



**Improving the Experience of Community Mental Health Services for
Black, Asian and Minority Ethnic People in Tower Hamlets,
Newham and City and Hackney**

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***“People will respond more if they know that their way of life is respected and
empowered” (participant)***

1.0. Introduction

N.B. Although I will use the term “BAME” within this report to refer to people from ethnic minorities, it is recognised that this term does not do justice to the diverse range of cultural experiences and histories of the individuals involved in this project.

1.1. Background and Aim

It is widely known that mental health services struggle to meet the needs of Black, Asian and minority ethnic groups. Despite this knowledge and previous attempts to engage with the BAME communities, many of the same issues remain: difficulties engaging the BAME community, an overrepresentation of BAME people in acute settings and an underrepresentation in psychological therapies.

The Transformation Programme within the East London NHS Foundation Trust provided an opportunity to identify and address the unmet mental health needs of BAME people within local communities in Tower Hamlets, Newham and City and Hackney.

Between February and March 2021, we ran a series of BAME “Let’s Talk” focus groups in each of the three boroughs respectively. The aim of these groups was firstly to understand the experience of Black, Asian and minority ethnic people with lived experience of accessing mental health services, or caring for someone accessing services. There is a lot of literature and data from previous focus groups that highlights the issues experienced by BAME people in accessing and engaging in mental health services. However, it was important to allow participants in these groups to share their experiences with one another and have their stories felt and validated. A second aim of the groups was to generate ideas for change, building on the momentum of the wider Transformation work within the Trust.

1.2. Participants

Service users and carers who identify as BAME were recruited in each borough through liaison with community organisations and Primary and Secondary NHS services. Some staff and community connectors also attended sessions.

In Newham between 7 and 10 people attended each session. These sessions included people of Punjabi, Indian, Bangladeshi, Caribbean, African and White European heritage.

In City and Hackney, between 6 and 9 people attended each session, with the majority being of African and Caribbean heritage.

In Tower Hamlets, between 10 and 15 participants attended each session, with participants of Bangladeshi, Indian, Pakistani, Somali, African, Caribbean and Chinese heritage.

The turn-out in each borough largely reflected the demographics of the general population within each borough.

1.3. Co-facilitation

Focus group sessions in Newham and City and Hackney were co-facilitated with Trainee Clinical Associates in Psychology (CAPs). Sessions in City and Hackney were also co-facilitated with a psychotherapist. All were from BAME backgrounds and had a specific interest in this project.

In Tower Hamlets sessions were co-facilitated with a Trainee Clinical Psychologist and a Peer Specialist who both identified as BAME. One of the service users in the group and a community connector also co-facilitated some of the latter group sessions.

It was felt that co-facilitation was important, not only from a practical perspective but also to embed the work within community mental health teams and support the sustainability of the project. It was also important to be able to debrief after each session, given the emotive content of the material discussed in the groups.

1.4. Format of Sessions

All “Let’s Talk” focus groups adopted the same style. The initial half of the meeting aimed to provide an open space for people to talk about their experiences. In later sessions, we adopted a format where we spent half a session reflecting on experiences and issues and the other half focusing on solutions and potential actions.

We ran 8 sessions in each borough, however we held two additional sessions in Tower Hamlets due to the size of the group and the amount of feedback generated.

2.0. Themes from Across the Three Boroughs

2.1. Cultural awareness, empathy and compassion

Participants in all boroughs highlighted a lack of cultural awareness as a key issue. Misunderstandings, and a lack of knowledge about different cultures was thought to perpetuate stereotypes and reduce compassion and empathy. This creates a “them and us” narrative that further disenfranchises people from mental health services. Furthermore, participants said that staff do not take the time to ask about people about their culture, traditions and “what is normal for them”.

“When someone is admitted, asking them where they are from, making an effort to sit down and talk about things that are normal for them, things that they believe, what looks abnormal to them rather than what looks abnormal to someone else”

In particular, differences in communication between cultures was discussed. Participants felt that styles of communication that were normal for them were often perceived as aggressive and taken out of context. As a result, people spoke about feeling “gas lighted” by some professionals.

Intersectionality was also important to consider, particularly as some participants highlighted specific stereotypes such as “the angry black woman” and the criminalisation of black men that may affect how they are treated in services.

A lack of cultural awareness was compounded by the lack of diversity in staff teams, particularly in professions such as psychiatry, psychology and corporate management.

“I don’t see a representation of myself in mental health [services]”

2.1.1. Solutions

1) Training in Cultural Competence

Participants said that staff should have mandatory training in cultural competence which they undertake on a periodic basis. This could involve:

- Role-playing scenarios involving people from different cultures,
- Using specific training materials (for example a ‘role reversal video’ where BAME people are the majority)
- Hearing first-hand accounts of people with lived experience
- Unconscious bias training

It was felt that this training should be co-produced with service users and should predominantly focus on cultural understandings of ethnic groups that are predominant in each borough. This training could be supplemented by training in person-centred approaches and active listening skills.

It was mentioned, however, that in order to be able to put training into practice, staff need protected time to be able to reflect on their work and the impact of culture on the experiences of service users.

2) Increasing Diversity in the Workforce

Participants said that they wanted to see more Black, Asian and minority ethnic staff in services, particularly in psychiatry, psychology and corporate management. However, they also recognised that positive discrimination may not feel comfortable for staff.

*“for me I do not like getting opportunities **just** because I am BAME or a Carer. I feel like it marks me with a scalding hot iron like I am livestock”*

Some participants felt that having staff from the same culture and background as themselves may make communication easier. However, others said that it was not enough

just to have staff from BAME backgrounds, but that these staff also needed to have an accurate knowledge of offering culturally sensitive interventions and be understanding and compassionate. Ultimately, participants felt that having more diversity within certain professions would offer more choice for service users.

2.2 Accountability

The accountability of staff was another key concern highlighted by participants across the three boroughs. Participants spoke the difficulty of holding staff members to account, particularly those in powerful positions, and highlighted that the lengthy complaints process made this even harder.

“The concern/complaints process is unnecessarily formal and long.”

Participants felt that there was a lack of opportunity to provide feedback about the services they were receiving. However, even if there were opportunities to provide feedback, some participants said that it would still be challenging for service users to give an honest opinion, either because they felt that their voices would not be heard, or because of a lack of knowledge about what they should expect from services and staff.

Participants also spoke about the lack of communication about what changes have been made in response to feedback provided.

“Once you have given feedback, communication needs to be made with service users that it’s been received and what the steps are [being taken]. Keeping people in the loop. [Giving] updates on what they did with that feedback.”

2.2.1. Solutions

1) Staff Probationary Period

It was recognised that it can be difficult to get a full understanding of the values and cultural sensitivity of staff within the short time frame of an interview and the inconsistency between what staff may say in interviews and how they act once employed. It was therefore suggested that new staff members should undergo a 6 month probationary period to assess their cultural competence. During this period anonymous feedback from colleagues and service users should be sought to understand how staff are interacting with service users.

“You should be able to watch new staff within the first few weeks, are they reaching out to all patients? Are they engaging? Are they going out of their way?”

If it was felt that staff were not performing in line with Trust values, they should be offered support and an extended probationary period. Participants felt that this would improve service users’ confidence that the Trust was employing people who act in line with Trust values, but would also signal to staff that their attitude and behaviour towards service users is an integral part of their role.

2) Regular service user feedback forums

Some participants felt that there should be regular, quarterly forums for service users to feedback to senior management about their experience of services as people from BAME backgrounds. The format of these sessions might be similar to the currently described focus groups, with service users coming together to informally discuss their personal experiences. It was felt that the collective voice of service users would be more effective in holding those with power to account.

Themes from these sessions could be collated by an advocate or staff member and fed back to management and the wider staff team, with action points for improvements. Cultural competence and responsiveness of services and staff should therefore be an ongoing process and aspiration, rather than a goal or target to be met.

3) Training and education for service users about their rights

The power differential between service users and staff may be further exacerbated by service users' lack of knowledge and understanding about their rights. As a result, it can be difficult for service users to know what they should expect from services and staff.

Participants therefore felt that service users should be educated about their rights and options through:

- Peer support groups
- Information leaflets
- In conversation with staff at first point of contact

This might include for example: understanding your rights about medication, understanding alternative options for treatment, understanding legislation in relation to the Mental Health Act, understanding how service users can provide feedback about their care, understanding and accessing advocacy.

4) Advocacy

Participants felt that advocacy should be more accessible for service users and should be promoted by staff. Additionally, they felt that there should be more advocacy roles created within the Trust, with an emphasis on recruiting those with lived experience.

“A hard-hitting service user who can hold people with power to account with little fear would be best placed. Not disrespectful, but really speaking up”

Advocates might attend meeting with service users to observe and provide feedback to staff. They might also attend board meetings and act as a representative for the collective voice of service users they are working with.

2.3. Holistic understandings

Participants felt that a more holistic understanding of distress was needed both for professionals and for the community to reduce stigma, increase understanding, and allow services users to be “seen” in their entirety.

For staff, this means recognising the positive aspects of culture and religion on mental health and focusing on the strengths of an individual by asking them about what is going well in their life and having an understanding of who they are beyond their identity as a service user. It also means seeing the individual within their systems and families, as opposed to an individualistic perspective.

However, participants also felt that it was important for communities to understand mental health to reduce fear, blame and stigma and increase engagement with services.

2.3.1. Solutions

1. Moving beyond medical understanding of distress

i) Incorporating cultural, spiritual and religious beliefs

Participants said that medical understandings of distress do not account for the cultural, ethnic, religious sensitivities, beliefs and needs of service users from diverse backgrounds.

Many felt that cultural and spiritual beliefs needed to be incorporated into their care.

“My Christian beliefs may impact my reality and understanding. [I] want it to be seen and considered” (Participant)

Some participants felt that it was difficult to discuss their faith with staff and that when it was brought up, staff tended to change the subject. Participants wanted staff to be able to recognise the positive role that faith can play in helping them “get through” their difficult moments and provides purpose and resilience.

Participants also felt that culture and cultural preferences should be taken into account in support plans, but should be approached with curiosity and openness in conversation with service users.

“When someone is admitted, asking them where they are from, making an effort to sit down and talk about things that are normal from them, ways that they would believe, what looks abnormal to them rather than someone else.” (participant)

ii) Understanding psychological and social causes of distress

Participants highlighted how medical diagnoses can obscure the psychological and social aspects of mental health. This, as a result, may perpetuate systemic racism because people

from minority backgrounds are disproportionately affected by social inequalities as noted by one participant:

“People of certain colour are in prisons, most deprived areas, schools, poor health treatments.”

Participants felt that services should consider ways to address the social causes of distress by, for example, providing support with housing, benefits, accessing legal support and finding employment.

Furthermore, participants said that services and clinicians were quick to offer medication, but that there was a lack of opportunity to access talking therapies, occupational therapy and alternative therapies such as art and poetry groups.

Participants noted the dominance of Western ideologies underpinning many models of intervention within different disciplines (for example psychology, psychiatry, occupational therapy and nursing). They felt that this should be highlighted on training and that staff should be knowledgeable about alternative therapies developed and researched in non-Western cultures.

2. Reducing Stigma in Communities

Participants said that there was a lot of work to do within communities to reduce stigma and increase the likelihood that people from diverse backgrounds will seek help from mental health services. It was recommended that the Trust engage with community organisations and faith leaders / groups to:

- Increase awareness of mental health in the community
- Address misconceptions around mental health
- Co-produce materials and/or talks that provide holistic explanations of mental distress, that work within the belief systems and use language and concepts that are familiar to specific communities

Underpinning all of this work should be the valuing of multiple perspectives. Staff should be able to take a ‘both/and’ approach to different explanations of distress and encourage service users to seek help from various organisations.

3. Involving Family

Participants said that within non-western cultures, the role of the family is significant. However, they felt that there were significant gaps in staffs’ understanding of how to support families from diverse backgrounds.

Some participants felt that the involvement of families was seen negatively by staff and that not enough was done to include families in their care. Whilst it was recognised that families could have a negative or positive effect on service users’ mental health, participants said

that it was necessary to understand the importance of family for each individual. This might include asking service users about norms and expectations within their family.

Some participants felt that services should be more supportive of families and should “help the family, not break them up” by signposting to counselling if there were difficulties identified in family relationships.

“For example, within domestic dispute try mediating rather than breaking them up for good. Try to signpost into counselling, support them, walk through experiences with them.”

Furthermore, participants said that staff should be more aware of, and ask about the social circumstances of families. For example, recognising the informal caring roles that family members may adopt and the impact that this may have on them.

“If you have the finances, poor families do not have that. How can you expect people to change that are in physically demanding situations?”

4. Honest Conversations about Medication

Participants across the three boroughs spoke about the lack of explanation and clarity about the potential negative side effects of medication.

“Pharmacists need to provide a fuller explanation of reactions to medication, especially in the early stages [where there are] unpredictable negative side effects.”

Some participants felt that the information they were given about medication was not clear enough and emphasised that information should be given when service users are “in the right space” to take this on.

They spoke about not feeling heard when they complained about the side effects of their medication. Some participants also spoke about being “forced” to continue to take medication when they believed they were making progress in their recovery.

Participants in City and Hackney said that information about medication could be given in group sessions, for example having service-user led groups (similar to the Recovery College) where information could be provided.

Participants also said that it was also important for medication to be explained to family members, particularly where families played a role in caring for the service user.

“Parents didn’t understand use of medication and there were no efforts to help family understand. Ended up not complying to medication for years.”

3.0. Themes in Specific Boroughs

3.1. Accessibility

Accessibility of service was also a key issue for participants in Newham and Tower Hamlets who highlighted specific barriers for BAME people.

1. *Addressing Practical Barriers*

Some participants spoke about the practical barriers, including the timings of appointments (usually between 9am and 5pm), the need to travel in to services and the lack of childcare to enable attendance. Participants felt that these barriers disproportionately affect people from BAME backgrounds. Furthermore, long waiting times mean that some people are unable to get the support they need, when they need it.

2. *Increasing Awareness of Services*

Participants felt that more needed to be done to increase awareness of services within local communities. They said that whilst there were a lot of NHS and community services available, service users and staff were sometimes unaware of these.

“I live on the same road as the Carers’ Centre but had no idea for 20 years”

They suggested that this could be done by:

- Providing information about services in different languages. This information should be co-designed with service users and should not include jargon. It should be available in various languages and formats (for example: leaflets, posters, on the internet or via text message). They should also be accessible to people with learning disabilities and autism.
- Outreach into the community, for example, by holding sessions/ running clinics within community spaces and organisations
- Improving signposting from community services and organisations

Outreach and signposting will require the Trust to build relationships with services and workers in social, third sector, community, and people within religious organisations. It may be helpful to consult with these organisations to develop shared materials as outlined above (see Holistic Understandings).

3. Moving Beyond GP Referral Model

Participants highlighted that some BAME people may not be accessing care from their GP and that in these cases a deterioration in mental health might be more likely to be noticed by relatives, carers or in housing, social, community or religious settings.

Participants felt that it is important for those who are concerned to be able to seek advice and for other organisations to be able to refer into services.

4. Support Out of and Back Into Services

Many participants highlighted the lack of support for people within the community once they had been discharged from services, and spoke about how this might lead some people to relapse. Participants spoke about the need for services to be able to “check-in” on people periodically. Loneliness was cited as one of the most challenging, but also one of the most important aspects of maintaining good mental health in the community. Participants felt that services should do more to support service users to build networks and connections within their community as part of their discharge plan.

Participants also said that services need to be more responsive when service users’ mental health deteriorates and provide easy and swift route back into services.

5. Signposting to alternatives

Some participants spoke about a need for services to have a ‘directory’ of alternative support (including paid services) within the community. Participants seemed hopeful about the ‘Blended Team’ approach that is being trialled within secondary care services and felt that referrals to community connectors would be particularly important in linking people in with alternative sources of support.

3.2. Community spaces

Participants in Newham and City and Hackney spoke about the importance of being able to access support within their communities via a ‘hub’ or central service where service users and the local community could access activities and social groups.

Many participants spoke about the closure of the ‘day hospital’ and the value of having spaces where they can *“relate to others not feel alone...and have a sense of belonging”*.

“Social activities are needed in the community, for service users to go and see people, to feel like you have got a warm space to turn to, have friends and make links with people experiencing similar or different problems.”
(participant)

When asked to describe what the space would look like and include participants' said that a community hub should:

- Be open between 9am-5pm
- Include social outings
- Offer activities like yoga, nature groups, music, cooking, sports and family events
- Run specific support groups (Asian group, women's groups, Black men's group)
- Provide advice (e.g. housing, employment, finances, nutrition)
- Offer counselling, peer support and befriending
- Exercise classes
- Q&A sessions for service users and families

4.0 Next Steps

When I began this work, the most important objective was to ensure that suggestions arising from these focus groups were actioned within the Trust and that this was fed back to participants, service users and carers.

In order to do this the next steps will be to:

- Feedback themes and potential solutions to senior management, teams and service users (presentations and reports) to reach as much of the Trust as possible
- Create working groups of service users and staff within each borough to take these actions forward
- Identify key individuals and teams that can support this work
- Link with third sector and community organisations who we could work alongside to action changes

4.1. Important considerations

The conversations and themes arising are not necessarily new ideas and some service users spoke about how they had previously fed back their views and experiences in other forums. Participants reflected the sadness and frustration they had felt when they had previously been involved in steering groups and were encouraged to speak out and recount painful experiences which did not result in real change.

However, it is not enough to just hear people's experiences - we must think about how to implement solutions.

All of the work to action suggestions made within focus groups should be co-produced with service users and carers to maintain authenticity. Any changes that are made should be communicated to service users, carers, residents and staff.

It might be useful to consider the local demographics of BAME communities within each borough and target specific initiatives these ethnic groups. Furthermore, we need to continue making links with people and services that can support this work so that the changes made are sustainable.

“Prevention is better than cure” (Shahina Chowdhury)

The NHS is seen by some BAME communities as being a reactive service and not one that is necessarily preventative. Based on this report it is important to look at ways that we can incorporate new strategies under our individual frameworks, to walk alongside the people that we work with and move away from a one size fits all policy. We must continue to develop, strategize and adapt for our diverse populations, being mindful of structural inequalities and experiences of our residents to strive to achieve a service that truly cares, respects and is inclusive.