Sexual Orientation and Mental Health: Understanding the relevance of sexual orientation in the planning and delivery of care.

A multi-agency seminar

Monday 3rd October 2011
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Sexual Orientation and Mental Health: Understanding the relevance of sexual orientation in the planning and delivery of care.

The aim of the seminar was to raise awareness of the importance of recording sexual orientation identity and responding appropriately to the needs of lesbian, gay, and bisexual service users. As well as presentations, there were stands provided by a number of organisations presenting opportunities for networking and to obtain further information about services and training (see Appendix 2).

This seminar was organised by a working group comprised of:

Carol Harrison Read, Sector Manager, CNWL Adult Mental Health Services in Harrow
Dominic Joannou, Community Development Worker, CNWL Mental Health Services in Harrow
Alison Devlin, Trust-wide Equalities and Diversity Co-ordinator, CNWL
Oliver Davidge-Stringer, LGBT Outreach Worker, Harrow CAB
Lorraine de la Hoyde, Acting Manager, Family Action Marlborough Hill
Mohammed Ilyas, Corporate Policy Officer for E&D, Harrow Council
Mark Gillham, Chief Executive, MIND in Harrow
Helen Taylor, Outreach Health Worker, CNWL Older Adults Mental Health Services in Harrow.
Sue Bruno, Advocate, Loud and Clear Advocacy

The seminar was chaired by Alison Devlin, Equalities and Diversity Co-ordinator, CNWL.

Opening remarks
The Conference was opened by three presentations given by:
• Bill Stephenson, Leader of Harrow Council
• Tom Whiting, Assistant Chief Executive, Harrow Council
• Robyn Doran, Director of Operations and Partnerships CNWL

Bill Stephenson drew attention to the fact that 1 in 4 people will be affected by mental health problems. He stressed the importance of mental health services and that mental was one of Harrow Councils top priorities. He highlighted that the best services were informed by understanding, knowledge and research, both qualitative and quantitative.

Describing the need to collect data, he emphasised that organisations and their services needed to know the Equalities characteristics profile of the Borough, the needs of their local communities and the kinds of support required. The practice of monitoring service users accessing services by the protected characteristics as defined by the Equality Act 2010 was important because first of all it was the right thing to do, and secondly it was part of the process of meeting the requirements of the general equality duty. He drew attention to the fact that sexual orientation was now being included within equalities monitoring processes at the council.
Bill Stephenson also stressed the importance of listening to patients in order to understand and best respond to their needs. He cited the role of engaging with communities in order to inform service provision and promote understanding of the services being offered and how they can be accessed.

Tom Whiting described his role as one of ensuring that Equalities is centred within Board processes and decision-making. He stressed the importance of designing personalised services and again stressed that good client understanding was they key to offering effective services, and that this was even more important when helping vulnerable people. He highlighted how many languages are spoken in Harrow Borough – 139 – and that there was a lot of experience of working with diversity. However, he also asked the question as to whether organisations are as good at planning and providing services for LGBT people as for other diverse groups.

Tom drew attention to up 6% of the national population identifying as LGBT, and therefore 13-14,000 people within Harrow Borough population and made the point that those delivering services need to stop being afraid to ask service users about their sexual orientation.

Robyn Doran described how in preparation for her presentation she had scanned the internet for ‘lesbian mental health’ and got 14,000 pages. Many were from the US. She highlighted research showing that depression and mental health were the highest areas of concern for the lesbian community, followed by drug and alcohol issues. Additionally, she drew attention to the lesser known fact that nearly 1 in 4 people within the LGBT community experienced domestic violence. Robyn then made reference to UK research, highlighting the experience of rejection by family members when coming out, that LGB people were more likely to be diagnosed with a mental illness than the heterosexual community, that members of the LGBT community experienced discrimination in accessing services and the issues of isolation that mental illness and LGBT identity can exacerbate.

Robyn described how she had recently attended a meeting with the local Somali community, and made the point that for people from that and other communities there could be a triple stigma affecting their getting appropriate support: their racial identity, sexual orientation and the fact of having a mental illness. Referring to research undertaken in Wales by Stonewall, she highlighted that 39% of service users entering services experienced homophobia, and gave the example of one service user from the research who described how a key worker refused to work with her after she had been ‘outed’ in conversation by her mother. The research also indicated that two thirds of service users felt they could talk about their sexual orientation. Many service users identified that being LGBT contributed to their mental illness.

Robyn then emphasised areas that services needed to be more up to speed with.

- health and social care staff not making assumptions about a person’s sexual orientation or only asking about whether they are married which then makes it harder for the person to talk about their relationships with a partner or within a civil partnership.
posts on noticeboards, not only presenting positive images of LGBT people, but also emphasising good practice in attitudes and behaviours.

organisations ensuring staff have training to understand LGBT issues, overcome ignorance and confront unacceptable behaviours within services

services need to be places where staff feel safe with their sexual orientation or trans identity.

In relation to the last point, Robyn described how the LGB profile within CNWL was probably higher than average at senior levels including the Board, but that junior staff felt that visibility was important to encourage a sense of safety, with issues of homophobia dealt with. She made the point that if staff cannot feel safe being visible, how can service users feel safe.

Finally, Robyn challenged participants to reflect on what they learn from the morning, asking all present to consider what they are going to do differently as a result of what they hear, and how their practice will change?

‘So what’s sexual orientation got to do with mental health and care?’
Tim Franks, Chief Executive of PACE

Following the opening presentations, Tim Franks, Chief Executive of PACE, addressed ‘So what’s sexual orientation got to do with mental health and care’. Tim began with a brief overview of the Equality Act general duty and the legal reasons for understanding the specific needs of people who have a protected characteristic. He made the point very clearly from the start that being LGBT does not give you mental health problems, stressing it’s the reactions of others to your LGT identity that is the issue. He emphasised that it was important is to think in terms of the disproportionality of mental illness amongst the LGBT communities. He drew our attention to the fact that in the UK being gay was a mental illness until 1992, and that we need to be careful not to pathologise.

Referring to research by Professor Michael King for the National Institute for Mental Health published a systematic review: “Mental disorders, suicide and deliberate self-harm in lesbian, gay and bisexual people.”

• Rates of attempted suicide more than double for LGB people (NB gay men over 4 times more likely)
• At least 1.5 times more likely to suffer from depression over 12 months or a lifetime
• At least 1.5 times more likely to become alcohol or drug dependent (NB lesbian women 4 times more likely to become alcohol dependent)

Quoting research by Tim quoted further research by Apu Chakraborty which found that:

1 NIMHE (2007) Mental disorders, suicide and deliberate self-harm in lesbian, gay and bisexual people
London: NIMHE

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- 4.1% of non-heterosexual people reported having had a depressive episode within the last week compared to only 2.1% of heterosexual people
- 10.4% of non-heterosexual people reported alcohol dependence compared to 5.4% of heterosexual people
- 8.6% of non-heterosexual people reported self-harming compared to 4.6% of heterosexual people.

Tim also drew attention to the disproportionate level of mental health problems within the trans community, citing the new mental health framework: “People who identify with this protected characteristic are subject to some of the greatest discrimination in our society. They are at increased risk of alcohol and substance misuse, suicide and self-harm. It is important that staff in health, social and education services are aware of the raised risks in these groups.”

Tim made the point that all the evidence points to discrimination as a key cause in the development of mental health problems within the LGBT communities, and stressed the significance that unlike in some other areas of diversity, the discrimination associated with sexual orientation reached directly into families and family systems, and hence the importance of working with families.

Introducing the concept of ‘minority stress’[^3], which Tim defined as a way of understanding the impact on the individual of being part of a group that is less valued by society, he then highlighted four key effects to be addressed when working with members of the LGBT communities:

- Internalised negativity. He made the point that gay people are not beamed down fully formed from the planet homosexual, but they are individuals developing their identity through life-experience, and that by age 10 children are already using the word ‘gay’ as a term of abuse. Tim stressed the important factor that the individual will have learned this as a term of abuse before they may realise they are themselves part of that group which is being stigmatised. So the negativity develops before the sense of identity leading to a range of emotional reactions which can include guilt, shame, disgust, all of which can then impact on the individual’s mental health.

- The actual experience of discrimination and violence as a personal reality that leaves you knowing yourself to be a target and at risk.

- Expectation of rejection and discrimination. People stay silent, they don’t wish to come out and disclose because they have learned from an early age that they can expect discrimination and rejection because it has been the reality in their experience. They are therefore always on their guard.

- Young people who can be utterly distraught over being unable to tell their parents and who therefore carry a great deal of anxiety linked to their expectation of their family’s

response. The family may in fact be OK about it, but the young person who has not told them will carry added anxiety and symptoms of distress.

Tim next cited a survey by King of NHS therapists and counsellors found that 17% admitted trying to ‘cure’ people of lesbian and gay feelings. In addition, the Where to Turn 2010 user survey of LGB&T people who had experienced suicidal distress showed that 23% of those who had used a mainstream service reported a negative experience relating directly to their being LGB or T. He also drew attention to research showing that LGBT people’s experience of discrimination was due more to ignorance than homophobia.

Tim then moved on to consider issues relating to data collection and monitoring, first of all making the point that it’s all very well collecting data, but it has to be analysed and used to inform service developments, and that a survey by PACE of 1200 mainstream mental health organisations had shown that whilst 31% routinely collect sexual orientation data and 21% routinely record trans identity, only 8% analysed this data.

Addressing why people avoid asking about a service users sexual orientation, Tim made the point that for many staff they simply have no concept of how this information might lead to them working in a different way. He stressed that asking about a person’s sexual orientation has to be done sensitively, and that it has to be understood that the asking is not a request for information about someone’s sex-life, or some kind of personal intrusion, it is about asking for a person’s sexual orientation identity. In some cases this may simply be for monitoring purposes, in other cases it will be to inform the language used in communication and should awaken the service provider to the kinds of issues that may be affecting the service user.

In terms of asking young people about their sexual orientation which many professionals do have difficulty with, Tim suggested that it could be offered as one of a number of areas the young person might want to explore as factors affecting how they are feeling: home life, friends and relationships, sexual orientation, pressures in their life, school work, for instance.

Tim also stressed the importance of being comfortable with the words: ‘gay’, ‘lesbian’, ‘bisexual’, ‘transgender’, ‘partner’. He drew attention to that little hesitation that can occur just before these words are spoken by many people, and this is picked up by LGBT people who are rightly sensitive given that their experience is often of these words being used as a prelude to a verbal or physical attack. People have to get over it, get used to it, if they are to convey an ease when in conversation with gay people. Also, to affirm the person’s sexual orientation identity in a positive way which again is much easier if you are not stumbling or hesitating over the key words. How can you expect a service user to be relaxed with you, to trust you, if you cannot convey an ease towards them and towards what is a crucially important aspect of their identity.
‘The Significant Other: Michael’s Story’, Brian Baylis, Member of the Age UK Opening Doors Project.

The next speaker was Brian Baylis, Member of the Age UK Opening Doors Project. His talk, ‘The Significant Other: Michael’s Story’ was a deeply moving account of his relationship as a carer and advocate with Michael, a gay man having advanced dementia. As a gay man himself, Brian described and explored the issues that he encountered with service providers as the significant other in Michael’s life.

Michael was a gay man, experiencing an extreme form of dementia with an extreme form of short term memory loss, as well as other life threatening illnesses. He was placed in a number of settings over the years: a general psychiatric hospital, a smaller care home and a nursing home for the severely mentally disabled and eventually continuing care in a mental health hospital. Brian described Michael’s mental state as ‘little islands of memory in an ocean of confusion’. Michael also had liver failure, diabetes and was sometimes aggressive towards staff due to his fears and response to treatment. Michael’s next of kin were in Ireland and at one point his sister came over with the intention of taking out power of attorney and taking him back to Ireland, but then decided not to do so, so he was made a ward of court.

Brian visited Michael regularly over the years and over time the visits increased to daily. He would take him out to places which were familiar to him including a particular gay pub for lunch where people were very kind and would have brief conversations with him again and again without Michael realising because of his condition. Michael derived much pleasure from this, along with a very simple game of dominos which he re-learned to play.

Brian spoke of how he sought to have Michael moved from the hospital setting into the community, and he was transferred to small care home. Other residents at the home were diagnosed with schizophrenia. This was not Michael’s condition. He was the only patient with dementia, however, as he was only 54 at the time it was felt this was a better setting for him. He shared a room, but the person he shared with at first only used it for sleeping, so Michael could spend time watching films and video’s (Brian had pressed for him to have his own TV) which he loved. He had seen a lot of films, particularly musicals in his early life and over time he was able to remember them and was able to anticipate the dialogue and remember the words of the songs so that he could sing along.

However, when his roommate died, the new person spent more time in his room reading, and Michael was unable to watch the films in the same way. He was deaf and had to have the volume lower so as not to disturb his room mate. It was an extremely frustrating time for Michael. Brian also noticed that at times Michael seemed to be increasingly dopey from the medication he was given.

The decision was taken to move him to a psychiatric ward. He developed a psoriatic condition and would withdraw, confused by his new surroundings. The consultant and
Brian eventually managed to persuade Michael’s carers that he should be moved back into the care home, however the care home had closed and at the new home he no longer received regular psychiatric input and was given increasing doses of medication. Michael became more lethargic, his speech became slurred and he developed double incontinence. He was diagnosed as having Risperidone poisoning. He was regularly admitted to hospital until his death 6 months later.

Michael’s family made contact during the time that Michael was in the nursing home, asking social services for Brian to no longer be involved in Michael’s care. All that Brian could do was to continue to visit Michael regularly which towards the end he did on a daily basis.

On one occasion when Michael was admitted to the hospital, staff refused to allow Brian to see him although they relented after Brain had remained waiting for over an hour. When he came to Michael he found two burly orderlies holding Michael down to stop him leaving the bed. Michael recognised Brian and was able to communicate to him what his needs were, and he quietened down and the orderlies were persuaded to go on their way. But staff still refused to involve Brian in Michael’s care and care-planning. Eventually Michael was put into continuing care in a mental health hospital and Brian was not allowed to attend the meeting which led up to this decision. This was an entirely different kind of setting and Michael was unable to come to terms with this new location.

Brian raised his concerns about this new situation with Social Services and received no reply. He then wrote to the team leader of the continuing care team who replied to say they were unable to discuss the case with him for reasons of confidentiality. There were additional problems with Michael getting eye-tests and new glasses and dentures, processes which Brian had played a key role in facilitating in the past, leaving Michael now without glasses or teeth.

Michael entered a comatose state and one evening Brian was told when he visited him it was likely he would be that way for a few days. In fact Michael died that night, Brian was told by phone the next morning. By the time he arrived, Michael’s body had been taken away by a family member along with possessions from his room, some of which (photographs in particular) actually belonged to Brian and had been put there to provide some familiar images for Michael.

Brian was told he was not able to see Michael’s body, and the family refused to let him come to the funeral. Brian wrote to the family asking them where Michael’s ashes were buried in Ireland and to request his photos were returned – he received no reply. Brian took the case to the ombudsman. The Council had to re-write two of its policies as they had acted in error. They were required to issue apologies and had two financial penalties imposed upon them.

For many years Brian was the only truly significant other in Michael’s life, a person with whom Michael had had a 40 year relationship, the one person who could communicate with Michael and had an understanding of his personal needs and difficulties, and the only person who could help Michael access his past memories.

For many years Brian was the only truly significant other in Michael’s life, a person with whom Michael had had a 40 year relationship, the one person who could communicate with Michael and had an understanding of his personal needs and difficulties, and the only person who could help Michael access his past memories. The issues of discrimination...
were vividly illustrated by Brian’s deeply moving and personal account of the difficulties he had in being the gay ‘significant other’ helping in the process of Michael’s care. He spoke of this problem being experienced by other LGBT people and the need for a proper process to contextualise the mental capacity act for LGBT people.

The many letters and papers relating to the case are available in the Hall-Carpenter Archives in the LSE Library and have been used in research to promote and deepen understanding of the issues that arose and how they could more effectively have been addressed, particularly issues of inclusion of the person who is the significant other.

Panel session
The final session of the morning involved a question and answer panel discussion involving Tim Franks, Brian Baylis, Nick Maxwell (Age UK) and James Taylor (Stonewall). The questions were wide-ranging. LGBT issues in the context of older people was raised, the particular challenge in enquiring about their sexual orientation in the context of their having lived through the time when homosexual acts were criminal and people were ‘treated’ for their homosexuality which included aversion therapies and chemical castration. It was highlighted then that it is no wonder that older LGBT people are less likely to come forward with their sexual orientation or trans identity. A further issue raised relating to older people was in relation to how geared up older peoples services are to providing care for people who have HIV.

The issue of the tension between staff attitudes rooted in religious belief and LGBT service users (and staff) was raised. The Stonewall Guide on religious belief and sexual orientation was cited and the importance of focusing on the behaviours of staff and ensuring that they are in line with organisational policies of behaviour and that public bodies challenge behaviour that is unacceptable. What is important is to understand that diversity issues relating to sexual orientation need to be addressed in terms of relationship, not simply about an act of sex. It was also highlighted that there was a case for mandatory training as you needed to reach the staff who didn't want to be trained. The importance of unpicking the reality of religious beliefs, what actually is and isn’t acceptable in terms of talking about sexual orientation, was stressed, and that there can be myths based on prejudice that have little or no foundation within the teachings of a religion.

Data issues were raised, and the question of how many LGB people there are within society. The Integrated Household Study showing 1.5% of the population identified as LGB was mentioned, however, concern was expressed over the accuracy of this figure given this was a doorstep sample and therefore it was highly likely that a significant number of people may not make their LGB sexual orientation visible. Stonewall’s view is that it is closer to 6%. The view was expressed that there really needed to be more research into how best to enquire about a person’s sexual orientation.

The discussion moved on to the question of different cultural perspectives on sexual orientation, the point raised that LGBT awareness is more developed in the ‘West’, but languages from other countries may not even have the words for ‘lesbian’, ‘gay’, ‘bisexual’,

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‘transgender’ or partner in a same-sex context, or where they do they may have different cultural traditions relating to same-sex roles and relationships within society. The challenge for interpreting services was raised in this context. The point was then highlighted about engaging with BME LGBT communities and the fear of offending people by asking, or anticipating that they will get angry.

The challenge of developing dialogue not only between those who share and do not share a protected characteristic, but also across protected characteristics to strengthen a greater climate of inclusion was also highlighted.

The suggestion was made that there needed to be preparation before asking what may be experienced as awkward questions, making it clear that there is no intention to offend, it is part of the process of ensuring that effective services are delivered for all people.

The point was made that in order to make changes within organisations, to promote visibility and positive images of LGBT people and to ensure data is collected and used appropriately, there needed to be a multi-faceted approach including training, posters, role models, just getting LGBT issues into the workplace conversation in a positive way and enabling people to feel more at ease and trusting of those around them.

The question of working with young people was raised and the need to work with families and family systems was emphasised. The point was made that young people are coming out at an earlier and earlier age and that young people having access to supportive environments to come to terms with issues and situations arising from their identifying as LGBT. Also, the need for parallel initiatives to address issues within the significant environments affecting the young person – family, school, for instance.

The event ended and there was a real buzz of conversation over the food and drink on offer to participants and a real sense that some important links were being made – between people and organisations, and in terms of individual understanding and practice. The multi-agency working group will continue to meet and to build on the event and the dialogues that have already taken place, providing what will be an extremely valuable resource within Harrow for ensuring that the sexual orientation and mental health agenda is addressed more robustly within service provision.

“Today was excellent - I have put up the Stonewall posters in our reception!”

Mark Gilham, Mind in Harrow
Appendix 1 - Feedback from participants

Feedback from participants was positive, with encouragement to run more of this kind of event, to bring in more representation from BME communities and faith groups in the presentations, to make training and awareness raising mandatory, to include workshops in any re-running of this kind of event and to provide guidance in asking about sexual orientation for monitoring and identifying support needs.

There were:

52 attendees, 34 of whom were not connected to the planning group nor stallholders

Of these 34, there were attendees from:
- MIND in Harrow,
- CNWL Adults – in-patients and community,
- CNWL Older Adults – community team
- CNWL CAMHS
- Harrow Council Children’s Services
- Harrow Council - other Social Services departments
- Richmond Fellowship

Evaluation
36 evaluation forms received – 26 out of 31 women attending (84%) and 10 of the 21 men attending (48%)

Regarding how useful they found the presentations by the two speakers – very useful, quite useful, not useful or irrelevant.

30 (83%) found Tim Franks’ presentation ‘very useful’, 6 (17%) found it ‘quite useful’
10 (27%) found Brian Baylis’ presentation ‘very useful’, (3 of them commenting how moving they had found it) and 26 (72%) found it ‘quite useful’

Regarding the effectiveness of the training:
- Did the training improve your understanding of the relevance of sexual orientation to mental health? – Yes, in part or no
  31 (86%) yes 4 (11%) in part 1 no
- Did the training leave you feeling more confident in data collection on sexual orientation from service users? – Yes, in part or no
  28 (78%) yes 7 (19%) in part 1 not applicable
- Did the training leave you feeling more confident about exploring and addressing sexual orientation related issues with service users? – Yes, in part or no
  26 (72%) yes 9 (25%) in part 1 no

Analysis revealed no significant differences in the evaluation outcomes on the basis of organisation, age, gender, faith, ethnicity or sexual orientation.
Appendix 2 – Stall holders and contact information

PACE
Paresh Dodhia
www.pacehealth.org.uk

Stonewall
James Taylor
www.stonewall.org.uk

Harrow CAB
Oliver Davidge-Stringer
www.citizensadvice.org.uk/harrowcab

Harrow LGBT Forum
Luke Martin
www.ealingcvs.org.uk/index.php?nuc=all&id=162

West London LGBT Project
Luke Martin
www.ealingcvs.org.uk/index.php?nuc=content&id=128

Mind in Harrow
Mark Gillham
www.mindinharrow.org.uk

Relate London NW
Carmel Brown
www.relatelondonnw.org.uk

Age UK Opening Doors Project
Nick Maxwell
www.openingdoorslondon.org.uk

West London Gay Men’s Health Project
Daniel Winstanley
www.westlondongmp.org.uk