



THE CARERS CENTRE FOR BRIGHTON AND HOVE

MIND THE GAP

MARCH 2021

An engagement study/report on the barriers to accessing NHS and voluntary sector support, experienced by carers who identify as LGBTQ+, carers from diverse ethnic backgrounds and carers from Gypsy, Roma, Traveller communities (GRT).

Contents:

- Page 2: Background and Local Context
- Page 3: Aims and Details of the Project
- Page 4: Successes and Challenges
- Page 5: Findings
- Page 8: Sustainability and Dissemination
- Page 9: Recommendations
- Page 10: Summary
- Page 11: Case Studies
- Page 14: Other Quotes from Carers

1. **Background:** i.e. a brief summary of why you focused on this community. What evidence is there?

The project focused on engaging with carers who identify as LGBTQ+, carers from diverse ethnic backgrounds and carers from Gypsy, Roma, Traveller communities (GRT).

We know that some carers do not feel confident in accessing support from NHS services, which in turn can lead to poorer physical and emotional well-being. There is evidence from sources such as the GP patient survey and the State of Caring survey that carers face inequity as a result of their caring role (NHS Long Term Plan 2019).

Evidence from surveys carried out in 2020 showed that people from LGBTQ+ Communities, Black, Asian and diverse ethnic communities were disproportionately affected by Covid 19 and experiences of lockdown. 'Hidden figures', a survey carried out by the LGBT Foundation found LGBTQ+ people reporting significant difficulties in accessing medical care or care for their mental health (LGBT Foundation 2020).

A local survey carried out by Trust for Developing Communities and partners in 2020 with people from diverse ethnic groups (including refugees and migrants) highlighted that 49% had negative experiences of accessing the NHS. This included communication and language difficulties, cancellation of appointments often leading to poor health outcomes and perception of discriminatory treatment.

Members of GRT communities are expected to live between 10 and 25 years less than the wider population and to spend less years of their lives in good health. The way that health and social care systems have been designed can often make it more difficult for members of these communities to access the support, care and treatment they need (Friends Families and Travellers Website).

2. **Local context:** what was the situation in your system before the project started

Prior to applying for the 'Mind the Gap' funding we had established a successful pilot "Inclusion Project." This project began in February 2020. As part of this project we had been working to develop tailored support to engage carers who identify as LGBTQ+, carers from Black, Asian and diverse ethnic backgrounds, and carers from Gypsy, Roma, Traveller backgrounds.

Since June 2020 a regular Zoom peer support group for carers who identify as LGBTQ+ has been set up, as well as additional 1-2-1 casework support for carers from these groups. We were also successfully awarded funding from the Carers Trust in August 2020 to work on digital engagement for carers from the backgrounds highlighted. We were able to provide 18 free laptops/tablets for digitally excluded carers and provided a series online activity workshops from August to December 2020.

We have also been working on improving the accessibility of our services and are keen to find out more from carers about how we can reduce the barriers they face in accessing support.

In addition to this project we have a quarterly Carers Voice panel facilitated by our Engagement Lead. Through participation in the programme, carers gain peer support and knowledge to sustain their caring role.

3. **Aims and Objectives of the Project-** i.e. what did the project try to achieve? You may want to copy the aims and objectives from the original bid submission adding your local context

- A broader, deeper, evidence-based understanding of the barriers which prevent carers from underrepresented groups from accessing support
- Service improvements as defined by carers that can be implemented by our organisation, The Carers Centre for Brighton & Hove
- Improvement recommendations for local NHS trust services that will reduce health inequalities. We have a Primary Care worker we can liaise with so that recommendations are seen and where possible agreed with Trusts and Practices
- Develop resources which will be sustainable and can be integrated into our service e.g. translated documents, Easy Read, video and audio information, development of representatives in Expert groups, links with religious groups
- Develop resources in line with needs identified through co-production
- Strengthen co-production across the organisation, working towards a more diverse Carer Experts programme for example
- Forge and embed robust and consistent links with external organisations which will lead to greater sustainability and diversity of referrals

4. **Details of the Project:** please summarise the activities that took place during the lifetime of the project. How were stakeholders central?

In November 2020 we put together a survey. It included demographic based questions such as how carers identify their ethnicity, their gender and sexual orientation. We also asked about experiences of Covid-19 on carers' lives and what support they had received this year. We subsequently asked questions about barriers that carers feel they have faced when accessing services. In later questions, we asked about what might help to make services more accessible and what sort of support carers feel is important for them.

The survey was sent to all carers known to us who identify as LGBTQ+, or are from Black, Asian and other diverse ethnic backgrounds, including Gypsy Roma and Traveller communities. It was sent out in both electronic and paper forms, including 10 surveys translated into Polish, French, Arabic, Farsi and Turkish. These were languages which we identified as more commonly requested by those carers referred to us. The survey was sent electronically to 140 individuals in December and 40 paper copies of the survey were posted to non-digitally engaged carers.

The survey was also shared with other relevant partner organisations in Brighton including Trust for Developing Communities, Sussex Interpreting Service, Friends, Families and Travellers, LGBT Switchboard and Mind OUT.

In December 2020, 3 focus groups were run via Zoom. These were aimed at consulting more deeply with carers about their experiences of accessing NHS services and barriers which they may have faced. One group aimed to consult specifically with LGBTQ+ identifying carers. We also held 2 focus groups to consult with carers who identify as Black, Asian or from diverse ethnic backgrounds, at different times of day.

Some carers who were known to us were emailed directly to invite them to the focus groups. A number of these individuals were carers who are registered to our carer engagement panel, Carers' Voice. Details about the focus groups were advertised within our weekly activity bulletin for carers, on social media and with other relevant partnership organisations.

In addition, some carers contacted us who would prefer to have an individual discussion over the phone rather than attend a computer-based group. We adapted the focus group questions to make them suitable for a short telephone interview. We also worked in partnership with Friends, Families and Travellers in Brighton to identify some carers who we would invite to speak to us over the phone.

5. What went well and why? Reflecting on your experience, what were the successes of this project

We had a good level of response to our survey with some useful and detailed responses about experiences of accessing services, and barriers faced.

In carrying out the survey we have strengthened our working relationships with some local organisations, especially Sussex Interpreting Services, LGBT Switchboard and Friends Families and Travellers.

We have been able to gather some rich, in-depth data from the carers that we have spoken to so far in focus groups. We were successful in creating spaces over Zoom, where carers felt comfortable to share openly and honestly with us, and each other which we were really pleased about. One advantage of having smaller groups is that it did create a more relaxed, informal space, with plenty of time to allow each participant to fully share their stories and experiences.

Some of the best engagement we had for both the survey and focus groups, was from carers who we already had an established and trusted relationship with. Some of these were carers who regularly attend the LGBTQ+ peer support group. Other carers who engaged in focus groups were those who regularly participate in Carer's Voice consultations or attend the Working Carers group. It is felt that those who did attend may have felt more comfortable and accustomed to the experience and dynamics of a Zoom group and also more confident with using the technology. They may also have felt more comfortable with Steve or Louisa as facilitators as they have attended groups run by them before.

In terms of project delivery, we found that it was an asset for our Inclusion Worker Louisa and our Engagement Lead, Steve to work closely together. Although both were working remotely they were able to meet via Zoom every week to ensure that they could plan and initiate all elements of the project in a timely fashion and meet all deadlines set.

6. What difficulties were found in carrying out the tasks? Challenges you faced during the project- how did you overcome them?

In hindsight, engagement levels may have been better if we'd run the focus groups at a different time of year, rather than in the lead up to Christmas when carers have many other demands on their time. During the winter lockdown many carers reported feeling additional strains on their mental health which may mean they would be less inclined to want to attend a group/speak on camera.

Another issue that we were mindful of was that there were other carer-related consultation projects happening at the same time and also several other surveys that had taken place locally in recent weeks to capture experiences of lockdown. We were aware that for some carers they were feeling saturated with surveys and may not have been as motivated to take part.

If we had not had the limitations of the pandemic and lockdown it would also have been beneficial to offer groups both in person and via Zoom to improve engagement levels. For some carers they would be more likely to engage in a face-to-face group, at a location familiar to them. Although we also recognise for carers with anxiety or who find it difficult to leave their dependant that groups run via Zoom have been really helpful.

For the carers from the traveller site, we identified in conjunction with Friends Families and Travellers that the best way to engage the carers would be to visit the site in person and to run groups in conjunction with them. Unfortunately, only phone contact was possible due to lockdown restrictions.

We are also very mindful that, as with accessing many aspects of our service during Covid times, that not being digitally engaged continues to be a barrier, particularly for some of our older carers. Some carers have told us that even if they have the technology, they don't feel happy/confident to access groups via Zoom. 2 carers did contact us to tell us that they would take part if we could talk over the phone rather than join a Zoom group. We were then able to contact them individually to go through the focus group questions so they could still be involved.

Although we were able to identify those who did not have email addresses to distribute paper surveys, we did not have the resources/time to directly contact those carers to follow up with offering digital support if they needed or wanted it. This could be something we could follow up on at a later stage.

When analysing our findings from the focus groups it was difficult to draw general conclusions from a smaller sample size, particularly as individual experiences were so varying.

7. Were the project objectives and outcomes achieved? Were the project objectives and outcomes achieved and how did you measure this? Refer to key milestones and include any changes from the original plans that resulted as part of your activity.

We created and distributed a survey in November 2020 to all carers identified to us as LGBTQ+ or from diverse ethnic backgrounds and Gypsy Roma Traveller (GRT) communities. In total 24 carers completed the survey.

In December 2020, as planned, we ran 3 focus groups on Zoom. 6 carers attended and participated in the focus groups.

- 3 carers attended the LGBTQ+ focus group
- 3 carers attended the focus groups for Black, Asian, and diverse ethnic backgrounds

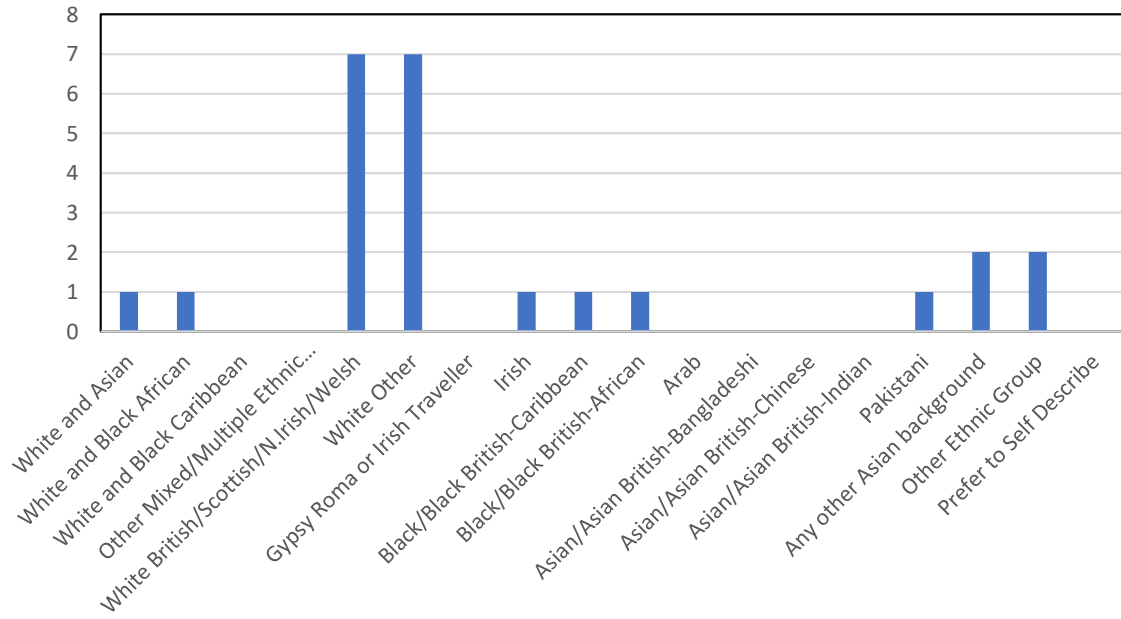
We interviewed 3 carers over the phone - 2 carers who identify as LGBTQ+, and 1 carer who identifies as from a GRT background.

In January and February 2021, we analysed the findings of the survey and groups, and began to compile recommendations. In March we compiled case studies and evaluated recommendations based on the Place Based Approach.

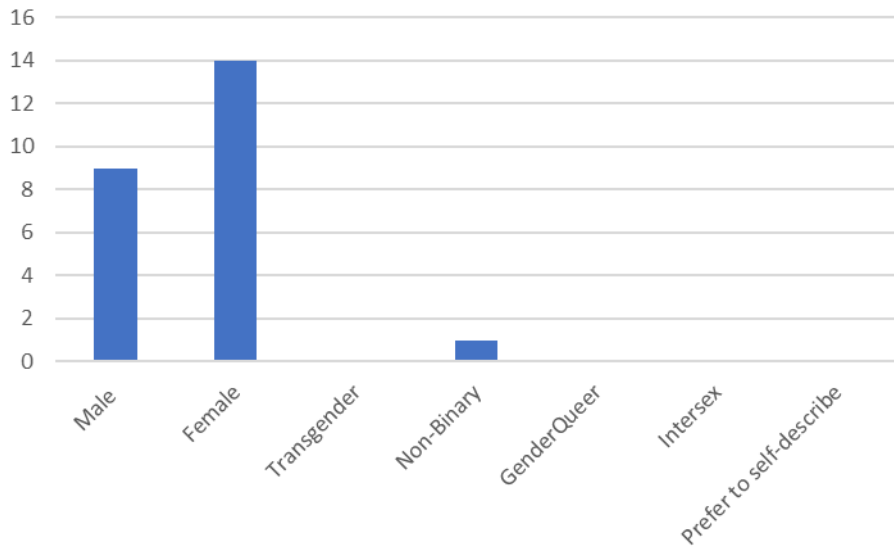
Survey findings

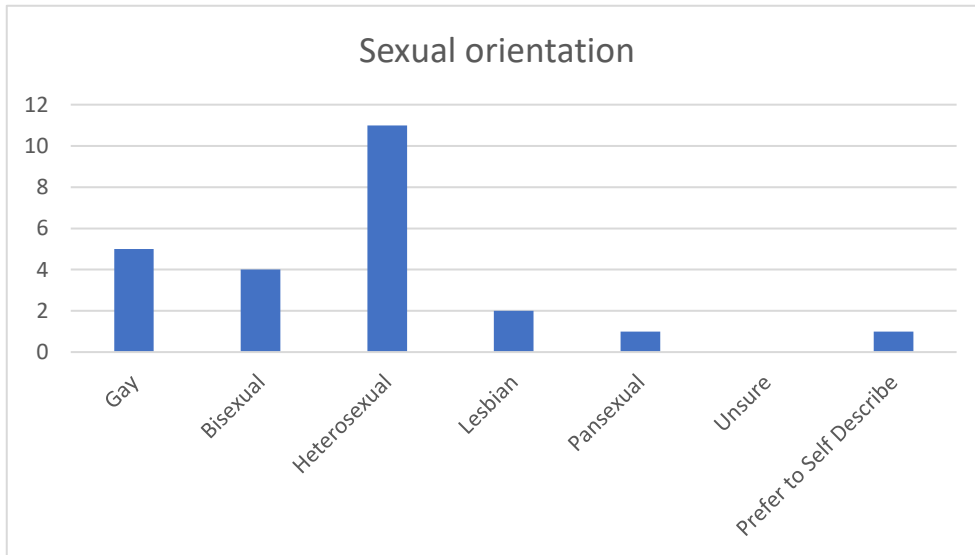
Survey results (24 replies):

Demographic - Ethnicity



Gender





Experiences of Covid and Lockdown

- Feelings of boredom and frustration featured highly, many stated having experienced mental health difficulties during the pandemic, including anxiety depression, and feelings of isolation
- 50% of respondents said support for mental health and emotional wellbeing would be helpful.
- Carers worried about keeping themselves and loved ones safe
- A frequent concern was that there was a lot of initial contact from local services in the early months of Lockdown which then tailed off, leaving carers unsure which services to turn to for help
- Carers felt a more regular 'proactive' contact from services would help
- 3 carers voiced a lack of support for caring for someone with dementia
- Frustration at only being able to speak to GPs over the phone

Barriers to services

- Only 10.53% of survey respondents indicated there were no barriers to accessing services
- Several respondents felt more information was needed in alternative formats such as translation/videos
- Many carers felt that they had to fight for everything
- Carers felt they often needed to prove their entitlement to services, particularly if they had moved to the UK from abroad
- Frustration that many services are phone based – presenting a problem for English second language speakers
- 45% of respondents said they would use online groups to meet other carers
- Some felt that they did not want to or did not feel confident to access online support
- Others felt the technology was too unreliable

Focus Groups and 1-1 interviews

Experiences of accessing NHS services-positive and negative

- 2 carers stated no barriers existed for them when accessing healthcare. This included 1 GRT carer
- Experiences with local GPs in Brighton and Hove were mixed and depended on the practice/individual GP. One carer couldn't give enough praise for The Pavilion Surgery and how helpful they were in offering home visits.
- Frustration in accessing NHS Mental Health services. One carer found their GP to be dismissive of mental health issues and chose to access counselling at a local LGBTQ+ charity Mind OUT instead. They found this service excellent, and beneficial to speak to a worker who also identified as LGBTQ+
- Frustration at telephone only support by GPs during lockdown
- Emergency services were praised highly by carers who had needed to use them this year

Experiences unique to being LGBTQ+/GRT/ or from a diverse ethnic background

- Carers talked about experiencing direct discrimination. One carer reported experiencing racism at a local hospital
- A carer from America reports that they are continually asked for proof of entitlement to free NHS services
- In the LGBTQ+ focus group, carers talked of assumptions being made about the relationship between them and those they cared for. One carer spoke of an upsetting experience when asked if her wife was her sister
- For one LGBTQ+ carer they felt that services discriminate against LGBTQ+ people wanting to start a family. Free IVF is not available and private clinics are very costly
- Difficult experiences led to many not wanting to access those services again or disclose information
- Some felt they had had no problems recently in relation to identifying as LGBTQ+ or being from diverse ethnic backgrounds

8. How will the work be sustained and spread within existing systems and processes? Has this changed from the initial view in the bid document you submitted? Have you worked with any partners to sustain and spread, if so who and why those partners?

We decided to use the Place based Approach to help us evaluate the recommendations from our engagement work and look at how they might be implemented.

The 'Place Based Approach' is a model which identifies that reasons for health inequalities affecting different individuals are complex. Health inequalities are not caused by one single issue, but by the interactions of environmental and social factors which occur in a particular locality. When applying it to a project like this it is important for helping us to identify how we can work with local communities and their members to help them overcome any barriers faced (NHS Place Based Approaches 2019)

We have been able to recruit new members to be part of our Carer's Voice consultative panel. It is planned that going forward we will consult our Carer's Voice group on changes implemented as part of the recommendations that have arisen for The Carers Centre from this project.

We have also now identified a yearly budget to ensure that we can pay for translation and interpreting costs. We are also working closely now with bilingual advocates from Sussex Interpreting Services to help reduce language and cultural barriers when accessing Carers Assessments and Carers Services.

We plan to develop more accessible information e.g. videos and Easyread information and consult with our Carers Voice group as well as local communities, e.g. Gypsy Roma Traveller communities to ensure it is useful and accessible.

We plan to discuss key findings of this report within our staff team and also to deliver Equality and Diversity training to all staff in the coming months.

We are aware of similar health inequality projects taking place in the Brighton and Hove area. Friends Families and Travellers have an ongoing project addressing health inequalities. We hope to build on links with them, particularly in this area, to extend the work of this project.

LGBT Switchboard in Brighton also have a Health and Improvement Project. Our Inclusion Worker will meet with their new worker to find out how we can involve some of our LGBTQ+ carers in future consultations. Some recommendations from our project link closely to their work and to meeting project actions e.g. recommendations about staff training and LGBTQ+ awareness.

LGBT Switchboard are working to implement the NHS Rainbow Badge awards scheme with a Bronze/Silver/Gold tiered awards model. Awards will be linked to objectives around LGBTQ+ training, monitoring, inclusive policies and support for LGBTQ+ staff and patients.

We plan to disseminate wider recommendations for local NHS and health and social care services, via our local networks. We have a Primary Care worker working closely to improve outcomes for carers through local GP surgeries. She attends Multi-Disciplinary Team meetings for all local GP surgeries so could help disseminate our recommendations through these channels.

The Carers Commissioner for Brighton and Hove will also help us to disseminate recommendations within the local CCG and relevant services.

9. Key learning points/ recommendations which will be taken forward next year. Subject to further funding. Summarise the key learning from your project, reflecting on co-production/what matters most to communities?

Key Recommendations

For Carers Centre and local Carers services

- Carers support should be more proactive rather than waiting for carers to call
- Providing translating and interpreting would help with overcoming language barriers. Using local translation services such as Sussex Interpreting Service
- Providing information in alternative formats e.g. information videos, Easy Read

- Improving provision of ongoing specialist support for dementia carers after the initial diagnosis

For NHS Services

- 57% of respondents felt community specific healthcare champions would help
- Better NHS support for LGBTQ+ people wanting to start a family
- Shorter waiting times and more funding needed for mental health services
- GPs to offer call backs and more options for home visits especially for elderly and disabled patients
- NHS staff using clear accessible language (Plain English) and not relying heavily on medical jargon
- Involving carers in Patient Participation groups and other similar forums

For All Services

- Consistent and meaningful LGBTQ+/ Equality and Diversity training for all staff in NHS services and other health and social care services (Not just a 'tick box exercise'). Having training provided by members of these communities as experts and involving local organisations e.g. LGBT Switchboard
- 42% felt having advocates from the same community would be beneficial e.g. working with advocates from local organisations such as Sussex Interpreting Service and MindOUT
- 28% felt services demonstrating they are welcoming towards specific communities would help e.g. displaying traveller symbol, LGBTQ+ Rainbow flag
- Ensuring carers feel involved in care and appointments for those they support and not overlooked
- Better recognition of all that unpaid carers do and how much money this saves other statutory health and social care services

10. Summary: A brief summary of the key issues raised.

The project focused on engaging with carers who identify as LGBTQ+, carers from diverse ethnic backgrounds and carers from Gypsy, Roma, Traveller communities (GRT). We wanted to find out more about experiences of these carers in accessing NHS services and carers services locally as well as information about particular barriers they face. We planned to work in collaboration with carers to identify recommendations.

We created and distributed a survey in November 2020 to all carers identified to us as LGBTQ+ or from diverse ethnic backgrounds and GRT communities. In total 24 carers completed the survey.

In December 2020, as planned, we ran 3 focus groups on Zoom.

6 carers attended and participated in the focus groups.

3 carers attended the LGBTQ+ focus group

3 carers attended the focus groups for Black, Asian, and diverse ethnic backgrounds

We also interviewed 3 carers over the phone.

We encountered some challenges in delivering our project. These included challenges brought about by the Covid-19 lockdown which meant we could not meet with any carers in person as planned. It was felt that numbers of carers engaged in focus groups may have been higher if they could be delivered face-to-face in places familiar to carers e.g. community meeting places, rather than just remote groups on Zoom. A significant proportion

of carers don't want to connect to online groups or don't have the confidence/available technology.

We were able to identify several recommendations for both carers' services and local NHS services from the consultation. This included recommendations about LGBTQ+/ Equality and Diversity training for staff. Also, better accessibility of information including providing interpreting/translations and alternatives to written information e.g. video. Flexible approaches by GPs to offering home visits and call backs were also highlighted. It was also felt that involving carers and inviting them to be part of Patient Participation Groups would be beneficial. Carers also highlighted that a more proactive approach from services would help rather than waiting for carers to approach us with a difficulty.

11. Anonymised Case studies

Caring Situation 1.

Carer B is in her 70s and cares for her long-term partner who has physical health issues. They live together in sheltered accommodation. B identifies as LGBTQ+.

What have your experiences of accessing the NHS been in the past year?

"We are lucky to have a GP surgery that is below the building where we live. Recent interactions with the GP have only been by telephone which was not always helpful. When I tried to access support for panic attacks, I found him to be quite dismissive. The best mental health support I received was from a local charity, **MindOUT**, who were brilliant. It really helped knowing you were talking to another LGBTQ+ person."

Have you faced any barriers?

"As a carer I feel whenever there is any sort of medical consultation about my partner, I feel overlooked. I feel carers are often side-lined. They know so much about the person...you don't feel encouraged to take part...I feel like we need more recognition in appointments. When you've been with a person 40 years you know so much."

Can you recall any positive experiences of staff being inclusive/welcoming/affirming of your LGBTQ+ Identity?

"In Brighton, there has never been a problem, I've always felt staff to be inclusive. They treat you with respect as a human. In other areas I have had bad experiences, which one of the reasons we moved here."

How can we work together with the NHS to help remove or minimise barriers?

"Involving carers is so important and valuing their experience. They should acknowledge you have the knowledge."

Key Takeaways

1. They sought mental health support, but felt the GP was dismissive.
2. The support received was from a specialist voluntary organisation and talking to a fellow LGBTQ+ person was extremely helpful.
3. They frequently feel they and their experience as a carer is overlooked by healthcare services.
4. Brighton and Hove present a more welcoming and inclusive space than other areas.

Caring Situation 2

Carer D is in her 30s and cares for her wife who has physical and mental health issues. They have a 2-year-old daughter. She identifies as LGBTQ+ and has Indian heritage from one side of her family.

What have your experiences of accessing the NHS been in the past year? Have you faced any barriers?

“For my wife access to the local hospital for migraines/ liver/ Addison's disease. I hit a brick wall, they had wrong extension numbers, we were lost in the system. My only option was to go private. This cost £980.”

“I've had no respite not even from friends or family as I have been shielding. Mental health has been awful, and the services have not been there, so I have gone private. Lack of funding seems to be the main issue. “

“The barrier that we felt the most was when we wanted to start a family. If we were a heterosexual couple the wife would have been given fertility treatment. We really didn't want to fight but there was no NHS support all.”

“On the other hand, my GP has been brilliant. GP has been very supportive, regarding us having kids.”

Have you experienced any discrimination when accessing healthcare?

“At (a local hospital) it was terrible. They asked my wife if she is my sister and they said, oh because you look the same. We don't look the same except we have dark hair and dark eyes. It's an assumption they're making. We don't get apologies for this behaviour. If a man and a woman went in, would you assume they were husband and wife or brother and sister?”

How can we work together with the NHS to help remove or minimise barriers?

- Services demonstrating that they are friendly towards LGBTQ+ people, eg through using the LGBTQ+ rainbow symbol.
- Offering safe spaces and peer support for LGBTQ+ carers
- Having lists of places available that are LGBTQ+ friendly as not all are
- Better support through the NHS for LGBTQ+ people wanting to start a family

Key Takeaways

- 1. Navigating the healthcare system has been a major issue and led to private healthcare being sourced – this is not an option for all.**
- 2. Mental Health has suffered due in part to lack of respite even provided by family, due to shielding. Lack of funding highlighted.**
- 3. For LGBTQ+ people, access and provision of fertility treatment is seen as discriminatory compared to heterosexual couples. NHS (Trust) response viewed as unsupportive while GP seen as supportive.**
- 4. Assumptions by staff at hospital around relationship of two women.**
- 5. Services should demonstrate they are LGBTQ+ friendly and offer welcoming safe spaces.**

Caring Situation 3

Carer P is in her 50s and has a primary caring role for her mother who has mental health needs. Her father is now living in residential care. She identifies as from a mixed ethnic background.

What have your experiences of accessing the NHS been in the past year?

“I had two instances of care, one for my mother for whom I'm the primary carer and one for my father for the last two years who has had to move to a care home. In the care home the nurse was very good”

“Dad had a stroke and then they found cancer so they said that they couldn't give an MRI or a biopsy. This led to an ongoing issue regarding my father's treatment his pain medication and his ongoing cancer (?) treatment.”

“I was not listened to regarding the level of his pain medication which was the reason given for him not having an MRI. I doubted he was getting the correct treatment. When they found the cancer, which may not actually exist anyway, the treatment for his stroke stopped. They told him he had months to live. I had to campaign to get any ongoing treatment.”

Have you or your family faced any barriers?

“I don't feel that the doctors like to listen to families but we're the ones who know our loved ones.”

“At xxx hospital I felt some element of racism. One nurse was so dismissive I felt something was underlying.”

“Age also seemed to be a factor. Over 70 you're written off. There is definitely an attitude that you don't matter compared to younger people.”

“Doctors might have to say certain things because they have to be clear with other doctors but to a patient, they have to speak in layman's terms. If your language is not perfect or you don't have a huge vocabulary doctor speak can be a huge problem. “

How can we work together with the NHS to help remove or minimise barriers?

“Maybe carers need to be more represented in patient and hospital groups and forums.”

Key Takeaways

- 1. Issues around a diagnosis leading to doubt and a cessation of treatment for a separate condition**
- 2. Doctors not taking into account the carers experience and views. Greater carer involvement in patient participation groups is needed**
- 3. This carer felt that racism by a member of staff at a hospital was a factor**
- 4. Age was also felt to be a factor in determining the treatment received. Older patients being offered a lesser level of treatment**
- 5. Healthcare services often use language based on medical terminology. This can be especially problematic for people with English as a secondary language**

Conclusion

Themes – General

- 1. There are inconsistent responses from healthcare staff re support/ treatment available and attitudes**
- 2. Mental health is an issue which needs additional support**
- 3. Carers views are frequently overlooked or dismissed**
- 4. Navigating healthcare is seen as problematic**

Common Themes – Related to identity

- 1. Discrimination (race, sexuality, age) can be evidenced but is not the experience of all**
- 2. Accessibility to services can be a barrier in a number of ways:**
 - Lack of feeling there is a safe space, representation and understanding**
 - Language used (medical and level of English required to understand)**
 - Apparent differences in healthcare (including elective) options available based on the identity of the individual or family group**

12. Quotes about experiences of carers support

“Carers support needs to somehow be more proactive...we don't have time to seek out help, particularly at times of crisis.”

“I think generally I'm treated the same as everybody else in my experience. My problems were at the GP surgery. GPs all work in different ways for example privacy. Why should I have to tell the receptionist my health details?”

“Being almost completely alone in the world of dementia care, a specialised work which I am expected to muddle through, it seems”

“Carers have to fight for everything and we always come last on the list of being cared for.”

“At the hospital it was terrible...they asked my wife if she's my sister and they say oh because you look the same...we don't look the same except we have dark hair and dark eyes it's an assumption they are making. We don't get apologies for this behaviour. If a man and a woman went in would you assume they were husband and wife or brother and sister? This is one of the problems with making assumptions about people's sexuality”

“Proving everything...proving you are vulnerable...prove you can use the health service”

“The barrier that we felt the most was when we wanted to start a family... if we were a heterosexual couple the wife would have been given fertility treatment we really didn't want to fight but there was no NHS support all”

“I've had no respite not even from friends or family as I have been shielding. Mental health has been awful, and the services have not been there so I have gone private”

“At xxx hospital I felt some element of racism. One nurse was so dismissive I felt something was underlying.”

“I used the GP, he was incredibly helpful, he even volunteered home visits.”

“What will help us to have a health service that is equal to all is that people need to get back to real anti-discrimination training...I've been a trainer all my life and I know that often training just means that they've been asked to read a document or tick some boxes on a form.”

“As a carer whenever there is any kind of medical consultation about my partner I feel overlooked. I feel carers are often side-lined...I feel we need more recognition in appointments.”