



The LGBT Health and Inclusion Project

LGBT Carer's Consultation in Brighton & Hove



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Brighton and Hove NHS Clinical Commissioning Group (BH CCG) and Brighton and Hove City Council (BHCC) have commissioned the LGBT Health and Inclusion Project at Brighton and Hove LGBT Switchboard to conduct a series of consultation and engagement activities with local lesbian, gay, bisexual and trans people (LGBT) people. The aim is to use the information gathered to feed into local service commissioning, planning and delivery.

Please note, the following report presents information about the consultation and engagement work conducted by LGBT HIP, and should not be taken as a position statement of Brighton and Hove LGBT Switchboard or of any participating organisation.

Introduction

LGBT HIP is a mechanism for engagement with the LGBT communities of Brighton and Hove. Discussion with commissioners indicated that there were perceived to be constituencies within those communities who were seldom heard and who were understood to find consultation and engagement activities less accessible than other groups. LGBT HIP sought to undertake activities to address this exclusion and to engage with those groups. One such group was LGBT carers.

A legacy of homophobia and discrimination can act in subtle ways to make it difficult to access services to support caring. As one older gay man involved in the set-up of a support group for LGBT carers described.

*"As older gay men and lesbian women we bring with us to this task of caring a significant amount of baggage from a previous age. The men remember all too clearly being 'illegal' and being victims of police harassment. The women similarly know about that kind of society and also one where people hardly believed that lesbians actually existed. All of us have a past knowledge of beatings, murders and discrimination in the workplace and, over the years, we have consequently learned to build protective walls around our lives making us relatively anonymous and giving us the maximum possible feeling of safety. But should the time come when we are suffering from a life-threatening disease, have a requirement of long-term healthcare, have the need to get help from social services, and possibly require residential care, then all those carefully constructed defences are immediately at risk (p. 266)."*¹

The views and experiences of LGBT carers have only recently received policy attention.² One study, found that LGBT carers were often absent in data collection and monitoring, encountered heterosexist responses and hetero-normative assumptions from health and social care professionals and that there were issues in distinguishing the needs of LGB and transgender carers.³

It is part of the mission of LGBT HIP to work collaboratively with partner organisations when appropriate in its consultation and engagement work. The Carer's Centre in Brighton and Hove has operated since 1988 and has expert knowledge of the needs of carers in the city. It seeks:

¹ Newman, R. (2005) Partners in care: Being equally different: lesbian and gay carers. *Psychiatric Bulletin* 29:266-267.

² Willis, P., Ward, N. and Fish, J. (2011) Searching for LGBT Carers: Mapping a Research Agenda in Social Work and Social Care. *British Journal of Social Work*, 41(7):1304-1320.

³ *Ibid.*

“To make a positive difference to the lives of carers by encouraging a wider recognition of their caring role; enabling them to fulfil their own needs as individuals and offering them appropriate support.”⁴

The charity offers a range of services including information, support, outreach and advocacy. It has recognised the need to respond to LGBT carers with different initiatives during recent years, with LGBT drop-in sessions and groups. However, the uptake of these was variable and the Information and Development Worker indicated that the timing was right to consult with LGBT carers about needs and future activities.

Method

The Carer’s Centre and LGBT HIP worked collaboratively to organise an LGBT carers lunch in November 2013 to discuss with LGBT carers their needs and views about specific initiatives. This was felt to be an approach that would enable LGBT carers to express their views in a relaxed and welcoming environment. The local charity Lunch Positive was commissioned to provide the food, and LGBT HIP in partnership with the Carer’s Centre led an open discussion about needs and experiences. In addition, the meeting had a brief presentation by BHCC Carer’s Development Manager, Adult Social Care about the services available from BHCC. In total, six local LGBT carers attended. The LGBT HIP Coordinator took notes from the session.

Finding:

We did not ask participants to complete demographic or evaluation forms in keeping with the intention for a relaxed and informal event. Insofar as it is possible to report, it appeared that one woman and five men attended with an approximate age distribution of 20s to 70’s.

Here we present a brief summary of the key issues and topics that emerged from the discussion.

- A key difficulty appeared to be that of coping with the bureaucracy of being a carer: completing necessary forms for benefits, accessing services and where necessary, managing the affairs of the person cared for. There was extensive discussion about this and it appeared to be a significant problem. For example, one participant made reference to a detailed form that he had completed that was 40 pages in length.
- Related to this were issues of access to benefits. The benefits system was described in terms suggesting that it was complex, impenetrable, inaccessible, slow to respond and difficult to get help with.
- There was also frustration expressed with the move to using online mechanisms to access services and benefits. Participants explained the ways in which this excluded them and the confusion and stress that this caused.
- In a related point, participants spoke of a kind of ‘information overload’. Upon taking on caring responsibilities, some spoke of the ways in which agencies and services had given them information but there was often a great deal of this and a lot of knowledge to assimilate. This often felt overwhelming.
- Participants also spoke of the need for respite care but explained that it could be difficult to access and there were sometimes concerns about leaving their partners or relatives in the care of others. This appeared to stem from a sense of personal responsibility and also, where the person being cared for was LGBT, worries that the care provided would not be LGBT aware and respectful.
- Similarly, where there was a need for help with care in the home, some participants were concerned about whether this would be appropriate. For example, where help was needed with maintaining personal hygiene, would this be respectful of the person’s dignity and wishes (for example, a gay man may not be comfortable receiving intimate care from a woman)?
- Some of the older participants spoke of the difficulties in maintaining the care role to the standard that they wanted when they themselves had health needs or other issues confronting them.

The presentation from BHCC Carer’s Development Manager outlined how the Council’s existing services may be helpful in addressing some of the concerns raised. This included:

⁴ The Carer’s Centre. Vision and mission. <http://bit.ly/1kfUIwp> [accessed 28th February 2014].

- Undertaking carer's assessments, which could be done at any time and reviewed annually. This would examine issues such as the support needed for the carer's role, maintaining a life outside of caring and issues of health, employment, housing and leisure.
- Access to the Carer's Grant, which was a ring-fenced fund that carers could apply to on an individual basis.
- A carer's emergency back-up scheme, whereby carers could register a plan of action to be followed if they themselves became ill or otherwise unable to provide care. This also included a free one-month trial of the CareLink Plus Telecare Alarm Service.⁵
- Carer's weekend breaks to enable carers to have some rest and relaxation in the company of other carers in similar circumstances.
- Access to relaxation sessions for carers, including links with the Buddhist Centre, which included drop-ins and mindfulness courses, with alternative care arranged to enable carers to attend.
- Access to a carer's card, which provided discounted access to BHCC leisure and well-being services.

The Information and Development Worker at the Carer's Centre was also able to detail the services provided by the Carer's Centre that could also assist. This included:

- Advice and information.
- Advocacy and individual support.
- Group meetings and social activities.
- Sign-posting to other organisations.

Participants expressed that information about these services and initiatives was helpful and that it would be beneficial if more could be done to make these initiatives more widely known about among carers.

The LGBT HIP Coordinator was keen to explore whether a specific LGBT Carer's group would be a useful intervention that might be recommended. The feedback indicated that a regular group would be welcomed, with consultation with member needed regarding frequency. It was advised that this should be set up in a way that made it feel like a 'treat' for carers; something fun, engaging and social that carers would enjoy attending. However, it was also important to have expert workers available who may be able to advise on issues in an informal way and sign-post to sources of support, information and advice.

Conclusions

This brief consultation exercise was useful in exploring with a group of carers their experiences and concerns. However, it is important to acknowledge that the number of participants was small and there may be important perspectives missing. Not least the experiences of parents of children with special needs, which was not a focus of this work.

However, we were able to capture some important information about the experiences of local LGBT carers. The main conclusion was that many of the difficulties and issues that they faced might perhaps be experienced by any group of carers: the barriers of bureaucracy, an inaccessible benefits system, information overload, difficulties accessing respite care etc. However, there was an additional concern that when accessing support, advice or services, this should be LGBT aware and able to respond to the concerns that carers (and their partners where relevant) had as LGBT people. Writing in 2005, a gay man who detailed his experiences of caring for his partner with Alzheimer's disease wrote the following, his words continue to remain relevant.

*"There remains a deep need within the health and social service sector, and indeed in the residential home sector, to learn more about us as 'gay' people, to learn how to empathise so that we feel safe to talk about our relationships and our needs, and to encourage us to request help without feeling threatened (p.267)."*⁶

⁵ See the following link for further details about the CareLink Plus Telecare Alarm Services. <http://bit.ly/NCozAT>

⁶ Newman, R. (2005) Partners in care: Being equally different: lesbian and gay carers. Psychiatric Bulletin 29:266-267.

Government policy currently promotes what is known as the 'personalisation agenda'.⁷ This policy context offers a significant 'driver' to respond to these concerns. In a helpful briefing from the Social Care Institute for Excellence on the implications for LGBT people of personalisation, it is defined as follows:

*"Personalisation means recognising people as individuals who have strengths and preferences and putting them at the centre of their own care and support (p.6)."*⁸

The aspirations of personalisation are important because they aim to put recipients of care at the heart of service provision and support, and this includes attending to issues of sexuality and gender identity. Significantly, the principles of personalisation apply equally to services **for** carers when performing their caring roles.

Both the Council and the Carer's Centre have important initiatives already in place that would address many of the concerns raised by LGBT carers taking part in this exercise. There would appear to be two challenges: 1) making LGBT carers aware of the services available, 2) providing the reassurance that those services will be accessible and culturally competent to respond to their needs as LGBT carers.

Recommendations

The SCIE briefing usefully identifies a set of key messages. These have been reproduced here as potentially informing a set of principles that should govern initiatives and activities for LGBT carers in the city.

Social Care Institute for Excellence Personalisation briefing: Implications for lesbian, gay, bisexual and transgendered (LGBT) people - Key Messages

- LGBT people are increasingly likely to become more confident and visible as people who use services and carers, so care and support services need to be ready to welcome them.
- LGBT people need to be able to choose services that are supportive, safe and culturally appropriate for them in both community and residential settings.
- LGBT people are more likely to come out to staff if they feel comfortable and safe to do so. Training for non-judgemental, relationship-based working is key.
- Sexual orientation and gender identity are just aspects of who people are and LGBT people have many other facets to their identity such as disability, race, faith and age.
- LGBT people need to have accessible, sensitive mainstream services as well as the opportunity to get support from specialist services.
- Commissioning for personalisation means nurturing the type of peer support, community and voluntary activity that happens in LGBT communities.
- Commissioners, providers and practitioners should treat every individual with dignity and respect.⁹

In addition, we suggest the following specific recommendations to meet the needs of the LGBT carers in the city who do such vitally important work, and who might gain so much from the valuable services and initiatives available.

For the Carer's Centre:

- The Carer's Centre to continue its programme of work in reaching out and making its services accessible to LGBT carers in Brighton and Hove. This should include continuing to have a visible presence at LGBT community events (LGBT Pride, Trans Pride, World AIDS Day etc.) as well as other community events where LGBT carers might be reached.

⁷ Department of Health (2010) A Vision for Adult Social Care: Capable Communities and Active Citizens. <http://bit.ly/1hpMXRw> [accessed 28th February 2014].

⁸ Social Care Institute for Excellence (2011) Personalisation briefing: Implications for lesbian, gay, bisexual and transgendered (LGBT) people. <http://bit.ly/LoSsnp> [accessed 28th February 2014].

⁹ *Ibid.*

- To liaise with the recently elected LGBT representatives of Community Works on activities to develop a high profile among the LGBT and HIV services and projects in the city.
- To develop the proposed LGBT Carer's meetings and to consult and involve participants on their future development.

For BHCC's Adult Social Care Team:

- To continue to work collaboratively with the Carer's Centre to promote its activities and services for carers to LGBT carers.
- To produce a summary of its services and initiatives for carers to be specifically targeted and marketed to LGBT audiences.
- To monitor uptake by LGBT people of the services provided for carers and to publish an annual statement on this.
- To consult with LGBT service users about the accessibility and acceptability of services provided by BHCC for carers and include this in the annual statement.

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