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# Background

## Setting the scene

As a result of recent legislation, such as “The Equality Act 2007”, local Primary Care Trusts and NHS bodies have undertaken research into the needs of the LGBT community. Bradford’s Equity Partnership (2007) looked at how many people accessed services, their accessibility and people’s understanding of them. Blackburn with Darwen looked at LGBT employees of Blackburn with Darwen NHS and the local LGBT community’s take-up of local NHS services.

Any research that specifically looked at disabled LGBT people seemed to be sponsored or at least supported by academic institutions.

“Rainbow Ripples” (Leeds 2008) and “Secret Loves Hidden Lives” (Bristol University 2005) are two studies that investigate the issues of disabled LGBT people and their use of health and care services.

As expressed within the above reports, there are multiple issues that depend upon the consideration of peer group members, volunteers, health professionals and service providers - whether it's supporting a lesbian at a lesbian group meeting or building the confidence with carers to discuss issues around same sex relationships it is easy to see that meeting the needs of the disabled LGBT community would be very difficult within one diversity policy.

A number of Equity Partnerships, the 'Disability Rights Commission' and Stonewall have employed consultants to undertake research in this area, such as that from Scotland: "The Equality Network, On Safe Ground - LGBT disabled people and community groups", (2006) looked at disabled LGBT people's community engagement across Scotland.

With so little previous research done in this area, and hardly any across Central Lancashire, Preston DISC (Disability Information Services Centre) secured funding from 'Central Lancashire NHS' to undertake a small, discrete research study to get disabled LGBT community members' experiences of health services, and start the process of change.

## **Questions to be addressed included:**

*Could Central Lancashire NHS assume that all their services were accessible in its widest sense?*

*Did disabled LGBT people have access to LGBT social events and gay venues – and to what extent did the LGBT community’s emphasis upon “Body-image”, and perceptions that the “scene” included the consumption of alcohol in upstairs noisy environments have on this?*

*Were there possible opportunities for disabled LGBT people to actively engage with the LGBT scene in Central Lancashire?*

Thus the ‘Rainbow Health’ research project is a unique partnership challenge by Central Lancashire NHS and Preston DISC.

## **Population Size**

While Scottish and English parliaments are still discussing whether to include an optional question on sexual orientation in the national census, there can only be estimates of population size. To some

extent this is true of disabled people too. Also, using the 'Social model' of disability (see 'Definitions' p.7) challenges the LGBT community's perception of what is meant by the term 'disabled'. LGBT members who had episodes of depression, had cancer or were HIV positive would choose not to label themselves as being disabled, even though they were defined as such by the Disability Discrimination Act (DDA).

Bearing this in mind, relevant figures to use in estimating the population of LGBT disabled people in Central Lancashire are:

- Total adult population in Central Lancashire is 329,000 (Census 2007)
- Most organisations estimate that between 8 and 10 percent of the population identify a lesbian, gay or bisexual. This gives 32,900 LGB people in Central Lancashire
- Accurate estimates for the number of transgendered/transsexual people do not exist. This is complicated further in that many do not complete gender

reassignment for different reasons.

- Using the social model definition of disability, it is estimated that 20% of the total adult population would be defined as being disabled.

- For the purposes of this research and using the estimates above the population size of LGBT disabled people in Central Lancashire could be approximately 6400. (i.e.  $(329,000 \times 10\%) \times 20\%$ ). This figure would increase if accurate numbers for transgendered and transexual people were also included.

# Definitions

Preston DISC works within the ethos of the social model of disability as defined by disabled people. This informs all the activities and research it undertakes.

## **Disabled People**

A distinction needs to be made between disability, impairment and ill health. Impairments are long-term characteristics of an individual that affect their functioning and/or appearance. Ill health is the short term or long term consequence of sickness or disease. Many people with impairment, ill health or who have used mental health services may not class themselves as disabled. Disabled people face a wide range of barriers.

For research purposes we defined disabled people as anyone who defines themselves as Deaf or disabled because they have a sensory or physical impairment, mental distress or have used mental health services, together with those labelled as having a learning difficulty, living with HIV or other long term health condition.

## **The Medical/Individual Model**

The Medical or Individual Model of Disability is the most common/popular understanding of disability.

It assumes that the person with the impairment or health condition is the problem and that this is the reason they cannot do things. It makes 'disability' the responsibility of the individual. The emphasis is on the impairment or health condition and it does not describe the social/political and environmental barriers that people with impairments face in their daily lives.

The 'medical model' assumes that if you cannot be 'cured' you must be 'cared for'. This means that disabled people's lives are often regulated by health and social care professionals and are seen as a burden to society.

Many people with impairments or health conditions still identify with this model. As it is all pervasive in society, this may lead to internalised oppression.

## **The Social Model of Disability**

The widely accepted framework for understanding disability is the 'social model'. This model suggests that disability should be distinguished from impairment and/or ill health. Disability is defined as disadvantage experienced by an individual resulting from the barriers that they face in their daily lives.

These barriers may be:

- *Attitudinal and cultural*: for example among employers, health professionals, other service providers, the media and the general public.
- *Policy and organisational*: resulting from policy design and delivery which do not take disabled people into account
- *Physical and environmental*: for example through the design of the built environment and transport systems etc., and
- *Lack of empowerment*: as a result of all the above in which disabled people are not listened to, consulted or involved.

The cumulative effect of these barriers results in the marginalisation of disabled people from the mainstream of our society and economy. Removal of these barriers is the key to ensuring that disabled people have the opportunity to become full and active citizens.

# Methodology

A variety of research methods were chosen to ensure accessibility, confidentiality and to elicit as many responses as possible. These were: Questionnaires, focus groups, 1-2-1 interviews and telephone interviews.

Using the Social model of disability, as defined by disabled people, challenges the LGBT community's perception of what is meant by the word 'disabled'. LGBT members who may indeed be disabled in terms of the social model / Disability Discrimination Act may not identify as disabled. This is all part of the negative connotation attached to the word disabled and general stereotyped perceptions. The Rainbow Health questionnaire defined 'disability' to the community to ensure that those living with HIV or with cancer understood that it was relevant to them individually.

## **Questionnaires**

The questionnaire went through many stages of development. Meetings were held to discuss the

merits of particular layouts and design. A pilot group was selected and asked to complete the draft questionnaire. Their feedback was invaluable to the final questionnaire's design.

It was important that the questionnaires were easy to read and would not take too long for participants to complete.

An Easy Read, picture supported version of the questionnaire was produced and included some sex images to explain the questionnaire's content and ensure people with learning difficulties would be able to take part in the research.

Likert scales (1=strongly agree – 5=strongly disagree) were used for the majority of the study's questionnaire, but there was also the opportunity for participants to make comments on each question.

The questionnaire consisted of twelve questions about health services. Three additional questions were also asked on hate crime / incidents, sexual health and drinking behaviour, all of which were felt

to be equally relevant issues on which to get people's views – and also areas where Preston DISC felt they would have influence to feed these back to key partners.

In an attempt to reach disabled LGBT members, the questionnaire was sent out across Lancashire's LGBT community by email via a number of mailing lists; and we are grateful to our partners for this. Paper copies were also distributed via our drop in centre and other organisations we work with. No-one responded via email, all respondents either were given an in-house printed copy, or they printed the questionnaire from the email and completed the paper copy.

Eighteen completed questionnaires were received between December 2008 and February 2009, which we felt was a fair response given that the Christmas holiday period fell between.

## **Focus groups**

Two focus groups were arranged, one in Preston on the 28th January 2009 which had nine participants and the other in Chorley on Tuesday 10th February (Unfortunately this one was cancelled due to low numbers, instead the people registered were contacted and invited to complete a questionnaire).

The focus group started with a group agreement and concentrated on issues such as; labels used for disabled LGBT people, language, internal feelings, external messages, issues with health services and solutions.

One to one interviews with 2 people where also arranged for those who didn't want to meet in the focus group.

# Findings

## General

- The disabled LGBT community in general felt very isolated and unsupported.
- The lack of a flexible and accessible transport system is a major barrier to accessing social events
- Lack of confidence coupled with lack of accessible gay venues limits disabled LGBT people's activities and leads to social isolation.
- Very little provision is available to members of both communities; there are hardly any support groups and/or specific services for members of the LGBT community.
- Specific provision narrowed even more when looking at services for disabled LGBT members
- Access to generic services was highlighted as a barrier. In some areas such as Skelmersdale and Ormskirk there were no groups at all.

- There was more support if you belonged to only one specific group (i.e. LGBT or disabled) e.g. sexual health services or a local disabled people's organisation.
- The experience of participants highlighted that non-disability related support services are not accessible to disabled LGBT members. This is due to lack of knowledge and awareness of either disability or LGBT issues.
- What is extremely worrying is that 50% of respondents reported experience of hate crime. Over two thirds of these reported that in their perception this was because they were a both a disabled *and* LGBT person. A quarter stated that they perceived it was because they were solely LGBT.

## **Health services**

The majority of respondents did not mention the names of specific services or GP practices but offered generic names across the area. Those with specific impairments had to travel out of the area to access an appropriate specialist service.

**Services mentioned were:**

The GP, Physiotherapy, Psychological Group Therapy, Strand Road Health Services, St. Paul's Eye Unit, Beech Hill Healthcare Centre, Wigan, Thomas Linacre Centre, Wigan, Psychiatric Services, Diabetic Clinic, Eye Specialist, Sexual Health Clinic, Fracture Clinic, Dentist, Emergency Admission Ward, Outpatients, Pain Clinic, Blackburn Royal Audiology Department.

Perceptions of the health services used by respondents demonstrated that although the majority of service providers appeared to have knowledge of the legal requirements of the Disability Discrimination Act, this was limited to physical access arrangements, most health service buildings having been audited.

There is, however, a real lack of awareness around the public duty to provide 'reasonable adjustments'. This means the provision of accessible information, signage and staff support. There is even less knowledge around the Disability Equality Duty and impact assessments. Participants also found that

staff were not aware of disability issues and that more equality training is needed.

Disabled LGBT people highlight that they face more disabling barriers than issues to do with being an LGBT person. There is a lack of knowledge about the social model and most health services, predictably worked to the medical/individual model. This is understandable as very little disability equality work has taken place within health services. However, it is vital in terms of the disability equality duty to ensure that health services undertake training for - and raise staff awareness of - the social model of disability in order to address some of the concerns raised by participants in this research.

LGBT status can be hidden more easily than a visible impairment or health condition - although this is by no means always the case. The literature review suggests that there is still reluctance by many LGBT members to 'out' themselves to medical staff, and our research results were consistent with this. In some cases this could lead to individuals being hospitalised for treatment as services are unaware of

the social support at home from a partner.

There was also the perception that not enough training is being carried out around issues of privacy and confidentiality. In certain circumstances, unsuitable comments have been made. These are not often challenged due to individual lack of confidence and/or internalised oppression.

When asked specifically about what for them were the main issues - most individuals said 'pre-judgement and isolation'.

Other issues raised were around the media and the lack of attention paid to LGBT and disability issues generally. More positive role models are needed

## Responses from Focus Group 1, Problems and Solutions for Health Services in Central Lancashire 2009

### Problems with Health Services

### Solutions

Parking (x3)

More disabled parking bays should be provided

They are often impersonal and not concerned with individuals

Train more people in interpersonal skills

Insufficient meaningful attempts to reach people in an appropriate way, 'one size fits all'

Look at every possibility and where necessary appoint and train someone within each service who is responsible for and sensitive to specific needs

No provision for LGBT patients and being 'individualised'

Work together to discuss needs, awareness of needs, send suggestions (hoping for these to be taken on board)

Wheelchair access

Better access and understanding required

Poor management on wards

Better management on wards, not thinking every disabled person has all day, every day on their hands

LGBT awareness

Education and training

Doctors' receptionists are not used to visually impaired patients

Awareness training, all medical literature to be provided in a range of access medium, e.g. Braille, CD, tape and making appointment systems easier to access.

# Other Recommendations

Respondents'/participants' reports of feeling isolated and unsupported have an effect on general health and help-seeking behaviour. Whilst not within the remit of health services we recommend that more public awareness of the needs of disabled LGBT people could be promoted with the LGBT community and others.

The exploration of the potential of developing a Lancashire wide LGBT Centre incorporating a support group for LGBT disabled people where they can meet and share experiences.

Further Disability Equality Training for health service staff.

The involvement of Disabled People's Organisations in impact assessments.

The establishment of a Hate Crime liaison group and/or reporting centres based in disability organisations.

# Acknowledgements

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# Research & References

Bradford's Equity Partnership (2007)

"Rainbow Ripples" (Leeds 2008)

The Disability Studies Department, Leeds University

"Secret Loves Hidden Lives" (Bristol University 2005)

"The Equality Network, On Safe Ground - LGBT disabled people and community groups", (2006), Scotland, Disability Rights Commission and Stonewall

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It's Not Just About Ramps and Braille: Disability and Sexual Orientation, M. Brothers

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