

EQUAL ACCESS?

For Lesbian, Gay, Bisexual
and Transgender People



A Report by

**CAPS - The Consultation and
Advocacy Promotion Service**

on behalf of the

**LGBT Centre for Health and Wellbeing
Mental Health Demonstration Project**

Part of Lothian Voices

NOVEMBER 2012

CAPS
**independent
advocacy**
The Consultation & Advocacy
Promotion Service

LOTHIAN VOICES



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“Equal Access?”
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Acknowledgements

We would like to thank everyone who came along to the focus group we ran at the LGBT Centre for Health and Wellbeing and filled in the online survey and took the time to give us their views.

Collective advocacy only works and exists when people come forward with their views and we are very glad that you share our opinion that this is an important issue which is worthy of discussion and action.

What is CAPS?

CAPS is an independent advocacy organisation for people who use, or have used mental health services.

CAPS works with mental health service users as individuals or as members of a group to set their own agenda, to find a stronger voice, to get their point across, and influence decisions which affect their lives.

CAPS is set up so that the organisation and its advocates are as free as possible from conflicts of interests with the people it supports. CAPS provides independent individual and collective advocacy in Midlothian and East Lothian. CAPS also hosts a number of Lothian-wide experience-led collective advocacy projects covering a range of issues.

Collective Advocacy is about groups of individuals with a common cause who come together to raise awareness, campaign and influence service planning and provision.

Individual Advocacy is about a person having an advocate to help them express their views and have more influence over decisions being made about their lives.

CAPS does this by:

- developing and supporting user groups;
- encouraging a spirit of partnership between service users and the people who plan, pay for and provide those services;
- publishing service user views on mental health issues;
- involving service users in the development of services;
- making service users aware of new kinds of services and options that are available to them;
- providing advocates to work with individuals;
- recruiting, training and supporting volunteer advocates;
- promoting the principles of independent advocacy.

CAPS is funded by East Lothian & Midlothian Councils, NHS Lothian, and East Lothian Community Health Partnership.
CAPS is a Scottish Charity, Number SC021772

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Why Produce this Report?

Local Context:

In 2010 the LGBT Centre for Health and Wellbeing was funded by the Scottish Government to run a Mental Health Demonstration Project for people who identify as LGBT. The project is based in the LGBT Centre for Health and Wellbeing and offers support on a one to one and group basis on a range of issues including support groups, information sessions, short courses and workshops.

CAPS has worked closely with the LGBT Centre for Health and Wellbeing and the Mental Health Demonstration Project over the past few years. We have run a number of joint events such as information and discussion sessions on the diagnosis of personality disorder and psychosis and exhibitions, film screenings and ceilidhs in the Scottish Mental Health Arts and Film Festival.

In 2010 CAPS was also asked to join the LGBT Mental Health Demonstration Project Advisory Group and has subsequently become a member of the Evaluation and Monitoring Subgroup. The remit of this group includes working towards the development of an audit tool for the Mental Health Demonstration Project which can also be used by other services.

CAPS has extensive expertise in running experience and user-led evaluations and focus groups and has recently been funded by NHS Lothian to provide feedback from service users about their mental health strategy 2011-2016 - A Sense of Belonging.

With a background of strong partnership working, a commitment to user involvement and expertise and interest in user and experience-led feedback and evaluation, the Mental Health Demonstration Project asked CAPS to facilitate a focus group with Centre Drop-In members to find out their views about the positives and negatives of accessing 'mainstream' mental health services. The aim of this focus group was to inform the development of the audit tool and ensure the outcome measures are user and experience-focused from the outset.

Policy Context:

The Scottish Government Mental Health Strategy 2012-2015 explicitly covers the need for equal access to mental health services under Commitment 14:

“Equality of Access to Services

Some people can experience more difficulty than others in accessing mental health services to meet their needs. This can be because some groups are less likely to try to access services, for example due to stigma, or because there are gaps or lack of capacity in some services.

We need to understand who is accessing services to identify where there might be unmet need or where additional preventative action could be taken. Consistent recording of data about ethnic background and other information, for example, gender, sexuality and disability provides us with information about whether services are delivered in a way that meets people's specific needs.

Commitment 14: We will work with NHS Boards and partners to improve monitoring information about who is accessing services, such as ethnicity, is consistently available to inform decisions about service design and to remove barriers to services.”

In light of this commitment undertaking research into the experience of LGBT people when accessing mental health services will help to inform the strategy and with future implementation of best practice.”

Research Context:

In November 2012 Stonewall produced a briefing on LGB mental health following research carried out in this population which demonstrated significantly higher rates of mental illness and mental distress in the LGB population. This backs up some key findings on the mental health of LGB people reviewed by the National Mental Health Development Unit:

- *'LGB people are at significantly higher risk of mental disorder, suicidal ideation, substance misuse and deliberate self-harm than heterosexual people'* (NIMHE 2007)
- *'LGB people have been shown to be at greater risk of deliberate self harm'* (DoH 2007)
- *'There is at least twice the risk of suicide attempts in LGB people compared to heterosexuals'* (NIMHE 2007)
- *'Discrimination has been shown to be linked to an increase in deliberate self-harm in LGB people'* (DoH 2007)
- **Self-harm and suicide rates:** *The UK's largest survey of trans people (N = 872) found that 34% (more than one in three) of adult trans people have attempted suicide.*

The following figures give an idea of the prevalence of different mental health problems for LGB people compared with the general population. It is based on a review of UK research studies.

Mental health issue	LGB people	General population
Anxiety	18%	5%
Depression	28%-40%	6%
Eating disorders	5%-20%	2%
Self-harm	20%-25%	2.4%
Suicide attempts (lifetime)	20%-40%	4.4%

Meads, Pennant, McManus & Bayliss 2009

Research consistently shows that rates of mental illness and mental distress are higher in LGBT populations which further demonstrates the importance of ensuring equal and easy access to services.

What Did We Do?

In order to gather information for this report and the subsequent audit tool used the following process:

We discussed the audit tool and Service User and Experience-led Outcomes Model at Mental Health Demonstration Project Advisory Group

CAPS staff met with the Mental Health Project Lead to 'fine tune' the process by deciding the best time and place for a focus group, the type of questions that should be asked and the format of the focus group. It was decided that the questions should be as open and non-directional to gather as many views as possible and to ensure the process was as user/experience-led as possible.

We arranged the focus group for Drop In night and advertised this in advance. This was because the Drop In is a very popular event, but also informal. This meant that more people were likely to be there than at a separate focus group but that they would also have the option whether or not to take part, by running the group in a separate room from the Drop In.

CAPS staff met with people in the Drop In and explained why we were there. We spent time before the focus group socialising and giving people the chance to ask us questions so that they could feel more comfortable coming along to the focus group.

CAPS staff ran the focus group which was based around a few open questions – see Appendix - but fairly informal and unstructured to find out people's views. Two people took notes and on person facilitated the discussion

CAPS staff wrote up their notes and this report will be shown to participants for verification before it is circulated

We also designed an online survey to try and capture the views of people who don't use the LGBT Centre.

What Did We Find Out?

'It is good to have spaces where you can be normal'

Many people had very positive experiences and felt they were treated no differently to others who did not identify as LGBT. Some people had used mental health services both before and after openly identifying as LGBT and had not seen any difference in the service and support they received.

It was a good experience because I knew what I wanted and knew how to articulate myself; I lead the process and got what I wanted out of it

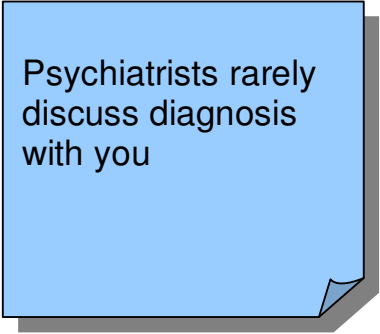
You can go through services where you're accepted, you're not asked and it doesn't matter

There are no barriers if it's acute; you are just another patient on the ward

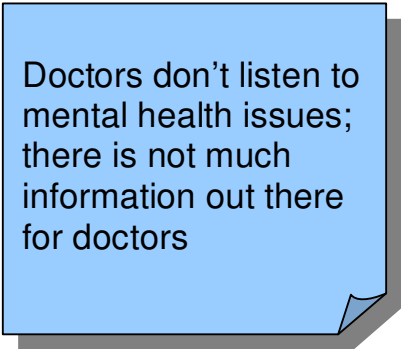
'I wouldn't say there are barriers, but...'

There are not necessarily barriers to using 'mainstream' services but there are issues that would make it easier to use them if they weren't there.

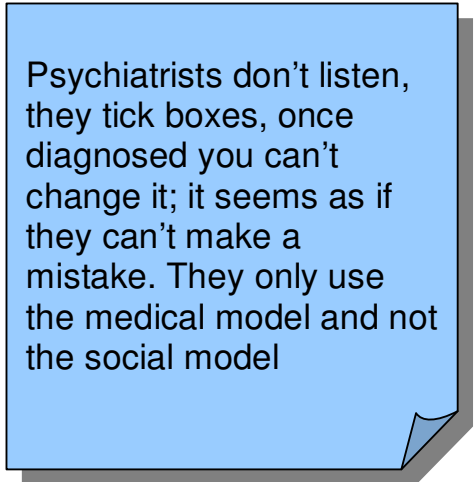
People said that it can be difficult when mental health services are strictly medical model focused.



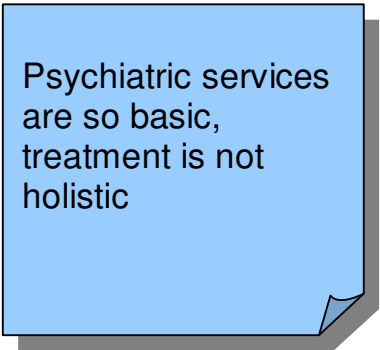
Psychiatrists rarely discuss diagnosis with you



Doctors don't listen to mental health issues; there is not much information out there for doctors



Psychiatrists don't listen, they tick boxes, once diagnosed you can't change it; it seems as if they can't make a mistake. They only use the medical model and not the social model



Psychiatric services are so basic, treatment is not holistic

‘When you are being treated then there are assumptions made’

It can be very difficult when the default assumption that everyone is heterosexual and born the right gender unless they say otherwise. This can come across in the language they use for example assuming your partner is the opposite sex to you. It's important that people are careful about language and respond when you correct them.

The NHS is family obsessed, which is the atmosphere in services. People assume that you're heterosexual

The language is heterosexual, if you say partner they assume it is a heterosexual relationship. They should mirror the language you use.

Subtle things like language make a difference and are a cheap change. Small, but significant. Use the right pronouns in notes

'I feel worn down by it – I don't want to have to argue about it every time'

It can be very difficult if your partner is not accepted in the same way as a partner of the opposite sex is accepted. This can be an issue especially when you are trying to identify emergency contacts or legal issues such as a Named Person.

In terms of a Named Person I ended up having to list my brother as well as my partner instead of just my partner as I'd wanted

The NHS asked 'What is she to you?' which felt intrusive and unnecessary and implies a secondary relationship and is derogatory

*‘As soon as they find out, there is
a different strategy for treatment’*

When you're in therapy or treatment and you say that you identify as LGBT it can lead to different assumptions about you and also why you have mental health issues in the first place.

People treating you can assume there is a causal link between your mental health and your LGBT identity. It would be better to ask the individual if they think being LGBT has any bearing on their mental health.

If a transgender person has mental health problems they assume they are linked and are not treated separately

A psychiatrist said that now that we have this information we have to start looking at your mental health problems differently

There can be a link between LGBT identity and your mental health but this shouldn't be assumed

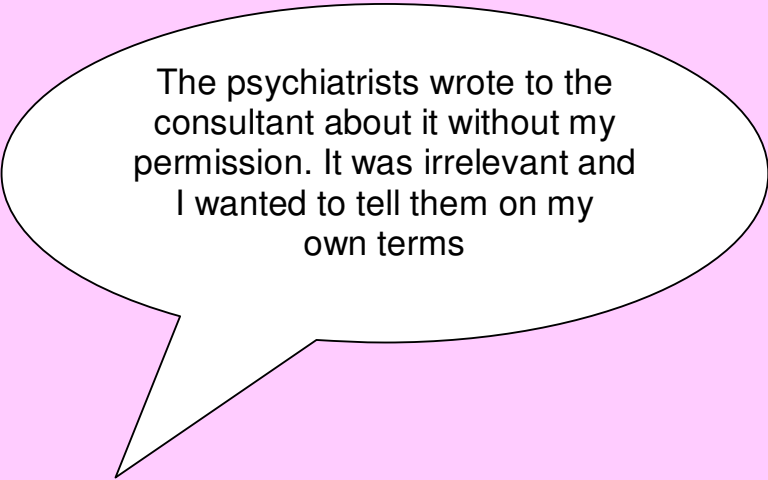
It is possible that mental health and being LGBT are linked but psychiatrists ears prick up when you tell them and assume it is the cause of the diagnosis

CASE STUDY – Owning Your Information

Another issue which arose from this discussion was about information sharing between different staff about your sexuality or gender identity. People felt very strongly that staff shouldn't share information without your permission, especially if it's not relevant to your medical condition but is purely personal information.

CASE STUDY:

A transgender man told a doctor in one area where he was receiving treatment that he was in gender transition. When the man went to an appointment with a different member of staff in a different treatment area it became clear that this information had been shared between the two unrelated departments without his permission and without him requesting this should happen.



The psychiatrists wrote to the consultant about it without my permission. It was irrelevant and I wanted to tell them on my own terms

*‘People can create barriers for themselves;
it’s a two way thing’*

People also discussed the possibility that concerns about using certain services or mentioning your sexuality or gender can also come from your own fears and preconceptions about how people might respond.

If you think that a GP might have an attitude towards you about being gay then you will come in with an attitude in response, this can create a vibe between you both

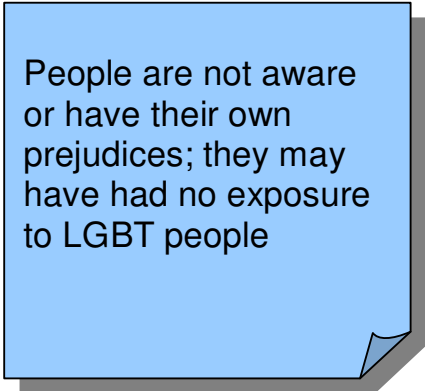
You can have preconceptions about how someone is going to treat you nine times out of ten its fine

'It's an education issue for all staff – it would be good to offer training for staff from people who identify as LGBT'

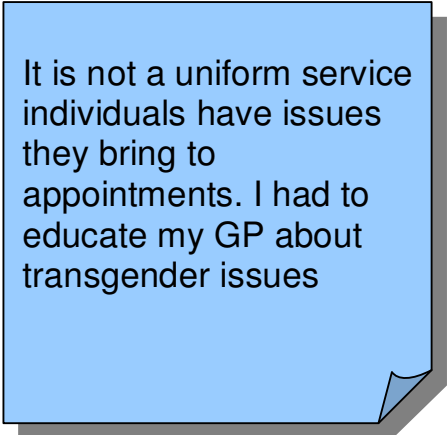
People felt that education and awareness training was an extremely important area.

People also felt that there has to be an acceptance that people who use mental health services and identify as LGBT are a minority within a minority.

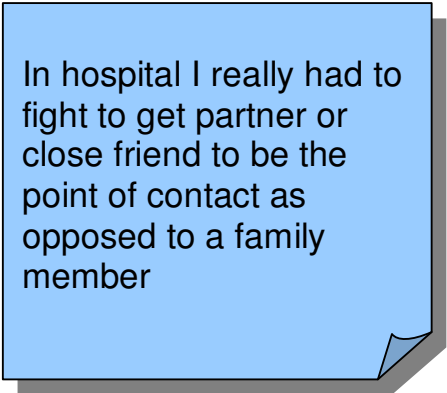
What can be unhelpful is when the service is not holistic or flexible and there is a lack of recognition of a same sex partner or friend as a next of kin.



People are not aware or have their own prejudices; they may have had no exposure to LGBT people



It is not a uniform service individuals have issues they bring to appointments. I had to educate my GP about transgender issues



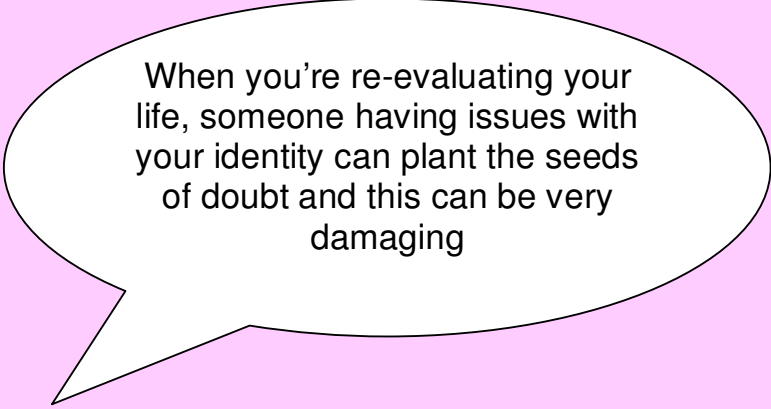
In hospital I really had to fight to get partner or close friend to be the point of contact as opposed to a family member

CASE STUDY – Sexuality as a Given

Pushing your views on someone for example telling them to wear more feminine clothes or act in a more masculine manner is unhelpful, does not accept who they are and is ultimately damaging.

CASE STUDY:


A woman attending counselling found that the counsellor she was seeing focused on her sexuality even though this was not the issue that she was seeking counselling for and was comfortable with her sexuality and identity. The counsellor commented that she should try to act and dress in a more feminine manner. The woman sought out a counsellor who was bisexual and an environment where her sexuality is a given not an issue.



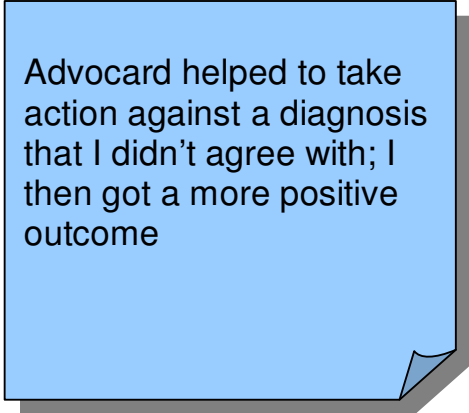
When you're re-evaluating your life, someone having issues with your identity can plant the seeds of doubt and this can be very damaging

'People don't know about CAPS, you need to be steered by GPs or by a pamphlet. If you're acute they legally have to tell you, it is not so clear in other situations'

Advocacy can have a huge impact as it can provide people with information, clarity and can address the power imbalance that exists when people access health services. People should be informed about advocacy as soon as possible when using mental health services.



Health in Mind
information and
signposting was good



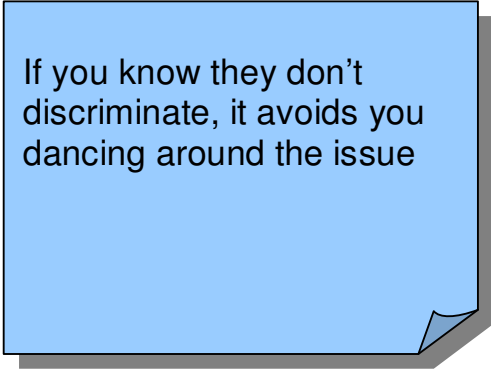
Advocard helped to take
action against a diagnosis
that I didn't agree with; I
then got a more positive
outcome

*'If there are LGBT posters up or a mission statement
then it is a prompt to be able to speak about it'*

A non-judgemental, non-labelling space is very important especially when there can be non-accepting messages coming from 'outside' such as through the media.


It would be good to have a visible statement that the service is both LGBT friendly AND will not tolerate homophobia or transphobia towards clients.

A service should also be happy to discuss these issues.



If you know they don't discriminate, it avoids you dancing around the issue

Some people said it would also be good if staff could be open about their sexuality and you could feel that you were seeing someone who understood where you were coming from.



It is good at the LGBT centres; there is acceptance of being a minority in a minority. LGBT provides a safe space; it is friendly and non-judgemental

*'We're a minority within a minority –
staff need to watch out for discrimination'*

Staff should be aware that homophobia or transphobia can come from other people using the service and should be prepared to tackle this within groups or environments they are working in.

Often it is not the professionals but other service users that are threatening, professionals need to create the safe space

You can't separate services from the people who use them

Due to homophobia in respite I chose not to come out – staff need to respect that and avoid mentioning things that might out you such as referring to 'your partner'

*'Transsexual people are visible,
gay people can choose to disclose'*

It's important to realise some of the issues are different for people who are transgender as this is not something you can necessarily keep to yourself in that way that you can with sexuality.

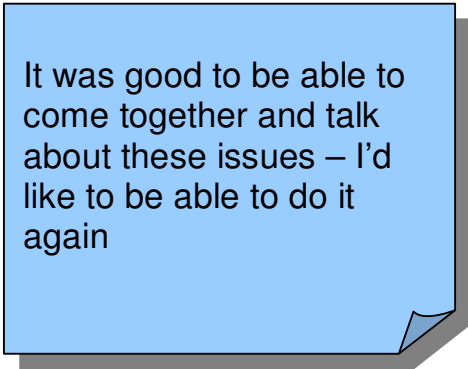
There can be physical health needs that are overlooked when you are in transition and unnecessary treatment offered to you at the same time.

When you change your details, you are told that you may get sent smear tests reminders and that it will be your responsibility to get prostate checks. This also offers anonymity but you can fall out of the prostate checks

If you are transgender you are visible, LGB people can choose what to tell people

*'It's useful to have space to hear
others' views and experiences'*

There is a lot of value in being able to talk to people who have had similar experiences to you, who understand the issues you have and who can validate your experiences.



It was good to be able to
come together and talk
about these issues – I'd
like to be able to do it
again

Conclusions

So what makes a service 'LGBT Friendly'?

A. A Service which Demonstrates Acceptance

This happens when:

- people don't treat you differently
- people don't make assumptions
- you are able to talk about your experiences and feelings
- you are able to talk about your identity if you want to
- professionals being interested in you as a person
- you feel that staff are informed and that the service is personalised
- services lead by example by employing openly gay people – for example it would be good if there were one gay male and female in a service and they could make this known

B. A Service which provides a Welcoming and Inclusive Environment

This happens when:

- there is a friendly and relaxed atmosphere
- the service works with people to create a community
- there is a notice stating zero tolerance of stigma and discrimination clearly displayed and clear information about how to address any issues
- there is information about LGBT services
- even better there could be information on display which actively celebrates LGBT identities, history and culture
- The service recognises that it is not necessarily professionals but other service users that are threatening and professionals work to create a safe space and tackle discrimination
- a service explores something like having a 'Charter Mark' for services that are LGBT friendly, but this mark would have to have integrity and not just be a tick-box exercise

C. A Service which is Clearly Willing to Learn More

This happens when:

- they acknowledge there is an education gap around LGBT issues
- they offer or arrange training and workshops around how to approach people that identify as LGBT
- they work closely with LGBT organisations and other relevant organisations to improve their learning and practice
- they recognise that it's OK to ask people about their sexuality or gender identity, but there has to be a good reason for asking

D. A Service which is Honest about its Limitations

This happens when:

- there is honesty about what can be offered by the service
- someone who is uncomfortable working with people who identify as LGBT is upfront and honest about this
- it signposts to alternative support and safe spaces

Next Steps

CAPS will:

- Circulate the report to the people who attended the focus group for final approval
- Deliver the report to the LGBT Centre for Health and Wellbeing Mental Health Demonstration Project to inform the Audit Tool they are developing
- Share the report with people working in health equalities at local and national level
- Share the report with other mental health services including advocacy services
- Use the report to inform our own practice
- Use the report to inform the 'Lothian Voices' work which feeds back to the NHS Lothian Mental Health Strategy and will inform future service provision and delivery across Lothian

If you have any suggestions about other things CAPS should do with this report or people we should send it to please let us know:

contact@capsadvocacy.org
www.capsadvocacy.org

References

Stonewall Mental Health Briefing:
<http://www.healthyives.stonewall.org.uk/lgb-health/briefings/mental-health.aspx>

National Mental Health Development Unit Sexual Orientation Overview:
<http://www.nmhdu.org.uk/news/mhep/sexual-orientation/>

A Mental Health Strategy for Scotland 2012-2015
<http://www.scotland.gov.uk/Publications/2012/08/9714/7>

Scottish Independent Advocacy Alliance:
<http://siaa.org.uk/>

CAPS – The Consultation and Advocacy Promotion Service;
<http://capsadvocacy.org/>

Advocard:
<http://www.advocard.org.uk/>

LGBT Centre for Health and Wellbeing:
<http://www.lgbthealth.org.uk/>

Appendices

A. Equal Access Focus Group Information Sheet

B. Equal Access Focus Group Questions

C. Equal Access Online Survey

Appendix One

EQUAL ACCESS FOCUS GROUP 17/09/12

What makes a mental health service LGBT friendly or unfriendly?

Who are we?

CAPS is an independent advocacy organisation for people who use, or have used mental health services.

CAPS works with people who have lived experience of mental health issues as individuals or as members of a group to set their own agenda, to find a stronger voice, to get their point across, and influence decisions which affect their lives.

CAPS works and campaigns with a variety of people and organisations and really value our partnership working with the LGBT Centre for Health and Wellbeing.

What are we doing?

One of the aims of the LGBT Centre for Health and Wellbeing Mental Health Demonstration Project is to make a tool that measures how 'LGBT-friendly' mental health services are.

So that this tool is as accurate as possible we think it is very important to ask people who identify as LGBT and use mental health services what they think.

Today at the focus group we will ask a few questions and also give everyone the chance to bring up anything that they think is important.

What will we do with the information?

We will make notes of the things people say – with their permission – and then write them up anonymously. If you want to see the information we have written up we can send it to you. We will share this with the LGBT Centre for Health and Wellbeing to help them develop the measurement tool.

If you would like to continue to be involved in the process of developing this tool please let us know.

Thanks very much for taking the time to be here and giving us your views

Naomi, Donna and Kirstin from CAPS

If you have any questions or would like to discuss the issues from the focus group in more depth please contact us on the details below.

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Appendix Two

EQUAL ACCESS FOCUS GROUP 17/09/12

What makes a mental health service LGBT friendly or unfriendly?

- Are there barriers to accessing mental health services as an LGBT person?
- What would make you feel comfortable using a service?
- What would make you feel uncomfortable using a service?
- What would demonstrate that a service is LGBT friendly?
- Have you got any examples of good experiences using mental health services? What made this a good experience?
- Have you got any examples of bad experiences using mental health services? What made this a bad experience?
- Are there any specific barriers to using advocacy services? What would help to make access easier?
- Do you feel there are different barriers or issues around sexuality and gender?
- Is there anything else you'd like to comment on that you think is important?

If you would prefer to give us your answers to us directly please get in touch with us on the contact details below:

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5 Cadzow Place, Edinburgh, EH7 5SN

Phone: 0131 538 7177
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Appendix Three

Online Survey - Equal Access:

What Makes a Mental Health Service

LGBT Friendly or Unfriendly?

Introduction:

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CAPS - The Consultation and Advocacy Promotion Service is an independent advocacy organisation for people who use, or have used mental health services.

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CAPS works and campaigns with a variety of people and organisations and really value our partnership working with the LGBT Centre for Health and Wellbeing in Edinburgh.

What are we doing?

One of the aims of the LGBT Centre for Health and Wellbeing Mental Health Demonstration Project is to make a tool that measures how 'LGBT-friendly' mental health services are.

So that this tool is as accurate as possible we think it is very important to ask people who identify as LGBT and use mental health services what they think.

In this survey we will ask a few questions and also give you the chance to mention anything that you think is important.

We would especially like to hear from people who don't use the LGBT Centre for Health and Wellbeing services currently.

What will we do with the information?

We will collect everything people write in the survey and then write them up anonymously. If you want to see the information we have written up we can send it to you. We will share this information anonymously with the LGBT Centre for Health and Wellbeing and other health agencies to help them develop the measurement tool.

If you would like to continue to be involved in the process of developing this tool please let us know.

Thanks very much for taking the time to give us your views.

Naomi, Donna and Kirstin from CAPS

If you have any questions or would like to discuss the issue in more depth please contact us on the details below.

Naomi Salisbury or Donna Strachan

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Questions:

Where do you live?

For the purposes of answering this survey which sexual orientation and gender identity do you identify with?

Are there specific barriers to accessing and using mental health services as an LGBT/QIA person? If so can you tell us what these are?

What do you think demonstrates that a service is LGBT/QIA friendly?

Have you got any examples of good experiences using mental health services as an LGBT/QIA person? What made these experiences good?

Have you got any examples of bad experiences using mental health services as an LGBT/QIA person? What made these experiences bad?

Do you feel there are different issues that are important in using mental health services for people who identify as lesbian, gay or bisexual and for people who identify as transgender? If so what do you feel the differences are?

Is there anything else you would like to say that you think is important?

If you would like to be kept informed about the progress of this work please leave contact details here. Your details will be stored separately from your answers.

Thank you very much for taking the time to fill in the survey.

Further Information

For more information about our work or to discuss this report further please contact:

Naomi Salisbury or Donna Strachan

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