Community Mental Health Transformation
Lived experience Survey Report
LGBTQIA+ Communities

June 2024

Contents

Introduction

In April 2023, Inclusion Gloucestershire and the Gloucestershire VCS Alliance ran a survey of people's experience of mental health support. This survey aimed to identify mental health issues or concerns, understand which services people currently access, what they have found helpful, and whether they experience challenges in getting their needs met.

The survey was run as part of the Community Mental Health Transformation programme. This is a partnership between the NHS, voluntary and community sector organisations and groups, social enterprises, housing providers, and social care. More information about community mental health transformation in Gloucestershire can be found here: https://www.ghc.nhs.uk/cmht/

A report of the survey results was published in May 2023. This report can be found here: https://www.inclusiongloucestershire.co.uk/wp-content/uploads/Inclusion-Gloucestershire-Community-Mental-Health-Transformation-Lived-Experience-Survey.pdf

This report noted that some people were less likely to have taken part in the survey. There were very few responses from people who identified themselves as belonging to the LGBTQIA+ community.

We were keen to learn and understand more about the experiences of people with these identities. With support from the Gloucestershire LGBT+ Partnership, and NHS Gloucestershire's Engagement team, the same survey was shared across LGBTQIA+ networks in the county in January 2024.

Content Warning

As this report focuses on people's experiences of mental health services, it may contain information that some readers find distressing. This report mentions:

- Suicidal ideation, self harm and experience of mental illness
- Upsetting experiences of accessing health care and support

How we found out what people think

We used the same survey questions that were used in April 2023 for the original report, so that the data we collected would be comparable.

A group of people had worked together to develop this survey in a co-produced (joined up) way. This group involved staff members from Inclusion Gloucestershire with lived experience of mental illness, NHS Gloucestershire Engagement staff and LGBT+ Partnership Cheltenham and Gloucestershire volunteers.

The survey was open for 7 weeks between 15 December 2023 and 31 January 2024. The survey was available online and in paper versions. Support was available to anyone on request to have help to fill out the survey on the phone or in person.

Information about the survey was shared throughout Gloucestershire via social media and email networks by organisations including FFLAG Cheltenham, Gay Glos, Pride in Glos, Stroud Pride, Gloucestershire Gay and Lesbian Community and the LGBT+ Partnership Cheltenham and Gloucestershire.

How many people told us what they think

29 responses were received to the survey. All of these were online through a Google Forms Survey.

No requests for the survey in an alternative language or format were received.

All respondents consented to be involved so have been included in the summary of results below.

Of the 29 responses, 13 people (45%) gave us their name and contact details for further contact, whilst 16 (55%) people preferred to be anonymous.

Who told us their ideas and opinions

41% identified themselves as female.

24% identified themselves as male.

28% identified themselves as non-binary.

7% identified themselves as other.

72% of respondents were under 35. The largest groups of people who gave us their ideas were aged 18-25. Just 7% of people were aged 66-85.

97% identified themselves as White British.

100% of respondents identified themselves as belonging to the LGBTQIA+ community.

79% identified as having a long-term disability or illness.

Most people live in Gloucester, but there were respondents from all 6 Gloucestershire districts.
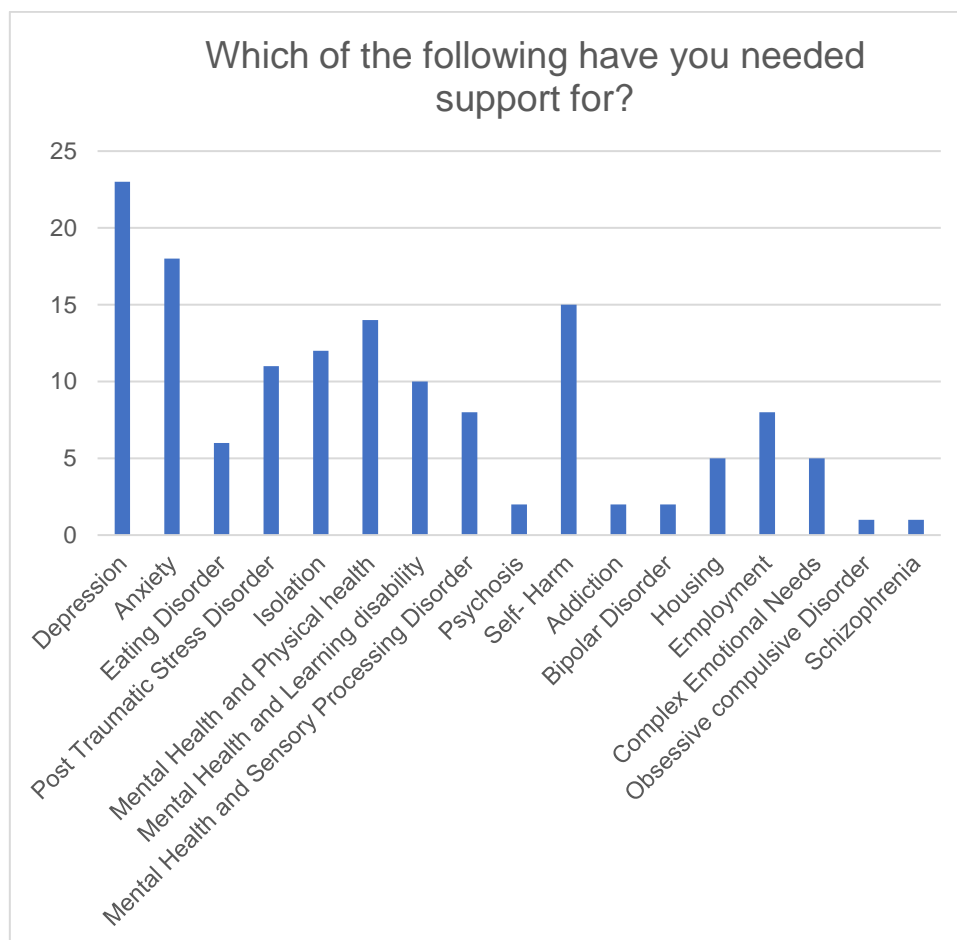
WHERE ARE YOU BASED?

■ Cheltenham ■ Cotswolds ■ Forest of Dean ■ Gloucester ■ Stroud ■ Tewkesbury
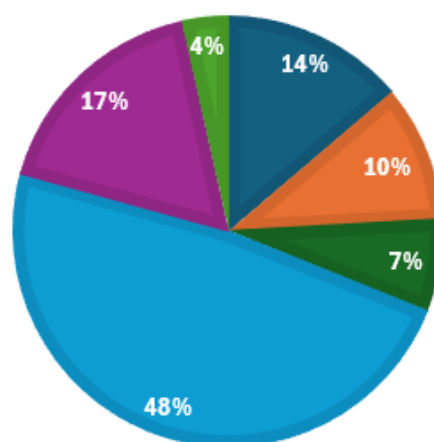
Lived experience and areas of support

We asked people to tell us about the areas they have needed support for.

- 2 people did not respond to this question.
- 100% of people told us they had needed support in more than one category.

People also told us about other support they have needed including:

- Autism x 4
- Gender Dysphoria x 3
- Transgender Physical health
- Attention Deficit Hyperactivity Disorder (ADHD)
- Homelessness
- Restorative Justice
- Complex Post-Traumatic Stress Disorder (PTSD)
- Post Natal support

- Social Anxiety
- Borderline Personality Disorder

Highlight of results

66% of people who responded consider that they, or someone they care for, has a Serious Mental Illness. 28% of people said they provided unpaid care or support for a family member or friend with mental health needs.

54% of respondents are volunteers, or professionals who regularly support people with serious mental health needs and 60% of these respondents would like to meet with other volunteers/professionals to reflect, support each other, and share learning.

90% of respondents have needed support for their mental health over the last two years and identified the following organisations/ services that they received support from:

- NHS online therapy – silver cloud
- Mental Health Intermediate Care Team (MHICT)
- Crisis Team
- Accident & Emergency (A&E)
- Let's Talk
- Gloucestershire Rape and Sexual Assault Centre (GRASAC)
- GP
- Young Gloucestershire
- Samaritans
- Shout
- Recovery Team
- Eating Disorders Service, Brownhill Centre
- Wotton Lawn
- Health in Mind
- Private Therapy via employer
- The Listening Post
- Teens in Crisis (TIC+)
- Restorative Gloucestershire
- Supported Housing
- NHS Autistic Spectrum Disorder (ASD) and ADHD referral

- Complex Emotional Needs Service
- Oviva (Diabetes prevention) Programme
- Independence Trust
- Gloucestershire County Council Enablement Team
- Gloucestershire Counselling Services

28% of these respondents said they had received or begun to receive the support that they needed. There were some positive comments about the support received:

"A few weeks of therapy helped me come to terms with what happened."

"Counselling sessions helped me get back on track and gave me methods to use to help me with my mental health".

Other respondents noted there were some gaps in the support they had received:

"It took a long time, was told I wasn't serious enough so put on waiting list for let's talk, then told I was too complex for that, then got worse and got into crisis and took another month after an attempt to finally get support"

"Yes and no, I'm in a better place but talking therapy was mostly not useful and i am still on waiting lists for autism and trans stuff"

"I have only just started it was not quick enough."

Significantly, 62% of people told us they felt they didn't get the support they needed. Some told us more about their experiences and identified barriers to accessing appropriate services, particularly where there are coexisting conditions e.g. neurodivergence or substance misuse and lack of trauma-informed, holistic, person-centred support. Some people told us this had implications for both them and their wider family.

"I feel I have a lot of health concerns that are not being met by the NHS particularly around trans healthcare, and neurodivergence (adhd and autism). They offer some mental health services but without actually supporting the causes of my depression and anxiety."

"Although the charity young Gloucestershire worked with me for about a year and provided mental health support, I have been on a Gender Identity Clinic waiting list since 2018 and have never

received professional help. I also received minimal help from professionals when I lived in temporary accommodation and was unemployed and not in education."

"I feel as if my problems were dismissed and skirted around. Previous attempts to get help have left me feeling unheard and invalidated."

48% said travel and/or location <u>was</u> a barrier to accessing in person support, advice and information.

People told us more about these barriers including availability and reliability of public transport, the impact of mental health which can make using public transport more difficult, accessibility of public transport for those with coexisting conditions including sensory impairment and physical disability, those who are unable to rely on family or friends to travel to appointments and those who work and would not be able to travel long distances to get support around their work commitments.

"Public transport has always been prohibitively difficult for me (autism, sensory issues, anxiety) and my physical health is now a barrier too. Unless a subsidised taxi service is available I can only manage to reliably access places ≤1 mile from my home."

"Having to travel longer distances can be daunting, even travelling somewhere local can be difficult if you struggle to leave your house because of mental health issues."

31% of people said travel and/or location would not be a barrier to accessing in person support, advice and information.

"I can drive, as long as there is available parking I can travel and if I was told that my partner could access treatment that would seriously improve their mental health but we needed to travel I would have no issue in getting them there."

"I'm a student, i live fairly centrally and have access to a car. If i didn't have a car i would struggle as bus routes are not good to various places."

"I'd go anywhere to get the correct help."

41% of people told us that accessing support, advice or information online would not be a problem. Some people told us that they would prefer to access support online and were able to do this. Others told us

that whilst they would be able to access support online they had concerns around this replacing face to face support and concerns about security:

"I have internet and prefer online to enforced phone calls."

"I have access to the internet however I do not agree with offering online support as a replacement for face to face support. Online support it limited on the benefits it can offer."

"I can use the internet fine, but I am always suspicious of the online space due to all the bots and false information. The other major issue is that if there is a lot of information to process, it is really easy for me to shut down."

21% of people told us that there would be barriers to accessing support advice or information online. Some people identified issues with equipment or where to find appropriate support, others identified motivation as a challenge to accessing support online:

"There are not physical barriers to accessing online support however the can be issues of motivation particularly with depression."

"Easier to forget and struggle with changing platforms being used."

Local challenges

The things people told us they would find most valuable in their local area were:

Trained mental Health Worker – **97%** of people said this would be very valuable or quite valuable to them.
Community Advocacy –**93%** of people said this would be very valuable or quite valuable to them.
Person with personal experience of Mental Health recovery - **83%** of people said this would be very valuable or quite valuable to them.
Local Information Point or Phoneline – **79%** of people said this would be very valuable or quite valuable to them.

The things people told us they would find the least valuable in their local area were:

One to one buddying (Peer mentoring or befriending). For a time limited period, limited sessions – 41% of people said this would be valuable to them, and **17%** said it would not be of value to them.

Access to learning and training on mental health and recovery – 59% of people said this would be valuable to them, and **14%** said it would not be of value to them.

One to One buddying (Peer mentoring or befriending) fluid and variable – 59% of people said this would be valuable to them, and **14%** said it would not be of value to them.

We asked people what would be valuable to support their mental health or the mental health of people they support and what challenges exist for them. People told us local and timely support would be beneficial. A greater awareness of neurodivergence and autism for professionals would be helpful as well as specific support being available, more safe spaces in the community, more support for those who are transgender, more acceptance and less stigma around mental health and LGBTQIA+ communities and employment support.

> *"One to one access to a professional quickly."*

> *"Having access to support for specific issues, for me it would be my experience with being trans and neurodivergence."*

> *"The challenges that I have faced is the stigma towards mental health which in turn reduces the help and support available."*

> *"Just more designated spaces. Spaces I as an ND with sensory problems can go that are quiet and i can see others, without being my bedroom at home."*

> *"It is a challenge for someone to get support for transgender need. I've been in need for the past 4+ years and still have not got any support from the NHS or even private services.*

> *It is also a challenge for someone like me who lives alone and struggles heavily with depression and anxiety to get anything done, so having someone who can help go through with all of my specific needs and help organise them and help me gain access would be invaluable."*

> *"More acceptance of LGBT people in our community."*

We asked people what challenges exist for them or the people they support, in accessing good mental health support in their community. There were common themes including:

- Lack of suitable services (47%)
- Waiting lists and timeliness of support available (27%)
- Navigating services and knowing what is available (20%)
- Cost (13%)

> *"Told I'm too complex for let's talk due to mental health history even though that was the past and current problems weren't complex, but then told I wasn't serious enough for NHS support. Lead to no help and eventual crisis."*

> *"Based on my experience it's mostly hard to find a group because they don't really get talked about all that often where I am."*

> *"Feeling worthy, finding right groups."*

> *"Financial barriers. Everything costs money."*

Safe Spaces

People told us which community groups, spaces or resources that currently exist, which respondents or those they care for have felt safe at and were supportive of positive mental health. 66% of respondents provided responses to this question. 47% of people who responded said they had not found or could not identify a safe space in their community. Other responses included LGBTQIA+ specific spaces, groups or resources:
- Trans in Gloucestershire (11%)
- Gloucestershire Group Counselling for LGBTQIA+ communities
- Trans Men's Support and Advice Facebook group

There were a number of voluntary sector organisations identified including:

- Art Shape
- The Door Youth Service
- The Nelson Trust
- Samaritans
- Gloucestershire Rape and Sexual Abuse Centre (GRASAC)

Some spaces/ resource and groups were identified that don't have a primary mental health focus including:

- Community Dance Groups (Stroud)
- Private gym

Public sector services were less commonly identified, but included:

- Adult Education Gloucestershire
- Gloucestershire County Council Family Support/ Children's Social Services

We asked people what made these groups/ spaces and resources feel safe.

- The attitudes of the staff/other people who attend
- Shared identity/experience
- Non-judgemental
- Ease of access/ timely support

> *"A couple of personal mentors I can contact by email with expectation of a reply within 24 hours, who can talk me through options and possibilities in most circumstances."*

> *"The people I communicated with were calm and non-judgemental."*

> *"Non-judgemental, real-life experience, people who have similar experience to you community, easy to access - no barriers."*

> *"A safe space to connect with others that share my LGBTQIA identity and process my feelings in a held group."*

What has this told us

There are some significant differences in the responses we received from individuals identifying as belonging to the LGBTQIA+ community and from the general population responses we receive in our May 2023 survey. These include:

Symptoms:

Gender dysphoria and transgender mental and physical health appear as other areas where people from LGBTQIA+ communities need support and did not appear in the general population. 39% of respondents identified as experiencing gender dysphoria and/or identify as non-binary. Of these respondents 73% told us they self-harm, and one of these has told us they have attempted suicide.

Self-harm (48% - 3rd highest category) and isolation (41% - 5th highest category) are more commonly identified by people from LGBTQIA+ communities as areas where they need support than the general population.

Support:

None of the services identified by LGBTQIA+ respondents as being accessed in the last 2 years are specific LGBTQIA+ groups or services. Only 11% of respondents identified Transgender spaces that were supportive of mental health. Only 1 person identified a counselling group for the LGBTQIA+ community. This is a critical gap when we look at the high incidence of isolation experienced by respondents.

Just 29% of LGBTQIA+ respondents said they had managed to receive, or started to receive, the support they needed. This is significantly lower than the general population respondents (45%). A number of respondents also identified coexisting conditions as a barrier to the services they can access.

36% of respondents who identify as transgender and/or non-binary told us about their challenges with NHS wait lists, with at least one individual waiting since 2018 with no alternative support provided by statutory services. This identifies a care gap for patients experiencing gender dysphoria. The wait lists for these services can be 4-6 years before diagnosis begins.

What we think is needed

There are common themes in what people would find helpful in their community for both LGTBQIA+ respondents and general population responses. These include:

- Trained mental health professional

- Person with lived experience of mental health recovery
- Community based advocacy

Both surveys told us that there is a preference to move to needs based service rather than diagnosis/ criteria led and that people want more communication and support in accessing and navigating services.

From the data we have gathered from LGBTQIA+ respondents, we specifically recommend:

1. The Integrated Care Board review the identified care gap and local pathway for those experiencing gender dysphoria to ensure timely referral to gender affirming health treatment. Providing early diagnosis and support is critical if we are to reduce the harm being suffered by these patients, and by the family and friends who are trying to sustain them.

2. Review of resources available for service delivery staff to support awareness of intersectionality and provide person-centred, gender and sexuality affirming care and treatment.

3. Those delivering mental health services have training and awareness of intersectionality and provide person-centred, gender and sexuality affirming care and treatment. Wherever possible this should be codesigned and delivered by those with lived experience.

4. Specific facilitated connection between LGBTQIA+ groups and the locality partnership networks and community mental health teams, so that there is more joined up support available providing relevant and safe connection around sexuality and/or gender identity to meet the identified need around isolation for this community.

This data has been focussed on 18+ adult population, we recommend that for youth services a separate workstream and research is undertaken.

Thank you

We would like to thank everyone who took part in this survey project. In particular, to those who shared their experiences, we understand that sharing your experiences can sometimes be challenging and we thank you for speaking up. We also want to thank those who volunteered their time to this work and shared the survey through their networks. We will use your feedback to help shape improvements to mental health services.

Appendix

Definitions

We have used the following terms in the report, to reflect what we believe to be the most accurate and inclusive based on the views of people with lived experience.

Gender/ sexuality affirming interventions designed to support and affirm an individual's gender or sexual identity.

Intersectionality a concept for understanding how aspects of a person's identities combine to create different and multiple discrimination and privilege.

LGBTQIA+ this is an abbreviation for Lesbian, Gay, Bisexual, Transgender, Queer/ Questioning, Intersex and Asexual. The + is used to describe all of the gender identities and sexual orientations that letters and words cannot describe.

Trauma-informed a strengths-based approach to support, which seeks to understand and respond to the impact of trauma on people's lives.

inclusion-glos.org

cmht@inclusion-glos.org

01452 234 003