LGF)

Group members in Moore (2002) expressed concern about revealing their sexual identity and were concerned about the emotional effect this may have on the others. All group members noted their struggles to decide to tell their personal story or not because of the intense feelings encountered in a traditional support group. The group members also expressed how different their experiences were in coming to terms with their partner's dementia than that of heterosexual couples. They all noted that other support groups allowed heterosexual partners to reminisce about their partners, families, shared interests and careers and how Alzheimer's robs them of their future plans. The importance of tailored LGBT specific support groups for carers was highlighted by Jill:

*'my partner has dementia. ... my partner's 44. And she's got dementia.... it's quite an eye-opener when they're diagnosed with dementia, regarding we found how people dealt with it. And sometimes it's just nice, to talk to somebody else that knows what you're going through.... she's only been diagnosed ... two years with dementia. We went on those that people that are gay, Alzheimer site, but there's not- not a lot there. There's plenty of posts on dementia but not for gay people. That's why we're seeking gay people out but it's just- just nice to have something else in common.'* [...] *'I love Sally beyond belief, she's just everything to me, but sometimes, you- you just think, I just want to talk to somebody'* (Jill, BFG)

Furthermore, Price (2008) found that a carer who was caring for her mother with Alzheimer's disease noted that although there were support groups available, being in one which was predominantly heterosexual did not give her the opportunity to raise the issues that were important to her as a lesbian woman. Therefore, further supporting the need for LGBT support groups. Another gay man caring for his mother commented on the importance of a gay and lesbian support group: "It's great to have a place where I can talk regularly about what's going on- but more important for me, they also understand all the gay issues so I don't have to

explain these first” (Alzheimer’s Society, 2004b, p.5). The issue of ‘double isolation’ was raised by June:

*‘dementia, as a condition, is very isolating, perhaps more isolating than lots of other conditions based on a person with dementia, and people caring for them, can be very, very isolating...and I think possibly for LGBT people it is doubly isolating because you know, in terms of your friends, not just wanting not to talk to other carers but other carers who are really in her situation, lesbian carers rather than heterosexual carers’ (June, LFG)*

This importance of LGBT specific dementia support and spaces was emphasized as a ‘gift’:

*Josie: That’s almost the greatest gift you can give anybody. Is to allow them, the space to be free enough to be who they are. Without the judgments and-  
Emma: And the constantly explaining...  
Josie: Yeah. It’s so tiring.  
Emma: ...that you’re LGBT. I go to a LGBT group I don’t have to explain that I’m LGBT.*

And this links between appropriately tailored support and mental health and wellbeing were highlighted:

*Jose: just such a relief to be able to not be hiding something...that’s the biggest single thing that people have said to me. That it’s just so nice not to have to think which pronouns I’m using and think, you know, how am I dressed? How am I walking? Have I said something I shouldn’t have? Did I drop a name that I shouldn’t have? I can be me. I can talk about my ex-partner, I can talk about my current partner. I can talk about anything I want to. And that in itself relieves a lot of the mental stress. I mean it’s very good for your mental health to be able to be who you are. It’s very damaging to not be able to. And if- if you feel that you are losing yourself to some form of dementia, then to me the one thing that I would want to put against that is, the bits of me that are still there, I want to be able to celebrate! I want them there and I want people to see that I’m still here. Um-  
Jill: That’s what Sally says. I’m here now. Let’s celebrate it for now. Not a year down the line.*

## Recommendations for DEEP Groups

- Ensure that members are not assumed to be heterosexual.
- Raise awareness within the group about LGBT people lives and experiences.
- Encourage group leaders and participants to challenge any instances of heterosexism and homophobia.
- See if links can be made with local LGBT groups (e.g., via the Consortium of LGBT voluntary and community organisations <http://www.lgbtconsortium.org.uk/> ).
- Ensure all group members are actively included and that LGBT people and same-sex relationships are valued.
- Actively signal that your DEEP group is LGBT friendly (e.g., by using a rainbow, or pink triangle logo, by making LGBT materials such as those from the ‘Opening Doors’ project in Camden available <http://openingdoorslondon.org.uk/about-us/> ).

## Recommendations for Health and Social Care Professionals

- Quality Care Commission to audit care homes on LGBT friendliness: *‘compulsory provision on the part of all inspectors, to ask this question...what are you doing for LGBT?’* (Arnold, I)
- Training for care home staff: *‘with great care there should be an attempt to establish when somebody comes into [a] care home, whether- what their sexual orientation is.’* (Arnold, I)
- Recognition that older LGBT people may not have partners: *‘they might have some close friends. Maybe these close friends are their extended family.’* (Arnold, I)
- Explicit recognition that older LGBT people may have partners, and be in legally recognised relationships with them (civil partnership or marriage in England and Wales).

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## **Appendix: List of organisations involved in promoting/engaging OtR**

Birmingham LGBT

PACE Health

Innovations in Dementia

University of Worcester, Association for Dementia Studies

Berkshire Older Lesbian & Gay Forum

Age UK Derby & Derbyshire

Merevale House Special Dementia Care Home

Age UK Shropshire, Telford and Wrekin

Opening Doors London / Age UK Camden

Stonewall Housing

Solomons Centre for Applied Psychology

Young Dementia UK

Early Intervention Dementia Service Worcester

Walton Hospital, Chesterfield

Birmingham and Solihull Mental Health Foundation Trust

Buckinghamshire County Council

Napier Homecare Services Ltd

The Change Explained Ltd

Alzheimer's Society

Healthwatch Birmingham

Age UK Birmingham

Dementia Friendly Hampshire

Policy Manager Dementia, Public Health England

Birmingham and Solihull Mental Health NHS Foundation Trust

Lesbian and Gay Foundation, Manchester