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Challenges and opportunities to improving mental health services for LGBT people in Ireland: A narrative account

Running title: Mental health services LGBT Ireland

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ABSTRACT

The views and opinions of people who use mental health services are being increasingly acknowledged in relation to rights-based, socially inclusive and recovery-oriented care. However, little is known of the experiences of lesbian, gay, bisexual and transgender (LGBT) people in this respect. The aim of this study was to explore the experiences and needs of LGBT people in relation to mental health services. The study was an exploratory design utilising mixed methods. Both quantitative and qualitative data were collected using a survey instrument (n=125) and in-depth semi-structured interviews (n=20) with a sample of people whom had completed the survey. This paper will report on the findings from the interview data. The data were thematically analysed and the main themes that emerged included accessing services, treatment choices, mental health service experiences and other supports. The findings inform the discussion and recommendations are made in terms of future mental health practice, education and research.

Keywords: Lesbian, gay, bisexual, transgender, mental health, nursing, service users

Word Count: 4998

Challenges and opportunities to improving mental health services for LGBT people in Ireland: A narrative account

INTRODUCTION AND BACKGROUND

Little is known about the experiences and views of lesbian, gay, bisexual and transgender (LGBT) people in relation to mental health service provision in terms of access and treatment choices. The current study aims to address some of the shortcomings in the literature and to inform current and future mental health policy and practice initiatives.

Mental health services worldwide have seen major transformations in recent years through deinstitutionalisation programmes and more enlightened ways of organising and providing mental health care, particularly in relation to rights-based, empowering and service user-led policy initiatives (Australian Government 2010; Department of Health and Children 2006; Government of Scotland 2006; Mental Health Commission 2008). However, in terms of social and emotional well-being, issues still persist for LGBT people. Heterosexism, homophobia and transphobia can all lead to specific challenges in relation to health equality and social inclusion (Equality Authority 2002; Health Service Executive 2009; World Health Organisation 2009; Department of Health 2013). Furthermore, stigma-related prejudice, discrimination and heterosexist experiences can have a negative impact upon a person's well-being and may contribute to minority stress (Meyer 1995; Kelleher 2009). In a seminal study conducted in Ireland, *Supporting LGBT Lives* (Mayock et al. 2009), important issues were highlighted relating to minority stress including high incidence of stigma, discrimination, depression, and suicidality, and concerns around social exclusion. In a more recent Irish study involving transgender people (n=153), findings showed that 78% of transgender people had considered suicide and a majority of survey respondents reported having negative experiences of health care services (Transgender Equality Network Ireland 2013). Clearly, these issues require urgent attention in services, however a significant proportion of

respondents in one study (77%) thought their healthcare provider lacked knowledge or sensitivity to LGBT issues (Mayock et al. 2009). Furthermore, health and social care systems are often seen as unwelcoming for LGBT people (Pachankis & Goldfried 2004; Grant et al. 2011; Coleman et al. 2011). For safety and economic reasons, many LGBT people's sexual identities have had to remain hidden, which may lead to further isolation and invisibility (Phillips & Marks 2007; Makadon 2011). In one United States (US) study, a majority of service users in mainstream mental services spoke about feeling compelled to hide their sexual orientation or gender identity, leading to mistrust and the poor uptake of mainstream mental health and social services (Newcomb & Mustanski 2010). Some of the negative reactions displayed by practitioners may include embarrassment, anxiety, inappropriate reactions, rejection of the patient, hostility, suspicion, pity, condescension, ostracism, avoidance of physical contact or even refusal of treatment (Heck et al. 2006; McCann et al. 2013). This can have a serious and compounding impact upon a person's mental health (King et al. 2008; Kuyper & Fokkema 2011). Consequently, accessing appropriate services and the development and sustainability of social networks becomes problematic for LGBT people (Health Service Executive 2009; Health Service Executive 2012). In spite of these challenges, some studies reveal resilient traits used by LGBT people and an ability to thrive in perceived heterosexist and transphobic environments (Butler 2004; McNeil et al. 2012; Meyer 2003). Identified strengths that LGBT people may possess include enhanced coping skills, acceptance of diversity, creation of families of choice and flexibility in gender roles. In terms of resilient traits specific to transgender individuals, more than 80% of participants in a UK study felt that they had gained something positive as a result of being transgender, transitioning or expressing their gender identity. These included increased confidence, new friends, better quality relationships, a sense of community and belonging, enhanced self-expression and acceptance, increased knowledge and insight, and increased happiness and

contentment. (McNeil et al. 2012). Despite these positive attributes, obstacles persist in terms of discrimination, stigma and heterosexist attitudes towards LGBT people. Nevertheless, there is a distinct lack of studies that explicitly explores the views of LGBT people in relation to mental health need and service provision. This is particularly evident where transgender people are concerned (Collins & Sheehan 2004; Grant et al. 2011). In the recent *Burning Issues* Report in Ireland that sought the views of LGBT people around current LGBT priorities (n=1127), mental health concerns came top of the agenda for a majority of people (National Gay and Lesbian Federation 2009). This paper presents the findings from the current study that highlights the views and opinions of LGBT people in relation to mental health services.

METHODS

Aim and objectives

The aim of the study was to examine the experiences of LGBT people concerning mental health services in Ireland. The objectives included: uncovering positive and negative experiences; identifying potential barriers, opportunities and gaps within mental health service; and highlighting evidence of good practice that may inform future mental health policy directives.

Design

The study was an exploratory design utilising mixed-methods. Both quantitative and qualitative data were collected using a survey instrument (n=125) and semi-structured interviews (n=20) with a sample of people whom had completed the survey. This paper will report on the findings from the interview data. The survey results are reported elsewhere (McCann & Sharek 2013).

Recruitment and interviews

The existing literature revealed challenges faced by researchers conducting sensitive research among hard-to reach populations and recognises the invisibility and marginalisation of LGBT identities in society (Shankle et al. 2003; Grossman & Hollibaugh 2008). Therefore, a rigorous recruitment strategy was adopted in order to promote the study. LGBT and mental health organisations, including hospitals and clinics (n = 170), throughout the country were sent packets with study information. Relevant LGBT and mental health organisations were sent emails requesting that they share the study information through their email lists and social media pages. Following completion of the online survey, respondents were informed of the option to participate in an interview about their experiences. If they were interested, they were asked to fill in the interest form online or to contact the researcher by email or phone. The principal investigator and the advisory group developed the semi-structure interview guide. The schedule was piloted and alterations made. Finally, interviews were conducted with a number of participants who had completed the online survey (n=20) and had elected to participate. All interviews were tape recorded and lasted between 45 minutes and 1 hour. The data were collected in 2011 over a three month period.

Inclusion criteria and sampling

People could participate in the study if they were over 18 years of age, identified as LGBT and had used Irish mental health services in the last five years. In order to increase the response rate in hidden or hard-to-reach populations, a convenience sampling strategy was used (Flannigan & Hancock 2010).

Ethical approval

The study was reviewed and ethical approval to conduct the study was granted by the relevant Research Ethics Committee. Further, due to the sensitive nature of the research, LGBT Research Guidelines were utilised (Kandirikirira & Botfield 2004). Throughout the

interview process, the researcher was aware of and acknowledged the sensitive nature of potential discussions. Verbal information was given to participants and they were encouraged to ask questions at any time. Interview participants were also informed of their right to stop the interview at any time without consequence. When a few of the participants became emotional during the interviews, the researcher was able to offer supportive counselling. A list of national mental health organisations and help-lines were also provided to each participant in case they wished to speak to anyone further. All participants signed an informed consent form. All study files, including audio recordings, transcripts and surveys, were stored in accordance with the Data Protection (Amendment) Act 2003 (Government of Ireland 2003).

Participant profiles

In total, 20 people participated in the semi-structured interviews. The mean age of participants was 34.1 years. All of the participants were under 65 years of age and there was an even distribution in the 18-64 year age brackets. About 75% were from Ireland with 80% living in an urban location. Eighty per cent of the sample were working or were students and 15% were unable to work due to permanent sickness or disability. A majority of participants were single (70%), with smaller percentages dating or in a relationship. In terms of sexual orientation, 45% of the participants identified as gay, 45% as lesbian, and one person as bisexual. Forty percent of participants described their gender identity as male, 45% as female and 15% as transgender.

Data analysis

An independent person transcribed the interview data verbatim. Transcripts were reviewed and any identifying information removed by the principal investigator. The computer programme NVivo Version 8.0 was used to assist in the organisation and analyses of interview data (QSR International 2008). The first two interviews were open coded and a

coding guide developed that was used to analyse the remaining transcripts for new concepts or emergent themes. The data were further examined for meaning and similar themes combined. This constant comparative process continued until major categories were formulated. A synthesis stage followed where the interview findings were reviewed (Lincoln & Guba 1985).

STUDY RESULTS

Categories and sub-categories emerged that were organised systematically. The key categories included: accessing services, treatment choices, service experiences, other supports and main concerns and recommendations.

Accessing services

People had a variety of reasons for seeking out mental health services and conveyed diverse experiences. The first contact usually involved a consultation with the person's general practitioner (GP). The student counselling service would see people at university or college and referrals would then be made to mental health services. The following excerpts highlight preliminary expectations and needs of some of the participants:

I used the college services actually because they were free access and that was a major thing because I can't afford to actually go to other services, even though I did have a medical card, there's a long waiting list...so I made use of the GP services who referred me then to the mental health services. (001 Lesbian female)

My dad died...and I took it pretty bad, and then I was raped. I took an overdose. I was in the general hospital for three weeks and then transferred to the psychiatric hospital for three months. Can't remember much, I was sedated a lot of the time. (009 Lesbian Female)

Several people were able to give very poignant accounts of how their mental health experiences impacted upon them emotionally:

Agony...I'd never ever attempt suicide. I wanted something else to happen. I wanted to get cancer. I wanted to get hit by a car. I wanted the mental pain to be taken off my hands. (014 Gay male)

My mum brought me to a priest, hoping that he'd fix me....I know from an early age I used to suffer from depression. Actually, it got so bad that I was admitted to the psychiatric hospital. I was suicidal and mentally exhausted and totally lost and confused. (016 Gay male)

One participant, who had been diagnosed with HIV/AIDS and had been living in London, returned to rural Ireland, where he had spent his formative years. He was referred to mental health services and had spent over one hour being assessed by a consultant:

I was lying on her (consultant) bench one afternoon sobbing, but she never so much as asked me, "How are you?" And that is a really serious issue for people with HIV. If she'd asked me how I was I'd have said, "I need help", but I wasn't able to ask for help because I was in such a depressed state. (012 Gay male)

The services to transgender people remain extremely limited and the frustrations related to accessing appropriate services became increasingly apparent for some participants:

I was seeing another psychiatrist in London, having tried to get the hospital to provide the signature to go for the HSE's [Ireland's National Health Service] treatment fund. It's an enormously long process....I'd even contemplated suicide. (006 Transgender female)

Despite evident setbacks, some transgender people were able to express feelings of positivity and demonstrate resilience:

The one thing that he did say, I'll never forget it... "You've such hope." I just thought I was something to be ashamed of, something to be embarrassed over, whereas that sentence just...made me feel like a human being.

(008 Transgender female)

She returned from her consultation with the psychologist and decided to explain to her partner of fourteen years, the mother of her two children: *"As much as she knew I was trans, she certainly didn't think I would go the whole way with it....The relationship went downhill from there* (008 Transgender female)." The situation had reached breaking point and whilst she was coming to terms with her own life and the Gender Identity Disorder (GID) diagnosis, she felt the relationship was in jeopardy and feared for the wellbeing of her family, and herself:

It was absolutely awful....it wasn't the sexual orientation. She [partner] was my best friend, we were just so close, we never went anywhere without each other, but the fear of everyone else was just something that she couldn't do....there was no counsellor, there was no support. I totally contemplated suicide and the faces of my two children kept me alive. (008 Transgender female)

Being diagnosed and being LGBT

Being raised as an LGBT person in Ireland has specific challenges, especially around minority stress and its manifestations. Participants spoke about the impact of psychiatric diagnoses and whether or not the person's mental health issues were closely linked with being LGBT:

"Borderline personality disorder," they said. It meant nothing to me until I went

home and researched it on the internet...There's nothing wrong with my personality. I spoke to the [a Catholic volunteering organisation] to talk it through and they considered it [my sexual orientation] sinful... (009 Lesbian female)

Because I kind of have had that experience, like when they ask about your sexuality, like it's tied up with some kind of theory that it's linked with your mental health. Like if someone said they were heterosexual I don't think it would even be written down, "Ooh, gay, troubled..." (017 Lesbian female)

Treatment choices

Medication

Most of the participants had been prescribed medication at some point and all but one had concerns about taking the medication. The two participants below described fears around developing an addiction to medication and of not being listened to by their doctor:

I was slipping further and further. I went down to my GP and he put me on Valium and sleeping tablets and...I mean it was great for a short-term fix obviously. I'm still on Diazepam, but I only take it when I need it because I'm not developing an addiction to Diazepam. (014 Gay male)

He kept upping it...they [the doctors] are not really for receiving feedback about what you're opinion is. (005 Gay male)

Other participants echoed these fears, while others voiced concerns about increased anxiety around sexual dysfunctions related to psychotropic medications.

Talking therapies

Some people had experienced different forms of therapy namely Cognitive Behavioural Therapy (CBT), Mindfulness and Psychoanalysis. People generally had positive reactions to therapy but appreciated the challenges of finding the ‘right’ therapist. However, there were financial costs involved and only open to those who could afford it:

My counsellor referred me to a mindfulness group run by a psychiatric nurse300 Euros...The mindfulness group helped me to be able to forgive. Living like that is good. Making time for myself. It is good value. And it works!

(019 Lesbian female)

Service experiences

Engaging with practitioners and services

In the present study, the desired qualities and attitudes for a good practitioner were identified and articulated by some of the interviewees. Qualities that participants spoke about appreciating were feeling listened to and that their needs and wants were taken into consideration.

My GP [general practitioner], she takes the holistic approach. It's like we're going to look at the bigger picture, and I think that was important because, one of my big fears was that I'd end up in the mental hospital... (003 Gay male)

One participant, who had had a negative experience of general medicine where there was poor communication about his condition, felt ambivalent about the treatment he would receive from mental health services:

You see that having been my experience with the health services, it was just like would mental health be the same, but I was thankful that it was very supportive, very understanding, they really did understand. The talking was the important thing...They did check to see that you understood what they were saying. (003 Gay male)

Others commented on the positive input they had received from various mental health practitioners:

When you're in one to one counselling, before you actually mentioned your sexuality, you feel fear of rejection, and it's after...say your girlfriend or whatever and...they're positive, that you feel more comfortable to talk. I was lucky to get somebody who was understanding and compassionate. (001 Lesbian female)

Some participants were appreciative of the empowering nature of services that had input and the involvement from service users.

It was service user run. We were put in charge basically. We volunteered. We had meetings where all the decisions were made, our budget, but at the same time, we had a huge input into that which I think was good; it was reminding us that we were still in control. (003 Gay male)

The obverse of the more positive attitudes alluded to by participants included healthcare practitioners ignoring or making presumptions about a person's LGBT identity, judging the client, or offering inappropriate treatment. The importance of attributes such as being treated with respect and dignity is demonstrated in the following quotes:

I didn't like their attitude...assumed that I liked to play football and all this...it was a bit odd...made me feel strange, that was one of the things. I was asked by one of the counsellors if I ever had a relationship with a girl...I've never had a girlfriend, it was just so awkward. (010 Gay male)

...He [psychiatrist] was talking about me like I wasn't there in the room. That was horrible, and he was sitting there and he was talking to my dad as if ...it was like

being a dog at the vet...it was like being completely objectified.

(014 Gay male)

I'd like to see them give a little bit more time and a bit more compassion.

(002 Lesbian female)

Lack of treatment choices

The dominance of the biomedical approach within mental health services in Ireland was apparent for some people. Furthermore, a significant proportion of participants had major concerns about the distinct lack of therapeutic choices or appropriate care environments:

I remember looking at the place thinking "Dear god almighty." It was like something out of One Flew Over the Cuckoo's Nest. It really was horrendous. You could imagine Nurse Ratchett walking down that ward and being horribly cruel to everybody, not a very good memory of what mental health services should be, just wasn't positive. (007 Lesbian female)

In 20 years of using the services, the HIV services, the best medical services; however, we have the worst mental health care system in the world. We don't even have a mental health care system. HIV and mental health are not linked service wise at all. (012 Gay male)

Being LGBT and service provision

Participants were asked if being LGBT affected the kind of services they received or how they responded within mental health services. For some people, the attitudes of practitioners were important:

Unless you're aggressive which might be seen as more heteronormative, heterosexual

or whatever...they might not respect you as much and they're not as likely to listen. You're trusting them with your health and they spit it back in your face...and if they dose you up enough you'll be quiet, like a good little puppy.

(014 Gay male)

Other people spoke of fears related to being admitted to the psychiatric hospital and potential institutionalisation:

You're only allowed one visitor, it's just because...it's scary. And if you're in there it's because unfortunately there's nowhere else, that was my biggest fear...that I would be there forever..... (003 Gay male)

People were asked how comfortable they were about revealing their LGBT identity and the kind of reaction they received from service providers:

I had a team meeting...I think it was on the Monday that I had already talked to my social worker about my being gay. I was brought into the team meeting and my consultant brought up about me being gay...I asked to leave the room because I felt so uncomfortable... (010 Gay male)

One participant, whilst attending a therapy group, found it difficult to divulge her sexual orientation and recalled painful memories:

I didn't tell them because there was a little voice inside of me that reminded me of school. I was outed to the entire school by a girl. I went back after Christmas and like the entire school were asking if I regretted it. You just want to curl up into a fetal position and rock backwards and forwards and go "Oh my God, go away..." and use

the invisibility cloak that they have in Harry Potter. (002 Lesbian Female)

Stigma and discrimination

Mental health media campaigns in Ireland and work being carried out in LGBT groups in the non-statutory sector around raising awareness may be positively affecting societal attitudes toward LGBT people. However, a significant number of people in the study mentioned stigma and discrimination and the perceived challenges that still exist for LGBT people. Some of the key issues are highlighted in the following excerpts:

There's a stigma about being gay, especially with the older generation. My generation, it's kind of okay, but if you're rural-based there's still a massive stigma. It could be hard to access services, if they exist at all. (003 Gay male)

I feel absolutely let down. They [practitioners] don't think we have a voice, or that we're too weak to complain or no one will listen to us because "they're crazy". They're using the stigma...to think that those people will be quiet, they'll sit there quietly in the corner and take what they're given. There is a lot of shame there. You can feel it in that room. (014 Gay male)

Apart from issues around sexual and gender identity, some of the participants spoke of the additional stressors related to 'not being Irish' or 'white' and the negative societal consequences.

One woman articulated her concerns:

Discrimination doesn't really happen just because you're lesbian. I mean you probably mightn't get a job because you're a lesbian. You mightn't get to the top of the ladder because you're a lesbian, but I think when there are other areas of discrimination going on, it's really hard, it gets mixed up sometimes. You're not sure.

Is it because you're lesbian? Because you're working class? Because you might be disabled? You might be black...and that gets mixed up. (011 Lesbian female)

Giving consideration to tackling discrimination, several people recognised national campaigns being run primarily by Non Governmental Organisations (NGOs) and the importance of changing attitudes:

Take Care of your Mental Health campaign [a mental health anti-stigma campaign]. It was actually done quite well. Someone might have it but you don't treat them any differently. (004 Gay male)

You can have all the legislation in the whole wide world, but if your attitude hasn't changed, then that legislation is absolutely useless because the enforcers have the attitudes, so where do you go with that? (011 Lesbian female)

Other supports

Intimate relationships

In terms of intimate relationships and coping with the other person's experiences of mental distress, the strain on the partnership was evident for some of the participants:

My partner asked to come and see me. Like I'd already told him I wanted to end it all. I don't think he really realised how bad I can get and I just knew I was heading for a breakdown and I didn't want him to see me this way. (010 Gay male)

That relationship broke down and that's one of the reasons I went off the rails, kind of like because while I had the friends to support me, he was in a way, trying to be, but he didn't know how to deal with it. (003 Gay male)

Some participants recognised the importance of the support that they received from their partners in terms of openness, understanding and making sense of the person's experience.

As one person described:

It's healthy, like we're very honest with each other...with my depression, I talked to my partner about it, and he was actually really supportive at the time, he's like my counsellor. (004 Gay male)

Supportive family and friends

Many of the participants spoke of feeling supported by family and friends and how this was influential in the person's recovery trajectory. As one young man described:

I try to see it as something that anyone can go through and so we should be able to talk about it. I am really lucky with my friends, they really rallied around me and supported me, and my family as well, and I was extremely lucky there was always someone looking out for me. (003 Gay male)

Although, for some, family members displayed negative emotional responses to the person's sexuality and this appeared to compound issues that may be related to minority stress.

My grandmother's view on it...she told me that I needed to be fixed. She's the only person who has ever made me feel that there was something wrong with me and at the same time, I knew there wasn't anything wrong, but she knows how to push my buttons. (004 Gay male)

Well, my father has a very poor attitude...[he believes that you should] deal with your problems without a psychiatrist....deal with your problems yourself forms you as a

person. (005 Gay male)

Social support groups

One person alluded to a service provided by the non-statutory sector and run along the lines of a therapeutic community. There is a sense of shared understanding and mutuality of support to one another:

The various support groups that Schizophrenia Ireland ran, we had great input in how it was going to be run and everything. We were involved in running the groups and that was important. We all had this sense of ownership and it's hugely empowering. (003 Gay male)

Support at work

Increasingly, there are policy directives for employers to help them recognise and support people at work in terms of mental health. The issues are highlighted by one participant:

I've an employer now who recognises these things and it's been amazing like even working for them part time I could access every single service if I needed it. They organised it, they were fantastic and all on company expenses.

(003 Gay male)

DISCUSSION

The main directives in guiding mental health policy in Ireland, *Vision for Change*, are explicit and clear in their drive towards a recovery-orientated, consumer-led, rights-based mental health service (Department of Health and Children 2006, Mental Health Reform 2013). Furthermore, a recent review of mental health nursing highlighted the need for responsive, skilled, competent practitioners who value equality, respect for diversity, empowerment and human

rights (Health Service Executive 2012). However, many of the directives and recommendations contained in these documents have yet to be realised in terms of mental health service provision (Bracken et al. 2012). Whilst some participants in the present study reported positive experiences, it has become more evident that current services are not in line with national policy. Participants indicated that they would like to see the existing service provision reviewed and changes made in order to be more responsive to the needs of LGBT people. This included: increasing access; providing knowledgeable and responsible practitioners; and allowing for the choice of a range of therapeutic approaches, including the provision of talking therapies that are accessible and affordable. Participants spoke of their hopes around ‘responsive, seamless and holistic services.’ For some, long waiting lists and having to pay for health care were burdensome. Most people wanted a service where people were treated with dignity and respect and they provided valid ideas around tackling stigma and discrimination, such as media campaigns to raise public awareness, aspects that lie at the heart of a recovery approach and form a fundamental part of a modern mental healthcare system (Department of Health and Children 2006; Mental Health Commission 2008). Several participants wanted mental health practitioners to be better educated around LGBT issues and suggested ‘equality training’ in the workplace. They spoke about creating good practice guidelines that would assist in the provision of the necessary services and treatments and identified more work needed around ‘silent carers’ and significant others in terms of systematic support and psychoeducation. Some people recognised the effects of minority stress in young people and the risks associated with suicide (Meyer 2003). Opportunities were highlighted around educating young people

about LGBT issues in schools.

Limitations

This study provides important insights into the experiences of LGBT people in relation to mental health services. However, the researchers were unable to recruit LGBT people from a variety of ethnic backgrounds, older LGBT populations, and people staying in psychiatric hospitals or residential care facilities. Future research should include strategies to include these populations.

CONCLUSION

Mental health nurses are in a prime position to influence the development and delivery of services and therapeutic interventions that would be truly responsive to the needs of LGBT people. Whilst appreciating resilient attributes, nurses can give LGBT people support in response to specific mental health concerns, such as depression and anxiety. Furthermore, there are distinct steps that nurses can take to ensure that their practice is more inclusive to the needs of LGBT people, such as appreciating the fears associated with coming out, homophobic bullying, violence and harassment. Nurses can challenge anti-gay bias and adopt an LGBT-affirmative approach by using inclusive language, displaying LGBT information leaflets and using signs that recognise diversity. Finally, current mental health policy directives should support the development of practice and education initiatives to demonstrate openness, respect and understanding towards LGBT service users.

Conflict of interest

No conflict of interest has been declared by the authors.

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