Kindred Minds

A call for social justice

Creating fairer policy and practice for mental health service users from Black and Minority Ethnic communities

Raza Griffiths

Contents

Dedication

A Call for Social Justice is respectfully dedicated to Robert Dellar and Patricia Chambers, two mental health service users who campaigned tirelessly for social justice. Tragically, their lives were cut short during the writing of this Manifesto. The world needs such people more than ever, and they continue to be an inspiration to us.

Robert was a key figure in the formation of the internationally influential Mad Pride, which helped galvanise us to realise that we have the power to reclaim and redefine our experiences of madness in a way that makes sense to us, rather than having to accept the labels the mental health system attempts to impose on us. For a time, Robert sat in the same office as the author of this document, offering him his unstinting support, as did Jeremy Dawes and others at the mental health service user campaign group Southwark Association for Mental Health.

Patricia was one of us – a Black and Minority Ethnic mental health service user, who was known for her smile and passion for social justice. Her words of encouragement reached many of us at the times and in the places we most needed to hear them. This was during her time as co-ordinator of Catch-a-fiya, the former national strategic BME mental health service user network. We had lost touch with her at the time of her tragic death, but her passing away is already galvanising us to take action around the causes that she believed so passionately in.

A. Acknowledgements

B. Introduction – Our collective challenge

Who wrote this Manifesto?

This Manifesto is the work of mental health service users from Black and Minority Ethnic (BME) communities, primarily from Southwark but also from across London and other parts of the country. This includes those contributing to as well as those leading the consultation and writing processes. Collectively, these individuals are the "we", "our" and "us" of this document. We also recognise the many allies who stand behind us from a range of communities, including those who have direct experience of using mental health services and those who do not.

Why did we write this Report and Manifesto?

Black and Minority Ethnic communities face disadvantages, reduced opportunities and structural and institutional racism. These factors all contribute to our higher rates of mental distress compared to the White British population. On top of this, we are more likely to experience unfavourable treatment and outcomes when we come into contact with the very mental health services that should be helping us get better. These factors constitute what have been termed *racial inequalities in mental health*. And those inequalities have been known about for decades. Nevertheless, they persist due to a lack of focus and political will and the absence of a joined-up, long-term strategy and concerted action to tackle structural and institutional racism backed by adequate resources. This document focuses on tackling this situation.

What we believe

We believe that this situation is intolerable in a society that claims to treat people fairly and to value each of us as equal citizens irrespective of considerations like the colour of our skin and cultural differences. We believe that this document's recommendations should be implemented as a matter of urgency. We also want the learning from past and present initiatives on BME mental health to be put into practice, in order to counteract the racial inequalities in mental health that BME communities face.

How did we go about writing this Manifesto?

This Manifesto is based on a thematic analysis of 18 consultations that we undertook with BME mental health service users in Southwark, Lambeth and Hammersmith and Fulham from 2015 to 2017. It also draws on the advice and guidance of an advisory group made up of a majority of BME mental health service users. In conjunction with this, we completed a literature review of initiatives, projects and reports relating to racial inequalities in mental health. Given the large total Black populations in Southwark and neighbouring boroughs and the long-standing urgency of the issues they face, our focus is mainly on Black communities though we also address serious issues confronting some other BME communities. We do this in the awareness that more work is needed to tackle many of the issues that different BME communities are facing.

Active agents driving change

As Black and Minority Ethnic mental health service users, we want to be supported to play a full role in putting this manifesto's recommendations into practice. We believe our role must be that of equal partners working with a broad range of allies who are committed to striving for a fairer, more just society. At the same time, we want to be supported and resourced to lead independent BME mental health service user-led services, which can have unique benefits for many BME mental health service users.

The need for action

Ours is not an agenda that can be satisfied by tinkering around the edges. This is because meaningful positive change requires large-scale social, cultural, economic and political reform at the community, borough, London-wide, national and international levels. What our country's political leadership – whatever the party – must do is go beyond declarations of good intent and mere audits of the mental health and wider inequalities we already know exist. It is now long past the time for action.

C. Executive Summary of Recommendations

Based on our consultations and extensive literature review, the summary below highlights the actions we believe are needed to change policies and practices to improve the lives and wellbeing of BME mental health service users.

1. Create a race equality strategy

The government must show it is willing to take the lead in challenging racial inequalities by developing an ongoing *race equality strategy* that is properly resourced and staffed. This strategy must call for targeted reduction in racial inequalities across a range of life areas affecting BME communities. Responsibility for the strategy should rest with a newly appointed Secretary of State, with clear accountability and governance arrangements in place across government departments to push forward delivery and liaison with devolved governments.

2. Join up the many different agencies whose work affects BME communities

The race equality strategy must ensure that different agencies in areas like education, employment, benefits, housing, mental health and criminal justice work together across different life stages and at the local, regional and national levels.

3. Address the multiple forms of marginalisation faced by BME service users

The race equality strategy must ensure that the multi-factorial nature of the disadvantage experienced by many BME mental health service users informs all future actions. This will require proper consideration of gender, class, gender identity, sexual orientation, age, ethnicity, refugee or asylum-seeker status and levels of English language proficiency.

4. Strengthen and upscale independent BME mental health service user peer support

Local and national government, the NHS and other funders must better prioritise the funding of **independent** BME service user-led peer support. In dialogue with BME service users, the government should consider how to scale up this support so it plays a pivotal role as an accessible service that emphasises a community strengths-based approach.

5. Make mental health services safe, accessible and appropriate for BME communities

The Mental Health Act must be brought into line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and ban detention and compulsory treatment. At the same time, Mental Health Trusts must learn from the non-coercive approaches that have already been adopted in some areas and comply with the Mental Health Units (Use of Force) Bill 2017 introduced by Steve Reed MP, to tackle racial bias by requiring hospitals to publish data on how and when physical force is used, and ensure that any non-natural death in a mental health unit triggers an independent inquiry.

Mental Health Trusts need to move away from the purely biomedical approach long applied in clinical settings and towards a diversity of approaches that BME service users find beneficial and can access in community settings. All this must be done in active partnership with BME mental health service users, the BME voluntary sector and BME communities.

6. Strengthen and realise the potential of the BME voluntary sector

National and local government, the NHS and grant givers must ensure proper funding for the BME voluntary sector in recognition of the specialist knowledge it provides and its links to the BME communities they serve. This funding is needed to redress the damage caused by cuts that have disproportionately affected the BME voluntary sector – it is, thus, essential for nurturing the sector's potential.

7. Create a fairer and more accessible benefits system for BME service users

The government must ensure that future benefit reforms comply with the International Covenant on Economic, Social and Cultural Rights (ICESCR, 1966), which the UK has ratified. The government must also conduct a comprehensive review of the cumulative impact of benefits changes so that the overall disproportionately negative effect of these policies on BME communities can be exposed and mitigating steps taken.

Campaigning groups should make greater use of Freedom of Information requests, employing ethnicity markers to highlight instances of unfair practices against applicants. Professional bodies like the British Psychological Society whose members are involved in assessments that could lead to benefits sanctions must develop proper ethical guidance to ensure members' actions do not harm clients.

8. Tackle racial inequalities in employment

The race equality strategy must tackle racial inequalities in employment, including higher levels of unemployment among BME communities compared to the rest of the population. The strategy must also address race-based discrimination in recruitment and promotions, wage inequalities and the greater risk of people from BME communities being in insecure or low-paid work with few legal rights

including as undocumented migrants. Mental health services must be kept completely separate from jobcentres so that mental health service users are not put off seeking the support they need.

9. Provide safe and adequate housing for BME communities

The race equality strategy must ensure that national and local government housing policies make proper use of Equality Impact Assessments so that they do not disadvantage BME communities. The government must also abolish the Bedroom Tax, which is discriminatory against BME communities. Local and national policies must ensure that there is an adequate supply of social housing. Councils need to adopt a gold standard for the private rental market and put a cap on private rents while also taking action against slum landlords. Agencies must take proper account of the wishes of vulnerable Lesbian, Gay, Bisexual, Transgender or Questioning (LGBTQ) asylum seekers and refugees when they are being housed.

10. Improve support for children and young people

Overcoming the underachievement and exclusion of BME pupils and supporting Black university students must be high priorities in the race equality strategy. Within schools, tough action against bullying is essential. School curriculums must focus more on the positive achievements of BME people by emphasising Black contributions to history. The goal should be to help young BME people develop pride in their identity and counteract negative racial stereotypes that can be internalised early on and inhibit achievement. Increased funding is needed to improve the accessibility of Child and Adolescent Mental Health services and ensure they meet the needs of BME young people.

11. Improve support for parents and other adults

Local and national level government must draw on the lessons of the now defunct Sure Start programme and provide better signposting to services and advocacy about parenting and managing life transitions. The government must also increase funding for the teaching of English as a foreign or second language (EFL/ESL) without imposing any language-learning requirements, which would be stigmatising and discriminatory. Local Recovery Colleges need to better reflect the diverse populations they serve, offering courses that reflect the interests of BME service users and are developed and led by us.

12. Create a fairer criminal justice system that BME communities can trust

Senior police and mental health services must improve their liaison in order to challenge undesirable practices such as the use of police cells as "places of safety" and the transporting of people to hospital in police vans. Senior police must improve liaison with BME service user groups to help find ways to de-escalate incidents without using a Section 136. The government must fund programmes to increase trust between police and BME communities. Police must also change their ways of working including introducing proper monitoring of stop-and-search and physical restraint. Better access to legal redress is required for relatives and those campaigning for justice in cases of deaths in police custody. The Independent Police Complaints Authority must be abolished and a new, truly independent watchdog created to ensure that the police work in a lawful and non-discriminatory way. We need to see systematic monitoring of race-based disparities in sentencing, bail and parole conditions as well as in policing.

13. Tackle physical ill health together with mental ill health

More effective programmes must be set up to address mental and physical health together. The focus should be on improving services so that BME people's negative experiences within the mental health system no longer inhibit their engagement with any kind of health professional. More should be done to highlight the positive ways that BME service users look after their physical health using a strengths-based approach rather than one limited to risk minimisation. There must be more focus on providing information from accessible and trusted sources such as BME advocacy and BME peer support within non-clinical settings. Information about the physical side effects of medication must be provided to BME service users as early as possible.

14. Develop more meaningful BME service user involvement and power-sharing in mental health and society at large

The race equality strategy and all organisations/projects engaged in service user involvement must follow the recognised guidance on good practice in involvement that was developed with Department of Health funding, the *4PI Framework* (Faulkner, A, 2015). It should also be guided by the guidance on how non-BME, non-service user led organisations can respectfully work with BME service user led initiatives like the *Dancing to our own tunes* Charter (Kalathil, J, 2009). This guidance should inform all efforts to meaningfully involve and work in successful partnership with BME service users, ensuring that wherever possible mental health service users take leading roles and receive all support needed to this end.

15. Support service user production of knowledge and research

Knowledge producers who are not BME service users must better recognise the value of the knowledge that BME service users produce. They should also develop greater self-reflexivity around their own knowledge production in terms of White privilege, Eurocentrism, sanism and other biases that disempower BME service users and strive to work with BME service users to correct these blind spots.

Those involved in developing policy and practice, must also better recognise the knowledge and research that BME mental health service users have developed, in order to develop policy and practice that is fit for purpose.

D. Manifesto Priorities

Through our work on this Manifesto, we have been able to distil our demands into top-line priorities for change. In particular, we are calling for:

- Establishment of a government ministry position which is responsible for developing and implementing a **national race equality strategy**

- Improved co-ordination among agencies working on race equality across interlinked life areas and different life stages

- Policies and practices which better address the multiple forms of marginalisation affecting people within BME communities, and not solely racism

- Strengthening and upscaling of *independent* BME mental health service user-led peer support

- Mental health services that exclude detention and compulsory treatment, which are accessible, and provide support based on diverse understandings of mental health that BME communities can relate to

- Mental health services which are co-developed with BME service users and communities and based increasingly in the community rather than in clinical settings

- A BME voluntary sector which is not disproportionately affected by funding cuts but instead strengthened in recognition of the important role it plays in maintaining BME mental wellbeing

- A fair benefits system which is not cut back in a way that disproportionately penalises BME communities but offers us adequate and timely support and takes proper account of our life circumstances

- The tackling of racial inequalities in employment, with greater protection against insecure and unfair work conditions, including for undocumented migrants

- An end to the pressure on mental health service users to take on work before we are ready

- Elimination of housing policies that particularly disadvantage BME communities along with the creation of more social housing, better regulation of private sector rents and standards and proper consideration for the wishes of LGBTQ BME asylum seekers when they are being housed

- Schools that put the wellbeing and resilience of BME students at the heart of the curriculum by celebrating Black achievement and taking tough action against racist and other bullying

- Better support for BME parents and other adults including more funding for English language classes without any strings attached

- Recovery Colleges that better reflect the ethnic diversity of the areas where they are located

- A criminal justice system that BME communities can trust in based on better liaison among police, mental health services and BME mental health service users

- A ban on heavy-handed and discriminatory police practices including the use of police cells as places of safety and stop-and-search

- Better access to mechanisms to challenge injustice and the creation of a new independent police and criminal justice watchdog to monitor police involvement in mental health incidents and highlight discriminatory practice

- A more coordinated response to physical ill health and mental distress with a focus on community-based supports developed in conjunction with BME service users and the BME voluntary sector

- More accurate and timely provision of information about *all* effects of medication

- More power, decision-making and meaningful involvement for BME mental health service users in health policy and practice
- More equal and respectful cooperation between BME service user and non-BME service user organisations
- Adoption of practices that facilitate meaningful involvement of BME service users in mental health and social justice issues including: mental health legislative reform, community policing and teaching of future mental health professionals and
- Better recognition of the value of BME led research and knowledge within academia and knowledge production and greater self-reflexivity by knowledge producers around White privilege and other biases that disempower BME service users

E. Who we are

The people who led the writing of this Manifesto and the contributors to the consultations behind it are part of an informal network of Black and Minority Ethnic mental health service users and allies in Southwark, London, the U.K and increasingly, internationally. We believe that the best way to improve the lives and mental wellbeing of BME mental health service users is by working towards a more just society.

We grew out of the Kindred Minds Pop-In, a peer support group for Black and Minority Ethnic mental health service users in Southwark, London.

From this base, we talked with mental health service users from Black and Minority Ethnic communities in our borough to find out about the key issues they were facing. We also formed contacts with groups in other boroughs. Through our online activities, we connected more widely with Black and Minority Ethnic mental health service users across London, the U.K and across the globe, finding solidarity in the face of our overlapping struggles.

We are first and foremost a growing network led by and for Black and Minority Ethnic mental health service users. But we also have allies who share our values and goals and come from a wide range of communities. Some of these people have direct experience of using mental health services while others do not. Only by striving together can we build a better tomorrow.

F. Methodology

This Manifesto began with an extensive literature review spanning work over the last two decades. An advisory group with a majority of BME mental health service users suggested useful literature, reports and consultation findings for the Project Lead and Manifesto author (Raza Griffiths) to read. To help broaden the scope of the review, the project lead also read literature found through Google searches for the following terms: "BME mental health key issues", "BME mental health racism", "BME mental health social justice", "BME mental health social factors" and "mental health policy UK BME communities".

The literature review led to the identification of a number of key themes for discussion during 18 consultations with BME mental health service users. 16 of these consultations were held in

in Southwark borough from 2015 to 2017. The consultation with NAZ took place in Hammersmith and Fulham borough. NAZ is one of the few BME-specific projects in the country which works with lesbian, gay, bisexual and transgender people from BME communities, and it was approached for this reason. Another consultation was held in Streatham in Lambeth borough with Amardeep, a mental health support group for people of South Asian descent and the only such project in London.

During the consultations, which were led by either the Manifesto Lead and author, or BME survivor campaigner and researcher Jayasree Kalathil (NAZ consultation), consultees were asked to identify the key issues affecting their mental health and the changes to policies and practices they believed would improve the situation. A list of tentative priorities compiled from the literature review was also discussed. A thematic analysis of data from the consultations was used to produce this Manifesto, and this led to our final list of top-line priorities.

The consultations mostly confirmed the themes that had been identified in the literature review, with the notable exception of "challenging multiple forms of marginalisation", which emerged as a critical priority largely through the NAZ consultations. These discussions also shed more light on other issues, particularly the vital role of BME communities' trust (or lack of trust) in social institutions.

The consultations showed that our identified priorities require change at not just the mental health trust-wide or borough level but also at London-wide and national levels. This is important as it means we will need to engage with a complex group of stakeholders at local, regional (London-wide) and national levels to begin the process of taking the recommendations forward. Ultimately, we believe, there also needs to be work at the international level.

The material gathered from the consultations was shared and debated within the Advisory Group. This informed the writing of this Manifesto by the Project Lead, as did discussions on our Facebook page. All participants in the consultations, a majority of the Advisory Group and the Project Lead all identify as BME mental health service users.

G.   Aims and objectives

This Manifesto aims to:

- Highlight the effects that current policies and practices are having on Black and Minority Ethnic mental health service users

- Recommend changes to policies and practices to improve our mental health

- Identify who we need to talk to and engage with to bring about positive change

- Provide Black and Minority Ethnic mental health service users and our allies with a reference point for future collective action and

- Put much of the learning and wisdom from past and current initiatives in one place so we do not have to waste time continually reinventing the wheel

H.   Definitions

This is a **BME mental health service user-led Manifesto**. There was much debate and discussion around the meaning of these words and we finally arrived at the following definitions:

BME – This commonly used umbrella term stands for Black and Minority Ethnic. What we really mean to emphasise through our use of this term is our common experience – despite our diversity – of coming from communities that have historically faced racialised discrimination based on ideas rooted in the history of colonialism about the superiority of White communities. Our common experience includes our oppression and Othering by the dominant White society based on physical characteristics like skin tone, as well as "race", ethnicity, cultural practices and beliefs, religion, nationality and migration status. In this Manifesto, it is BME mental health service users that we refer to when we use words like "our", "we" and "us", unless otherwise stated.

Service user-led – The consultees and Report and Manifesto writer are all BME people who have used mental health services. Many of the people in our Advisory Group also identify as BME mental health service users.

Mental health – Mental health describes a state of balance or wellbeing which is influenced by a broad range of personal, familial and wider political and socio-economic factors including racism.

Manifesto – A manifesto is a declaration of intentions, motives and views which draws on a wider consensus and promotes a plan for achieving change through defined actions

I.   Limitations

Southwark has the highest Black African and the second highest total Black population of any London borough. These communities have some of the worst experiences and outcomes related to using mental health services and so we largely concentrated on these communities. We also talked with members of London's South Asian, Latin American and Vietnamese communities. We need to acknowledge that we did not consult all the ethnic communities that have been identified in Southwark. We strongly hope that this Manifesto will be developed further by increasing numbers of communities, thus helping broaden the range of people who support this document and take it forward.

J.   A note about quotations

Where quotations are taken from work that has been published in print or online, their sources are listed in parentheses and full references are given in the bibliography. Quotations without

citations have been taken with permission from individual BME mental health service users who came to one of the 18 consultation events.

K.   The political context and report overview

"Racism is a political issue. Inequality is a political issue. Mental health is a political issue. We should hold politicians to account."

"It's not just about looking at improving services that fix us; it's also about looking at what broke us in the first place."

"There's a modern day Bermuda Triangle for black men, which is located between the 3 points of; Education (the entry point), Criminal Justice and Mental Health. Thousands will pass through, but a disproportionately high number will quite literally disappear within this black man's Bermuda triangle."

The reality of racial inequality in modern-day Britain

Data recently released from the Race Disparity Audit (Cabinet Office, 2017) highlight racial disparities as shown in unfavourable life experiences across a wide range of areas of life. This audit, the most ambitious and comprehensive stocktaking of racial disparities ever undertaken in this country, brought together old and new information across the areas of education, housing, employment and criminal justice. Criminal justice was also covered in the Lammy Review's overall assessment of racial disparities (Lammy, 2017).

Some of the top-line findings of these audits include:

- Education - Black Caribbean pupils are three times more likely than their White British counterparts to be excluded from the school system, with even higher exclusion rates for those from the Roma and Traveller communities
- Housing - Almost all Asian and Black groups experience significantly higher levels of overcrowding and rising damp in their homes than their White British counterparts; 30% of Bangladeshi households are overcrowded as opposed to 2% of White British households
- Criminal justice - BME people as a whole are three times more likely to be stopped and searched than White Britons, while Black people are six times more likely to be stopped and searched. Black Caribbean people also report significantly lower levels of confidence in the police (60% as opposed to 79% for White Britons)
- Mental health - Black people are four times more likely than White people to be detained under the Mental Health Act, while people from south Asian countries as a whole also have higher than average detention rates (although Indian people were the exception in not having higher rates). Diagnosis of psychotic disorders is almost three times higher for Black people than for White people and a staggering **ten times** higher for Black men than for White men, with higher than average rates among south Asian groups as well

The figures come at the same time as new research showing that minority ethnic households have been hardest hit by austerity policies, having experienced the biggest drop in living standards.[1]

From audit to action?

Theresa May, who had pledged to undertake the Racial Disparity Audit on becoming Prime Minister in July 2016, said on its publication: "People who have lived with discrimination don't need a government audit to make them aware of the scale of the challenge. But this audit means that for society as a whole – for government, for our public services – there is nowhere to hide. These issues are now out in the open. And the message is very simple: if these disparities cannot be explained then they must be changed" (quoted in Asthana and Bengtsson, 2017).

For many BME campaigners, there was a growing sense of urgency around government inaction on racial inequalities, some of which had been known about for decades. There was also frustration that successive governments of different parties had not just failed to tackle these inequalities but presided over policies that exacerbated them. The Runnymede Trust, for example, pointed out the lack of proper consideration in the 2015 Budget for the life circumstances of BME communities (for example, their larger family size, higher rates of child poverty, lower wages, lower percentage of pensioners and higher percentage of part-time workers than White British communities) (Khan, 2015). This, in turn, had meant that BME communities were disproportionately harmed by cuts to benefits including tax credits and child benefits and the lowering of the benefits cap, thus leading to an increase in race-based inequalities (Khan, 2015). Campaigns like Black Activists Rising Against Cuts (BARAC) have continued to raise awareness about these injustices[2] alongside groups like Disabled People Against the Cuts (DPAC), which highlights the negative effects of cuts across all communities.

Following the publication of the audit data, another key question arose: How – if at all – would this data, released with such sombre ceremony, inform basic policy and practice reform?

We know that racism and socio-economic disadvantage are part and parcel of the lives of BME mental health service users. A recent comment from the Chair of the Equalities and Human Rights Commission sums up this situation: "If you are black or from an ethnic minority community in modern Britain, it can often still feel like you're living in a different world, never mind being part of a one-nation society" (quoted in BBC, 2016).

The links between racism, discrimination and mental distress

Racism and discrimination in the UK have been linked to an increase in (what the biomedical model calls) psychosis, and research indicates that they can lead to increased physical ill health, including hypertension and cardiovascular diseases (Karlsen and Nazroo, 2002; McKenzie, 2003; Rees and Wohland, 2008; Williams, 2008; Nazroo, 2009). These findings, we believe, suffice to show why racism must be treated as a major public health issue (McKenzie, 2003; Kalathil, 2010; Afiya Trust and ROTA, 2010).

A lack of trust

The consultations we held with BME mental health service users confirmed that far too many BME mental health service users experience public services and institutions – particularly mental health, education and criminal justice systems – as contributing to rather than decreasing racial inequality. As one commentator has put it: "State institutions are not concerned to address social inequalities that might underpin increased risk of criminal activity or severe mental disorder; rather, they … amplify race inequality" (Nazroo, 2008).

This situation reduces our trust in institutions, which are meant to be there for all citizens, irrespective of their racial background or cultural difference. This lack of trust cannot be dismissed as baseless. Rather, it is justified given the demonstrably worse experiences and outcomes of BME people who come into contact with these agencies.

Racial inequalities in the mental health system

According to the *Count Me In* census, which was conducted every year from 2005 to 2010, Black people especially face higher rates of detention than White Britons under the Mental Health Act (Care Quality Commission, 2011). Over the period in question, the rate of detention actually increased by almost 70% for Black groups, from 2700 to 4600 people per year (MacAttram, 2011). Compared with the White British population, Black communities also experienced longer hospital stays, were more likely to be diagnosed with schizophrenia, were more likely to be admitted to forensic and secure services and had poorer access to psychological therapies. They received higher dosages of anti-psychotic medications and experienced seclusion more often. Black men were much more likely than their White counterparts to be brought into the mental health system by police under a Section 136. Similarly, BME women had a higher chance than White women of not being placed on a single-sex ward. Within services, Black people particularly were seen to pose a higher level of risk, either to themselves or to others. In 2010, South Asian populations and some Black groups were more likely to face a Community Treatment Order upon discharge than White Britons.

We believe that the *Count Me In* findings are a result of the overall socio-economic disadvantage and discrimination which Black African and African Caribbean people experience in the UK and which are the primary causes of much of our distress. These statistics also reflect our treatment within the mental health system where we are all too often disadvantaged further rather than made to feel better (Fernando, 2003).

A number of reports have highlighted the poor access of BME communities to suitable mental health services, in particular primary care, psychological therapies and mental health promotion services (Keating, Robertson, McCulloch and Francis, 2002; Sashidharan, 2003). Our communities also report greater levels of dissatisfaction with mainstream services than with community or voluntary sector support.

As the ground breaking report *Breaking the Circles of Fear* showed, BME communities believe that mainstream mental health services misunderstand our situations and experiences (Keating, McCulloch, Robertson and Francis, 2002). Black people are put off using services because of an

understandable and realistic fear of heavy-handed treatment as well as the fear that our mental health status will lead to stigma and discrimination from all communities.

Since Black people are deterred from accessing support where it is available, our distress is more likely to reach a crisis stage, which then often provokes more extreme and traumatising responses from services and/or the police. Shockingly, more than 15 years after *Breaking the Circles of Fear* was published, there has been no improvement in the poor mental health status and negative experiences and outcomes of mental healthcare among BME communities, particularly Black communities.

The wider context of BME mental distress

It is important to understand that our focus in this Report and Manifesto is not simply on the need to improve mental health services. Rather, we want to look more broadly at what is causing our distress. As the Joint Commissioning Panel for Mental Health (2014) points out, there is a need to consider how racism in important social institutions can hinder the socio-economic mobility of BME communities. This in turn reduces our sense of inclusion in a society which, we are told, is based on principles of merit, equality and social justice.

BME mental health service users experience disproportionate socio-economic disadvantage across areas such as benefits,[3] housing[4] and employment.[5] Moreover, this is happening at a time when austerity policies make it increasingly difficult to get support in these areas. Disability-specific benefits essential to the livelihoods of many mental health service users are being slashed. At the same time, the benefits application process has been made so disorientating and upsetting that some mental health service users have taken their own lives because of the strain of this process, which comes on top of often severe mental health issues and multiple disabilities.[6]

Along with racism and socio-economic inequalities, BME mental health service users face discrimination from within BME communities and society at large on account of our mental health diagnoses. This discrimination affects numerous aspects of our lives from finding and keeping a job, to being accepted and feeling valued within families and wider social networks.

We may be marginalised by racism on the one hand and by sanism on the other. Sanism can be defined as the privileging of the idea of sanity or rationality over what is construed as insanity/irrationality or madness; the result is blatant as well as subtle discrimination against those with mental illness labels (Ingram, 2011). Research shows the need to address discrimination based on mental health status together with racism, including racism from within mental health services (Owen and Rehman, 2013). For those of us who are women, lesbian, gay, bisexual, transgender, queer or questioning, the pressures are even more complex and acute given widespread misogyny, homophobia and intolerance of non-traditional gender identities.

There is an urgent need for work that addresses stigma and discrimination in these areas. However, many projects of this kind have not had their funding renewed. Among those denied funding is 300 Voices, a project that built bridges between Black communities and the police (Owen and Rehman, 2013).

Some BME communities are also contending with our pejorative representation in the media where we are routinely portrayed as outsiders and Other. These depictions can take various forms. If we are refugees or asylum seekers, we are often portrayed as scroungers. If we are Muslims, we are called terrorists. If we are Black mental health service users, we are Mad, Black and Dangerous. Racist rhetoric which scapegoats migrants for the loss of British jobs has not been adequately countered by advocates making the real point that we should all unite behind having a decent wage for everyone. Many of us feel that a divide-and-rule strategy is at work with the political debate now pitting community against community – in many cases the White British working class community against White European or BME communities. This situation leaves us with the sense that we do not belong and are not equal and valued citizens of this country. It is, to say the very least, not good for social cohesion.

The erosion of support

In the face of all our challenges, independent BME service user-led peer support and advocacy offer critical protections. These supports are needed now more than ever at a time of reduced statutory services and the slashing of legal aid, ESL/EFL support and benefits on top of NHS reforms. But instead, they too have been drastically cut.

Under the banner of austerity, our communities have seen cuts to services that we rely on including advocacy to access our entitlements, lunch clubs, respite care and day centres. Meanwhile, cash-strapped local council funders have made only half-hearted attempts to conduct Equality Impact Assessments (EIA). An EIA is the process which organisations should use to ensure their policies and work methods do not discriminate against or disproportionately affect any community. In many cases where services have been cut, there has been no EIA at all.

We have seen the wholesale loss of the regional voice of the BME voluntary sector, which previously spoke out for smaller BME voluntary organisations.[7]

Overall, this is a devastating withdrawal of the support that we need to remain well.

In our own patch in Southwark borough, we lost Kindred Minds Women's peer support group (known as the "Women's Pop-In"). Even our general peer support group (the "Pop-In"), which helps many BME service users manage recovery or cope with difficult circumstances, had to be cut back and at one point was in danger of disappearing due to a loss of funds. The Pop-In was eventually brought under the administration of Lambeth and Southwark Mind, but the uncertainty that hangs over its future is deeply demoralising for facilitators, and this feeling feeds through to service users and is extremely destabilising. Other groups for BME service users such as Maroons have been axed. With so many BME service users now in a constant struggle to survive economically and keep mentally well, there is often little energy left for engagement in political action that could make a difference. But it is this energy which we hope this Manifesto will help rekindle.

Fundamentally, the issues that affect our mental health come down to imbalances of power. Sadly, the power imbalances that work against us in society are all too often reflected in the involvement activities set up by the NHS, local government and other agencies, including for the development of knowledge and research. These are initiatives that could potentially learn a

lot from BME mental health service users. But our experience and wisdom are all too often missing from, or only inadequately inform, the many projects that claim to involve us. In fact, some of these projects sideline our voices even while claiming to exemplify "working partnerships" and "co-production".

To tackle the many areas of interlinked disadvantage, disempowerment and social injustice that we face, this Manifesto proposes a joined-up programme of actions to be undertaken by many different people in pursuit of a common goal. In all cases, BME mental health service users must be positioned as equal partners. This programme must be informed by the growing understanding that tackling mental distress requires tackling the social and economic factors impacting on mental wellbeing. As the United Nations Special Rapporteur on the right to health has said: "New ways of thinking need to permeate the public sector, and mental health must be integrated into the whole of public policy" (UN Human Rights Office of the High Commissioner, 2017).

L. Report findings, discussion and recommendations

Fourteen key themes emerged from our consultations and literature review. These themes are set out below together with our main recommendations:

1. The need for political leadership, focus and long-term resources to challenge racial inequalities

"There is a bigger picture to our mental ill health but all we get are scattered initiatives – inadequately funded and temporary – which attempt to deal with bits of the jigsaw."

"These are socially constructed problems pathologised as mental illness."

We want to see a meaningful strategy that tackles the racial inequalities that lead to higher rates of distress among BME people and our worse experiences and outcomes of contact with mental health services. This strategy should spell out the systematic work needed to end these inequalities across all the areas of life which impact on our mental wellbeing which are highlighted in this Manifesto.

As one BME service user put it in a previous report that also aimed to join the dots of disadvantage: "I would take mental health out of health totally and put it into the rights based, social context based framework … I think a lot of issues are about money, employment, housing … I don't know why health has kind of appropriated distress … If we address some of those social issues, some of those rights issues, people do recover or people do find a way" (quoted in Kalathil, 2009).

But we also maintain that piecemeal reforms are not enough. Simply funding this or that temporary local initiative, no matter how good it is, will just result in yet another flash in the pan with little or no lasting value. This is because the issues we face demand action at not just

borough-wide but regional, national – and sometimes international – levels. These actions must be ongoing and sustained.

We want the UK government to show leadership and devote adequate resources to a national race equality strategy. This will require the creation of a senior government post to oversee programme coordination and take final responsibility for meeting targets for the reduction of racial inequalities. This programme must also be ongoing and secure.

The issues that affect our mental wellbeing must be tackled simultaneously with agencies and initiatives from various areas of life all working together and not in isolation. This cooperation is essential quite simply because these factors do not affect us separately – they are interrelated concerns that are woven into the totality of our lives.

What this means in practice is that, for example, strategies addressing the gap between the educational attainment of some BME communities and the White British majority will need to tackle employment inequalities. They will also need to confront the reality that the higher educational qualifications of people from these BME communities have not led so far to a narrowing of the pay gap by ethnicity, suggesting that we are far from living in a meritocracy. Similarly, programmes that confront the high numbers of Black people in the criminal justice system will also need to address the role of mental health services in helping people have stable lives before, during and after their time in prison. And efforts to improve signposting to mental health services must happen in tandem with work to make those services safer, less oppressive and more appropriate for us.

It is essential that we address the current lack of a strong BME mental health service user voice in initiatives to improve the NHS and other organisations. A critical issue is the impact of austerity policies, which have led to the political disengagement of people whose subsistence is being threatened by benefits sanctions. Many of these people are already dealing with the traumatising effects of being subjected to control and restraint while in mental health services – experiences which deter many of us off from ever engaging with mental health services again. Some people have also disengaged from physical health services due to their negative experiences with professionals in the mental health system.

Along with action at multiple domestic levels, there is a need to tackle international aspects of BME mental health in the UK's foreign policy. We must consider the effects of war and catastrophe, harsh economic conditions and the persecution of certain BME groups including lesbian, gay, bisexual and transgender people who have fled their home countries and become refugees and asylum seekers in this country. We must also address attacks on Muslims and other BME people affected by the growth of right-wing extremism and Islamophobia nationally and internationally. We acknowledge that we have not progressed far in finding solutions to these issues at international level, but we believe it is imperative that future strategies cover these topics.

At each and every stage of the strategy, BME service users must receive the support we need to play a meaningful part in decision-making, and wherever practical, to take up leadership positions.

- The UK government must develop a national race equality strategy under the leadership of a new ministry-level officer with a mandate to implement the strategy.

    This officer must:

    - arrange for extensive and systematic audits of all areas of life affecting mental health in order to monitor all identified racial inequalities
    - oversee audits which compare the performances of different trusts in reducing racial inequalities in experiences and outcomes of mental health services and support. These audits should enable comparisons of inequality levels across geographical areas and highlight good and bad practice
    - ensure that Race Equality Impact Assessments are always performed when developing and rolling out national policy and developing new legislation and
    - ensure that race equality strategies already nominally in place are actually being put into action. These efforts must create momentum so that these strategies become prescriptive rather than descriptive.

    Throughout all these tasks, this officer must be supported by a national reference group including a significant number of BME mental health service users. These service users should in turn be well supported by NSUN (National Survivor User Network) as part of its work in strengthening mental health service users' voices. NSUN will need to be adequately resourced to offer this support.

- Examples of good practice for reducing BME mental health inequalities have already been identified by the Black Thrive campaign (focusing on Lambeth borough). We should disseminate these examples and ensure that BME mental health service users receive all the support they need to play a meaningful role in developing these programmes. The NSUN co-ordinator for London should work with the Black Thrive campaign to ensure BME mental health service users play a greater role in its campaign as well as in the pan-London Thrive campaign.
- Race equality champions should be appointed within Health and Wellbeing Boards, which have a duty to address race equality. These champions should help make racial equality a clear priority by insisting that agencies, including the NHS and local authorities, carry out rigorous Equality Impact Assessments of their services and apply the results properly, including when deciding on service cuts.
- Meaningful BME user involvement should be ensured across every stage of the development and implementation of the national race equality strategy. To this end, the NSUN 4PI Involvement Framework and the *Dancing to Our Own Tunes* Charter must both be followed.[8]

2. Challenging multiple forms of marginalisation

"Services are sometimes just about able to talk about cultural appropriateness when it relates to one aspect of diversity, such as race. But they do not acknowledge that some of us experience oppression on account of other factors too, like gender or sexuality."

"The way masculinity is socially constructed and is used to legitimise violence against women is a big problem. Sometimes men, who are used to gender-specific norms and being in positions of power, lash out against the women in their households when they are forced to do cleaning work, which is traditionally seen as women's work."

"Social isolation as an asylum seeker is not just a human phenomenon – it is state-sponsored discrimination."

"You leave yourself open to homophobia [from other service users]. The staff does nothing to intervene and can itself be homophobic."

The BME mental health service users who contributed to this Manifesto are united by our common experiences of racism and sanism.

At the same time, we must emphasise our diversity. We do not come from one homogenous community but rather from hundreds of different BME communities. Many of us are women who experience the restrictive patriarchal norms of both mainstream UK society and our BME communities. Many of us come from working class backgrounds and face a range of structural barriers that prevent us from realising our potential. These barriers are deeply entwined with the racism we face. Some of us are also lesbian, gay, bisexual and transgender people who feel compelled to hide our sexual orientation or gender identity to avoid rejection or even physical violence including from within our own families and faith communities. We are Muslims who are called "terrorists" on the streets and in the media and told we have "alien", "un-British" values, which makes us feel strangers in this country. Some of us are also asylum seekers whose legally inferior status prevents us from accessing a range of services that British citizens – including those from BME communities – take for granted, even if they may be far from adequate.

Power differences cut across and exist within groups including Black and Minority Ethnic communities. We have differing experiences of disadvantage and also privilege. The concept of *intersectionality* can help us understand and address the complexity of our lives.[9] We want policies and practices to reflect the true complexity of our experiences and confront the intersectional nature of the disadvantage we face.

As Black lesbians, for example, we may find ourselves labelled "aggressive" based on prevailing racist stereotypes about Black people. At the same time, we may meet with homophobic suspicion from mental health staff. We may receive specific diagnoses based on prejudices about sexuality and sexual orientation – and these will, in turn, affect the kind of care and treatment we receive within services. Staff may also downplay the homophobic discrimination and traumatising attacks we face, ignoring homophobic slurs and attacks directed at us on inpatient wards when we are at our most vulnerable. Memories of this kind of treatment may impinge on our later interactions with healthcare professionals.

As Black women, we may feel marginalised and unable to talk about issues in our lives when we are placed in mixed-sex groups with other BME service users.

As LGBTQ (Lesbian, Gay, Bisexuyal, Trans and Questioning) mental health service users from BME communities, we are eligible to join a dwindling number of self-proclaimed "safe spaces" such as peer support services (including BME-specific peer support). Nevertheless, we may steer clear of these spaces because of our fears of meeting with homophobic and transphobic responses. Sometimes BME-specific LGBTQ groups, which understand the multiple oppressions that we face, are more appropriate for our needs. These groups are, however, few and far between. Very few are mental health-specific and those that do exist have been hit by funding cuts.

As BME asylum seekers, we contend with generally hostile attitudes and are dismissed as scroungers. These attitudes permeate all communities including BME communities. They can leave us feeling that we have arrived in an especially hateful environment where we are not wanted.

Some of the discrimination we face as asylum seekers comes from rules restricting our use of food banks and housing, health and social care services as well as our access to education, employment and support systems including advocacy and language support. These restrictions can drive us into poverty and social isolation, which lead to greater distress, thus creating a vicious circle. At present, care coordinators have little understanding of the specific predicaments we face as asylum seekers, including the need, very often, to prioritise buying food over medication.

As asylum seekers, we are sometimes unsure about whether we are entitled to medications under the National Asylum Support Service. There seems to be no clear rule about our use of food banks, however our extremely poor diet and food access have been highlighted (Loopstra et al., 2015; McVeigh, 2016). What little support we receive tends to come through voluntary sector organisations specialising in the needs of specific groups such as BME asylum seekers. These initiatives are, however, very rare and inadequately funded. The general lack of information about services is exacerbated for those of us whose first language is not English. And yet our access to English language courses has been slashed, isolating individuals even more.

In order to address the intersecting forms of discrimination that we face, we need to see more links between groups working on mental health issues and groups dealing with other rights-based issues affecting the mental health of BME communities. Links with groups like Violence Against Women and Girls Strategy would allow us to campaign together against the current system that requires survivors of violence and domestic abuse to obtain a mental illness diagnosis to qualify for help. Similarly, we need to forge links with Refugee Action, which is challenging the discriminatory laws that prevent asylum seekers from accessing food banks and work and educational support, increasing their isolation, hardship and mental distress. We need to connect with LGBT campaigning groups that are working to change the rules that stop LGBT people from fleeing homophobic regimes and expose them to traumatising processes when they seek asylum. We need to break out of the narrow silo of "mental health".

- The government's race equality strategy must address multiple and overlapping forms of disadvantage using a framework of intersectionality. To ensure good practice around intersectionality, there should be ongoing consultations with a key stakeholder group made up of organisations that address multiple types of disadvantage in their work.

- National and local government and mental health trusts must allocate more funding for safe spaces and peer support for BME service users who experience multiple forms of marginalisation.

- In Southwark: the fortnightly Kindred Minds BME women's group should be reinstated. This group was popular and well attended and had a track record of facilitating the recovery of BME women but it was cancelled in 2015 due to a lack of funding. Women-only groups of this kind are essential since they are the only space where some women may find it possible to speak about some issues.

- The current Prevent strategy must be abandoned since it has only alienated Muslim communities. Instead, work should be done in collaboration with Muslim communities to develop anti-radicalisation strategies that stop our young Muslim citizens being drawn into extremism.

3. Strengthening Black and Minority Ethnic peer support

"This is a place where I feel safe and understood, it has really helped me to cope and recover."

"The realisation [in the peer support group] that we are all in the same boat can be very liberating."

"The huge positive potential of peer support has not been allowed to be realised."

"Having to constantly be on the look-out for new funding is very demoralising."

"If a peer support group is working well and helping people's recovery, why make us do things differently? This can be very demoralising. But I say:' If it ain't broke don't fix it!'"

Peer support alone cannot repair the damage caused by the wider social challenges which contribute to our mental distress. There is a need for changes to the policies and practices which harm and break us in the first place – and not just efforts to create better services and supports to "fix" us when we become unwell.

Having said this, it is clear that BME peer support can be extremely important for BME mental health service users, because it can reduce our sense of isolation in what is often a hostile and unjust world. The benefits of peer support have been shown at different levels (Faulkner and Kalathil, 2012).

Peer support often offers a safe space to share and connect around our experiences of mental distress. This includes experiences relating to racism and other forms of oppression and hardship (Faulkner and Layzell, 2000).

This support is especially important for marginalised groups like Black and Minority Ethnic communities because mainstream mental health settings do not always make it easy for us to talk about the things that matter to us.[10] While the peer support open to all communities including White communities is certainly helpful, it can be difficult to use these spaces to talk about specific challenges we face such as racism.

In the circle of BME peer support, many of us have found we can share our own stories and daily struggles and listen to the stories of others in similar circumstances. This builds a sense of social connection and helps overcome the social isolation and shame that often accompany mental distress. The recovery cultivated through peer support focuses on collective recovery. This is very different to the neoliberal view of recovery, which understands recovery as an individual enterprise.

Peer support spaces can also enable us to share skills and specific information – for example, information about accessing benefits and entitlements – which can build our knowledge base and promote self-confidence (Faulkner and Bassett, 2010). A unique aspect of peer support (whether general or BME-specific) is the opportunity it offers to give as well as receive support when we can. This can help develop a sense of social purpose and nurture our self-esteem – aspects of our lives that often have no place in professionally-led services and support.

Peer support workers in peer support groups receive additional important benefits. They are recognised as having a valued role, which is good for their self-confidence. Meeting other service users can also give them a sense of how far they have come in their own recovery (Reynolds and Seebohm, 2010). This can be a unique benefit of peer support groups; one study found that by modelling recovery, peer support workers inspired more hope in mental health service users than their experience of mainstream services (Repper and Carter, 2010).

In terms of wider social impact, well-run and adequately resourced peer support can also build people's self-belief so that they are ready and able to engage in self-advocacy and campaign for their political rights.

As actively engaged citizens – and not just passive recipients of care who have been de-voiced by discrimination – we have challenged the effectiveness of the biomedical model and service cuts. In broad alliances with others, we have also taken a stand against the racism, injustice and discrimination that affect our mental health. We want to continue this political advocacy together with our allies and friends. Peer support can also help us feel supported and informed enough to get involved in improving mental health services as service users (Griffiths, 2013).

Despite the considerable advantages of peer support, many peer support groups have been eliminated across all communities. Others – including Kindred Minds – have been left to rely on ad hoc funding. These grants are time-consuming to bid for and the situation creates an almost permanent sense of uncertainty, which is bad for the morale of peer support workers and the whole peer support group. Often funders seem to want novelty and "big ideas", but given the

time-tested benefits of grassroots peer support confirmed in our consultations and the literature, we think these are the wrong priorities.

We believe that higher priority should be given to independent peer support, which is an essential bread-and-butter support for many BME service users. This BME peer support must be adequately funded so it can be scaled up to cover new activities. We are convinced that it has a critical role to play as an appropriate, accessible and non-stigmatising support that emphasises a community strengths-based approach.

When funding peer support, grant givers and statutory bodies should prioritise groups that are truly independent. While locating peer support within statutory services might seem to offer some theoretical advantages in terms of greater access to decision-making and influence, this is not borne out in practice. Rather, the reality of such a placement is that it puts peer support in constant danger of being taken over by statutory services and/or not adequately protected from rampant cuts within mainstream services and the different priorities within services they create. Placement in the statutory sector may also force us to work within mental health service hierarchies that disadvantage us or require us to comply with policies such as control and restraint. Those policies are fundamentally at odds with the ethos and values of peer support, which are self-determination, reciprocity, empathy and shared experience.

RECOMMENDATIONS

- Funders nationwide including the NHS, charities attached to mental health trusts, local authorities and other grant awarders must give high priority to sustainable funding for independent BME mental health peer support.

- Within Southwark: South London and Maudsley NHS Mental Health Trust (SLaM), Southwark Council and Lambeth and Southwark Mind should pool resources and provide long-term funding for a dedicated part-time (2.5 days per week) co-ordinator of Kindred Minds peer support groups. A budget should also be provided for refreshments and outings to relevant cultural events.

- Within Southwark: SLaM, Southwark Council and Lambeth and Southwark Mind should fund a fortnightly Kindred Minds BME women's peer support group. This group should be part of the core activities of Kindred Minds together with the current fortnightly mixed group.

- Statutory organisations that are considering defunding BME peer support must perform thorough Race Equality Impact Assessments. The results must be made publicly available and scrutinised by the borough lead under the national race equality strategy.

4. Reforming mental health services

"Rather than help us heal ourselves when we are broken by society, mental health services break us even more, so why would we seek help there?"

It is clear that for Black communities in particular, mental health services are a source of distrust and fear. This was spelt out in the *Breaking the Circles of Fear* report (Keating et al., 2002), and it has been confirmed in numerous coronial enquiries implicating the mental health system in Black deaths. As the findings of the enquiry into the death of Rocky Bennett, who was killed in a mental health clinic in 1988, put it: "Institutional racism is a festering sore … on the good name of the NHS" (Norfolk, Suffolk and Cambridgeshire Strategic Health Authority, 2003).

Many of the *Breaking the Circles of Fear* recommendations for improving mental health support and outcomes in Black communities are now being taken up by Black Thrive, which is building on the work of the Lambeth Black Mental Health Commission. But action in a single geographical area is not good enough. We need to see action nationwide as part of a properly resourced race equality programme.

BME communities have higher – and in the cases of Black African and African Caribbean communities, far higher – rates of mental health-related hospital admission than White Britons. This is partly due to the socio-economic factors and racism that disadvantage us from birth onwards. But another big part of the problem lies in the fact that our contact with the mental health system perpetuates our disadvantage. Within mental health services, we are far likelier to be given severe and enduring mental illness diagnoses including schizophrenia – one of the most stigmatising labels. We are also far likelier to be compulsorily detained and medicated and subjected to control, restraint and seclusion (Care Quality Commission, 2011).

The United Nations Convention on the Rights of Persons with Disabilities, which the UK has ratified, clearly bans the use of force and restraint in mental healthcare. The UN Special Rapporteur for the right to health recently described the changes required from signatory countries: "[M]ental health systems are segregated from other healthcare and based on outdated practices that violate human rights. I am calling on States to move away from traditional practices and thinking, and enable a long overdue shift to a rights-based approach. The status quo is simply unacceptable" (UN Human Rights Office of the High Commissioner, 2017).

The Maat Probe project, which worked with African and African Caribbean service users in Sheffield, trained NHS staff in the RESPECT approach. The project sought to overcome reliance on compulsion through changes to professional attitudes and culture.[11] We believe this kind of programme should be a mandatory part of staff training and organisation development. Notably, Sheffield Health & Social Care NHS Foundation Trust now has the lowest use of the controversial face-down restraint technique of any trust in the country; in fact, the technique has not been used once inside the Trust in the 18 months since the training (Torr, 2017). Unfortunately, many of the BME groups which could deliver this training have now been shuttered – including Maat Probe. This is just one example of the need to link up different initiatives. Improvements to mental health services absolutely depend on the allocation of adequate support to BME mental health service user groups.

On the other hand, staff training alone will not ensure better practice. A real and meaningful change is needed in the way decisions are made within trusts, and this will take a shift in influence and power in favour of service users. This may mean ensuring service users sit on scrutiny committees to hear complaints on inpatient wards. It may also mean using a more

democratic and accountable system to choose chief executives so that service users can participate directly in their election. These changes need to be developed more fully, using some of the learning from the NAViGO initiative in Lincolnshire. We will need to remain alert to the hierarchical nature of the NHS and the way this can inhibit changes of this kind.

Racial inequalities in mental health also include options for mental health support: Black service users particularly are less likely to be given access to talking and alternative therapies in situations where force is not used. On the rare occasions we are offered talking therapy, it is likely to be cognitive behavioural therapy, with no access to a broader range of approaches.

Currently there is very little access to culturally appropriate and diverse treatments that we would find more helpful. This is despite a number of interesting initiatives that have been co-developed or delivered with BME service users and which BME service users have found useful. These projects need to be rolled out further. They include storytelling projects like Tree of Life, which focuses on strengths in the community and sees recovery as something people do together by discussing common issues (Griffiths, Byrne and Nolas, 2010).

RECOMMENDATIONS

- The government must honour its obligations to comply with the United Nations Convention on the Rights of Persons with Disabilities, which the UK has already ratified. The Convention bans the use of control and restraint in mental healthcare.

- Mental health trusts must adopt non-coercive approaches, drawing on learning from the RESPECT approach as part of wholesale system change. This change should include staff training and a rethinking of the physical layout of hospital wards. It will also require real and meaningful service user influence in scrutiny committees on inpatient wards and in the election of senior board members up to chief executive level. Lessons should be drawn from the NAViGO experience.

- Mental health trusts and other relevant agencies must adopt all 15 recommendations set out in the *Breaking the Circles of Fear* report (Keating et al., 2002).

- Mental health trusts and councils must offer a more diverse range of mental health services and not simply those based on the biomedical model. These services must be offered in a range of settings including in the community. They must be delivered in active partnership with BME mental health service users and the BME voluntary sector.

- Within Southwark borough: SLaM, Southwark Council and Lambeth and Southwark Mind should provide resources and support to Kindred Minds Pop-In so it can run sessions using the Tree of Life narrative storytelling approach within the existing Kindred Minds peer support group.

5. Strengthening the BME voluntary sector

"The BME voluntary sector has been slashed – [this includes] even some initiatives doing sterling work helping us negotiate life challenges and understanding our rights."

"The effect[s] of cuts to the BME voluntary sector on our mental health are intensified because of the closure of service user groups and cuts to mainstream services."

The BME voluntary sector has a vital role to play in providing advocacy that allows us to negotiate life challenges. This support can help us access our rights and entitlements around housing and benefits and become informed about mental health assessment processes. These are often complex procedures which many people find difficult to understand. The problem is particularly acute for people whose first language is not English. Advocates can act as cultural and linguistic interpreters and translators in our dealings with a range of agencies. Without this kind of support, ethnicity-based inequalities are bound to increase across the life course.

The voluntary sector also provides broader political advocacy through its campaigns which highlight the issues we face and call for essential changes to policies and practices.

While the voluntary sector can be an important part of people's recovery, we reject the notion that we must choose between cuts to the voluntary and statutory sectors.

Sadly, the voluntary sector, which has provided so much for so long and is a treasure trove of information about the communities it serves, has had its funding slashed and we know that this is hitting the BME voluntary sector disproportionately hard (Voice4Change). Often small-scale initiatives do sterling work on a shoestring budget and are critical to people's recovery and wellness in the community, but they do not have the resources to continually look for funding. The need to conduct this search is distracting and demoralising for workers and creates great instability for those who use services. The impact of cuts to the voluntary sector has been intensified by simultaneous cuts to mainstream services, leaving many service users with no support to turn to unless we are in crisis. Even then, help is not always available.

The decimation of community organisations is affecting Black and Minority Ethnic groups more acutely. The sector is not sufficiently resourced to meet the challenges that our communities face. Combined with the dilution of the focus on race equality in policy and increasing compulsion within mental health services, this situation has left many BME mental health service users reeling (CEMVO, 2010; Afiya Trust, 2012).

The positive potential of collaborations between the BME voluntary sector, service users and statutory services was shown more than ten years ago in the Cares of Life project, which took place in the South London and Maudsley area and had many mental health benefits.[12] Such a collaborative approach would, however, be difficult if not impossible today due to the destruction of the voluntary sector and cuts to BME peer support and services.

- Councils, the NHS and grant-giving bodies must ensure adequate ongoing funding for the BME voluntary sector. These authorities must also complete proper Race Equality Impact Assessments when considering cuts to the sector.

6. Creating a fairer and more accessible benefits system

"Vulnerable people are dying as a result of the political project of austerity and cuts to benefits."

"Psychocompulsion is more powerful […] with greater reach than the Mental Health Act. You can appeal, be discharged, abscond from a section. You can't appeal […] interventions demanding you do 'home work' or you starve."

The unemployment rate is high among mental health service users from all communities, and we often depend on unemployment and other benefits for our livelihoods. Gaining employment that would end our reliance on benefits can, however, be especially difficult for BME service users due to racism. This is on top of the discrimination that mental health service users from all communities face because of their diagnosis with mental illness.

The last few years have seen cuts to benefits with the constant threat of further reductions. This has created a climate of fear in which claimants are forced to cut back on household essentials like food and heating in some cases. It also increases the mental distress of many of us who are unable to work.

These are critical issues for mental health service users from all communities. In 2016, the United Nations Committee on Economic, Social and Cultural Rights made clear that the UK government has a duty to provide adequate support to people at risk of poverty. In this regard, the UN singled out the plight of minority ethnic groups and migrants (UN Human Rights Office of the High Commissioner, 2016.

We are still waiting for a comprehensive assessment of the cumulative impact of benefits changes in order to register the full impact of austerity. Nevertheless, it is clear that austerity is harming the poorest and most vulnerable people most, with the burden falling disproportionately on many BME communities. This is contrary to all principles of social justice and equity. We know, for example, that people in poverty (21% of the population) bear the impact of 39% of all cuts; disabled people (8% of the population) have incurred 29% of all cuts and those with the most severe disabilities (2% of the whole population) have been hit by 15% of all cuts (Duffy, 2013).

In common with mental health service users from all communities, BME mental health service users are now faced with an increasingly nightmarish and bureaucratic assessment process, which is not fit for the purpose of evaluating applicants' claims. At the same time, we have lost access to the advocacy, support and advice that could help us negotiate this process with a

proper awareness of our rights. This situation is particularly harsh on people who have difficulty understanding English.

Psychologists working with the Department of Work and Pensions often play instrumental roles in this anxiety-inducing process. The decisions they make about us can result in devastating benefits sanctions. We believe this use of psychology must be informed by explicit and stringent ethical guidelines.

RECOMMENDATIONS

- The government must complete a comprehensive audit of the cumulative impact of benefits changes in order to expose the effects on mental health service users and BME service users particularly. Action must be taken to mitigate the harm that benefits changes have caused to our communities.

- The government must follow the recommendations of the United Nations Committee on Economic, Social and Cultural Rights, which has called on the UK to ensure targeted support to people living in or at risk of poverty with special attention to the needs of ethnic minorities.

- A new national panel must be created to develop a more humane and fit-for-purpose assessment process for EPA, DLA and PIP claims. This panel should include officials from the Department of Work and Pensions and BME mental health service users.

- The British Psychological Society must develop strict ethical guidelines for psychologists involved in work that could result in the application of benefits sanctions. BME mental health service users must be meaningfully involved in the drafting process.

- Mental health groups and other campaigners should raise awareness among BME mental health service users and our allies about the processes for challenging the government's failure to conduct proper Race Equality Impact Assessments. We should also provide guidance on lodging Freedom of Information requests using ethnic and other demographic markers which can highlight injustices in application processes and uncover other racial inequalities.

7. Creating fairer employment practices and a national strategy on racial inequalities in employment

"Undocumented migrants are particularly vulnerable and have few rights."

It is deeply worrying that unemployment rates among many BME communities exceed the national average. We are particularly concerned that the unemployment rate for Black youth is double the level for White youth and that this gap is only widening as White youth unemployment falls (Equality and Human Rights Commission, 2016). We believe action must be taken to address critical issues including racist discrimination in recruitment and promotions,

the lower earnings of BME workers who have the same qualifications as their White counterparts and the greater risk of being in precarious and/or low-paid work in BME communities. Undocumented migrants especially have few legal rights and are in danger of being forced into domestic servitude or otherwise exploited.

At the same time, we share the view of mental health service users from all communities that it is wrong to promote work as a universal panacea for people recovering from mental distress. Under the right conditions and with the right support, work can be part of some mental health service users' recovery if and when they are ready for it. Like other mental health service users, however, we are extremely concerned at the way vulnerable people with mental health issues are being pressured to resume work before they are ready for it, in many cases after being threatened or faced with the loss of benefits. For some people, this pressure will precipitate another breakdown.

These concerns are particularly acute given the fact that workplaces are increasingly characterised by job insecurity, zero-hour contracts and unfair and humiliating practices (Lambeth Black Health and Wellbeing Commission, 2014). Workers have drawn attention to workplaces where they are required to obtain permission to go to the toilet. They have also detailed punitive practices including the use of "secret shoppers" to monitor employee performance and the sanctioning of whole groups of shift workers for the poor performance of one worker.

RECOMMENDATIONS

- The government must address the employment inequalities affecting BME communities within its future race equality strategy. Critical issues to be tackled include the higher rates of unemployment and insecure and low-paid work in BME communities, discrimination in recruitment and promotions and the lower earnings of BME people despite having the same qualifications as their White British counterparts.

- The government must abolish zero-hour contracts.

- Mental health services and jobcentres must ensure that mental health support is kept entirely separate from jobcentres so that mental health service users are not put off accessing the help they need for fear of being forced into work.

- The government must provide statutory protection for low-skilled migrants who are currently vulnerable to exploitation and domestic servitude because they cannot work legally and have few legal rights when employed.

8. Ensuring that everyone has safe and adequate housing

"Living in insecure and overcrowded housing can affect our mental health and even lead to violence between generations."

In a civilised society, the right to decent and safe accommodation should be a reality for everyone.

This access is, however, denied to many people from BME communities in the UK. We are more likely than White Britons to live in substandard and overcrowded housing with rising damp and other problems. The victims of the Grenfell tragedy came overwhelmingly from BME communities although there are obvious intersections with class status. BME people are more likely to be evicted. We are also disproportionately disadvantaged by penalties on social tenants deemed to have excess bedrooms (the "Bedroom Tax"); we are more likely to experience Bedroom Tax displacement and sanctions or to be forced to live in a single room. With more BME people living in large families in poverty and receiving benefits and tax credits, our communities have been disproportionately harmed by the government's welfare reforms and the introduction of universal credit with all the associated payment delays and difficulties (D'Souza, 2017).

Inadequate housing can have long-term effects over the course of people's lives, including on children's educational attainment. Our consultees also highlighted the important connection between inadequate housing and higher incidences of domestic violence.

In some inner city boroughs, new housing developments have been built on former council land. Social housing projects make up a low percentage of these developments, however, meaning it is very difficult for BME communities, who are likely to be poorer, to remain in places where they have long lived. This has led to instances of social cleansing with whole areas being cleared of poorer people who are more likely to be from BME communities.

We must also not forget that patterns around poverty and housing are also changing. There are now far more people living in poverty in the hugely expanded private rental sector than in social housing. Those in the private sector also deserve adequate legal protection against exorbitant rents, for example. The situation has been exacerbated by the decisions made by politicians over several decades to stop building sufficient numbers of new council homes while selling off existing homes to those who can afford to buy them – in many cases, slum landlords.

LGBT BME asylum seekers who are housed by the state are currently denied choice and control over where they are settled. There is a tendency to automatically settle these people with others from their home communities despite the fact that those others may have homophobic and transphobic attitudes, which can put LGBTQ asylum seekers at risk of abuse and violence. This shows a blatant disregard for these people's right to be free from violence as well as their right to live in decent and safe accommodation.

RECOMMENDATIONS

- The government must abolish the Bedroom Tax.
- Councils must apply higher social housing quotas to all new housing developments built on former council land and estates.
- The government must revise the national housing policy and ensure the building of more council housing.

- Councils must apply a gold standard to the private rental sector in their areas and put a cap on private rents.
- Councils must consult in more depth with LGBTQ asylum seekers from BME communities to ensure that they have an adequate say in decisions about where they live. Priority must be given to protecting these people from potential intimidation and violence, including from other asylum seekers.

9. Improving support for children and young people

"We desperately need to challenge the intergenerational transmission of inequality, which is a big issue for BME communities."

"The process of exclusion and disadvantage starts in childhood for Black people [….]A Black boy is excluded from school, experiences psychosis in his teens, is in a medium secure unit by age 20 and, after a period of long-term unemployment, in supported housing by age 40."

"Even if you are a well-qualified Black person, it is harder to get a well-paid job than for a White person who isn't as well qualified."

There is an urgent need to address the ways that racial and socio-economic disadvantage are passed on through families. Early intervention strategies must target children and young people – along with their parents and families – before they get caught in a downward spiral of disadvantage that can continue across the life span and contribute to mental health problems later in life.

Post-natal depression is more prevalent in disadvantaged communities. We need good and accessible maternal services as well as parenting information and advice for mothers and fathers if we are to tackle this problem. We also need more programmes that support parents from deprived backgrounds to gain employment and access decent housing. The Sure Start programme, which began in 1999, had some good examples of scaled-up approaches to early intervention. This initiative aimed to tackle concerns within deprived communities, including concerns around low birth weight, child development, relationships between parents and children and a slew of other deprivation-related social disadvantages. Unfortunately, Sure Start was handed over to local authorities after the 2010 general election and some councils decided to scrap the programme to reduce costs.

Within schools, individual BME communities fare very differently, with Chinese, Indian and Black African schoolchildren now outperforming White British schoolchildren, for example. In contrast, Bangladeshi, Pakistani and African Caribbean schoolchildren continue to perform below average (Equality and Human Rights Commission, 2016). Our consultees identified the low expectations of Black people along with negative portrayals – or the complete omission – of our cultures and histories, and the failure to depict positive Black role models, as factors that hold our young people back. These factors work in tandem with the social disadvantages described elsewhere in this Manifesto, and all these issues must be addressed together.

A key point which we cannot ignore is that even with qualifications (including degrees for university graduates), Black workers are paid significantly less than their similarly qualified White peers (Equality and Human Rights Commission, 2016).[13] This indicates that our society is far from a meritocracy and racism continues to play its part in perpetuating inequalities. This discrimination only reinforces the disadvantage that BME families, which are comparatively poorer, face in financing young people's increasingly expensive university education.

Another important issue affecting the future life chances of Black Caribbean and Mixed White/Black Caribbean children in particular is the fact that these pupils are permanently excluded from the school system at three times the rate for the general pupil population (Equality and Human Rights Commission, 2016).

Bullying is a problem that can predispose young people to mental distress.[14] We are concerned by the lack of any Department of Health guidance on preventing and tackling bullying in schools and the failure to make anti-bullying policies mandatory.

In the course of its inquiries, Lambeth Black Mental Health Commission (now Black Thrive) heard from public health officials that for every £1 spent on social and emotional education to build mental health resilience in children, £84 was saved in the longer term (Lambeth Black Health and Wellbeing Commission, 2014). This suggests that early intervention is a wise investment. We urgently need to devote more resources to this kind of social and emotional education in schools.

If children do become unwell, it is important that they get the professional support they need as early as possible. Under the current system, however, young people who require specialist support – including those who are themselves carers – face a lack of co-ordination between schools and mental health services; in most cases, they will also be denied support due to the strict eligibility criteria set by Child and Adolescent Mental Health Services.[15] We believe this situation must be remedied. At the same time, better signposting and joint work ***must*** go hand in hand with the dismantling of institutionalised racism and greater cultural competency within mental health services. Otherwise we will only be aiding and abetting the medicalisation and incarceration of a new generation of Black youth.

RECOMMENDATIONS

- The government must tackle the high rate of permanent exclusion of Black pupils as a key part of its future race equality strategy.

- The government must provide BME communities with better access to maternal services and advice and information on strategies for parenting and managing life transitions. These supports should all be part of a rebooted Sure Start scheme which also tackles race-based inequalities and socio-economic deprivation.

- Councils should adopt a "whole school'" approach in which mental health and related concerns including gang membership, drug use and teenage pregnancy are all properly addressed. The focus should be on building resilience and improving the chances for early intervention and prevention in order to decrease mental distress later in life.

- Schools should monitor and take action against any bullying based on race, ethnicity, religion, sexual orientation or gender identity.

- Schools must put more emphasis on teaching students about the achievements of Black people before Maafa (the Atlantic slave trade) so that this becomes an integral part of the school curriculum. The goal should be to promote a more positive self-image among young Black people and challenge racist attitudes across all communities.

- The government should increase funding for Child and Adolescent Mental Health Services so they can broaden their eligibility criteria and offer support to vulnerable young people who are currently not getting any support. This *must*, however, occur in tandem with work to make these services fit to meet the needs of young BME people.

10. Improving support for parents and other adults

As adults we also need access to educational opportunities, including technology, numeracy and literacy training and courses to improve self-confidence. These opportunities must not, however, be offered in environments linked to government-imposed employment targets, which have been shown to make us ill.

Parents, including single parents, need better access to parental services as part of a reinvigorated Sure Start scheme that also tackles the inequalities and socio-economic deprivation affecting BME communities.

There must be greater availability of English language courses for non-native speakers of English as well as better access to interpreters and translators. Better services in these areas are essential to help people feel more integrated in society and able to negotiate their lives in this country.

RECOMMENDATIONS

- The government must provide BME parents with better access to maternal services along with information and advice about parenting and life transition strategies. This should all be delivered as part of a rebooted Sure Start scheme, which also tackles the inequalities and socio-economic deprivation affecting BME communities. There should be a particular focus on BME single parents.

- Local recovery colleges should undergo independent BME service user-led assessments to determine how well they reflect the ethnic mix of the local area in which they are based. These colleges must offer courses whose content better reflects the interests of BME service users.
- The government must dedicate more funds at national level to improving the access of non-native speakers to English language lessons. Learning English should not be made mandatory, however, as this would be stigmatising and discriminatory.

11. Creating a fairer criminal justice system that we can all trust in

"Stop-and-search is used against us in a way that alienates us."

"I would not seek help from the police even if I were desperate."

We should be able to trust that the police and the wider criminal justice system will protect us when we are the victims of crime, and that any time we come into contact with the law, we will be treated transparently, fairly and impartially. These things are basic tenets of the social contract between a state and its citizens.

And yet, 22 years after the racially motivated murder of Stephen Lawrence and the botched investigation of this crime and disgraceful monitoring of his family, too many BME people – particularly Black people – have little confidence in the police. The continuing disproportionate use of stop-and-search powers on Black people together with the deaths of a number of BME community members – including Black people experiencing mental distress – at the hands of police have undermined our trust in the vital work that police do. Many of us feel that police powers are not being used in a way that is "intelligence-led", the explanation often given for shocking racial disparities in the use of stop-and-search and throughout the whole criminal justice process. Many of us believe these powers are being used in a way that is prejudice-led.

After the publication of another round of Home Office statistics in 2016, Home Secretary Amber Rudd highlighted the urgent need to tackle this issue, adding: "While today's statistics show that our stop and search reforms are working, with a continuing fall in the overall number of stops and the highest ever recorded arrest rate, it is completely unacceptable that you are six times more likely to be stopped and searched if you are black than if you are white … I am clear that, in a Britain that works for everyone, no one should be stopped on the basis of their race or ethnicity" (quoted in Dodd and Gayle, 2016).

Ethnic minorities are over-represented in prisons, a fact that we believe speaks to stop-and-search's place in a wider pattern of more heavy-handed policing in areas where Black people live. This may contribute to the high imprisonment rate for young Black people and young Muslims, whose representation among incarcerated youth has risen dramatically in recent years (Equalities and Human Rights Commission, 2016).[16]

Black people, in particular, are treated more harshly at every stage of the criminal justice process, including around bail conditions, sentencing and parole. This is the case even when we have no prior criminal record or our criminal record is comparable to that of a White person.

In line with patterns in mental health services, the police opt far too often to use violence on mentally distressed Black people when we are at our most vulnerable. The violence is followed disturbingly often by compulsory treatment within mental health services under a Section 136 and the overuse of control and restraint. This has led to a number of deaths of young Black men.

This situation contributes to a deep and bitter sense of injustice and feelings of fear, distrust and exclusion in our communities. All this adds to our mental distress and is toxic to good relations in a society that likes to portray itself as open, fair and multicultural.

Public debate about crime and Black communities tends to focus on the disproportionate number of crimes committed by Black people and put the blame on some supposed Black pathology, whether this is Black street culture, missing Black father figures or gang culture. This way of thinking is punitive and implies that Black people are born more likely to be criminal or that Black culture is defective, reinforcing the Black and Dangerous stereotype. BME service users face a particularly noxious version of these beliefs in the stereotype of Mad, Black and Dangerous (Prins, 1994).[17]

These erroneous interpretations completely ignore the fact that patterns of criminal activity are a consequence of wider inequalities, in a society where Black people, on average, experience greater economic hardship along with discriminatory attitudes and racist attacks (Nazroo, 2008).

Deprived areas where BME communities are concentrated also have greater incidences of crime. BME people are more likely to be the victims of crime, which exacerbates our sense of anxiety and not being safe.[18] This is not, however, due to anything inherent in being Black or in Black culture – it is about social deprivation.

BME communities are also the target of racist hate crimes. These incidents spiked following the Brexit debate in which politicians and the media sometimes resorted to anti-immigrant and racist rhetoric (Bulman, 2017). Racists took heart from this and directed their violence, not only at White European Union migrants but also (often BME) asylum seekers and refugees and long-established BME communities, including Muslim women wearing burqas or hijabs. We need to be aware of a double bind of gender-based violence that keeps women scared both within and outside the home, facing domestic violence on the first front and racism and xenophobia on the second. While the evidence for this situation needs to be documented more clearly, anecdotal reports are deeply troubling.[19]

Hate crime incidents particularly affect LGBT BME communities, who may be faced with racism, homophobia and transphobia and other kinds of attacks. There are also critical issues around police responsiveness (or non-responsiveness) to attacks on women and LGBTQ people within our communities. In our consultations, some BME women commented that police were more likely to dismiss reports of domestic violence because of their tendency to see violence against women within BME communities as "something your culture does"; the police attitude was "we don't want to interfere because we'll be seen as racist". It is imperative that police offer more support to empower vulnerable people in these situations.

These issues around trust in the police need to be tackled at the core so that BME communities can feel safe to report crimes and victimisation. Our communities need to feel that policing and the wider criminal justice system work for us, too.

- The government must disband the discredited Independent Police Complaints Commission and create a new independent police standards authority. This new body should record and monitor demographic data about stop-and-search to ensure that the procedure is only used in a lawful and non-discriminatory way.

- Police should develop links with BME mental health service user groups and work with us on street triage to prevent the overuse of Section 136 and the incarceration of service users in police cells.

- Wherever possible, efforts should be made to upscale initiatives that aim to build trust between police and BME communities through the sharing of stories. This includes projects like the now defunct 300 Voices in Lambeth.

- The government must create a body to perform robust monitoring of inequalities throughout the criminal justice system including around sentencing, plea bargaining, appeals and parole conditions. BME service users must have meaningful representation on this body

12. Tackling physical ill health alongside mental distress

"On average we [mental health service users with serious mental illness diagnoses] are dying 13 years earlier."[20]

"The culture of blaming us for our health problems is counter-productive."

As mental health service users, our physical health is likely to be worse than that of the general population. We also exercise less than members of the general public and self-medicate at high rates with nicotine, alcohol and street drugs.

There may also be other obstacles to our adoption of a healthy lifestyle. Some of us may feel uncomfortable about joining group exercise activities. We may lack the finances to eat as healthily as we would like due to rising prices and benefits cuts or low wages.

But we should not be blamed for our situations or guilt-tripped into making changes to our lives. Incorporating physical exercise or changing our diet can be helpful but it can be even more beneficial when the life pressures we face are acknowledged and efforts are made to counteract their negative effects. Rather than simply promoting competitive team sports, it may be more valuable, for example, to increase our access to a range of activities we consider helpful such as yoga and complementary/alternative therapies.

One critical issue we face is the unwanted "side" effects of psychiatric medication, which may include weight gain and other undesirable and potentially fatal health problems.

The harm caused by unwanted side effects could be minimised through several shifts in current practice. First, we need to see less prescription-happy mental health services. Second, mental

health professionals and doctors must provide us with clear and timely information about likely drug side effects so we can decide on alternative supports or reduce their impact by making lifestyle changes. It is crucial that we have the chance to take action before we develop chronic health issues, especially when drug use is long term.

Our trust in different sources of health-related information must also be considered when reaching out to people with health messages. Some BME service users may find it easier to obtain information from BME advocacy and support but these services must be resourced to be able to perform this role. The recent *The Healthy Lives Project Full Report* found that BME service users may put more trust in information and advice given in community-based rather than medical settings (Gould, 2017). We may prefer to deal with a range of agencies, charities and service user groups working with health professionals.

It is crucial to bear in mind that some BME service users may be reluctant to access *any* kind of health services – including physical health services – because of prior negative experiences within the mental health system. This suggests the need for more joined-up work between mental and physical health services alongside mental health system reform.

RECOMMENDATIONS

- NHS services should adopt all of the recommendations contained in *The Healthy Lives Project Full Report* (Gould, 2017).
- The Health and Wellbeing Board, which focuses on the better integration of mental with physical healthcare, should develop a plan to improve the physical and mental health of BME mental health service users by increasing our access to activities we enjoy. These activities could include yoga, team games, alternative therapies and dance classes with free or low cost access to sports and leisure centres. At the same time, individuals must never be shamed or coerced into joining in these activities.
- Mental health services and GPs must provide us with comprehensive information at the outset about the side effects of psychiatric drugs. This should include directing us to alternative treatment/support options that can help us counteract side effects.

- The Health and Wellbeing Board should explore the potential for cooperation between sporting institutions like football clubs and mental health service users. This may be one way to offer more accessible activities to mental health service users with an interest in sport.

- Mental health service users lacking in confidence should be offered the chance to join a "buddy up" scheme to help them participate in various activities they have expressed an interest in. This scheme could be run by BME peer support groups, for example, but this would take some modest funding.

13. Developing more meaningful service user involvement and power-sharing in mental health work and society at large

"It is difficult for us to engage with improving the services where we have often been subject to institutionalised racism and violation of our human rights."

"My experience of involvement has been very tokenistic."

"Why are there so many non-BME service user consultants involved when we [BME service users] are the ones with the expertise and experience?"

"To challenge racism we need to be critical of the Whiteness of [the] knowledge that takes away dignity from people."

"How do we facilitate 'informal' BME service user knowledge not in research papers and reconnect scattered BME initiatives?"

Involving our communities is not just about ticking a box. It is about bringing tangible benefits to BME service users and increasing our decision-making power within the services and supports we rely on.

Too often we have been engaged in tokenistic consultations that ask us the same questions over and over and put none of our recommendations into practice. This has created mistrust about any future involvement and comes on top of a general mistrust of state institutions, based, in many cases, on experiences of traumatising compulsory treatment within mental health services. In common with all service users, we are now struggling increasingly to cope with our everyday lives due to benefits cuts and growing poverty. This makes engaging in involvement activities like consultations more difficult.

Services wishing to involve us need to reflect very carefully on how they will engage with us so we feel safe and valued. This includes paying us for our contributions. During any involvement work, services should create a space where we can talk about the real issues that affect us like racism. They should be flexible about working with us in alternative ways that we feel comfortable to us. They must also remain open to the different ways we make sense of mental health experiences. Safe spaces can sometimes be created more easily from within BME service user-specific spaces.

In the past, a key starting point for our involvement was our participation in a BME mental health service user group. This was a ready-made support network that gave us a sense of being part of a constituency with shared concerns. It also signposted the way to involvement activities. Unfortunately, the funding cuts now decimating BME mental health service user groups have reduced the pool of BME service users who feel supported enough to engage in involvement activities.

Some of the key characteristics of meaningful involvement are set out in the Department of Health-endorsed 4PI Framework (Faulkner, 2015). This document was developed by NSUN in cooperation with BME and other mental health service users. The 4PI Framework looks at involvement in terms of the full cycle of decision-making from commissioning, service development and service delivery to monitoring and longer-term evaluation. Adopting 4PI will help ensure service users are involved at every stage of decision-making rather than being relegated to tokenistic roles when all the important decisions have already been made. This will require a fundamental change in the culture and values of many service provider organisations.

Another way of looking at this is to say that BME service users' involvement should cover aspects of our personal care, as well as the way a service works and also, the service's strategic decision-making, including commissioning. Often, however, our involvement is restricted to the personal level, and even then it can be fairly tokenistic. This is a wasted opportunity on the part of mental health services, as the mental health system could be considerably improved were our views taken more into account.

As the United Nations Special Rapporteur on the right to health has said: "There is now unequivocal evidence of the failures of a system that relies too heavily on the biomedical model of mental health services, including the front-line and excessive use of psychotropic medicines, and yet these models persist … This pattern occurs in countries across the national income spectrum. *It represents a failure to integrate evidence and the voices of those most affected into policy*, and a failure to respect, protect and fulfil the right to health" (our emphasis; United Nations Human Rights Office of High Commissioner, 2017).

As BME service users, our views are sometimes also whitewashed by those purporting to speak on our behalf. A recent Mental Health Alliance report, for example, claimed to have gathered the views of service users about the desired principles of the Mental Health Act in light of government announcements of reforms to mental health legislation.[21] The Mental Health Alliance has since been criticised for consulting only a disproportionately small number of BME service users, of whom an even smaller number had been subjected to detention and compulsory treatment. How this could have happened is unclear beyond the usual excuse of BME service users being "hard to reach". Given, however, that BME mental health service users are disproportionately the targets of restrictive measures under mental health legislation, this was a major oversight, as a critical letter from NSUN spelt out (NSUN, 2017).

Another development of great concern to us is the decision of grant-making and even statutory organisations to pay unjustifiable sums of money to external non-service user and non-BME consultancies. These payments are not only setting up the wrong kind of power dynamic. They are deeply insulting to BME service users, since they suggest that our input must be facilitated by someone else, who can then translate our words back to the commissioning organisation. We are more than able to undertake our own consultations – and often at a fraction of the cost of such consultancies.

The 4PI Framework highlights what service users have said is key to meaningful involvement (over 50% of those who were consulted in its development were from BME backgrounds). These key elements include: organisations undertaking involvement showing that they genuinely value service user involvement; involving adequate numbers of service users who

can support each other so our voices are not simply dismissed; developing accessible, transparent, fair and open ways of working and finally, ensuring that there is a demonstrable benefit arising from the involvement activity.

The DTOOT Charter, which appears in the *Dancing to Our Own Tunes* report, specifies ways of working that establish relationships of equality, trust and real partnership between non-BME service user-led and BME service user-led organisations (Kalathil, 2009). Often these relationships are characterised by power imbalances, which significantly compromise meaningful BME service user involvement. The Charter sets out shared values that should underpin these working partnerships and also deals with the practical considerations around setting up and maintaining these arrangements. It emphasises the need to create spaces where BME service users feel comfortable talking about the issues that affect us including racism.

In broader terms, involvement is about producing a shift in power from elites to the disenfranchised as part of a wider political process – as seen, for example, in the civil rights and anti-racism movements. These developments may take place within state health systems but they also happen outside the realms of the NHS or any local authority. For genuine and meaningful involvement to take place, there must be greater cultivation of the BME service user voice within movements and campaigns that address the issues affecting our mental health.

BME mental health service users, our allies and all those who believe in social justice must give more thought to the supports we need to engage properly in the systems which have a significant impact on our mental health. These are all systems from which we are largely excluded. They include health and social care systems, politics and policing as well as other areas of life.

RECOMMENDATIONS

- National government, the NHS and local authorities must fund a strategic national BME mental health service user/survivor body. This body's tasks should include supporting BME service user involvement as part of the national race equality strategy.
- NSUN should create a national network in which 4PI adopters and DTOOT Charter signatories can share news about their adoption of 4PI and the Charter. This network should establish a coherent picture of good practices around involvement in different contexts.
- On a broader scale, groups campaigning on social issues which disproportionately affect BME mental health service users – such as deaths in police custody and within the mental health system and cuts to support – should increase their networking with BME mental health-specific groups and individuals. These campaigns should encourage BME involvement and voices with the goal of creating broader alliances on racism and social justice issues.

14. Supporting our production of knowledge and research

"Knowledge [production] is important because it helps inform the training of professional bodies and government policies that affect our mental health."

We want to see a process of knowledge and research production that is genuinely inclusive of the knowledge and learning which BME mental health service users have developed over many decades.

Knowledge about our mental health is produced largely by White academics and White mental health professionals or by BME academics and professionals who do not have direct experience of mental distress. These people are seen as the experts. The fields of user-led research and survivor research, and the emerging discipline of Mad Studies have, however, challenged this notion of expertise. These disciplines show that our collective experiential expertise has an equally valid role in creating and critically engaging with knowledge about mental health.

As we have seen, this is also the position taken by the UN Special Rapporteur on the right to health, who links the failure of the current mental health system to its over-reliance on official biomedical knowledge and a "failure to integrate evidence *and the voices of those most affected into policy*" (our italics; UN Human Rights Office of the High Commissioner, 2017).

Nevertheless, BME service users' engagement and leadership in knowledge production are still impeded by endemic racism in academia and user-led research. This is an unacceptable situation given the presence of BME mental health service users with academic and research training and the vast body of knowledge that has arisen from our work.

As critically engaged BME mental health service users, we must not buy into and reinforce hierarchical patterns of knowledge production that exclude our voices. Rather, we should challenge these patterns and the power imbalances they encapsulate.

We must also call for greater self-reflexivity around White privilege, Eurocentrism, sanism and other biases in knowledge production, drawing inspiration from wider efforts such as the Decolonising Our Minds and Why is My Curriculum White? campaigns undertaken by students and academics from racialised backgrounds in universities across the UK.[22]

BME mental health service users without specialist training also need better access to support and training so they can participate in and lead knowledge production activities. Their voices should be prominent in Patient and Public Involvement and user involvement in research and evaluations. This is an essential step to expose the limits of projects which purport to be about us but all too often make wrong assumptions because of their blind spots.

A prime example of these biases and blind spots is a recent British Psychological Society report on schizophrenia, which billed itself as liberal and progressive (Cooke, 2016). Produced with the involvement of White service users and academics, this report was surely conceived with the best of motives. It was also forward-thinking in many respects including its reiteration of ways of understanding schizophrenia that are not only based on the biomedical model. Unfortunately, however, it utterly failed to address the fact that Black service users are

disproportionately labelled with schizophrenia. Furthermore, it ignored the vast knowledge base which is already engaging with the intersections between "race" and psychosis.[23] In this way, it whitewashed the knowledge, experience, insight and wisdom that BME service users and allies have accumulated over decades of painstaking work.

One of the stated aims of Synergi, a recently launched programme, is to ensure that the knowledge base around race-based mental health inequalities better acknowledges and recognises the knowledge generated by BME mental health service users.[24] It remains to be seen whether this will truly put the BME service user voice at the heart of knowledge production and research, and furthermore, whether any resulting new mental health narrative can make a concrete change by reducing race-based mental health inequalities.

RECOMMENDATIONS

- The National Institute for Health Research, INVOLVE, the Synergi programme and universities researching race-based mental health inequalities should endorse the NSUN 4PI Framework on involvement and the DTOOT Charter and apply these frameworks in all of their future research work with BME groups.

- BME mental health service user campaigners should network and hold dialogues with the organisers of campaigns such as Decolonising Our Minds and Why is My Curriculum White?, which are already doing the work of challenging White privilege. We should explore the potential for collaborations with these campaigns around our common goals.

Endnotes

[1] According to Runnymede Trust and Women's Budget Group, Black and Asian households are facing the biggest drop in living standards, with losses of 19.2% and 20.1% from 2010 to 2010 as a result of tax and benefit changes and lost services. This amounts to real-terms average annual losses of £8,407 and £11,678. For more details, see Hall et al. (2017).

[2] For more information about BARAC's work, visit http://blackactivistsrisingagainstcuts.blogspot.co.uk.

[3] For an extended discussion of benefits-related racial inequalities in the 2015 state budget, see Khan (2015),

[4] The Equality and Human Rights Commission (2016) reports that in 2011/12, 27.9% of Black households and 26.3% of Pakistani and Bangladeshi households were living in substandard housing. The figure for White households was 20.5%. Overcrowding was far more common in Pakistani/Bangladeshi (21.7%) Black (15.7%), Indian (13.4%) and "Other" (12.5%) households than in White households (3.4%). The effect of overcrowding on the educational attainment of young people requires further exploration.

[5] Overall, minority ethnic groups have a higher unemployment rate (12.9%) than White Britons (6.3%) (Equality and Human Rights Commission, 2016). While this gap has been closing for some groups such as Pakistani and Bangladeshi populations, the unemployment rate for Black youth remains double the rate for White youth and the disparity has only increased since 2006. Runnymede Trust (2015) reports a 40% rise in unemployment among young people from minority ethnic groups between 2008 and 2013. In contrast, the rate among young White people fell during this period.

[6] In August 2015, the *Guardian* reported that 80 people who had been declared "fit for work" were dying each month in the UK. The same article noted that the Department for Work and Pensions had issued guidance to its frontline staff on how to deal with claimants deemed to be a suicide risk. See Ryan (2015).

[7] For details of the dismantling of the BME regional networks, see the coverage on the Voice4change website: http://www.voice4change-england.co.uk/content/state-bme-sector-0#BUS camp.

[8] These two documents are crucial for meaningful BME service user involvement. For a full discussion, see part L13 of this Report and Manifesto "Developing more meaningful service user involvement and power-sharing in mental health work and society at large". For more information about the Department of Health-endorsed 4PI Framework, see Faulkner (2015). The *Dancing to Our Own Tunes* (DTOOT) Charter is part of the seminal *Dancing To Our Own Tunes* report; see Kalathil (2009), p.18.

[9] Defined by Black feminist writer Kimberle Crenshaw and further developed by Patricia Hill Collins and others, the concept of intersectionality highlights how cultural patterns of privilege and oppression are not only interrelated but tied together by intersecting systems in society, including gender, class, race, ethnicity and sexuality. See Crenshaw (2009) and Collins (2000).

[10] See Trivedi (2010) for an account of how mainstream models of recovery may prevent the discussion of the "difficult" issues facing BME women including racism, internalised oppression and questions of identity.

[11] This training was developed by NAViGO, a community interest company which involves service users and carers in the running of mental health services in northeast Lincolnshire. For more information about NAViGO, see http://www.navigocare.co.uk/.

[12] For more information about the Cares of Life project, see https://www.kcl.ac.uk/ioppn/depts/hspr/research/CEPH/Socandmentalhealth/projects/CaresOfLifeProject.aspx

[13] Black people who leave school with A-levels typically get paid 14.3% less than White people with similar levels of education and Black workers with degrees earn 23.1% less on average than White workers with the same level of qualification. See Equality and Human Rights Commission (2016).

[14] The Ditch the Label campaign (2016) highlighted strong links between bullying and the development of depression, social anxiety, suicidal thoughts, self-harm and eating disorders as well as other behaviours associated with reduced life chances and reduced quality of life. Bullied students were more likely to skip classes, run away from home and abuse drugs and alcohol. See the campaign website: https://www.ditchthelabel.org/wp-content/uploads/2016/04/Annual-Bullying-Survey-2016-Digital.pdf

[15] In Lambeth, there were an estimated 4,728 children under 16 years old with a mental health condition in 2014. Of these, only 799 (just 17%) were receiving Children and Adolescent Mental Health Services (CAMHS) support. This means that 83% of children with a mental health condition were not being supported by CAMHS in this borough (Lambeth Black Health and Wellbeing Commission, 2014).

[16] According to the Lammy Report's interim review, 41% of young prisoners were from minority backgrounds in 2016 compared with 25% ten years prior. This was despite a fall in total prisoner numbers by some 66% in that time. Meanwhile, the number of Muslim prisoners has almost doubled in the last decade (Lammy, 2017).

[17] This depoliticised way of thinking is replicated in some debates about mental health, which imply that the reason for the high rates of distress within Black communities is that Black people are genetically more predisposed to being "mentally ill".

[18] The evidence shows that the level of deprivation in London's boroughs increases as the Black population of the borough rises; crime rates also increase with deprivation. To quote one report: "It is clear that ethnicity, deprivation, victimisation and offending are closely and intricately inter-related" (HM Government, 2008)

[19] A member of the Report and Manifesto Advisory group reported that this matter had been discussed at a recent seminar on violence against women, which highlighted the dangerous fall-out of Brexit for BME women experiencing gender-based violence.

[20] This quote from a consultee is borne out by the results of a recent London-based study which examined the differences in life expectancy between people diagnosed with serious mental illness and the rest of the population. The findings showed that men with mental illness diagnoses lost 8.0 to 14.6 years of life while women with these diagnoses lost 9.8 to 17.5 years. Men with schizophrenia had the most reduced life expectancies. See Chang, Hayes, Perera, Broadbent, Fernandes, Lee and Hotopf (2011). Similarly, Laursen, Nordentoft and Mortensen (2014) found that people with bipolar or schizophrenia diagnoses died an average 15 to 20 years earlier than the general population, largely due to increased rates of cardiovascular and other diseases.

[21] The Mental Health Alliance is a coalition of more than 75 organisations from across the mental health spectrum and beyond which work together to advocate for fair implementation of the Mental Health Act in England and Wales. The Alliance is currently campaigning around the direction of future mental health legislative reform. See the Mental Health Alliance website: http://www.mentalhealthalliance.org.uk/. For details of the report in question, see Mental Health Alliance (2017).

[22] For information about Decolonising Our Minds, visit the campaign's website https://soasunion.org/activities/society/8801/ and the associated Facebook page. For more details about Why Is My Curriculum White?, see this film: https://www.youtube.com/watch?v=Dscx4h2I-Pk

[23] For a fuller critique, see Kalathil and Faulkner (2015) and Fernando (2014)

[29] For information about Synergi, visit the Synergi Collaborative Centre website: http://synergicollaborativecentre.co.uk/highlighting-ethnic-inequality-in-mental-health/

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