Report on Feedback at the Healthwatch Wandsworth Assembly September 2021 - Health Inequalities

Summary

Background:

The second Healthwatch Wandsworth Assembly of the year was held on Zoom on the 29th of September 2021. Discussions were held on health inequalities, which is a very broad topic with lots of concerns and this time we had a particular focus on ethnicity and mental health; establishing trust between staff and service users; and providing opportunities to make people's stories listened to.

What we did:

At our Assembly event, we heard from South West London CCG about what health and care organisations are planning to do to develop our services and tackle health inequalities in Wandsworth. Professor Sashi Sashidharan talked to us about an exciting new project that aims to tackle health inequalities by improving mental health care for BME (Black and Minority Ethnic) groups. Due to our event's focus on this project, we have continued to use the term BME throughout discussions and the report. Lastly, WCEN and the South West London CCG gave us an update on the Ethnicity and Mental Health Improvement Project (EMHIP) and talked about how relationships and partnerships can be developed between (large) service providers and community groups.

We then discussed how we can encourage trust between staff and service users. Finally, we broke out into smaller groups to discuss what services, individuals and communities can be empowered to do to make sure people's stories are valued and listened to and what can be done to ensure that there are opportunities for people to share their stories and that this is integrated into the system.

What we were told:

We started our discussion by talking about trust. We were told that trust comes from respecting people's experiences, views and stories, and that health and care organisations should put effort into raising cultural awareness. The importance of basing services within communities was also mentioned.

People thought openly acknowledging that health inequalities exist and actively advocating for change is key. While the topic might be uncomfortable, it is essential that those with any kind of privilege educate themselves and address any unconscious biases and assumptions that might distort their perception. It is also essential to tackle the power imbalance between people from white and BME backgrounds.

Other issues of inequality, such as sexism, ageism, ableism, homophobia and transphobia, and intersectionality (i.e., being discriminated against because of multiple personal attributes, e.g., ethnicity and gender) were also highlighted by a number of attendees.

In the breakout rooms, some people talked about how empathetic listening and building rapport with clients is as important as clinical knowledge for establishing a good relationship between people and services.

Short appointment slots seem to be an issue, as they often stop professionals from exploring the root cause of mental health issues, and this in turn impacts the quality of care provided as well.

People also said that there is too much emphasis on collecting quantitative, objective data, and that investment in collecting qualitative data and hearing collective stories of communities and individuals would be necessary if we were to truly shine a light on the systemic issues existing within health and social care services. However, reflecting on potentially traumatic events can be upsetting to individuals, therefore it is important to treat their stories with respect; this can be done by being clear about how the collected information will be used, gaining informed consent to using data, as well as using people's own words to fully represent their experiences.

Tackling inequalities in healthcare was said to require commitment, clear and consistent leadership, and drawing from both the above-mentioned qualitative data and systemic feedback obtained from services. Working on this issue on a long-term basis locally and on a manageable scale was suggested to be more effective than taking on too wide a scope and only carrying out one-off, short-term projects.

Read more below about the themes and discussions held at our event below.

Introduction

Healthwatch Wandsworth holds public events to discuss with local people key developments in health and social care. On the 29th of September 2021, we held our third online public event via Zoom. In total, 39 people attended.

Our event focussed on health inequalities. This time we took the particular example of racial inequality in mental health and the new Ethnicity and Mental Health Improvement Project (EMHIP) which is being put in place to tackle this. Looking at health inequalities through the lens of ethnic disparities in mental health and attempts to address this could offer learning for tackling other health inequalities. Due to our focus on this project and the terminology used by the project, we have continued to use the term BME throughout discussions and the report.

Our Chair, Stephen Hickey, introduced the topic, pointing out that health inequalities had been highlighted by the current pandemic. He pointed to three relevant facts about Wandsworth:

- Nearly 1/3 of the population belongs to an ethnic minority;
- 21% of the population are in relative poverty;
- and 17% of the pupil population have a Special Educational Need or Disability.

Before proceeding to the main topic, we first had an update from Gemma Dawson, Head of Strategy and Projects for the Merton and Wandsworth NHS Clinical Commissioning Group, on the new Wandsworth Health and Care Plan. The original plan, for 2018-21 and now being refreshed, focussed on priority areas where services can work together to prevent ill health, keep people well, and support independent living. The aim is to catch up on areas where priorities were redirected by the pandemic and roll the plan forward in

the light of people's perception of new and emerging priorities. Following a series of engagement events over the summer, it is hoped to produce a draft plan for comment in the course of October and submission to the Health and Wellbeing Board in November. The feedback received so far indicates a need to improve measurement and monitoring of outcomes, as well as communication, especially when plans change. There is support for maintaining the previous priorities of children's and young people's mental health and integration of health and social care. Collective action to reduce health inequalities has emerged as a key new theme. The refreshed plan will also draw on the findings of the draft revised Wandsworth Joint Support Needs Assessment 2021, as well as all feedback received from service users, carers, families and staff.

Our second speaker was Professor Sashi P Sashidharan from the University of Glasgow, an internationally recognised academic expert on mental health inequality and consultant to EMHIP, who set out for us the background to the project. Professor Sashidharan argued that the current pandemic has revealed that there is an urgent need to address underlying health inequalities, not least in mental health. It is crucial to recognise the social and environmental determinants of poor mental health, including all forms of inequality. In particular, he pointed to the longstanding disparity in access to, experience of, and both clinical and social outcomes of all types of mental health care for all BME groups across the country. Professor Sashidharan highlighted that in many cases there were barriers to accessing care, or the care provided did not work for people when they did receive it, which can lead to reduced quality and safety of care for BME people. He compared the situation to a burning house, with people sitting around asking why it has caught fire and debating the merits of different ways of putting it out, and highlighted that it is important to take action, rather than standing by and watching the situation continue. Professor Sashidharan believes that what is needed is continued commitment and leadership and recognising the important role of local communities. He saw EMHIP as a welcome recognition by communities and services in Wandsworth. EMHIP is a locally based, practical programme which involves people and aims to bring about wider change both within services and in the community. It is based on a review of 40 years' evidence and consultation with local people with the aim of building on existing community assets. Wandsworth is fortunate in having strong BME community organisations working to address inequalities, including Wandsworth Community Empowerment Network (WCEN), a key partner embedded in the programme.

Professor Sashidharan's account of proposed interventions for improving mental health support in BME communities was followed by a brief discussion of aspects of present practice. It was pointed out that the adult acute wards at Springfield and Queen Mary's Hospital, although locked, do make efforts to facilitate contact between patients and their families. Nonetheless, Professor Sashidharan pointed out, detention in such wards does cut people off from their families and communities in times of crisis. It is accordingly essential to reduce reliance on this form of treatment and find alternatives where possible.

We then heard from Malik Gul, Director of WCEN, who has worked hard to highlight racial inequality in mental health over many years and been a key figure in developing EMHIP. Malik explained where the project has got to and the challenges it has faced in reaching implementation by introducing the (admittedly uncomfortable) issue of racism, in particular institutional racism ("discrimination or unequal treatment on the basis of membership of a particular ethnic group arising from systems, structures or expectations that have become established within an institution or organisation"). Malik believed that

these circumstances could be found within the NHS system. He explained that overrepresentation of Black communities in acute mental health services has become normalised over many years, and little has been done by services that has addressed this. It has taken external pressure from community organisations, like WCEN, which has mobilised at annual conferences over 13 years, to bring the NHS to focus on the need for corrective action. Malik argued that for complex, long-term conditions like mental health, problems of inequality are only going to be solved if the role of communities and the community dimension of health is acknowledged. He argued that there has been little public investment in community-building and there is little in current integrated care plans about this, or steps needed to address BME mental health inequality in particular, although many frontline staff were supportive of the need to increase prevention and early intervention and shift resources into the community. Malik also acknowledged Healthwatch's role in supporting/amplifying the voice of the community in health and care in projects like EMHIP.

Gemma Dawson then reported on the progress being made in 2021/2 towards the phased implementation and funding for initial years of the EMHIP programme which was formally adopted by the CCG last year. The first Community Health and Wellbeing Hub, which will not be just an access point for mental health services but will provide an opportunity for holistic management of long-term conditions and for preventative work, is being launched later this year at The New Testament Assembly church in Tooting. Two further interventions are being funded by the CCG; one is a Crisis Family Placement Service Pilot to provide residential placements with local families as an alternative to hospital admission for Black people in a mental health crisis. The other is a project aimed at reducing restraint and coercion in in-patient care, by reviewing existing practice and introducing shared decision-making and cultural mediation. Work has also started on developing a curriculum for cultural capability training for mental health staff. These interventions across the mental health pathway are all being implemented in partnership with the community and community organisations and pilot projects will be evaluated.

Our speakers had been asked to be honest about the challenges of working on the project and for community and NHS collaboration at this scale. Malik commented that there was and continues to be a big challenge for the project and for the NHS in having the money to fund the different workstreams within the project. Gemma acknowledged that the implementation of EMHIP has been a difficult task: there are many partners involved with different challenges to face and there have been differences of view on both the direction and the speed of change. But, she said, these are not insurmountable: a start has been made and the team have big ambitions for Year 2.

Summing up, Stephen thanked our speakers. He acknowledged the challenges posed which it was necessary to hear. We are clearly in the foothills on this issue of racial inequality in mental health and need to go on moving forward. He paid particular tribute to Malik for his personal commitment, alongside the work of WCEN, over many years.

What we discussed

Following the presentations, we opened up a general discussion both on-screen and in the chat function of Zoom.

The initial topic suggested was the importance of trust, particularly between service staff and service users, but also more widely, if these difficult issues of inequality in health and healthcare, are to be talked about and addressed.

We then went into three breakout groups to discuss how individuals, groups and services can build trust, provide opportunities for people to share their stories and make sure that these are listened to and valued.

What people said

General discussion

Below are points made by people involved in our discussions.

Trust

Trust comes from genuinely listening to people, respecting their experience and views, and delivering on their needs. To deliver this, the NHS and many other organisations need to be much more culturally aware, and this should be an integral part of their philosophy and training regimes.

The question of trust points to the importance of services being based within communities at trusted places. Experience of Sure Start programmes was that many professionals were better received if they came out of their institutions and met people on their own ground.

Suggestions:

- Include **extensive and in-depth cultural awareness and unconscious bias training** in staff development programmes. Repeat these regularly as this area of knowledge is evolving rapidly.
- Aim to **base services within communities**, or as a minimum, strive towards co-designing with communities.

Acknowledging racial inequalities and how they are approached

There is a role for individuals to be advocates in the community, to start conversations and encourage others to learn about cultural differences and perspectives.

It can be a challenge to speak freely about difficult and emotive issues of inequality. We all need to address our unconscious biases and assumptions which can distort perception. This can be hard work for people, but we need not to shy away from it.

The problem can be compounded by a reluctance on the part of staff to acknowledge service shortcomings. This needs to change in service culture. Staff and leaders need to be prepared to change the way they do something if it is not working for some people, rather than assuming that the people need to change how they do something.

In particular, it was pointed out that the imbalance of power between BME and white people, or the people providing services and the people who receive those services, can skew decision making and this needs to continue to be challenged.

An example was quoted related to Sound Minds, a local user-led service with a proven and acknowledged record of helping BME service users over 25 years, which continued to face insecurity of funding. This can impact on trust and willingness to continue to attempt to tackle problems. Another example given later in the breakout groups of the negative impact of short-term measures was a project supporting a group of BME women in the community on a specific health related issue. The funding was only short term and so very little changed in the wider service delivery and the wider impact other than some outcomes for the participants in the project.

On the other hand, it was suggested that the Black Lives Matter movement had contributed to initiating new conversations within the NHS.

In concluding, Stephen Hickey, our Chair, gave his personal reflection that despite the daunting scale of the overall problem of racial inequality, the EMHIP project offered us in Wandsworth a welcome opportunity to take real, practical steps that make a difference locally.

Suggestions:

- **Encourage conversation and transparency** about unconscious biases, cultural differences, and even service shortcomings in this area.
- **Continue to level the playing field for people from BME communities** and strive towards representation of BME people in leading/decision making positions.
- Change in service culture: **staff and leaders need to be prepared to change the way they do something** if it is not working for some people

Other issues of inequality

A number of participants drew attention to other issues of inequality such as sexism, ageism and discrimination relating to disability, sexual orientation and transgender issues, as well as the fact that some people experience multiple disadvantages. It was also suggested that in the voluntary sector, established organisations sometimes failed to respect newly emerging groups.

Breakout room discussions

The discussion revealed a wealth of personal and professional experience. The main points raised were:

The importance of listening to and respecting individual stories

Empathy and relationship-building can be as important as clinical knowledge in helping people, particularly in the mental health field. Some clinicians are taught the art of empathic listening, but some are not. Professor Sashidharan highlighted that there is much research showing that it is not ethnicity, but empathy and ability to build relationship with a client/patient/service user that matters. Professional knowledge of the field of mental health, for example, in itself is not enough to provide effective help if the above empathy and the ability to build relationships is missing from treatment.

Time constraints can lead professionals to cut short their listening to clients/patients, which is detrimental to good care. It is important to enable staff and support involvement of patients so that there is time, and expect things to take longer. Professor Sashidharan referred to a study involving consultants where it was found that consultants believed that they do not have enough time to listen to someone's full story. Therefore, they are restricted to only ask patients about the symptoms they are experiencing and provide solution to those symptoms only. In reality, hearing the full story would be necessary to provide the best solution, however these are often too complicated and would take too much time to expand on. This phenomenon was experienced even more when white staff was dealing with black service users (i.e., they have even less time).

Too much emphasis is arguably put on objective and quantitative data. There is also a need for qualitative data and valuing people's individual stories.

As well as listening to an individual's story as a basis for giving care, the analysis of large numbers of individual stories can reveal patterns which point to structural issues requiring action at an organisational or systemic level. A focused investigation is needed to look at structural issues if on the whole people from certain groups give poorer feedback, or if they are providing less feedback. Frontline staff working with individuals should hear about the individual level experiences. However, storytelling should not be used as substitute for obtaining systematic feedback on services.

This also means going into community spaces and spending time with individuals and groups, preferably face to face rather than virtually. Engagement should be seen as an investment not a one-off process and should never be a tick-box exercise. One participant shared experience of working for the council and going to speak to the Somali community in Battersea. They felt it helped them better understand the people's concerns, issues, and fears. They found that there was a lot of mistrust.

It can be important to use service users' own words in order to fully capture, reflect and represent their experiences.

For some people telling their story can evoke trauma: their effort must be valued, and information should be shared between services to avoid the need to go through the process again.

It is important to be clear and upfront about how, and where in the system, stories, will be used and obtain people's informed consent.

It can also be important for services to reach out to some seldom-heard communities and listen to their collective story (even if it involves conflicting voices). Listening should be a learning experience for organisations but organisational learning and change require clear and consistent leadership.

Suggestions:

- Expand training in **developing empathetic-listening and rapport-building skills** to all healthcare staff to encourage in-depth assessment of patients/clients.
- **Invest in community engagement and qualitative research** to gather individual stories and reveal patterns pointing to structural issues, with a particular focus on seldom-heard communities.
- **Create time to listen and act based on what people had to say. Leadership should enable staff at all levels to act and create changes.**
- **Share information across services** to avoid the need for people to repeatedly recall traumatic events.
- **Clear communication about how collected information will be used** and handled is also needed to increase trust in services.

Issues with equality in healthcare

Fear and stigma about mental illness and similar disabilities can be even more acute within BME communities than it is within the general community. This can make it more difficult for BME people with such problems to have confidence they will be heard.

One person highlighted that regarding autism (which in itself is debated whether it is a disability, learning difficulty or a mental health problem, or a diverse combination of the prior), many people would not like to talk about it out of fear of the public's reactions. They said that that despite being Black and talking about their experience openly, they are approached by more White families, but they know that many Black people are still afraid to come out openly due to expected stigma and judgement.

Structural racism within the NHS does not mean that there are not hardworking people within the system who are not racist and try their best to provide the best treatment possible for everyone. But the persistence of racial inequalities within SW London NHS can be seen as a sign of systemic racism of the system and the way it operates.

It may be more effective to tackle inequality issues on a local and manageable scale rather than take on too wide a scope. But experience shows that one-off, short-term projects to address the needs of communities can fail to deliver change if ongoing support is not embedded in the wider system and sustained over time. Leaders need to be key enablers for staff to be able to act on what needs to change.

Suggestions:

- **Ensure that systemic issues are continuously investigated and tackled**, rather than running ad-hoc projects to tackle inequalities.