

The Adult Social Care Outcomes Framework

Lesbian, Gay, Bisexual and
Trans Companion Document



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Foreword

Jon Rouse

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As stewards of our health and care system the Department of Health is committed to ensuring high quality care and support is delivered to all who need it throughout England. Naturally this includes people from the lesbian, gay, bisexual and trans (LGB&T) communities who we know sometimes face discrimination and poor service.

The Adult Social Care Outcomes Framework is an important means of measuring how well councils are providing support to the people that need it most. This companion document, produced by the National LGB&T Partnership in its role as a Health and Care Voluntary Sector Strategic Partner, brings together evidence from a range of sources in order to build a picture of the current state of care for people who are LGB&T. It recommends a number of actions to improve both services themselves and the information we hold about experience of care for LGB&T people.

The Care Act 2014 will be a key driver of change to improve services; promoting personalisation, integration and preventative care. Local authorities will assume new responsibilities including providing further support to carers, ensuring all eligible users have a personal budget and increasing provider choice for service users. The evidence presented in this document suggests that people from LGB&T communities will particularly benefit from these changes as limited choice, lack of preventative care and the benefits of being able to manage a personal budget were drawn out as key themes.

We can, however, only ensure that these benefits are realised by continuing to seek out ways to monitor the views and experiences of LGB&T service users to ensure their needs and expectations are met by care services. It is important that we recognise the value of having and using this information to improve outcomes for LGB&T people and address some of the current inequalities highlighted in this report.



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Acknowledgements

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Introduction

The Adult Social Care Outcomes Framework (ASCOF) is the Department of Health's key tool for measuring the progress of the adult social care system, supporting understanding of the outcomes and experiences of people who use care and support, and carers. First launched for the year 2011/12, its role is to:

- ▶ support councils to improve the quality of the care and support services they provide;
- ▶ promote more joined-up working at the local level;
- ▶ provide a common basis for action;
- ▶ along with the Public Health Outcomes Framework and the NHS Outcomes Framework, form the basis for integrated working locally.

In 2014 the ASCOF, alongside the NHS Outcomes Framework, aims to support the government's ambition for joined-up services within, and between, health and social care. This companion document aims to assist commissioners to respond to their duty under the Health and Social Care Act 2012 for NHS England and CCGs to reduce health inequalities and promote integration between services for an often marginalised community.

Every person using health and care services deserves the highest quality care and support. The ASCOF, with its focus on promoting better outcomes and experiences for people who use care, and carers, measures how well care and support services are delivering the outcomes that matter the most to people.

This document brings together the existing evidence on the care and support needs of lesbian, gay, bisexual and trans* (LGB&T) people, recognising that the picture it paints is necessarily incomplete. There are significant knowledge gaps in this area, in large part due to the lack of routine monitoring of patient sexual orientation and gender identity across services and a lack of data relating to the health of LGB&T communities derived from population-based studies and statistical datasets.¹ However, there is a significant evidence base on the health inequalities experienced by LGB&T communities from peer-reviewed research, grey literature published by the LGB&T community, and indicative evidence. The evidence points to the significant impact of discrimination on LGB&T people's experiences of care and support and outcomes for their wellbeing. Research into LGB&T ageing indicates that these communities have particular needs in relation to care and support, as older LGB&T people are at greater risk of isolation and dependence on services, and around 1 in 20 gay and bisexual men are living

Trans* is an umbrella and inclusive term used to describe the whole range of people whose own gender identity and/or gender expression differs in some way from the gender assumptions made about them at birth and from the consequent biological sex assigned to them. This applies not only to those who identify as transgender or intersex but to anyone who feels that the gender assigned to them at birth incompletely or does not at all describe their own innate gender identity. (*Trans* includes but is not limited to: Transgender, transsexual, genderqueer, non-binary, gender-fluid, gender nonconforming, intersex, third gender, twin spirited, transvestite, cross-dresser, bi-gender, trans man, trans women, agender, gender independent, and non-gender, as well as other non-binary identities*).

¹ Boehmer, U. Twenty Years of Public Health Research: Inclusion of Lesbian, Gay, Bisexual, and Transgender Populations, *Am J Public Health*. 2002 July; 92(7): 1125–1130.



with HIV and will require social care and support. These issues are explored further in the domain chapters. What is not known is the role of resilience in determining better outcomes, nor the more positive protective factors that LGB&T communities have developed over time.

Evidence from our survey of adult social care commissioners and providers shows that monitoring of patient sexual orientation and gender identity is not comprehensive or consistent.² Where this data is collected, few use it to understand or improve LGB&T people's experience of services. Overall, the response rate to the survey from commissioners and providers was low, perhaps indicating a lack of engagement with this agenda. Many providers felt that a requirement to monitor sexual orientation, and a national framework around meeting LGB&T people's needs, would enable them to embed monitoring and use the data generated. It was also noted that more evidence on LGB&T people's needs at a local and national level would allow providers to contextualise their service access and outcomes data.

Some providers felt they needed a better understanding of how services are commissioned, and a better relationship with their commissioners and the CCGs.

Notably, some providers commented that sexual orientation and gender identity were never mentioned in service provision, and even that LGB&T patients were treated as non-sexual and advised to remain in the closet. Guidance for commissioners and providers to address sexual orientation and gender identity was specifically requested.

The findings from the survey of LGB&T people and their carers represent the largest overview of LGB&T experiences of social care to date, with over 250 respondents from across the country.³ Respondents commonly spoke of a need for LGB&T specific care services, and better training for staff in mainstream services on LGB&T issues. These findings inform the recommendations for commissioners and providers set out in each domain chapter and in our Universal Recommendations.

The LGB&T ASCOF Companion Document is aimed at strategic commissioners, care and support service providers and local authority providers. The document sets out the evidence on LGB&T communities in relation to each of the indicators under the four domains of the ASCOF. It makes recommendations for actions to address inequalities in outcomes for LGB&T people and communities. The Case Studies and list of Resources presented in each domain chapter provide further best practice examples and toolkits to support organisations in implementation of the recommendations in this document. We hope that future editions of the Companion Document will share more good practice and show improved experiences of LGB&T people and communities when they access social care.

The document has been developed by the National LGB&T Partnership working with the Department of Health, with thanks to experts from across the LGB&T community.

2 The National LGB&T Partnership conducted a call for evidence in Sept – Nov 2014 for local authorities, service providers and commissioners across the social care sector to share evidence and data on LGB&T people's access, experience and outcomes in relation to the ASCOF indicators.

3 The National LGB&T Partnership conducted a call for evidence in Sept – Nov 2014 for LGB&T people and their carers to share evidence and data on their experiences of social care.

Universal Recommendations

The LGB&T Adult Social Care Outcomes Framework Companion Document makes a number of overarching recommendations for Health and Wellbeing Boards, local authorities, the NHS and other partners to support the delivery of improved health and wellbeing outcomes for LGB&T people.

Recognition

- ▶ Health and Wellbeing Boards and Directors of Public Health should ensure that the Joint Strategic Needs Assessment explicitly considers the needs of the local LGB&T community in relation to care and support.
- ▶ Health and Wellbeing Board Chairs must ensure that Health and Wellbeing Strategy implementation plans and supporting strategies explicitly consider actions to reduce inequalities affecting LGB&T communities.
- ▶ Commissioners of social care should continue to use equality impact assessment frameworks, which include sexual orientation and gender identity, for population strategy documents and action plans.
- ▶ Providers of social care should implement the published guidance, as referenced in the Resources section of each domain chapter, on becoming LGB&T-friendly providers.

Engagement

- ▶ Healthwatch commissioning and contracting processes should monitor levels of engagement with LGB&T populations.
- ▶ Clinical Commissioning Group public and patient involvement initiatives should ensure that LGB&T communities are specifically included in CCG communication and engagement strategies.

Monitoring

- ▶ Commissioners of social care should include a requirement in contracts for service providers to monitor sexual orientation and gender identity in service users over 16yrs, and consider monitoring younger age groups where appropriate.
- ▶ National cohort studies and disease registers should include sexual orientation monitoring and gender identity in routine data collection.

Service Provision

- ▶ Health and Wellbeing Boards and local authorities should work closely with CCGs to promote the integration of health and social care which recognises the particular needs of LGB&T people.
- ▶ Commissioners of social care should use the data available to them to assess whether mainstream services they have commissioned are accessible to and appropriate for LGB&T people.
- ▶ Commissioners of social care should ensure provision of specialist services, where appropriate, to address specific LGB&T health care needs available in their local area.

Domain 1: Ensuring quality of life for people with care and support needs



These measures focus on individuals being able to take control of their own care and support; to ensure that support is delivered in a way that meets their needs, and that individuals are able to maintain work, family and social life in order to avoid isolation and loneliness. Domain 1 also provides for measures to ensure that carers can balance their own quality of life with their caring responsibilities.

Research has shown LGB&T individuals and carers often experience discrimination and marginalisation that impacts on their ability to access services and receive the most appropriate support.⁴ The National LGB&T Partnership conducted a survey to learn more about the views of LGB&T individuals in receipt of social care and their carers. This survey provides the largest overview of LGB&T experiences in the country, with 251 respondents and gives a useful insight for the Domain 1 measures.

⁴ Cartwright, C, M. Hughes, and T. Lienert. 'End-of-life care for gay, lesbian, bisexual and transgender people', *Culture, Health & Sexuality: An International Journal for Research, Intervention and Care*, 14:5, 2012, p. 539.

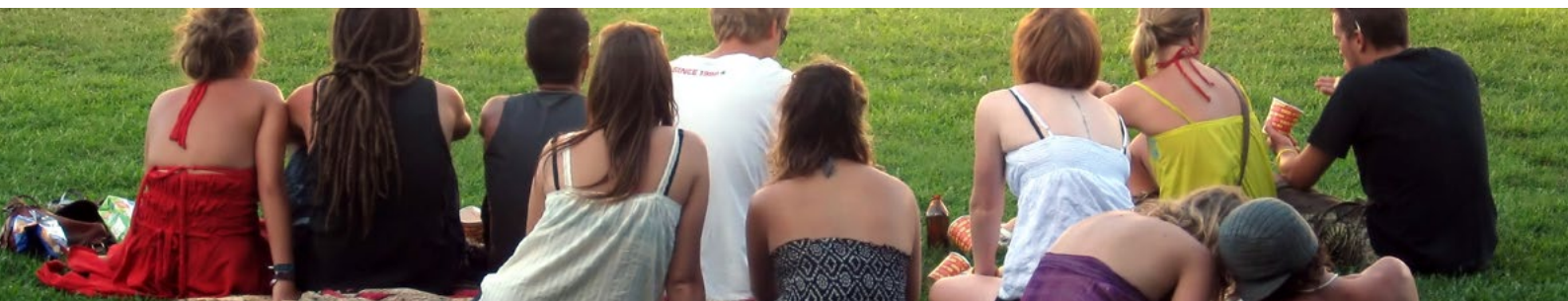
Overarching measure

1A. Social care related quality of life

Outcome measures

People manage their own support as much as they wish, so that they are in control of what, how and when support is delivered to match their needs.

1B: Proportion of people who use services who have control over their daily life



1C: Proportion of people using social care who receive self-directed support, and those receiving direct payments

Our survey of LGB&T people and their carers found that only 10% of respondents were in receipt of a personal budget or direct payment for their own benefit or for someone they were caring for. Of those respondents, all reported that they felt they had some form of choice and control over their personal budget or direct payment. This is comparable with data collected by Think Local, Act Personal in their survey of personal budget holders and carers where a majority of the 2,022 respondents (65 of whom identified as lesbian, gay or bisexual) indicated being able to have choice and control.⁵ However, it is notable that over half (53%) of respondents to our survey described the choice on offer as limited.

“Very poor information is given and I don’t feel in control at all”

“People who advise on personal budgets are often from their own organisation or service”

“Yes we had control. Choice of what to spend it on was somewhat limited”

A previous Think Local, Act Personal report highlights that levels of confidence around choice and control over direct payments or personal budgets may be high in LGB communities, thanks to the ability to be able to dismiss a carer who is discriminatory and choose carers whom they have a good relationship with.⁶

Recommendations:

- Social care providers should signpost LGB&T people in receipt of personal budgets or direct payments to appropriate providers of care who have a proven track-record in providing inclusive services. The LGB&T voluntary sector can support this by sharing information about relevant services.

5 Hatton, C. and J. Waters. Think Local, Act Personal: Second POET Survey of Personal Budget Holders and Carers. University of Lancaster: 2013. <http://www.thinklocalactpersonal.org.uk/library/POETNationalReportFINAL.pdf>

6 Commission for Social Care Inspection. Putting People First: Equality and Diversity Matters. In Focus, Quality Issues in Social Care: 2008 http://www.thinklocalactpersonal.org.uk/library/Resources/Personalisation/Localmilestones/putting_people_first_equality_and_diversity_matters_1.pdf

Outcome measure

Carers can balance their caring roles and maintain their desired quality of life



1D. Carer-reported quality of life

Evidence gathered through the survey on Adult Social Care shows that only 4% of LGB&T people surveyed felt they were able to balance their caring responsibilities with their own quality of life. The majority of respondents (64%) felt they couldn't balance these two together, with many describing it as very difficult to achieve. This is in stark contrast to the Think Local, Act Personal Survey of Personal Budget Holders and Carers, which reported that a majority of all groups of carers had a better quality of life thanks to personal budgets and direct payments.⁷

A number of parents of trans children, who felt they had a carer's role, indicated particular concerns for their own mental and physical health and wellbeing whilst caring for their child. This was a result of fear of discrimination and anxiety for how their child would be treated:

"Caring is just part of our lives but it does take up a lot of energy and I can't do as much as I used to. I definitely couldn't work"

"[Caring] broke me mentally and emotionally and was physically demanding. I was unable to work for the duration and I've struggled to work since due to the emotional strain I suffered"

"My son is transgender and I have found little or no support from the NHS for myself or for him. My quality of life is affected due to the anxiety I have for him and his future given his mental state."

Recommendations:

- ▶ Local authorities should provide social care services with appropriate resources and signposting information to enable carers, as well as service users, to have knowledge and information about appropriate community resources which may better meet their specific needs.
- ▶ Local authorities should establish appropriate referral pathways between carers and services provided by the local LGB&T voluntary and community sector.

⁷ Hatton, C. and J. Waters. Think Local, Act Personal: Second POET Survey of Personal Budget Holders and Carers. University of Lancaster: 2013. http://www.thinklocalactpersonal.org.uk/_library/POETNationalReportFINAL.pdf

Outcome measure

People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation

1E: Proportion of adults with a learning disability in paid employment

1F: Proportion of adults in contact with secondary mental health services in paid employment

1G: Proportion of adults with a learning disability who live in their own home or with their family

1H: Proportion of adults in contact with secondary mental health services living independently, with or without support

1I: Proportion of adults who use services and their carers, who reported that they had as much social contact as they would like

There is a lack of evidence on the proportion of LGB&T people who have learning disabilities and their experiences, but we know that people with learning disabilities have different sexual orientations and gender identities just like anyone else. When providing services to LGB&T people with learning disabilities, there must be a balance of responsibility between the individual's rights and the need to contain risks.⁸

Almost a fifth (17%) of respondents who had a mental health condition managed to remain in employment, although half of these indicated that they only just managed to remain in employment. We know that LGB&T people are far more likely to report having mental health conditions than the general population, which can lead to longer term health conditions requiring greater care and support needs.⁹

Over half of respondents (53%) reported they were unable to maintain social contact, for example due to impairment and poor care. A quarter reported being able to maintain some form of social contact although some described this as being hard.

"I have managed to stay at University but on a severely reduced timetable"

"I did try to return to work but impossible as the social care help I received did not come regularly in times which suited going to work"

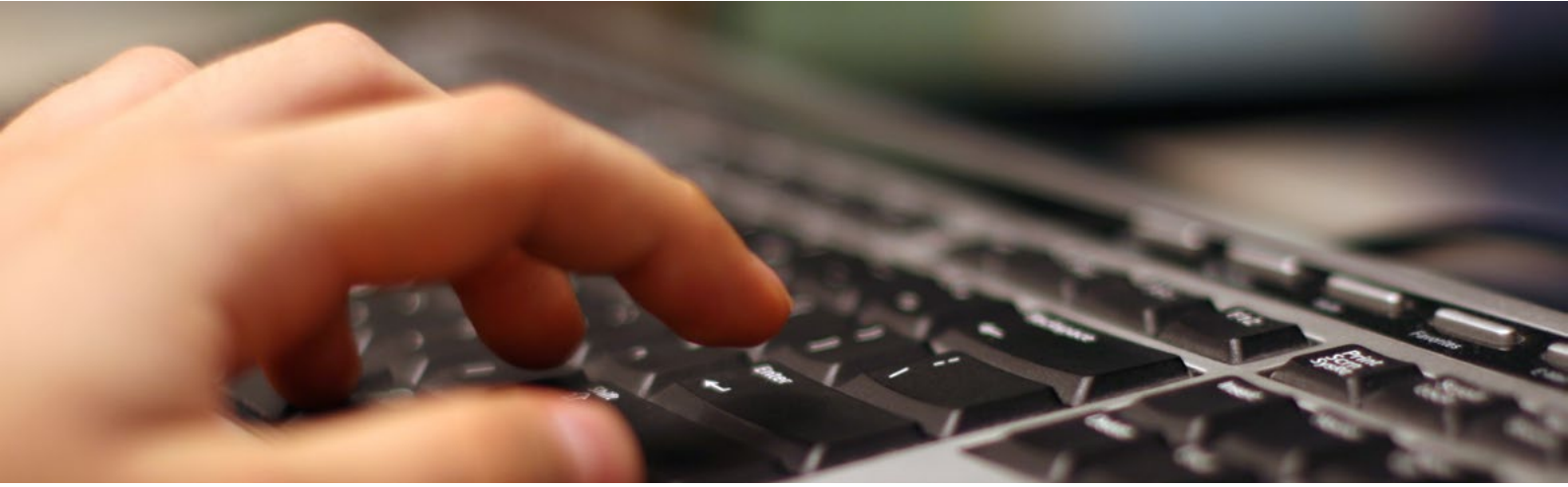
Recommendations:

- ▶ Social care providers should ensure that staff receive training on LGB&T issues and are able to sensitively discuss an individual's specific needs in relation to their sexual orientation and gender identity, so the impact on person-centred and personalised care can be assessed and responded to.
- ▶ Social care providers should ensure that any published materials use LGB&T-affirmative language and imagery, and that LGB&T-inclusive policies are made clear to all staff and service users.
- ▶ Commissioners of social care should include a requirement in contracts for service providers to monitor sexual orientation and gender identity of service users. Service providers should use this data to better understand and meet LGB&T service users' needs.

8 Social Care Institute for Excellence. Working with LGBT people with Learning Disabilities. Online film, available at <http://www.scie.org.uk/socialcaretv/>

Abbott, D. W. F. and J. Howarth. Secret Loves, Hidden Lives? Exploring issues for people with learning difficulties who are gay, lesbian or bisexual. The Policy Press: 2005.

9 Sexual Minorities in England Have Poorer Health and Worse Health Care Experiences: A National Survey, Marc N. Elliott et al, 2014



Social Care in Excellence: Working with lesbian, gay, bisexual and transgender people videos on Social Care TV

The Social Care Institute for Excellence (SCIE) aims to improve the lives of people who use care services by sharing knowledge about what works. It has produced a series of short films exploring the needs of LGB&T people:

www.scie.org.uk/socialcare/tv/topic.asp?t=workingwithlesbiangaybisexualandtransgenderpeople

Social Care Issues Affecting Older Lesbian, Gay and Bisexual People in the UK: A Policy Brief (2008)

Published by the International Longevity Centre, this brief outlines the evidence of social care issues facing older LGB people:

www.ilcuk.org.uk/files/pdf_pdf_71.pdf

LGBT Sexualities in Social Care Research (2011)

An independent review into LGB&T sexualities in social care research, commissioned by the NIHR School for Social Care Research:

www.lse.ac.uk/lsehealthandsocialcare/pdf/sscr_methods_review_2.pdf

Supporting older Lesbian, Gay, Bisexual & Transgender people: A checklist for Social Care providers

Published by Opening Doors London and Age UK Camden, this guide aims to assist organisations to become LGB&T friendly:

www.stonewall.org.uk/documents/older_lgbt_checklist_for_adult_social_care.pdf

The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people

The National End of Life Care Programme's guide was developed with stakeholders from the LGB&T community and care settings:

www.nhs.uk/resource-search/publications/eolc-rtg-lgbt.aspx#sthash.XcfSIsUB.dpuf

Case study: Personalisation



For most people personalisation means personal budgets, personal individual payments and direct payments. One of the respondents to our survey, which focussed on experiences of health and care services within LGB&T communities, talked of their experience of personal budgets in relation to being the carer of their partner.

Personalisation empowers citizens to take control of their lives, to be supported in ways which make sense to them and those who support them, including their chosen family. Being free to talk about themselves as individuals is at the centre of dismantling some of the remaining inequalities faced by LGB&T people; the idea of being able to openly name and talk about chosen families. Research into LGB&T people's experiences of personal budgets suggests that these budgets can allow LGB&T people to employ appropriate staff to support their specific care needs, and feel confident to disclose their sexual orientation without fear of discrimination. However, this confidence is not always guaranteed as so much depends on the care workers available and their knowledge and experience of LGB&T people.

For one respondent to our survey, having a personal budget for their partner enabled them to hire the care staff they wanted, creating a positive experience for both of them. Although they had rarely experienced homophobia when sourcing care staff, they were confident that this was down to judicious recruitment on their part. The respondent wrote of times when they had needed to use agency staff; in such instances they immediately noticed that the quality of staff varied wildly, and that they were more likely to experience homophobia from staff.

The respondent reflected on the lack of LGB&T awareness within carers groups and the inability of such groups to give practical advice when faced with LGB&T issues. LGB&T people accessing services provided by the LGB&T voluntary and community sector need to be supported to understand the eligibility and assessment process for personal health budgets, and supported to develop their care plans with their chosen provider. This also highlights a need for greater training of non-LGB&T health and care agencies on the specific needs of these communities.

For more information please see the Social Care Institute for Excellence's Personalisation briefing: Working with lesbian, gay, bisexual and transgender people
www.scie.org.uk/publications/ataglance/ataglance42.asp

Domain 2: Delaying and reducing the need for care and support



These measures focus on individuals' access to support and information to help them manage their care needs. When people develop care needs, Domain 2 measures whether the support they receive takes place in the most appropriate setting and enables them to regain their independence.

Most of these measures related to our survey of commissioners and providers of care. This found that the majority were not collecting data for LGB&T service users in relation to the indicators in this domain. Without this data, it is impossible to know whether LGB&T communities are under or over represented in these services, or to understand their experiences and outcomes.

What we do know from research into LGB&T ageing indicates that these communities should be considered as a priority for reducing the need for care and support. Older LGB&T people are less likely to have made plans for care in times of serious illness or in old age compared to peers in the general population.¹⁰ Relatively high proportions of older LGB people live alone compared to heterosexuals.¹¹ Older LGB people are also less likely to have children; less likely to live with children or other family members; and less likely to see their family regularly (less than a quarter of LGB people see their biological family members at least once a week compared to more than half of heterosexual people).¹² Without these links to family that older heterosexual people often rely on, older LGB people are more likely to have a greater need of formal care and support.¹³ Although there is not comparable research in relation to trans people, we would expect similar issues and experiences of isolation and need for formal support.

Successive studies have shown that LGB&T people often have poor experiences of health care (see Domains 1 and 3), for example, discrimination and heteronormativity (the assumption that all people are heterosexual); a lack of LGB&T-friendly environments for care delivery; discomfort disclosing sexual orientation or gender identity to healthcare providers; and actual experience of discrimination and abuse, as well as fears of such treatment (e.g. because of past negative experiences). These can all be major barriers for LGB&T people maintaining contact with health care providers and seeking the health care they need in a timely manner.¹⁴ One recent study even found that some trans respondents would rather end their own life than go into residential care.¹⁵ The result of these barriers risks escalating the individual's care needs so that they are more complex or severe when they do finally access care.

10 Heaphy, B. et al. Ageing in a non-heterosexual context. *Ageing & Society* 24, 2004, 881–902. Withall, L. *Dementia, Transgender and Intersex People: Do service providers really know what their needs are?* Alzheimer's Australia, 2014.

11 Heaphy, B. et al. Ageing in a non-heterosexual context. *Ageing & Society* 24, 2004, p.886. AND Stonewall. *Lesbian, gay and bisexual people in later life*. Stonewall, 2011. p.4

12 Stonewall. *Lesbian, gay and bisexual people in later life*. Stonewall, 2011. pp.4-6

13 Ward, R, et al. 'Don't look back? Improving health and social care service delivery for older LGB users', Equality and Human Rights Commission, 2010, p.9

14 Cartwright, C., M. Hughes, and T. Lienert. End-of-life care for gay, lesbian, bisexual and transgender people, *Culture, Health & Sexuality: An International Journal for Research, Intervention and Care*, 14:5, 2012, p. 539.

15 Withall, L. *Dementia, Transgender and Intersex People: Do service providers really know what their needs are?* Alzheimer's Australia, 2014.

Overarching measures

2A. Permanent admissions to residential and nursing care homes, per 100,000 population

Three quarters of respondents said that the service they provide or commission does not collect data for LGB&T service users in relation to the number of permanent admissions to residential and nursing care homes. Only 12% said this was collected, and a further 12% were unsure. Those respondents who did not collect the data indicated that it was not relevant to the service provided, indicating a lack of understanding of LGB&T inclusion.

Outcome measures

2B. Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement rehabilitation services

Three quarters of respondents said that the service they provide or commission does not collect data for LGB&T service users in relation to the proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into reablement/rehabilitation services. 13% said this was collected, and a further 13% were unsure. Again, the respondents who did not collect this data felt that it was not relevant, indicating a lack of understanding of LGB&T inclusion.

2C. Delayed transfers of care from hospital, and those which are attributable to adult social care

Seven in ten respondents said that the service they provide or commission does not collect data for LGB&T service users in relation to the number of delayed transfers of care from hospital, and those which are attributable to adult social care. A fifth said this was collected, and a further 13% were unsure. No further information was given by respondents in response to this question.

2D. The outcomes of short-term services: sequel to services

Six in ten respondents said that the service they provide or commission does not collect data for LGB&T service users in relation to the effectiveness of short-term services and/or reablement services. Over a quarter (27%) said this was collected, and a further 13% were unsure. No further information was given by respondents in response to this question.

2E. The effectiveness of reablement services (placeholder)

See 2B, above

Recommendations

- ▶ Commissioners of social care should include a requirement in contracts for service providers to monitor sexual orientation and gender identity in service users. Service providers should use this data to better understand and meet LGB&T service users' needs.

2F. Dementia – a measure of the effectiveness of post diagnosis care in sustaining independence and improving quality of life (placeholder)



Nearly three quarters (73%) of respondents said that the service they provide or commission, does not collect data for LGB&T service users with dementia in relation to the effectiveness of post-diagnosis care in sustaining independence and improving quality of life. A fifth said this was collected, and a further 7% were unsure. Respondents who gave further information had not considered monitoring sexual orientation or gender identity in this area.

The survey for LGB&T service users and carers found that nearly six in ten (57%) respondents had knowledge of, or experience of someone with dementia. When asked if receiving social care had sustained their independence and quality of life, or that of the person they care for, 53% said yes, 37% said yes 'to a degree', and 27% said no.

Some respondents provided more detail on their experiences, which were varied. Many said that receiving social care had helped to a degree; some explained that support from family or friends had also a part to play, while others noted that their poor health was the main determinant of their quality of life:

“To a degree, although the independence maintained has been primarily due to the family care.”

“It has done as much as is possible to do that, my health is what has made that difficult.”

Others mentioned general difficulties in accessing social care:

“stopped it due to cost I was paying council was more then they paid for service and could not afford it”

“It is a bit of a minefield trying to get access. I could benefit from a carer but the personal budget has been a blessing”

Some respondents had had negative experiences of social care because it did not meet the specific needs of LGB&T people, fear of coming out, or institutional discrimination:

“felt unable to come out in many situations.”

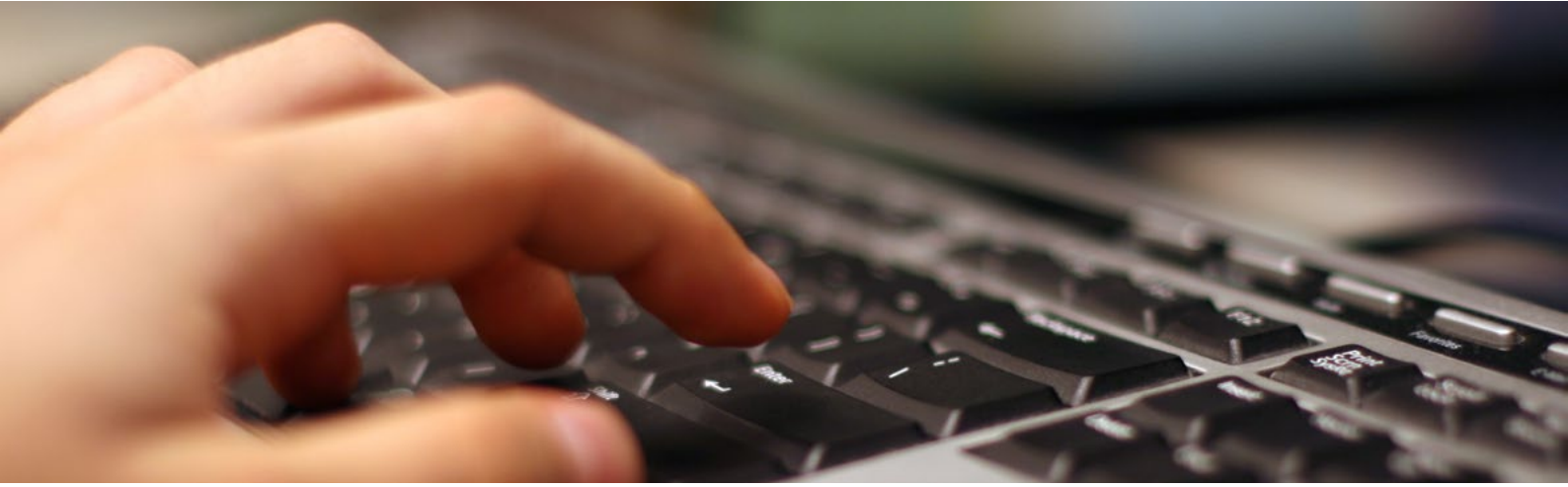
“A friend who I care for occasionally receives only a low level of DLA despite having multiple physical and mental health disabilities. He has support workers for only 6 hours a week (until recently only for 3!) and gets no assistance with the cost of this when he could do with more - and also some financial assistance. For example he lives several hours away from the gender clinic which he has to have support to attend but to do this with his Carer is over £200 and all he can claim back is £30 ish for the fuel! Due to this he cannot have the full gender support he needs.”

“We have been refused [social care] assessments (and yes I know that’s against the law) - that Social Services are institutionally transphobic is nothing special since so many other sections of society are...Every time we have sort direct support we have been blocked - even when we have been told by insiders exactly how to apply and that their is funding available.”

The proportion of respondents reporting no independence or quality of life sustained by social care is concerning. While issues accessing social care may be experienced across the general population, these responses clearly show that LGB&T people are experiencing particular issues in terms of care which does not meet their needs, and in some cases discrimination from services.

Recommendations

- ▶ Commissioners of social care should include a requirement in contracts for service providers to monitor sexual orientation and gender identity of service users. Service providers should use this data to better understand and meet LGB&T service users’ needs.
- ▶ Social care providers should ensure that staff receive training on LGB&T issues and are able to sensitively discuss an individual’s specific needs in relation to their sexual orientation and gender identity, so the impact on person-centred and personalised care can be assessed and responded to.
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www.lse.ac.uk/lsehealthandsocialcare/pdf/sscr_methods_review_2.pdf

The North West Housing Guide for the older lesbian, bisexual, gay and trans community

Stonewall Housing and the Manchester Older LGB&T Housing group produced this guide together to enable older LGB&T people to better understand their housing options:

www.stonewallhousing.org/files/MCRGuide_web.pdf

Building a sense of community: Including older LGBT in the way we develop and deliver housing with care

Stonewall Housing's report outlines ways in which the voices and needs of the older LGB&T communities can be included in the development and provision of inclusive housing with care:

www.housinglin.org.uk/library/Resources/Housing/Support_materials/Viewpoints/HLIN_Viewpoint39_LGBT.pdf

The dementia challenge for LGB&T communities

Paper from a roundtable held by the National Care Forum and the National LGB&T Partnership to discuss improving the experience of LGB&T people who develop dementia and be in need of care and support:

www.nationalcareforum.org.uk/viewNews.asp?news_id=2511

Case study: Befriending Service



Opening Doors London (ODL), with Age UK Camden as the lead agency, and in partnership with Age UKs across London, is the biggest project providing information and support services with and for older LGB&T people in the UK. ODL runs an LGB&T befriending project for older LGB&T men and women who may be more isolated and cut off from society in general and specifically from the LGB&T community.

Living in London can become a lonely experience as people grow older, especially if an individual can't get out and about as they used to. Having someone to spend time with and talk to can make all the difference in how supported a person feels.

The befriending service aims to reduce the stress of loneliness and isolation, increase people's confidence, and enable members to maintain their independence. The service matches a volunteer with an older person, for regular social contact. This could be to come along with them to social groups and community activities, go to exhibitions or events, or to visit them for a cup of tea and a chat.

The service has helped older LGB&T people in London to become more aware of a range of issues that affect their lives, including financial, psychological and practical issues so appropriate referrals and support can be offered.

The service also enables older LGB&T people to reduce their feelings of isolation and focus on positive aspects of living a full life, and to ensure that they are not alone.

In an evaluation of the work of Opening Doors London:

- ▶ 49% of people who engaged with the service felt it had helped them to retain their independence.
- ▶ 70% said it had benefitted their physical and mental health
- ▶ 81% said they felt more connected to the LGB&T community because of their involvement with ODL
- ▶ 73% said that they felt more comfortable attending ODL group than mainstream services

For more information, please see www.openingdoorslondon.org.uk

Domain 3: Ensuring that people have a positive experience of care and support



These measures focus on ensuring that people have a positive experience of care and support, including that those involved in making decisions on social care respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual.

Research has shown that many LGB&T people, especially those who are ageing, fear the prospect of using generic mainstream care services where engaging in activities that are associated with LGB&T identity are not perceived to be possible.¹⁶

Being LGB&T profoundly matters in the delivery of care and support services. Health and social care policy and practice is often underpinned, albeit unwittingly, by cisgender, heteronormative attitudes and behaviours (the assumption that all people are heterosexual and identify with the gender they were assigned at birth). Our survey of LGB&T individuals in receipt of social care and their carers provides the largest overview of LGB&T experiences in the country, with 251 respondents, and gives a useful insight for the Domain 3 measures.

¹⁶ Browne, K., L. Bakshi and J. Lim. "Ageing in Gay Brighton." Lesbian, Gay, Bisexual and Transgender Ageing: Biographical Approaches for Inclusive Care and Support: 2012:165.

Outcome measure

People who use social care and their carers are satisfied with their experiences of care and support services.

3A. Overall satisfaction of people who use services with their care and support.

3B. Overall satisfaction of carers with social services.

3E. Improving people's experiences of integrated care.



Our survey of LGB&T service users and carers found that 41% knew people in permanent residential or nursing care. A quarter of these said that the care and support provided in these settings had been poor. Research conducted with LGB&T people about the prospect of accessing social care indicates that many are reluctant to rely on care services for fear of having to 'go back into the closet', or experiencing stigma and discrimination.¹⁷ Little has been published however about the experiences of LGB&T people in care settings. Our survey of LGB&T people and their carers represents the largest overview of LGB&T experiences of social care to date, with over 250 respondents. A third of those who had used care and support services rated the care received as poor. If LGB&T people and their carers are not confident or comfortable to be out about their sexual orientation or gender identity in services, there is a significant risk that services fail to provide adequate services and address specific needs.¹⁸ Indeed, some respondents described care and support that was "appalling" and in many instances "patchy":

"They have had to go back in the closet! Staff do not acknowledge any sexual orientation other than heterosexual and are uncomfortable thinking/talking about it."

"Just a brief visit to my Great Aunt, she was sat in day room where everyone was sat around the edges of the room. She wasn't even in her own clothes and was in a colour she would never wear."

"Care workers were homophobic."

17 Ward, R., I. Rivers and M. Sutherland (eds) "Lesbian, gay, bisexual and transgender ageing: Biographical approaches for inclusive care and support. Jessica Kingsley Publishers, 2012.

18 Stein, G. L., N.L. Beckerman and P.A. Sherman. "Lesbian and gay elders and long-term care: Identifying the unique psychosocial perspectives and challenges." *Journal of Gerontological Social Work*, 53(5), 421-435, 2010.

For those that did report satisfaction with the services, it was tempered with comments about managing the care themselves. Those who were able to appoint their own staff on the whole reported being satisfied with the service:

“Hiring our own staff was a very positive experience but when we used agency staff the quality varied wildly very rarely we experienced homophobia but judicious recruitment helped with this.”

When asked about whether they were satisfied with the care and support received, only 13% said they were satisfied, with 33% describing the care as poor and a further 35% describing it as mixed. This is reflected in some of the comments:

“Very variable I was the gay one as they called me. The women assumed I fancied all the men and were disrespectful or abusive.”

“The mental health services I used were fragmented, confused and not focused on prevention or self management. A lot of the time it was left up to me or my friends to do anything beyond the clinical basics. Social workers in [Community Mental Health Team] seemed confused about their social support role.”



Recommendations

- ▶ Social care providers should ensure that staff receive training on LGB&T issues and are able to sensitively discuss an individual's specific needs in relation to their sexual orientation and gender identity, so the impact on person-centred and personalised care can be assessed and responded to.
- ▶ Social care providers should ensure that any published materials use LGB&T-affirmative language and imagery, and that LGB&T-inclusive policies are made clear to all staff and service users.
- ▶ The Care Quality Commission should consider whether service providers are LGB&T inclusive when assessing services, and monitor sexual orientation and gender identity when gathering service user and carer feedback to assess whether minimum standards of care are being met for LGB&T people.
- ▶ Commissioners of social care should include a requirement in contracts for service providers to monitor sexual orientation and gender identity of service users. Service providers should use this data to better understand and meet LGB&T service users' needs.

Outcome measures

Carers feel that they are respected as equal partners throughout the care process

3C. The proportion of carers who report that they have been included or consulted in discussions about the person they care for.

Although nearly a quarter (23%) of carers said they were satisfied with care and support services, two fifths reported being unsatisfied with them. 64% said there was too much red tape. Research suggests that the experience of caring is shaped by the heteronormative nature of social relations, not only for those being cared for but for LGB&T carers.¹⁹ Often heterosexuality is prioritised in normal daily living, both implicitly and explicitly, and LGB&T carers and those receiving care have to fit their experiences into a framework based on heterosexuality as the default position. This is reflected in comments made in the survey:

“There has been a distinct lack of true understanding of my ftm [female-to-male] son's needs and have had poor support on the whole”

“There seems to be such a bureaucratic barrier between what the person being cared for needs, and what you can get.”

Two fifths of carers reported that they were included in discussions about the care of the person they were caring for, although notably, 59% of those said that they didn't feel that they were listened to:

“We have been invited to meetings and discussions but have felt many times that we have not been heard.”

“consulted?? there has never been any consultation ever with me about what happened to the friends I have cared for, neither has there views been taken into account, its take what your given and shut up”

As in wider society, services are often framed in a way that assumes heterosexuality and cisgender status (the assumption that all people are heterosexual and identify with the gender they were assigned at birth), meaning the needs of these groups are prioritised. LGB&T people are often required to come out about their sexual orientation and/or gender identity repeatedly to service providers in order to make their needs known. The decision to come out can be problematic, especially if LGB&T people are unsure how their disclosure will be responded to, and sometimes they may decide not to disclose:

“it is difficult to be open about family circumstances and it is a pain having to ‘come out’ or make a decision whether to ‘come out’ constantly.”

Recommendations

- ▶ Social care providers should ensure that staff receive training on LGB&T issues and are able to sensitively discuss an individual's specific needs in relation to their sexual orientation and gender identity, so the impact on person-centred and personalised care can be assessed and responded to. This should include the concept of families of choice, and recognition that LGB&T communities are diverse.
- ▶ Social care providers should ensure that any published materials use LGB&T-affirmative language and imagery, and that LGB&T-inclusive policies are made clear to all staff and service users.

19 Cronin, A., and A. King. “A queer kind of care: Some preliminary notes and observations.” *LGBT Issues: Looking Beyond Categories. Policy and Practice in Health and Social Care Series*, 10 (6). 2010.

People know what choices are available to them locally, what they are entitled to, and who to contact when they need help.

3D. The proportion of people who use services and their carers who find it easy to find information about support.

Only 14% of respondents found it easy to find information about support, whereas three quarters said they had not found it easy. Research has highlighted that services need to consider not only how they look on the 'inside' but from the 'outside' for potential users, and provide easy access to information that is relevant and appropriate.²⁰ Best practice would include LGB&T-affirmative language and imagery in service promotion (e.g. using words such as partner instead of husband/wife, and including same-sex couples in imagery) to reassure LGB&T people that the service is welcoming. Services should also be aware of and signpost to specialist support provided by the LGB&T voluntary and community sector.

"This was the worst part for both my experience of someone with dementia and my own experience of mental health services. LA and NHS staff had no idea about alternative, community based or specialist support (LGBT mental health or peer support for self harm in my case)"

"No not at all!"

Some respondents reported using the internet as a source of reliable information on what support was available:

"In a lot of cases, we found information ourselves online when necessary."

"The web is our friend, it is only via the web that I find out about anything except occasionally when as part of my activism I know get to know someone on the inside and get told about stuff along the way"

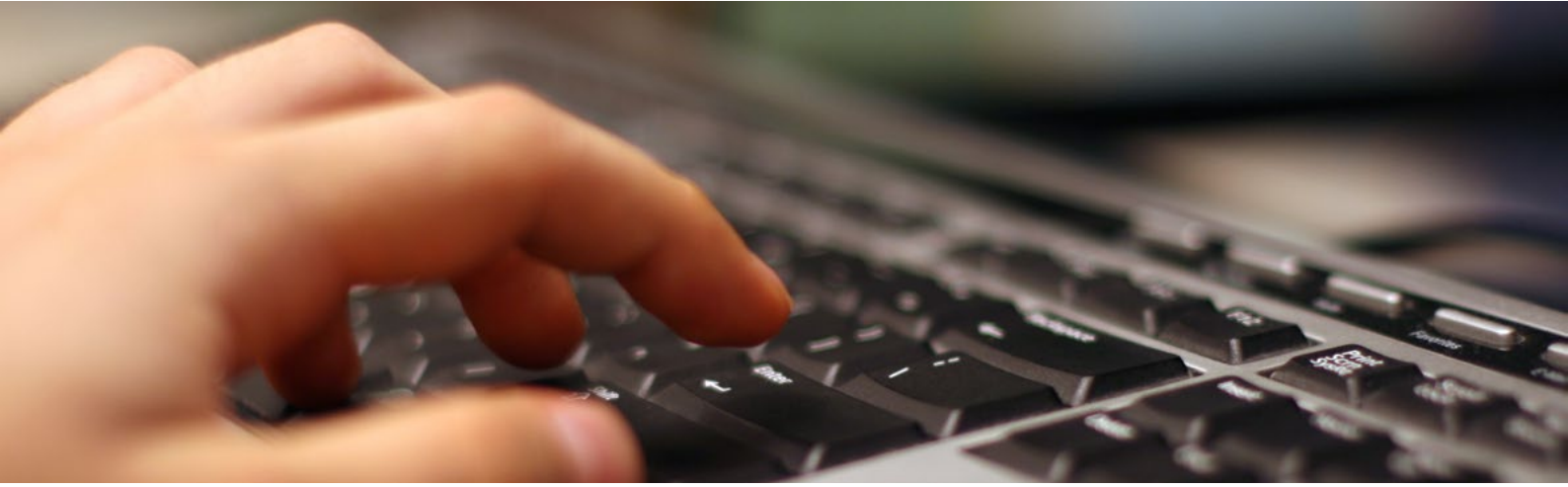
Recommendations

- ▶ Social care providers should ensure that any published materials use LGB&T-affirmative language and imagery, and that LGB&T-inclusive policies are made clear to all staff and service users.
- ▶ Social care providers and local authorities should ensure that information about services is readily available, and work with the LGB&T voluntary and community sector to promote this information to the LGB&T community.

People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual.

(This information can be taken from the Adult Social Care Survey and used for analysis at the local level) See 3C above.

²⁰ Ward, R., I. Rivers and M. Sutherland (eds) "Lesbian, gay, bisexual and transgender ageing: Biographical approaches for inclusive care and support. Jessica Kingsley Publishers, 2012.



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www.scie.org.uk/socialcaretv/topic.asp?t=workingwithlesbiangaybisexualandtransgenderpeople

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www.ilcuk.org.uk/files/pdf_pdf_71.pdf

LGBT Sexualities in Social Care Research (2011)

An independent review into LGB&T sexualities in social care research, commissioned by the NIHR School for Social Care Research:

www.lse.ac.uk/lsehealthandsocialcare/pdf/sscr_methods_review_2.pdf

Supporting older Lesbian, Gay, Bisexual & Transgender people: A checklist for Social Care providers

Published by Opening Doors London and Age UK Camden, this guide aims to assist organisations to become LGB&T friendly:

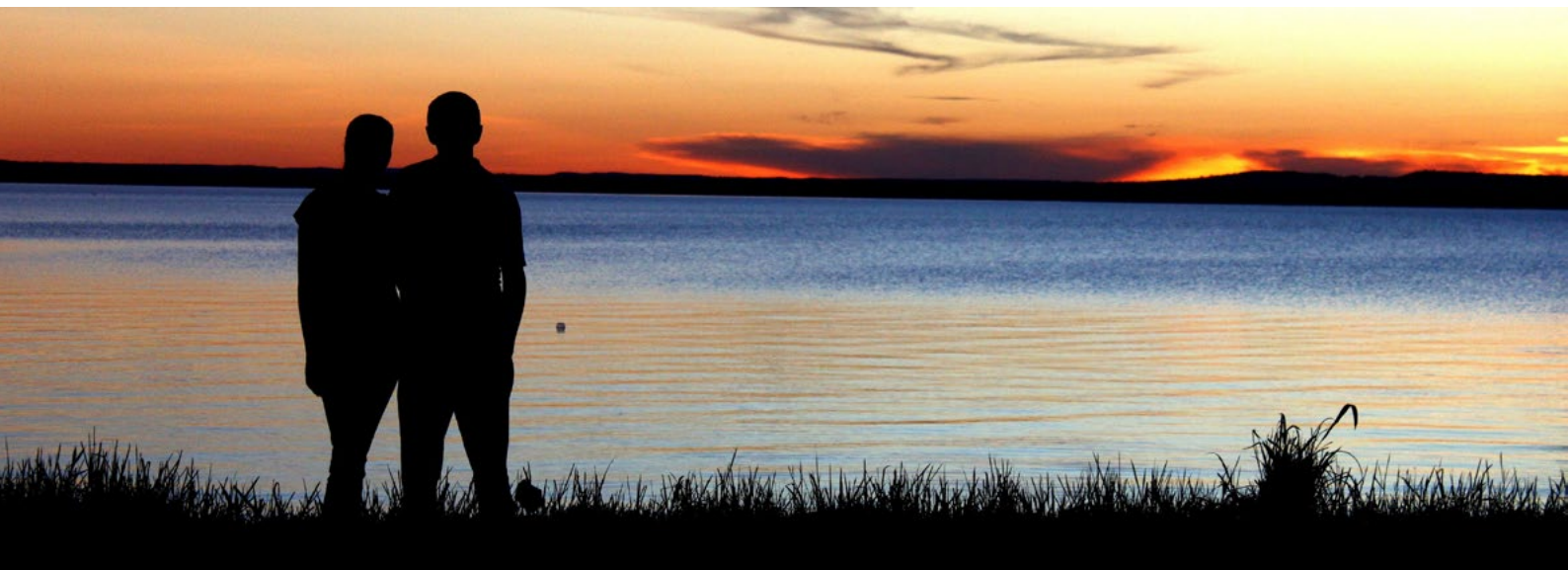
www.stonewall.org.uk/documents/older_lgbt_checklist_for_adult_social_care.pdf

The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people

The National End of Life Care Programme's guide was developed with stakeholders from the LGB&T community and care settings:

www.nhs.uk/resource-search/publications/eolc-rtg-lgbt.aspx#sthash.XcfSIsUB.dpuf

Case study: Multi agency working



Stonewall Housing is the specialist LGB&T housing advice and support provider in England. It provides housing support for LGB&T people in their own homes, supported housing for young LGB&T people, as well as free, confidential housing advice for LGB&T people of all ages. Stonewall Housing led a multi-agency approach with other providers to ensure that a trans service user was given the tailored support she needed.

CC is 54 and identifies as a male-to-female trans woman. She has spent most of her adult life living in a supported environment either independently or in a group setting, always with carers employed to assist her. When CC began to identify as a trans woman, her carers were made aware of this but nothing was put in place to assist her in her transition. Her carers didn't understand the importance of using CC's chosen pronouns or of wearing the clothes of her own choice. Consequently, CC didn't feel able to express her gender identity fully and this was having a negative impact on her health and wellbeing. She became uncomfortable to discuss or disclose her gender identity.

Stonewall Housing was commissioned to provide specific support to CC around her transition needs, outside her already existing service provision. Because of her experiences early on in her transition, CC didn't feel able to ask her carers to go with her to purchase and identify items related to her transition, so support workers from Stonewall Housing were able to provide this.

Stonewall Housing worked with CC to encourage her other providers to use her chosen pronouns and to discuss with Stonewall Housing any of their concerns about her transition and the process of transitioning.

It became clear very quickly that a multi-agency approach was needed, as it was much better for CC if all the agencies involved in her care spoke to each other and knew what was happening. Multi agency work means that all services providing support to CC are kept informed of all areas of her daily living and health and care needs. As specialists in LGB&T issues, Stonewall Housing is also able to act as advocates with other providers when needed. This approach means that CC is given the support from all the services that she needs to sustain her independence and engage successfully with issues around her transition. CC is now supported in a holistic way, which has improved her wellbeing

CC now lives in independent living accommodation and has carers who assist with her personal care and tenancy sustainment. Recently CC discovered that she has a progressive degenerative disease, which has been very distressing for her. The multi-agency approach means that all services are working together to support CC and are all involved in her care.

Domain 4: Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm



These measures focus on whether people feel safe, and keep free from avoidable harm, abuse, harassment and neglect. Domain 4 also provides measures to ensure that people are supported to plan ahead.

LGB&T people often experience discrimination and marginalisation that can make them more vulnerable in care settings. A history of homophobia, biphobia and transphobia in everyday life and in public service settings can mean that older LGB&T people and gay and bisexual men living with HIV are afraid to come out to care home staff or other residents due to a fear of discrimination.²¹ This results in their particular needs not being acknowledged, and may also make them more vulnerable to poor care or discriminatory treatment if they are afraid to complain.

The findings from our survey of commissioners and providers of care found that the majority were not collecting data for LGB&T service users in relation to the indicators in this domain. Without this data, it is impossible to know whether the needs of LGB&T communities are considered in care services, or to understand their experiences and outcomes.

21 Cartwright, C., M. Hughes, and T. Lienert. End-of-life care for gay, lesbian, bisexual and transgender people, *Culture, Health & Sexuality: An International Journal for Research, Intervention and Care*, 14:5, 2012, p. 539.

Overarching measure

4A. The proportion of people who use services who feel safe

Outcome measures

Everyone enjoys physical safety and feels secure.

People are free from physical and emotional abuse, harassment, neglect and self-harm.

People are protected as far as possible from avoidable harm, disease and injuries.

People are supported to plan ahead and have the freedom to manage risks the way that they wish.



The survey for LGB&T service users and carers found that half of respondents said being LGB&T affected the care and support they received. A third felt that it hadn't, but many respondents noted that they were not out in services about their sexual orientation or gender identity.

Over a third (35%) of respondents said that as a user of care and support services they did not feel safe and secure. A further 14% said they did not always feel safe and secure.

Six in ten respondents said that they did not feel supported to plan ahead for their care and manage any potential risks, and a further 29% said that this was limited.

Research into older LGB&T people's needs indicates that many are fearful of going into care and having to 'go back into the closet' after having lived a considerable period of their lives openly.²² Older trans people in particular are concerned that their gender presentation may not be respected in a care environment, especially if they lose mental capacity due to dementia or Alzheimer's.²³

While society is becoming more tolerant, discriminatory attitudes towards LGB&T people persist. Few care homes have specific policies about LGB&T inclusion.²⁴ A review of social care service delivery for older LGB people found that in residential care settings, the sexual expression of residents is

22 Hinchliff, A. A report of the Older LGBT network into the specific needs of older lesbian, gay, bisexual and trans people. Age Concern Cymru and Help the Aged in Wales. http://www.openingdoorslondon.org.uk/resources/Age_Concern_Cymru_Older_LGBT_Network_report_2009.pdf

23 Withall, L. Dementia, Transgender and Intersex People: Do service providers really know what their needs are? Alzheimer's Australia, 2014.

24 Guasp, A. Lesbian, gay and bisexual people in later life. Stonewall, 2011. http://www.stonewall.org.uk/documents/lgb_in_later_life_final.pdf

commonly problematized, meaning LGB individuals may be particularly vulnerable to discriminatory treatment. Furthermore, the review found evidence of the inappropriate use of safeguarding procedures in response to LGB residents entering into relationships, as well as disapproval of same-sex partners staying with service users overnight in residential care.²⁵

Self-harm and suicide ideation is around twice as common in LGB&T communities due to minority stress, influenced by the assumption of cisgender status and heterosexuality (the assumption that all people are heterosexual and identify with the gender they were assigned at birth).²⁶ Further studies have shown that bisexual people and trans people may be at even greater risk.²⁷

Around 1 in 20 gay and bisexual men nationally are living with HIV.²⁸ Immuno-compromised men are at higher risk of infection, which needs to be accounted for by providers.

Older LGB&T people are less likely to have made plans for care in times of serious illness or in old age compared to peers in the general population.²⁹ This should be taken into account when supporting people to plan for their care and to manage risks. Care workers should be willing to consider LGB&T people's particular needs and requests around involvement or not of biological family and family of choice (LGB&T people often form families of choice comprising friends and current or former partners, who provide support similar to traditional families and may take on a caring role).

4B. The proportion of people who use services who say that those services have made them feel safe and secure

See 4A above.

4C. Proportion of completed safeguarding referrals where people report they feel safe (placeholder)

In our survey of commissioners and providers of care, 47% of respondents said that the service they provide or commission does not collect data for LGB&T service users in relation to this indicator. 40% said that this data was collected and 13% were unsure. Respondents gave little further information in response to this question, indicating a lack of understanding of LGB&T inclusion.

Recommendations

- ▶ Social care providers should ensure that staff receive training on LGB&T issues and are able to sensitively discuss an individual's specific needs in relation to their sexual orientation and gender identity, so the impact on person-centred and personalised care can be assessed and responded to.
- ▶ Social care providers should ensure that any published materials use LGB&T-affirmative language and imagery, and that LGB&T-inclusive policies are made clear to all staff and service users.
- ▶ Safeguarding boards should ensure that representatives receive training on LGB&T issues and are able to identify and respond to relevant issues locally.
- ▶ Commissioners of social care should include a requirement in contracts for service providers to monitor sexual orientation and gender identity of service users. Service providers should use this data to better understand and meet LGB&T service users' needs.

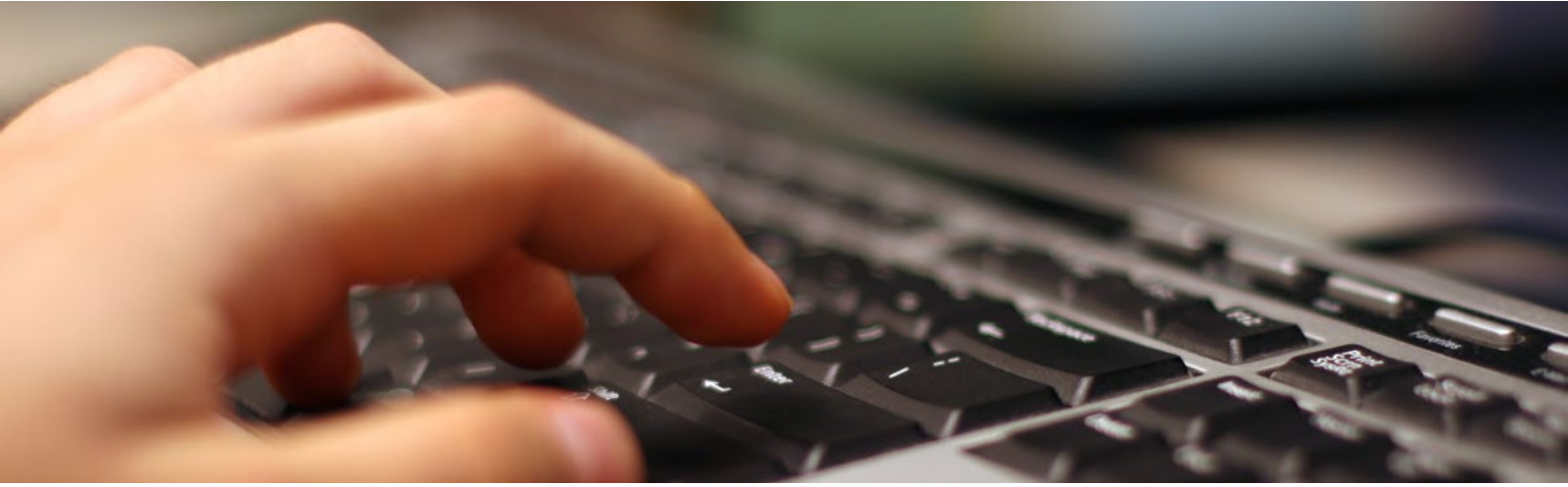
25 Ward, R., Pugh, S. and Price, E. "Don't look back? Improving health and social care service delivery for older LGB users", Equality and Human Rights Commission, 2010.

26 <http://www.tandfonline.com/doi/abs/10.1080/00918369.2011.534038>

27 McNeil, J, et al. 'Trans Mental Health Study 2012', Scottish Transgender Alliance, 2012. http://www.scottishtrans.org/Uploads/Resources/trans_mh_study.pdf. M. Barker et al. The Bisexuality Report. Open University: 2012.

28 NAT. Gay & bisexual men and HIV (online factsheet) <http://www.nat.org.uk/gb.aspx>

29 Heaphy, B. et al. Ageing in a non-heterosexual context. Ageing & Society 24, 2004, 881–902. Withall, L. Dementia, Transgender and Intersex People: Do service providers really know what their needs are? Alzheimer's Australia, 2014.



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Families and Social Care LGBT support Toolkit

Kent County Council's toolkit aims to help promote and embed good practice when working with LGB&T people:

www.kent.gov.uk/_data/assets/pdf_file/0005/18068/LGBT-toolkit.pdf



Gay Advice Darlington/Durham (GADD) worked with a care home in rural Durham to support the particular needs of a trans service user with dementia.

Sue is a male-to-female trans woman who transitioned in the late 1970s. She completed gender reassignment surgery in 1982 at the age of 42. At the age of 59 she was diagnosed with an Alzheimer's variant and managed to cope with the condition by herself for a number of years, but was eventually in need of 24 hour care and went into a care home.

Sue's medical history was known to her GP but not to the care home. Sue had no contact with family, as they had rejected her at the time of her transition. As her condition progressed, Sue experienced confusion about her gender identity. The care home management became increasingly worried as Sue began to refer to herself as 'Cliff' for periods of time, and was distressed by her appearance and physicality during these episodes. These episodes became more frequent and the care home was at a loss as to how to cope with the situation.

A social worker at the care home contacted GADD for advice. GADD formed a partnership group between the local authority social services, Sue's GP, the care home and GADD. This approach allowed all agencies to share knowledge and skills to develop a care plan that reinforced Sue's identity and sense of self using memory books and personal sense of gender. The care home staff received awareness training on trans identities, including the impact of stigma and misgendering, especially during the episodes of regression. This enabled them to offer appropriate care and support to Sue.

Although sadly Sue's condition continued to deteriorate, the agencies working with her now had a better understanding of the specific issues she was facing and delivered more empathic care, which significantly improved her wellbeing and quality of life. Healthcare staff at each agency had developed their knowledge and skills around LGB&T people's needs, which will improve their future work and care provision for other LGB&T service users.

Further information

For further information on this companion document, and support in implementing the recommendations, please contact the National LGB&T Partnership:

LGBTpartnership@lgbt.foundation

www.nationallgbtpartnership.org