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# Don't look back? Improving health and social care service delivery for older LGB users

Equality and Human Rights Commission

# Contents



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# Abstract

There are wide gaps in knowledge about the lesbian, gay and bisexual (LGB) UK population in relation to their physical and mental health outcomes, use of health and social services and experiences of health and social care more generally. Very little data exists that compares LGB and heterosexual populations. The evidence is even more limited for older LGB people. The existing evidence suggests that LGB people face many of the same issues as other members of society when ageing, including health and care concerns, however, their experiences and needs are mediated through a range of forms of disadvantage and discrimination related to their sexual orientation, and other aspects of their identities. Understanding how this affects the lives of older LGB people, and what it may mean to be older and LGB when accessing health and social care is at the heart of this paper. The paper demonstrates how older LGB people have been overlooked in health and social care legislation, policy, research, guidance and practice which assume service users are heterosexual.

The existing evidence points to discrimination and anticipation of negative treatment when older LGB people access services. Particular health and social care issues require greater attention and action: for example older LGB people may be likely to have different mental health needs to their heterosexual peers; some older gay men may become infected with HIV in their 50s or 60s, or are already living with it, and we know that older adults may present later than their younger counterparts for a diagnosis. Older adults appear to be a rising proportion of the overall population diagnosed with HIV, therefore prevention programmes will need to include older people, including gay men. LGB high level service users who are frail and depend upon care services, and LGB carers, have received the least attention, along with people with dementia or people requiring end of life care. The potential exists for the provision of care and support to older LGB people to become a 'litmus test' – an indicator for how well health and social care agencies engage with minority groups and deliver a non-discriminatory service that works for service users.

# 1. Introduction

Older LGB women and men have lived through periods of time when they had very few rights or protection in law as homosexuality was criminalised and pathologised (it was not until 1993 that the Government removed homosexuality from its list of psychiatric disorders in England and Wales. In Scotland it was 2000). In October 2009, the Equality and Human Rights Commission published research that included evidence on the prejudice and discrimination LGB people can face when accessing health and social care services (Equality and Human Rights Commission, 2009), though the impact of such treatment over time is not well understood.

The new Equality Act 2010 updates, simplifies and strengthens pre-existing legislation and provides a new cross-cutting legislative framework to protect the rights of individuals and advance equality of opportunity for all. Sexual orientation and age have been given a similar status to other protected characteristics (for example, disability, gender and race). The Act established a new Public Sector Equality Duty to ensure that public bodies consider how their policies, programmes and service delivery affect a wider range of groups, including LGB people of all ages, in order to eliminate prohibited conduct, promote good relations and advance equality of opportunity.

The Equality and Human Rights Commission commissioned this paper to provide an overview of the available UK evidence relating to older LGB individuals who use, or may be in need of, health and social care services in order to improve our understanding of their experiences and needs and to inform service delivery in the future.

## Aims

The aims of this paper are to:

- Highlight what is known about the experiences of older LGB women and men when accessing health and social care provision.
- Highlight what is known about the diverse health and social care needs of older LGB women and men, given that this group is not homogenous.
- Outline where the health and social care needs of older LGB women and men may be different to those of older heterosexual women and men.
- Highlight examples of health and social care services, where the needs of older LGB women and men are understood and met.
- Suggest what needs to be done to meet the health and social care needs of older LGB women and men.

The paper considers the perspectives and experiences of older LGB people and highlights the reasons why we should pay particular attention to their situation as users of health and social care. Written in the style of a 'think-piece', we review the limited but growing UK evidence available in order to discuss the findings and inform service delivery.

Older LGB people are not a homogenous group – gender, ethnicity, educational attainment, income and many other characteristics underpin their needs and influence their ability to access help and support. In health and social care policy older service users are also disaggregated on the basis of their level of need and use of services. For instance the National Service Framework for Older People (DH, 2001) suggests three groupings, namely:

- those 'entering old age' who live active and independent lives
- those making the transition from independence to frailty, and
- those individuals who are frail and may have accompanying conditions that require care and support.

At the heart of the paper is a recognition that older LGB individuals are often absent from research, policy and provision, as initiatives that consider the perspectives of older people are rarely inclusive of LGB people and efforts to address the needs of the LGB communities tend to neglect older people.

# 2. Background and policy context

## 2.1 Ageing Britain: Older LGB people and social change

Until recently it has seemed almost obligatory to open any commentary on ageing with forecasts of a 'demographic time-bomb' whereby older people are often cast as an unaffordable drain on the public purse. Indeed, with an ageing population comes a rise in many health conditions associated with old age and a consequent increase in demand for welfare services. However, a counter-narrative has begun to emerge where the capacities and contributions made by older people are gaining recognition, tied to a broader shift toward service users taking greater control and responsibility for their health. The nature of the contributions made by older generations to the economy and family life is now well established, as is the importance to health and wellbeing of social inclusion and participation. Yet we need to look beyond blanket references to old age and consider the social and cultural diversity of these older populations (Dannefer, 2006; Social Exclusion Unit, 2006). To date, older LGB groups have attracted limited coverage in policy on later life despite government concerns with fairness and equity.

Whilst it is currently difficult to enumerate the older LGB population (estimates vary from 2-10 per cent, Aspinall, 2009), a necessarily crude estimate would suggest the numbers of older lesbian and gay men in the UK may be up to 1.2 million people.[i]

Beyond these statistics, however, lies a complex story involving rapid social change which has occurred within the life course of older LGB people. For example, research in both the UK and US has highlighted the emergence of 'families of choice', a term that denotes the range of relationships shared by LGB people that extend the boundaries of biological families (Weeks *et al.*, 2004; Weston, 1991). However, we have yet to learn whether such chosen families evolve into networks of care for those individuals making the transition from independence to frailty.

In Heaphy *et al.*'s seminal 2003 study of 266 LGB people aged 50–80+, there was overwhelming emphasis on partners as the most likely providers of care in times of chronic illness; and partners and health professionals in the case of care in old age. Few expected family members to assume this responsibility. Qualitative data revealed that friendships can be an unexpected source of care in this context. Few participants had actually made plans for care in health crises or old age.

Older LGB people remain more likely than both their heterosexual peers and younger generations of LGB people, to be single and live alone, and are less likely to have children, so they are likely to have a greater need of formal care and support (Musingarimi, 2008). For this reason alone there is a pressing need to consider how welfare services can render themselves accessible and appropriate to this particular group.

## 2.2 The legislative framework and the strengthening of equality laws

The response to older LGB people's health and social care needs are regulated by the measures which establish health and social services and rights-based legislation.

Applying to all adults are the legislative arrangements that regulate the National Health Service (NHS), based upon the universal principle of free treatment according to clinical need. This includes a commitment to challenge any discrimination in service provision on the grounds of sexuality (DH, 2006). The primary legislative measures in England and Wales for social care are Sections 46 and 47 of the National Health Service and Community Care Act 1990. More recently, the Mental Capacity Act (2005) and the Adults with Incapacity (Scotland) Act (2000) have enacted important changes that should protect LGB people (and their carers) with provision for a Lasting Power of Attorney, designed to ensure that the wishes of older people are recognised and executed.

Social care legislation requires the establishment of need within the context of both eligibility criteria and a means tested assessment of an individual's ability to contribute to the cost of their care. This legislation is also influenced by equality legislation which protects the rights of all LGB people, namely: The Equality Act (2006), The Equality Act (2010), the Civil Partnership Act (2004) and The Equality Act (Sexual Regulations) (2007).

The Equality Acts 2006 and 2010 make it illegal to discriminate on the grounds of sexual orientation in the provision of goods and services, and the Human Rights Act 1998 confirms that such discrimination is an infringement of human rights. Health and social care agencies are required to identify and remedy areas in which they are not providing equality of treatment. The introduction of the Single Equality Duty will strengthen action on inequality and better services for older LGB users.

## 2.3 Contemporary service reform in health and social care

Health and social care policy in the UK has been aimed at developing a person-centred approach for the arrangement of individual care services under the banner of the 'personalisation agenda'. This holds the prospect of a significant change in how care is organised for all age groups (HM Government, 2007 and Department of Health, 1998), not least by enhancing choice and control of individual care arrangements. The intention is to transform the lives of people in need (DH, 2006), achieved in part through the dual

devices of Direct Payments and Individual Budgets, ensuring that each individual will receive a cash value attributed to their care needs. For older LGB people this affords the prospect of exercising greater choice over their own care arrangements and a closer 'fit' with their own circumstances. There is little evidence to date, however, that the additional costs associated with 'sexuality sensitive' care provision are being recognised and translated into financial provision (Gulland, 2009).

The National Service Framework for Older People (DH, 2001) set out a programme of improving the minimum standards in 8 areas of health and social care service provision for older people. Equally, the National Minimum Standards (DH, 2003) establishes standards of care provision within the residential care sector. Both of these documents represent another significant move in establishing minimum standards of care for older people.

Developments in the adult safeguarding agenda partly through the review of the 'No Secrets' circular in England (DH, 2009) and the 'In safe hands' circular of the Welsh Assembly Government ensure that sub-standard care practices are increasingly viewed as both abusive and/or neglectful, which in turn warrant investigation. All of these measures represent additional degrees of oversight/regulation of health and social care service provision in general and when associated with the equality legislation provide the tools to better address the needs of older LGB users.

However, in recent policy on later life, including the National Carers Strategy (DoH, 2008a), the End of Life Care Strategy (DoH, 2008b), the National Dementia Strategy (DoH, 2009) and the Dignity agenda (RCN, 2008), the extent to which older LGB service users are recognised, or their needs acknowledged, varies markedly, with little sign of a coherent policy response. The End of Life Care Strategy makes one brief reference to gay or lesbian carers, for example, and the National Dementia Strategy omits issues of sexual orientation, despite a commitment to serving 'diverse populations'.

# 3. The evidence base on older LGB service users of health and social care

## 3.1 Mainstream research and monitoring

There are wide gaps in knowledge about the LGB UK population in relation to their physical and mental health outcomes, use of health and social services and experiences of health and social care more generally. Very little data exists that compares LGB and heterosexual populations. The evidence is even more limited for older LGB people.

Historically, there has been a persistent omission of sexual orientation from mainstream research and data-gathering within service provision to older people. There is also, as stated earlier, a corresponding lack of supporting data available concerning the demographics of the LGB population and sub-groups (Purdam *et al.,* 2007; Aspinall, 2009). As a result, any evidence that does exist concerning older LGB users tends to be set apart from broader debates in gerontology and welfare policy and concern for the particular disadvantages faced by these groups remains an under-theorised adjunct to broader policy debates on health inequalities.

A number of major surveys measuring socioeconomic circumstances, such as the decennial Census and Understanding Society, the new United Kingdom Longitudinal Household Survey, do not currently include any questions on sexual orientation. Others have included age bars that exclude older respondents such as the National Survey of Sexual Attitudes and Lifestyles 2000 (NATSAL), with a cut-off at 44 years. However, there are signs of change. The 2010 NATSAL will extend the age range of those surveyed to 74 years. In Scotland, plans have been announced to add a standard question on sexual orientation to major national surveys (NHS, Scotland 2010).

Many NHS Trusts and local authorities now routinely gather information on sexual orientation across all adult service users, although it is not yet clear how this information is being analysed and used. In addition, questions regarding the sexual orientation of users have been introduced by regulating bodies such as the Care Quality Commission, for instance in their Annual Quality Assurance Assessment which applies across all registered adult social care providers including care homes. In primary care, the GP Patient Survey now has questions on both age and sexual orientation, allowing for the potential of data extraction and analysis of older LGB respondents.

At present, these questions are optional and existing evidence suggests that in certain situations older LGB people may be more reluctant to disclose their sexual orientation than younger groups (Warner, 2004; Fish, 2009) so it is likely that any data gathered will significantly under-represent the proportions of older LGB service users. There are also practical considerations, such as whether support is available for disabled individuals to complete forms and staff not understanding the need for a question on sexual orientation (or indeed being opposed to its inclusion) and so not asking it.

Mainstream health and social care research is not widely inclusive of LGB service users, meaning that the potential for comparisons across LGB and heterosexual groups is limited at present. Meads *et al.* (2009) suggest that without recording sexual orientation on hospital admissions or death records, the extent to which useful comparisons can be drawn between LGB individuals and the heterosexual population is currently limited in health. As Price (2005) has argued, in relation to research into dementia in particular, there is a tendency to homogenise perceptions of those diagnosed so that the notion of sexual identity becomes submerged below other, perhaps more visible issues.

## 3.2 Research with older LGB people

Older LGB people's experiences of health and social care are generally under-researched (Mitchell *et al.,* 2009), with the result that they are largely unacknowledged as service users (Pugh, 2005). Funding has focused on (mainly men's) sexual health with less information available on older bisexual and lesbian women.

Most existing studies involve small samples (less than 50 participants) – reflecting the challenges associated with identification and recruitment. There is a tendency to use convenience sampling and snow-ball recruitment methods which lead to a focus upon more 'visible' LGB individuals and those people who constitute what the National Service Framework for Older People (2001) describes as the 'entering old age' group of largely healthy and independent individuals. Moreover, there is a consistent under-representation of certain groups – including those 75+ years ('Older' tends to be defined as over 50 years of age) people from ethnic minority groups, and bisexual men and women.

There are also relatively few studies actually undertaken in health and social care settings (Addis *et al.,* 2009) hence much of the research that does exist tends to be either retrospective or prospective, asking participants to anticipate their future support needs and preferences for care, rather than focusing on those currently using or in need of services.

# 4. Key themes emerging out of the evidence that exists

There are a number of over-arching issues that consistently appear in the research and literature on LGB experiences of health and social care including that involving older users:

a) Accessing services – discrimination and negative treatment

b) Service delivery – invisibility and assumed heterosexuality

c) LGB specific health and social care issues

The following section explores these themes in more detail.

## 4.1 Accessing services – discrimination and negative treatment

Discrimination, and the anticipation of negative treatment, remains an endemic issue in the lives of LGB people (Hunt and Dick, 2008). Older LGB individuals who are long-term mental health service users (who sometimes describe themselves as 'survivors') may also have had negative past experiences of these services and of the professions that provide them. It was only in 1973 that homosexuality was removed as a mental disorder from the DSM (Diagnostic and Statistical Manual of Mental Disorders) and until this time LGB service users were subject to aversion therapies including electro-therapy, see Smith *et al.,* 2004 and King *et al.,* 2004). In addition, older LGB individuals have faced historical exposure to severe stigma and discrimination. Prolonged exposure to discrimination and stigma is recognised as having a detrimental impact upon physical and mental health outcomes (Keogh *et al.,* 2006; Wintrip, 2009), although little attention has been given to the cumulative nature of discrimination over time for LGB groups (Cant and Taket, 2004).

In a study for the Commission only 49 per cent of LGB people aged 60 and over, reported that they could be open about their sexual orientation without fear of prejudice in their local health practice or hospital (Ellison and Gunstone, 2009). This followed Heaphy *et al.*'s 2003 study, where they found that half of survey participants (53 per cent) were 'out' to health professionals. Only 35 per cent believed health professionals to be positive towards non-heterosexual clients. A notably smaller percentage (16 per cent) trusted health professionals to be generally knowledgeable about non-heterosexual lifestyles. Findings also suggest that older users of mental health services are less likely to disclose their sexual orientation than younger users (Warner *et al.,* 2004). However in Brighton, there is evidence that older LGB people are more likely to disclose their sexual identity to a GP than younger people in the local

context, suggesting that perceived improvements in practice can improve willingness to disclose over time. In the same study, 85 per cent of respondents said they will give information regarding their sexual/gender identities if they believe the service is lesbian, gay, bisexual and transgender (LGBT) friendly and the data is confidential and anonymous (CMIT, 2009).

There is a growing stock of evidence of the experience of using services and encounters with practitioners based upon first-hand accounts from older LGB users (for example: CMIT, 2009; River, 2006; Gay and Grey, 2006; Kitchen, 2003), much of which reveals the sometimes subtle and more everyday experiences of discrimination faced by these groups when seeking support.

'I was in for a smear, and erm the doctor said to me, "oh you don't need one you've had a hysterectomy"

And I said "Oh right" and I felt glad because I didn't have to have one and I went to move off the bed, off the couch thing and I said erm,

"Does it make any difference if I'm a lesbian?"

And he stepped back, and I felt oh god, it's almost like, I dunno'

Interviewer – 'Did he say anything?'

'Erm "no, no, no" almost like he didn't want to discuss it'

(Older lesbian interviewee quoted in Bytheway *et al.*, 2007)

'I came out in the 50s – and that was shit – now I am dependent on carers and I am frightened… I am very frightened of them… what if they find out that I am a lesbian… what are they going to do to me… I have de-gayed my house… this is much worse than the 50s. I want to be able to be gay in my last days – I don't want to have to hide again and I particularly don't want to have to hide because the home help is coming round…'

(Older lesbian interviewee quoted in Pugh, 2010)

## 4.2 Service delivery – invisibility and assumed heterosexuality

The professional bodies that regulate the education and training of nurses (Nursing and Midwifery Council), social workers (currently the General Social Care Council) and allied health professionals (Health Care Professions Council) all now require professional training that includes consideration of discrimination and equal treatment. These issues are also translated into national vocational qualifications for care staff.

Despite evidence that changes are occurring within health and social care more broadly, they appear to be happening less rapidly in services to older people. For instance, sexual orientation has been relatively neglected in education and training for health and social care workers with older users. Some guidance on good or progressive practice does exist, though the majority has been produced in the last five

years (for example: Cosis Brown, 2008; CSCI, 2008; Fish, 2009; Ward and Jones, 2010; RCN, 2003), including some that focuses specifically on older LGB users (for example: Bayliss, 2000; Concannon, 2009; Price, 2008; Fenge *et al.,* 2008; Langley, 2001; Pugh, 2005 and Pugh *et al.,* 2007). Certain commentators have argued for a model of cultural competence in practice (Charnley and Langley, 2007). Cultural competence is developing an awareness of the beliefs, needs and preferences of different cultural groups, and providing 'culturally appropriate' services for diverse older people. Other commentators have been critical of a 'culturally competent' approach, that over-simplifies sexual identity and culture (Hicks and Watson, 2003; Ward and Jones, 2010).

Individual health and social care staff have been left to their own devices in dealing with the range of situations, resulting in great variations in understanding, skill and competence (Musingarimi, 2008; CSCI, 2008).

A number of studies have revealed that practitioners avoid raising issues of sexuality with older service users (Gott *et al.,* 2004, Price, 2009). Charnley and Langley (2007) observe that in adult social services, sexual orientation is absent from charting patterns of referral, assessment, service allocation and staff recruitment.

In a study conducted by CSCI (2008); only 7 per cent of care homes and 8 per cent of domiciliary care providers reported carrying out specific work around equality for LGB people and less than 1 per cent of care homes had done any specific work around sexual orientation and assessment or care planning.

The National Service Framework for Older People (2001) makes much of the need to provide culturally appropriate services that reflect 'the diversity of the populations they serve' (p. 4). However, older LGB people usually use services that assume they are heterosexual and have an opposite sex partner for help and support.

> 'My (former) GP prescribed HRT and said that "it should make my husband happy". I was stunned by the sexist and heterosexist assumptions wrapped up in this comment.'
>
> Older lesbian respondent quoted in River (forthcoming)

> 'Recently after the death of my partner I went to see my doctor, who wasn't available that day, so I saw another member of the practice and my notes were all there... and I was feeling really very low and physically not well either, and this doctor dealt with my physical issues and then I just sat there and I said to him, "Do you believe in dealing with people holistically?" [It was] a bit of a shock to him to hear that and he said,"Of course I do. Is there anything else?" and I said, "Yes, I'm bereaved", and he said,"Oh, did you lose your wife?", and I was so angry at that stupid response that I just said,"No, it was my partner and I'm going. Goodbye."'
>
> (Gay man, 63 years, quoted in Bytheway *et al.,* 2007)

Until practices include LGB sexual orientation adequately in guidance, education, training, service user surveys or monitoring, services will continue to ignore LGB needs.

Less well documented are the less accessible aspects of provision such as decision taking on expenditure and resourcing or discriminatory practices in 'closed' environments such as care homes. In residential settings the sexual expression of residents is commonly problematised creating conditions where LGB individuals may be particularly vulnerable to discriminatory treatment (Ward *et al.*, 2005). Providers in sheltered and residential care demonstrate limited awareness and understanding about sexual orientation (Hubbard and Rossington, 1995; CSCI, 2008; Knocker, 2003). Evidence points to the inappropriate use of safeguarding procedures in response to LGB users entering into relationships and disapproval toward same-sex partners staying overnight in residential environments (CSCI, 2008). In the UK this is an area where further research is required, as much of the evidence base is from North America. For example in Canada, Brotman *et al.* (2003) found that signs of affection between lesbian and gay people within residential institutions have not been understood by the staff and as a result caused conflict. Apart from a lack of support for 'families of choice', discrimination against gay and lesbian older people in US residential settings was also found to include incidences or threats of involuntary 'outing', neglect and physical and sexual assault (Bradford and Ryan, 1987; Stevens and Hall, 1988; Bybee 1991).

Concerns have been expressed regarding the training given to agency workers delivering personal care, and whether they are adequately aware of the importance of respecting older people's sexual orientation in service delivery (River, 2006).

Older LGB people are entitled to increased choice and control over their care through payments made directly to them. This means that people can attempt to 'personalise' their own care, so that it works for them. In a 2008 CSCI survey of LGB people using social care services, two-thirds said that they did not specifically want to be supported by LGB staff – as long as the staff they encountered were positive about the sexual orientation of their service users. A proportion of service users do prefer to be supported by LGB, or identifiably 'LGB' friendly staff, although there are no obvious systems in place to assist users in identifying 'gay friendly' care workers (Gulland, 2009).

## 4.3 Specific health and social care issues

The existing evidence suggests that LGB people face many of the same issues as other members of society when ageing, including health and care concerns. However, their experiences and needs are mediated through a disadvantage and discrimination related to their sexual orientation and other aspects of their identities. This section addresses the specific health and social care issues affecting older LGB people.

## Health

The general literature on health inequalities largely ignores sexual orientation, although a number of studies and reviews have drawn attention to the particular health needs of LGB groups (e.g. Hunt and Fish, 2008; Hunt and Minsky, 2007; Meads *et al.,* 2007, Scott *et al.,* 2004). These reports consistently highlight certain differences between LGB groups and the general population, although it is not always possible to determine whether such differences are statistically significant. The balance of evidence available to date, points to two key health issues for older LGB people compared to older heterosexual people.

## Mental health

King *et al.,* in 2008, undertook a systematic review of the international research literature to establish whether LGB people are at higher risk of mental disorder (including substance misuse), suicide, suicidal ideation and deliberate self-harm than heterosexual people and to quantify this risk. The study extracted prevalence estimates and/or odds ratios for mental disorder, substance misuse and deliberate self-harm/suicidal ideation/suicide in LGB people and control groups. The included papers contained data on 207,420 heterosexual and 11,647 non-heterosexual people aged from 12 to over 74 years. They found that LGB people are at significantly higher risk of suicidal behaviour, mental health conditions, substance misuse and substance dependence than heterosexual people. There was a two-fold excess of suicide attempts and suicidal ideas in LGB people measured over the preceding 12 months or over the lifetime. Depression in the preceding 12 months was found to be two to three times more prevalent in LGB people. LGB people had more than twice the risk of alcohol dependence and almost three times the risk of drug dependence in the preceding 12 months. They conclude that the difficulties LGB people face in an unsympathetic society are likely explanations for these findings.

The Count Me in Too project gathered data through discussion groups and questionnaires completed by over 800 LGBT people of all ages who live, work or socialise in the Brighton and Hove area. Findings from the study highlighted mental health as a priority across all age groups, with older LGB people more likely to rate their mental health as poor compared to younger groups (CMIT, 2009).

Polari (a voluntary organisation that worked specifically with older LGB groups) consistently identified mental health issues as a priority for project participants throughout its lifetime. Despite increased vulnerability to certain mental health conditions in later life, some mental health services are unavailable for service users over 65, leading to claims that the mental health system is failing those over 65 years of age (Lee, 2006 and 2007). Given what is known about the particular mental health needs of both LGB and older groups there remains a worrying silence specifically concerning older LGB individuals and their experiences of mental health and of the services intended to support those with mental health needs.

## HIV

An ageing population living with HIV is becoming a reality. The number of people aged over 50 years living with HIV in the UK increased from 1,200 to just over 6,000 Elford *et al.* (2008). HIV infected adults aged 50 years and over accessing care more than tripled between 2000 and 2009 from 2,432 to 12,063 representing one in five of all adults seen for HIV care in 2009. This is due to an ageing cohort of people previously diagnosed as well as an increase in new diagnoses among the over 50s. New diagnoses among older adults more than doubled between 2000 and 2009, and accounted for 13 per cent of all diagnoses in 2009. Two-thirds (67 per cent) were diagnosed late. Adults diagnosed when aged 50 years and over are more likely to present late compared with younger adults (15-49 years). A recent study showed that the risk of short-term mortality (death within a year of diagnosis) was 2.4 times higher for older adults compared with younger adults and older adults diagnosed very late were 14 times more likely to die within a year of their diagnosis compared with those diagnosed earlier (Health Protection Agency, 2010).

Evidence suggests that gay men accounted for almost two-thirds of new infections in the UK since 2006, so remain most at risk Elford *et al.* (2008). The Elford *et al.* (2008) study reached some important conclusions regarding older gay men and HIV. It revealed that older gay men are becoming infected with HIV in their 50s and 60s, and are just as likely to report unsafe sex as younger HIV positive men. They recommend that HIV prevention programmes in the UK should target older gay men. Older people appear to be a rising proportion of those diagnosed with HIV, therefore HIV prevention programmes will need to include this group, including older gay men.

A recent study carried out for the Joseph Rowntree Foundation (Power *et al.,* 2010) found that a poor response from primary care was a particularly pressing problem for older people affected by HIV. Respondents reported high levels of accompanying long-term health conditions, mobility difficulties and problems with everyday tasks. Increasingly, the long-term effects of HIV medication are also being recognised including blood disorders, kidney problems and sexual dysfunction (www.tht.org.uk). With such findings in mind, Owen *et al.* (2009) highlight the need for liaison and closer working between specialist services, primary care and older people's services in future.

## Social care

Older people more generally are concerned about loss of independence. Evidence suggests that dependence upon social care or institutionalisation is a significant threat to older LGB people who have experienced discrimination or may have felt unable to reveal their sexual orientation to services in their younger lives (Hubbard and Rossington, 1994). In a scoping study conducted in central London, River (2006) found that some older LGB people with support needs had delayed their uptake of social care services for as long as possible. Again, this is an area where there is a need for further research in the UK. Much existing evidence is of North American origin (e.g. Taylor and Robertson, 1994;

Claes and Moore, 2000) where welfare systems are organised and structured very differently to the UK.

## Issues that have received the least attention

### High level service users

In this think-piece we are particularly keen to raise awareness of the need to consider older LGB high level service users who are frail and depend upon care services. Collectively, this group have rarely figured in research or policy into LGB needs or inequalities yet they may experience acute disadvantage and have specific needs, according to the evidence available. In a study of gender and sexual orientation in long-term care Ward *et al.* (2005) highlight an example from a care home where the staff group reacted with a mixture of mirth and disgust at the possibility that a female resident may have been a lesbian. Archibald (2002) describes how an older woman with dementia in a Scottish care home had support withdrawn from her during the last months of her life after she was labelled a lesbian by staff. Clover (2006) argues that more vulnerable groups are at higher risk of poor practice, but in the absence of advocates, the capacity to challenge such treatment may be limited.

### Dementia care

It is estimated that by 2021 there will be 940,000 people with dementia in the UK, a figure that is expected to rise to over 1.7 million by 2051 (Alzheimer's Society, 2010). A range of 21,000 (2 per cent lower estimate) and 63,000 (6 per cent common estimate) LGB people may be represented in these figures – though it is recognised that population figures are widely disputed and range from 2–10 per cent (Aspinall, 2009). Research on LGB people affected by dementia is currently limited and what does exist highlights the failure of service providers to recognise sexual diversity in provision (Mackenzie, 2009; Price, 2008; Ward, 2000). The National Dementia Strategy (2009) reports, for example, on a number of commissioning events at which extant and potential service users' views were elicited. More than 4,000 people took part in the events but LGB groups appear to have been overlooked. The accompanying Equality Impact Assessment notes the need for further research but proposes no actions or recommendations in terms of service delivery.

### End of life care

LGB issues in end of life care have received little attention outside of HIV-related services. The End of Life Care Strategy in England (Equality Impact Assessment) (DoH, 2008) consulted with LGB groups, concluding that sexual orientation was one of the most likely areas for discrimination to occur in end of life care, and made a commitment to staff training and awareness-raising as a result. Research conducted by Almack and colleagues (2010) found an overall failure to consult and involve older LGB users in mainstream end of life services. The authors highlight the importance of recognising families of choice and specific issues that may arise, for example, occasions when same-sex partners had been excluded from decisions in the end of life care of their partner by the family of origin.

Similarly, in bereavement care and support, attention has been drawn to the notion of 'disenfranchised grief' where LGB relationships, including friendships, have been treated less seriously by service providers at times of loss (Bevan and Thompson, 2003; River, 2006). Keogh *et al.* (2006) have argued for targeting support to LGB individuals at key periods of transition in the life course such as bereavement, while Fenge and Fannin (2009) also highlight bereavement as a period of heightened vulnerability for older LGB users. This can arise if their partnership status and grief is not recognised, but also because many feel unable to disclose their sexual orientation to practitioners and hence may not access appropriate support.

## Carers

Existing research suggests that a significant proportion of older LGB individuals may have caring responsibilities (e.g. 25 per cent of 50+ years' respondents in a study by Hubbard and Rossington, 1995). Outside of HIV services the needs and experiences of LGB carers are under-researched in the UK (CMIT, 2010). Wintrip (2009) found that older LGB carers of people with mental health difficulties faced a lack of support from mainstream services. In their work with older LGB caring couples, Cronin and King (2010) revealed dynamic relationships where the roles of carer and cared-for were often blurred, consequently the authors argue for the importance of practitioners recognising the often interdependent nature of LGB caring relationships. More needs to be done regarding the position of LGB carers. An example is where lesbian carers may lack recognition of their partnership by services, and therefore face multiple issues in caring for their partners (Manthorpe, 2003).

## LGB practitioners and services

Some older LGB people would prefer exclusive LGB services, in the belief that in such an environment they would have more in common with other users of services. For other older LGB people, this is less of an issue but they would still like their LGB identity to be recognised and valued within a 'gay friendly' environment. For others, their sexual orientation is private, and nothing to do with care providers (Gulland, 2009; CCSI, 2008). Fundamentally, these responses point to the issue of choice in service provision, which reflects their own sense of sexual identity, how they have lived their lives, and very importantly, how they wish to continue to live their lives. There is a need to open a dialogue over these issues in order to better understand the different needs and preferences of this diverse group.

There is little evidence on the role of 'out' LGB practitioners within services to older people. In other areas of health and social care, the existing evidence on LGB practitioners points to their own experiences of discrimination in the workplace, for example by being advised not to come out to clients (Hunt *et al.,* 2007; Abbott and Howarth, 2005). Yet, 'out' workers can be an important resource in supporting LGB service users (Quam, 2007), while formally appointed champions of LGBT issues can also help to influence positive change within care organisations (CSCI, 2008).

# 5. Evidence of positive and improving practice

## 5.1 Introduction

This paper points to recent changes and improvements in legislation, policy, research and practice that offer promise for improving service delivery for older LGB service users. The rise of the inclusion of sexual orientation in health and social care policies, surveys, administrative data and guidance, means that the assumption of heterosexuality is changing, as the diversity of sexual orientation is becoming recognised.

For example, in policy on carers, there are signs of positive change: 'Caring with Confidence', funded by the Department of Health, part of the National Carers Strategy and the 'New Deal for Carers', makes explicit its commitment to LGBT carers by working with a range of LGBT organisations to provide 'Caring with Confidence' face-to-face sessions for carers in the north west and south east of England.

The DH appointed a national Lesbian, Gay, Bisexual and Transgender Advisory Group, and states that it places at the centre of its work LBGT people who use and deliver health and social care services, in order to ensure opportunities for their experiences to inform service development and improvement.

As previously mentioned, there has been a rise in the provision of important guidance that focuses specifically on improving provision for older LGB health and social care users (e.g. Bayliss, 2000; Concannon, 2009; Price, 2008; Fenge *et al.,* 2008; Langley, 2001; Pugh, 2005; Pugh *et al.,* 2007) although it is clear there is a need for further and more comprehensive guidance on LGB issues for those engaged in services to older people. Added to this, we have identified a need to develop channels of communication for the sharing of good practice between different sectors and disciplines in respect to working with older LGB service users.

In the evidence of discrimination in accessing services, although around half of older LGB people over 60 said that they could not be open about their sexual orientation in their local health practice or hospital without fear of prejudice or discrimination, around half feel they can be open (Ellison and Gunstone, 2009). In some areas, such as primary care, there are indications that efforts to improve practice have led to positive outcomes:

'I lived in Manchester where many practices were given training in LGBT issues, mine being one. They were very courteous and understanding.' (Older gay man)

'I was lucky to have a particularly sympathetic GP who I trusted totally. In other circumstances I would not have been able even to mention my sexuality and my recovery would have been delayed (or even not effected).' (Older bisexual woman)

'The doctor made me feel so happy, she must have remembered meeting my partner during a home visit, it seemed to break the ice and acknowledge the relationship.' (Older gay man)

All quotes from respondents to survey on older LGB experiences of Primary Care – River (forthcoming)

## 5.2 Biographical approaches in practice

A prominent feature of recommendations for practice with older LGB users concerns the benefits of biographical and life-history approaches (e.g. Bayliss, 2003; Jones and Ward, 2010). Jones (2010) highlights the value of using a life course approach with older bisexual service users to take account of fluid identities over time, while Cronin and King (2010) have argued for the benefits of eliciting joint biographies when supporting caring couples and in developing social work practice with LGB carers (see also Cronin *et al.,* forthcoming). Practitioners in Community Mental Health Teams for Older People have been encouraged to expand their assessments to include a biographical context given the particular histories that LGB users may have of mental health services (Ward, 2010), similarly Pugh (2005) and Lee (2007) point to the importance of recognising the impact of past experiences on current attitudes to and uptake of welfare services by older LGB users.

## 5.3 Voluntary sector initiatives

Models of good practice have tended to come out of voluntary sector provision, often supported by new sources of charitable funding. A number of these initiatives have used participative action research (PAR) approaches. These have been designed to support and enable older LGB people to express their needs and preferences, facilitate networks between them and address the social isolation that many participants report. Examples of past work targeting older LGB individuals include the Polari in Partnership Project in London (see Davies and River, 2005); Gay and Grey in Dorset (2006); the Sefton Pensioners Advocacy Group/Get Heard (Kitchen, 2003); and the LGBT Support Network attached to the Alzheimer's Society.

Current initiatives include the Opening Doors agenda developed by Age UK (previously Age Concern). It contains a series of projects in different parts of the UK. One is a large-scale London-based befriending and support network that has attracted over 300 participants (Phillips and Knocker, 2010). The Rainbow Care Homes project in Oxford is working to raise awareness of LGB care home residents and offer training to staff. Age UK dedicates a

webpage to LGBT ageing and provides information specifically aimed at ageing as an LGB person.[ii] The organisation also commissioned a resource pack for professionals (Knocker, 2003) with a view to meeting the needs of older LGB people living in care homes and extra care housing.

Another initiative aimed at supporting LGB care home residents is also now underway from the LGBT Centre for Health and Wellbeing in Edinburgh.[iii] In Brighton, the Count Me in Too project is a partnership and knowledge exchange venture between Spectrum LGBT community group and Brighton University. Working with LGB participants of all ages the project has produced a series of briefings on the health and wellbeing of LGB groups including older people for use by local policy-makers and service providers and provides an exemplar of 'co-productive' working as currently promoted in welfare policy.[iv]

Most of these projects reported similar challenges including difficulties recruiting frail, housebound participants, those with dementia and individuals from ethnic minority communities. In most cases, the numbers of bisexual participants were low. It has also been suggested that difficulties in recruiting older lesbian women lie in part because many belong to often hidden, informal support networks (Heaphy *et al.,* 2004). However, by working across many different aspects of the lives of older LGB people these voluntary sector projects have highlighted the importance of not taking too narrow a view of 'need' in a climate of growing recognition of the overlapping and dynamic relationship of social, physical and emotional wellbeing.

## 5.4 Training

While access to targeted training remains limited, innovative approaches are being developed including the use of 'ethno-dramas' to highlight LGB user experiences (e.g. as developed by the Association of Greater London Older Women) and the use of kitemarking to support improvements in provision that include training to staff (Concannon, 2009). More general advice and standards for LGB training in healthcare are also available (Cree and O'Corra, 2006) as well as resources designed specifically to support service development with older LGB service users (Pugh *et al.,* 2007).

# 6. Conclusions: Looking ahead

## 6.1 Conclusions

The unequal treatment of any group of people brings with it clear and identifiable human costs. Health and social care agencies that are committed to empowering service users, promoting social inclusion and demonstrating a respect for diversity, fall short of their core values with regard to older LGB service users.

The paper demonstrates how older LGB people have been overlooked in health and social care legislation, policy, research, guidance and practice, which assume service users are heterosexual. The existing evidence suggests that LGB people face many of the same issues as other members of society when ageing, including health and care concerns, however, their experiences and needs are influenced by disadvantage and discrimination related to their sexual orientation. There are wide gaps in knowledge about the LGB UK population in relation to their physical and mental health outcomes, use of health and social services and experiences of health and social care more generally. There is very little data that compares LGB and heterosexual populations. The evidence is even more limited for older LGB people.

The existing evidence points to discrimination and the anticipation of negative treatment when accessing services. Service providers tend to assume health and social care users are heterosexual and have opposite sex partners, which excludes older LGB people. Particular health and social care issues require greater attention and action. Older LGB people are likely to have different mental health needs to their heterosexual peers. Older gay men in particular may become infected with HIV or are already living with it. LGB high-level service users who are frail and depend upon care services, and LGB carers, have received the least attention, along with people with dementia and those requiring end of life care.

It is clear then that positive change is required in the delivery of services to older LGB service users. The prospect of such change has arisen not only as a result of the legislation and social change reviewed in this paper, but also due to the campaigning efforts and discontent voiced by generations of LGB groups, influencing both social attitudes and policy.

## 6.2 Inclusion of older LGB service users

In order to better reflect older LGB people's concerns and experiences in research, practice and policy making, it may be helpful to adopt an approach similar to that undertaken in North America. Services and Advocacy for Gay, Lesbian, Bisexual and

Transgender Elders (SAGE), based in New York, in addition to campaigning for the rights of LGBT older people, organises an annual 'round table' of organisations and activists with a common interest in furthering the rights and interests of older LGBT people.

Implicit in the approaches adopted both by SAGE and UK groups such as Polari, Gay and Grey, the Opening Doors programme, the LGBT Dementia Support Network and the Count Me in Too project is the demand by older LGB people to be heard by the agencies that are required to serve their needs. Health and social care agencies in the UK have been engaged recently in numerous arrangements to garner the voices of older people in general, and have a duty to employ these voices to plan and shape service delivery, but all too often older LGB individuals are left out of this process. Engaging older LGB users as for example 'experts by experience' (a practice employed by CQC) has the potential to ensure that the voices of older LGB people are heard and responded to. The key to co-production and greater inclusion of older LGB people rests with the willingness of the range of agencies to seek out and actively engage this group. For such engagement to be meaningful, agencies need to understand that this is not a simple, quick fix exercise but one that requires time, effort, persistence and the demonstration of a consistent willingness to listen and then act.

## 6.3 Improving the evidence base to support service delivery

Recent efforts to monitor provision have generated increasing evidence regarding poor service responses to the needs of older LGB people (e.g. CSCI, 2008). The regulator, CQC, collate information related to service provision for LGB people, drawing evidence from their inspection reports of health and social care services of both commissioners and providers. Equally, greater levels of information, including that relating to older LGB service users, is required in order to deliver World Class Commissioning and broaden adult safeguarding. An improving evidence base is emerging, though it remains extremely patchy, and much depends upon the willingness of agencies to ask questions, where appropriate, and integrate the evidence in order to improve provision.

A challenge for research and data collectors lies in recognising sexual identity as a significant factor influencing access to and use of welfare services, as they have done with ethnicity and disability. Purdam *et al.* (2007) call for the development and resourcing of 'robust longitudinal research methodologies that synergise qualitative and quantitative data' (p. 137) in order to gain a better understanding of LGBT lives. We would add that many smaller-scale qualitative approaches such as life story and other biographical approaches also hold the potential both to educate providers and to support personalised working with individual users.[v]

## 6.4 Strengthening advocacy

Due to the efforts of organisations such as the Older People's Advocacy Alliance, advocacy for older people is developing rapidly in the UK. This development has been further supported by the Mental Capacity Act which established the Independent Mental Capacity Advocates (IMCAs) as a service to protect the interests of those individuals who may lack capacity to make key decisions about their lives. To date, there are very few examples of good practice with older LGB users and there is a clear need for awareness-raising and training for all advocates, whether they are volunteers or IMCAs. The development of LGB peer advocacy networks might also provide a cost effective response to under-developed advocacy arrangements.

## 6.5 Strengthening the use of regulation

Many of the developments that we have highlighted have been given greater impetus by the Human Rights Act and the Equality Act 2010. Sexual orientation and age have been given a similar status to other protected characteristics and the new Public Sector Equality Duty should ensure that public bodies consider how their policies, programmes and service delivery affect a wider range of groups, including LGB people of all ages, in order to eliminate prohibited conduct, promote good relations and advance equality of opportunity. This promises important positive changes to health and social care service delivery and for older LGB service users.

## 6.6 The silent 'B' in LGB

In this paper we have argued for the need to give specific consideration to the situation of those who by dint of frailty, ill health and impairment may be high level users of welfare services but are often overlooked. Our review has also highlighted for us the currently sparse evidence available concerning older bisexual service users. In terms of policy, research and practice, older bisexual people remain largely absent and their particular situation is little understood. This leaves open to question where practitioners should turn for guidance or information in working with older bisexual service users.

## 6.7 Older LGB people as a 'litmus test' for non-discriminatory service delivery

The potential exists for the provision of care and support to older LGB people to become a 'litmus test' – an indicator for how well health and social care agencies engage with minority groups and deliver a non-discriminatory service. By encouraging and requiring these agencies and their workers to respond to older LGB people in a manner that is both person-centred and sensitive to the broader challenges of LGB ageing, this may become the portent for changes in how all older people are treated in their engagement with health and social care services.

## Endnotes

i This estimate is drawn from population statistics produced by the Office of National Statistics (2005) accessed at www.statistics.gov.uk/focuson/olderpeople/ on 8th July 2009 and ONS (2010) accessed on September 23rd 2010 www.statistics.gov.uk/pdfdir/ihs0910.pdf. For Stonewall's estimate of the percentage of the population who are lesbian, gay and bisexual see the following site accessed on 8th July 2009 www.stonewall.org.uk/at_home/sexual_orientation_faqs/2694.asp

ii http://www.ageuk.org.uk/health-wellbeing/relationships-and-family/older-lesbian-gay-and-bisexual/?paging=false.

iii www.lgbthealth.org.uk.

iv www.countmeintoo.co.uk

v www.lifestorynetwork.org.uk

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