

# Ethnic Inequalities in Mental Health: Promoting Lasting Positive Change

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A Consultation with Black and Minority Ethnic  
Mental Health Service Users



## Acknowledgements

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## Introduction

This report outlines the results of a consultation carried out by NSUN with black and minority ethnic mental health service users for Lankelly Chase. The aim was to inform the programme of work currently being developed by Lankelly Chase and its partners the Centre for Mental Health, the Afiya Trust and Mind, to promote lasting positive change in the field of ethnic inequalities and mental health. A key concern for these organisations (and indeed for many other people and organisations) is the over-representation of people from some black and minority ethnic communities at the 'hard' end of services: entering services via the police or other emergency services, detained under the Mental Health Act or admitted to secure services. The aim of this piece of work was to find out what services and supports might genuinely help to change this situation.

The National Survivor User Network (NSUN) is a user led organisation (ULO), an independent network of individuals and groups who have direct experience of mental distress and/or using mental health services across England. It is a registered charity and limited company by guarantee. NSUN was created to give survivors and users of mental health services a stronger voice in shaping mental health policy and services, including people from communities and groups marginalised in our society.

Within the context of this work, NSUN is working to ensure that it engages with black and minority ethnic service users and user groups, and to root our model for involvement within an understanding of the diversity of service users and their experiences of mental health services. (The charter and guidelines from Jayasree Kalathil's *'Dancing to Our Own Tunes: Reassessing black and minority ethnic mental health service user involvement'* (NSUN, 2011) is given in Appendix B). The consultation reported here complements this work and will inform NSUN's forthcoming project aiming to map the activity of BME service users and user groups which has the aim of identifying their needs for capacity building and leadership development.

### Aims

The core aim of this consultation was to explore the kinds of supports and services found to be most helpful to people from BME communities: services and supports that might enable people to access help when they need it and so avoid the distress of emergency or coercive routes into services. This includes consideration of the support that people need and value from statutory mental health services, community based and voluntary sector services, and practical, spiritual, peer and familial support. Specifically, we explored the following:

- The experience of accessing support for mental health needs;
- Views on the impact of 'race', culture and ethnicity on the kind of support received or missed;
- What worked/what would have worked in receiving early support while in crisis, preventing further crisis and supporting recovery;
- Examples of community and user-led initiatives that support people holistically;
- Examples of factors that enable the kind of support that people actually need and find useful.

The goal is to start creating an evidence base of the factors and enablers to develop and sustain an alternative vision of support that is currently not part of mental health services or complements what is available now.

## Methods

1. We carried out 3 focus groups across England: two in London (one women only) and one in the North East (consisting of a high proportion of refugees and asylum-seekers). The focus group topic guide is attached in Appendix A. Our choice of groups was a pragmatic one, influenced by the timescale for the work and the strength of our local contacts. In each case we worked with local groups and their coordinators to recruit participants, and the group was co-facilitated by the local coordinator. All three groups were recorded and contemporaneous notes were taken. Participants were invited to fill in the questionnaires as well.
2. In addition we carried out an online survey using survey monkey, adopting similar questions to those used in the topic guide.

## Participants

The project reached a total of 80 people: 40 focus group participants and an additional 40 people who filled in the survey online. Nearly all of the focus group participants also filled in questionnaires (37), so the survey was completed by a total of 77 people.

### *Focus Groups:*

- Lambeth 17 (7 women; 10 men)
- Southwark 8 (8 women)
- Teesside 15 (7 women; 6 men; 1 transgender woman)

### *Thumbnail sketches of the focus groups:*

#### Lambeth focus group (London)

Large group of 17 BME mental health service users, 10 men and 7 women, many of whom had experienced the 'hard end' of mental health services. Difficult, painful experiences of mental health services, coercion and forced medication. Discussion of racism in services and society at large. Several participants became upset and angry during the discussion, e.g. one woman talking of our children dying in the service – there is nothing there for them, no hope after entering the mental health system.

#### Southwark focus group (London) women-only

Eight women, most British with English as their first language. This group began with the facilitator asking the women to talk about the special items they had brought with them. This introduced themes of identity, communication, spirituality, family, dislocation and struggle. Several of the women became upset and tearful as they talked but acknowledged this rare opportunity to share and discuss difficult experiences in a supportive atmosphere. Powerful discussions of racism and the difficulty of talking about racism, of raising it as an issue. Discussion of the inadequacy/irrelevance of the medical model approach to mental health; the social model of mental health has much more to offer people from BME backgrounds in giving the space to acknowledge the significance of race and culture.

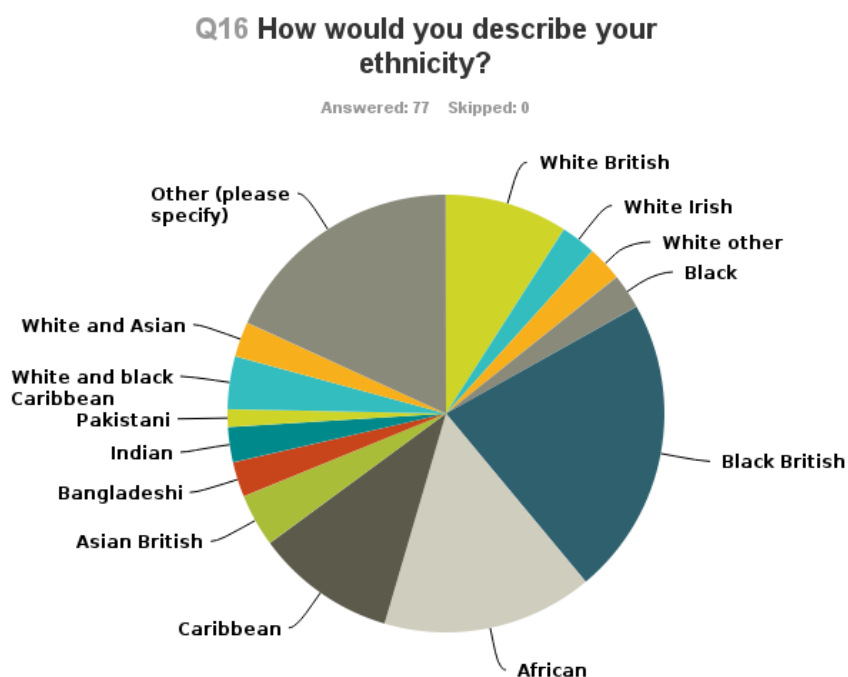
### Teesside (N.E. England) focus group

This was a mixed group of 15 refugees and asylum seekers and people who identify as lesbian, gay, bisexual or transgender. They raised many issues associated with refugee/asylum seeking status: powerful experiences and feelings associated with stigma and discrimination, isolation, internalised stigma and feelings of shame. Stereotyping of refugees/asylum seekers as liars, scroungers, not to be trusted, 'we are rubbish'. Also identified the issues faced on their journey towards achieving resident status in this country as contributing to or causing their mental distress: the struggle, isolation, poverty, not being believed, not trusted, difficulties accessing services, employment, education.

### *Survey participants:*

Of the 77 participants who completed the survey, 37 were focus group participants and 40 filled it in online.

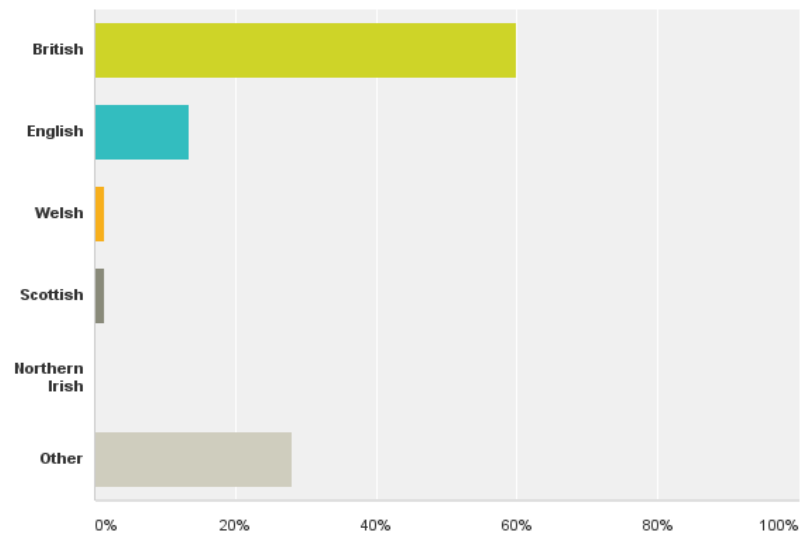
- **Gender:** 40 women; 34 men; 1 transgender woman; 1 transgender man; 1 non-response
- **Ethnic origin:** Almost half of the participants described themselves as either black British, African or Caribbean. The remaining half were of diverse backgrounds, including 14 (18%) who described themselves as 'other'. This category included: Black British African; Sri Lankan (3); Rastafarian; Arab/Asian/Portuguese; White Arab Gypsy; Global ancestry; Black African Caribbean; mixed heritage; White Scottish; Indian British; Welsh; rather not say.



- **National identity:** 60% (45) of participants described themselves as British (see chart below). 28% (21) participants ticked the box marked 'other'.

### Q15 How would you describe your national identity?

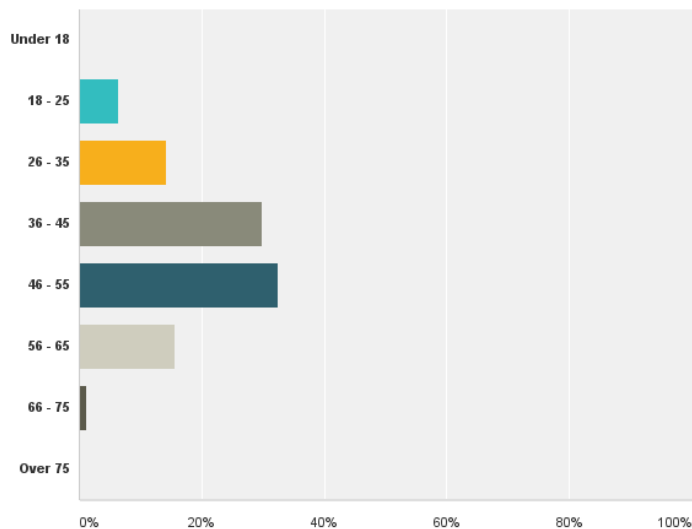
Answered: 75 Skipped: 3



- **Age:** The majority of participants fell into the age categories 36-45 and 46-55, which is significant in the sense that many people in the focus groups expressed concern about the fate of their children and young people.

### Q13 Age

Answered: 77 Skipped: 0



- **Sexuality:** 84% (64) of participants were heterosexual; 7 bisexual, 3 lesbians and 2 gay men.
- **Disability:** Just under 50% of the participants described themselves as disabled.
- **Lived experience of mental health:** Three people responded 'no' to this question; 97% of participants said they had lived experience.

## Key Findings

In this initial analysis, the findings have been grouped together for ease of reporting and to meet the deadline. However, it is possible to carry out more detailed analysis on the data at a later date if required. We address the findings in the following 3 sections:

1. The context of people's lives
2. Barriers to seeking help
3. Helpful services and supports

*Note:* where a quotation originates from one of the focus groups, it is given a notation to indicate gender and group; quotations from the survey responses are given no notation.

### 1 The context of people's lives

This section takes into account the survey responses to Questions 1 and 2, alongside issues raised in the three focus groups.

Almost without exception, participants in the focus groups described their experiences of mental distress in ways that were closely woven into the fabric of their lives. Although we have attempted to separate out these threads a little in this report, ultimately it is not possible to explore mental distress in isolation. People's understandings of distress incorporated their family, racial and cultural backgrounds, a search for identity or place, and experiences of discrimination, racism, dislocation, poverty and struggle. Consequently, the Western medical approach to mental health was at best irrelevant and at worst damaging for some people; several talked of the mental health services being too quick to turn to medication, a response found almost mystifying by some, coupled with a conviction that white British people are more likely to be offered talking therapies.

Race, culture and identity were powerful themes: identity as defined by race, culture and country of origin but also, crucially, of gender and sexuality. Black women talked of the complexities of being strong to overcome difficulties but facing the oppressive image of the strong black woman, that might be perceived as threatening to others or imply they do not need help. African men talked of the patriarchal culture of Africa compared with what they perceived to be a more matriarchal culture encountered in Britain. Used to being respected as the head of the family, they found that this was no longer as powerful a role in Britain and this resulted in feelings of anger and frustration.

Racism emerged as a powerful theme in all of the three focus groups. Refugees and asylum seekers talked of being seen as liars, scroungers and not to be trusted: *'People think we are rubbish'*. They talked of carrying this shame with them when seeking housing, employment, services or help. They often did not feel they were believed when talking to professionals, or felt that their problems were dismissed as being an 'immigration issue'.



*“Someone doesn’t respect you without thinking about your ethnicity, or about your race, colour, status in this country, this is the most important thing when you go to the community and the society.” [Man, NE]*

*“That piece of shit from the Home Office – it says ‘don’t trust this person’. It’s a shame piece of paper, it’s not an ID.” [Man, NE]*

A number of issues arose from both the focus groups and the survey in relation to gender. One was the oppressive image of the ‘strong black woman’ that some women felt had influenced their experiences of life and of services.

*“The ‘strong black woman’ image is to my detriment. People think ‘don’t mess with her’ when you do go for help.” [Woman, Southwark]*

One woman in the survey recounted the experience of a friend who had been raped; she felt unable to seek help due to not knowing where to go or who to talk to, as well as the effect of a cultural taboo about talking about such issues.

Black British women also talked of the fear of being seen as benefit cheats and scroungers, as well as talking about both overt and institutional racism. Black men talked of being stereotyped as weed-smokers, or as aggressive, violent, schizophrenic. The powerful media message about immigrants as benefits cheats has clearly struck home for many people who are already facing multiple discriminations on the basis of race, gender, class, sexuality and/or mental health status.

### ***The impact of background on mental health experiences***

The majority of the survey respondents (77%) felt that their background (race, culture, ethnicity, migration / refugee / asylum status) had had an impact on the kind of support they had received (Q2). The most common themes raised in relation to this were over-medication and poor access to psychological therapies, with several people mentioning both issues in their responses.

*“I feel services are institutionally racist as black people are over-prescribed medication but deprived therapeutic talking treatment.”*

*“We don’t want medication and drugs just to receive talking therapy to know how to deal with demons. Access to talking therapy for black people seems to be non-existent.”*

For many it was primarily a question of not feeling or being listened to or understood, or of having their concerns dismissed (due to illness or as an ‘immigration matter’) with the result that their needs were not met.

*“The G.P. has made me hesitant doesn’t understand what I am trying to say”.*

*“I felt that no one was listening as they thought they already knew me based on popular stereotypes.”*

One woman described this in relation to her experience of being offered CBT:

*“I eventually was given a student therapist delivering CBT (which was not applicable for me) who was the same age as my son, white and from the countryside (I'm black urban and in my late forties) I attended the sessions with the promise of a referral for further 1:1 therapy later (this was never done)...”*

The survey responses to Q1 (*Bearing in mind the context of your race and culture and the experience you have had of using services, do you have any thoughts or views about the experiences that you have had of mental health services?*) also bear this out. People talked of racism encountered in services, a lack of awareness of diverse cultures, of eurocentric services, and of a ‘one size fits all’ approach where the needs and issues of people from diverse cultures and backgrounds are simply not addressed.

*“The mental health system is very eurocentric and still falls short of taking into account BME cultures. For example, it is not good enough to provide European versions of our food even though that is a step in the right direction.”*

*“They do not consider me as a whole person, and within my cultural origins which are mixed. They do not understand issues of racial oppression which have impacted the cause of my mental health issues. Nor are they interested in finding out. They are just ticking boxes as far as I am concerned. They really scare me.”*

*“they are one size fits all, even person centred is eurocentric in approach and can not deal with language and cultural sensitivities”*

In the focus groups too, people talked of racism as a significant cause or contributor to their distress, as well as a barrier to seeking help. One of the key issues to emerge was the lack of space in which to acknowledge or discuss race or racism. Professionals and services, even voluntary sector groups, were said to be fearful or reluctant to discuss the role of racism in people’s lives, resulting in further distress for some people. One woman referred to it as the ‘R’ word that nobody wants to hear about or talk about.

*“Unfortunately when I went to [mental health service]... I was asked about what was successful about my previous experiences with counsellors – I said race has been issue... but they just put it under the carpet... For some women it might not be an issue but for me it’s an issue. I want to see someone who looks like me who’s trained in that capacity to help me with those issues. For me it was a particularly sore point because racism has been a trigger for my depression.” [woman, Southwark]*

People who talked about their sexuality as an issue felt that it was something that services could not or did not know how to deal with. One transgender woman felt that ‘services

*didn't get me at all*'. There was a real sense that professionals did not know how to respond or talk about sexuality.

*"They didn't put anything in place in relation to my sexuality, what experiences I'd had in relation to that, how I felt rejected by my family. Nothing to offer me at all. The staff were not understanding. I had nothing in terms of support around sexuality, support groups. I had nobody for a long long time."* [Transgender woman, NE]

Another source of discrimination was religion. A couple of people mentioned that their religion had been viewed with suspicion by mental health professionals: being monitored for religious obsession or encountering overt religious prejudice.

*"My religious faith has often been treated as an unhealthy obsession and potentially delusional."*

### **Positive experiences**

In the survey, 24% of respondents (18 people) said they did not believe their background had had any effect on the support they had received (Q2). This is a significant minority of the survey respondents and, although they did not respond to the follow-up question (Q3), a number of them made positive comments in response to Q1. One person who was brought up in Jamaica said there were fewer services there than there are in Britain. A couple of people reported being well tapped in to the services through their professional background:

*"I feel that as I am a qualified nurse health care professionals have been very good in letting me manage my mental health i.e. what medication I would take, what dose, what services I wanted to be referred to e.g. exercise on referral."*

*"My experience has not been that bad. Each time I went in to hospital (twice) most staff did their jobs very well and in a professional way. For some it was just a job but they were a minority."*

It is also important to note that a number of people in the focus groups were keen to express variations on the theme of *'it depends on the individual'*. Women in the Southwark group discussed some poor experiences of black staff and good experiences of white psychiatrists, for example, as well as expressing appreciation of those individual members of staff who had made a difference to them.

*"It's not necessarily always seeing a black counsellor. My doctor was black and for the first time I really felt I could relate to someone. But I've had good doctors and bad doctors from all communities...my psychiatrist at the moment she's white, middle class, you would expect her not to understand where I'm coming from, but she is the best I've ever, ever come across and she does more than her duty of care towards me. So I think it depends on the person..."*

## 2 Barriers to seeking help

This section addresses barriers to people initially seeking help from services (survey responses to Q5) and the range of issues discussed as barriers to seeking help raised in the focus groups.

In response to the survey Q5 (*'If you did not seek help straight away what stopped you seeking support when you first experienced problems?'*), the majority of survey respondents mentioned fear on its own, or fear in combination with stigma and discrimination. On further examination, there were subtle differences in these responses. Some people feared contact with mental health services for their potential to impose unwanted or unpleasant treatments, some feared the potential stigma and discrimination that would follow from their contact with services, and others feared services for their potentially discriminatory treatment of BME service users.

*"the stigma attached to seeking for a mental health problem. I thought it would affect my work/employment chances"*

*"Stigma and hearing tragic stories about Black men in the system."*

Some people talked of being 'in denial' or of struggling to cope for as long as they could before it was necessary to seek help. A few mentioned the distress or illness itself as a barrier (the voices, too ill to leave the house), and a few talked of anxiety about upsetting friends or family. For a few people it was a lack of trust or concern about confidentiality within a small community that prevented them from seeking help.

The focus group discussions allowed for more in-depth consideration of the barriers and disincentives to seeking help. The key themes to emerge were: racism, the medical approach to mental health, previous damaging experiences of mental health services, and a range of cultural differences experienced as barriers.

### **Racism**

Racism as a barrier to seeking help was significant for some people, and has already been touched on above in relation to the effect of background on people's experiences of services:

*"The problem is they have Black people down as scroungers – I didn't want to be a scrounger, I didn't want to be a benefits cheat, I didn't want to be relying on the state.. I was getting pretty angry with myself for becoming unwell. Up to this day it still upsets me. ... pointing the finger if you're a black person you can't be a British citizen, you can't be born in this country... see you as another person, as an alien stealing our money. So I felt I had no right to be ill." [Woman, Southwark]*

### **Medical approach**

A key theme was the inadequacy of the conventional Western medical approach to mental health and illness to address people's problems. The people we talked to did not, generally, conceive of their distress in this way and explored it in relation to their identity, race and culture and the oppressive experiences associated with these. Many people throughout the focus groups and the survey were dismayed by the immediate response of mental health services to prescribe medication without any other supports on offer. Some talked of the need for a more holistic approach linked to cultural understandings of health, healing and wellbeing. Some refugees and asylum seekers did not consider approaching a doctor or medical practitioner initially as a means of dealing with their problems.

Participants in the Southwark group explicitly discussed the social model of mental health, suggesting that it has more to offer people whose mental distress is understood against a backdrop of race and culture.

*"There should be a real balance between the medical model and the social models of mental health. The race and culture group doesn't fit in the medical model at all. I think it's really important that it is delivered through a social model and that social model is given as much prevalence as the medical model is. I think that both things have helped me. Mostly I think the medical model has helped me but often it's because the social model doesn't hardly exist... You don't have the choice because the medical model is so prevalent..."* [woman, Southwark]

### **Damaging experiences of services**

Many people, particularly those in the Lambeth focus group, talked of their damaging experiences of services, particularly of hospital admission, as a barrier to seeking help from services. Discrimination, over-medication and coercion featured in the discussions and gave rise to considerable anger and frustration. Referring back to the survey responses to Q5, some people were clearly aware of these issues prior to seeking help, as their reluctance to seek help had been influenced by the fear of how they might be treated as black people in the system.

*"My experiences during my time in hospital were negative [why was that?] during that time I would say there was discrimination. Being black, and diagnosed schizophrenia, you are medicated out of sight, out of mind. There was no alternative therapy".* [Male, Lambeth]

*"I've only been in hospital once and I'm trying my damndest so that I never go back to that hellhole ever again. As far as I'm concerned they don't explain to you what is going on when you are ill. They throw you in this cesspit of a place, really dirty, stinking and don't explain to you what really is happening."* [Woman, Lambeth]

*"I can't think of hospital; hospital is death to me. I hope there is a crisis house."*

[Woman, Southwark]

*"And then they abuse you when you're in there if you don't adhere to their rules... you have to guess what the rules are. And so as far as I'm concerned it's a very very bad place to be".* [Woman, Lambeth]

### **Cultural differences**

A number of distinct cultural differences discussed in the groups go some way towards explaining the reasons for people feeling misunderstood by mainstream services, and as barriers to seeking help. For example, people brought up in Africa or India talked of their unfamiliarity with the individualised nature of British society. One woman mentioned the strangeness of finding so many people in this country living alone; others mentioned the difficulty of talking to a stranger about your personal problems, and of the isolation of the individual from their family and community when they made contact with services.

*"In Africa you always have people around... So taking that first step was very daunting – I'm going to talk to a stranger about my life and I don't think that's right."*

[woman, NE]

*"Coming from a cultural background that does not believe in talking to strangers about personal matters hospital sectioning was the stuff of nightmares."*

For some people, the eurocentric and medical approach of services failed to appreciate that people from different cultures might have different goals and aspirations, connected with their culture and background:

*"The problem is that they make it clear to you what they want as their outcomes for you to be a successful patient. And I just think that is so so damaging. So you go back to work, be independent, be autonomous. For me as an Indian woman born in this country to a very traditional Indian family, you know, those aren't my ideals. My ideals are much more about.. I want interdependence, family, community. It's much more community based... I just don't think they get that. You know they've got this one model fits all."* [woman, Southwark]

Another example was given by a Nigerian man who found that his passion and exuberance could be, and had been, mistaken for mental illness. As a loud man expressing himself with passion, he felt himself misunderstood in British society and in mental health services. In a similar vein, another person pointed to the tendency of services to...

*"...assume that the European middle class way of acting is the only appropriate way of dealing with problems i.e. to take confrontation with a cool calm exterior and when you do not, to impose a diagnosis on you against your will."*

A couple of people in one group talked of cultural differences in disciplining children, and said that people they knew had come into contact with the police and the mental health or social services through physically chastising their children. They were at pains to distinguish discipline from abuse.

A few people talked of the way in which mental health is perceived in their culture, for example, their fear of the reaction of friends and family. One person described their fear of seeking help in relation to the understanding of mental illness in their country of origin:

*“I was scared of asking for help because where I come from if you have got mental health they say you have got evil spirit or demons.”*

Another cultural barrier for some smaller communities (the example discussed was Zimbabwean) was the fear of poor confidentiality. People felt that if they encountered someone from their country in hospital, the information would be spread round the community and their personal issues would not remain confidential. This resulted in a reluctance to approach services if they knew they might meet someone from their community.

### 3 Helpful services and supports

This section is divided into three parts: what people had found helpful in the past; what they would have found helpful when they first sought help; and what they would like to see funded or might find helpful in the future.

#### What has been helpful?

As the Q6 chart shows, the three most helpful sources of support identified by the survey respondents were the GP, voluntary sector services and family and friends; these were followed by community, faith groups and primary care services. Many of the sources of help named by those who ticked ‘other’ were also voluntary sector and community groups.

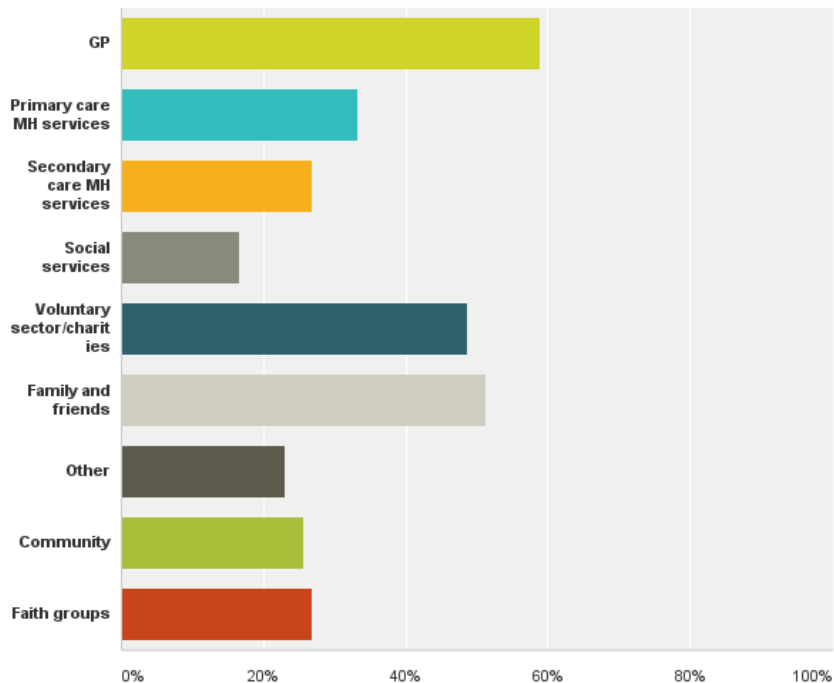
The reasons people gave for identifying these sources of help fell into three broad categories. Most people referred to aspects of **being listened to**: feeling understood within the context of their race, culture, refugee status and/or gender and sexuality; being treated with respect, valued and encountering a genuine sense of non-judgmental acceptance.

*“They accepted without judgement and received and welcomed you as you are, without compartmentalising me, my situation and the context of my life and experience.”*

Some people talked of the value of being **signposted** to sources of help or to access other services – e.g. talking therapies. A few talked of **learning new skills** and strategies.

**Q6 When you needed support, what are the kinds of support or service that helped you? Please tick one or more of the below**

Answered: 78 Skipped: 0



**What would have helped?**

When asked what people would have found helpful when they first sought help (Q9), the single most common response was some form of talking therapy.

*“I needed counselling because basically I was angry. Medication covered that up but did not deal with the problem.”*

Many people expressed a more general wish for ‘more listening time and real caring people’ or the need for ‘someone to talk to who would not judge, would listen and be able to give help or point me in the right direction’. For several people, this meant time and space with people from their own background, culture or gender, people who could identify with their experiences.

*“The human element. I felt professionals could not identify with the Black experience.”*

*“Go to places and sharing your story and knowing you are not the only one going through it. But I could not find such centres.”*

Focus group participants also discussed the value of being able **to talk to someone who understands**: someone who receives you, hears you without judgement, without bias.



The experience of feeling unheard, not valid, of feeling insignificant was described as having a huge impact on people's self-esteem and confidence.

*"It's the conversation, the talking without being judged, without any bias. Because you're talking to somebody who doesn't know anything about you. You're telling them about you, they don't already know you. So you give it to them and they give you back the support that you need."* [woman, NE]

Many of the focus group participants talked of the value of attending specific **named groups and services in the community** that offered them the opportunity to meet people from the same culture and background, or with similar experiences or struggles (e.g. asylum seeking, not necessarily from same country).

*"... as human beings we need society, people to talk to, to share those feelings of sadness."* [woman, NE]

*"From that day I feel I am living, doing something, got the confidence to do something with society. Totally informal but having a small group like this is a great opportunity for people like us to get back to our track and not to go down and not to get depressed. Now **we have a group we have the freedom to talk to each other, we can share our ideas, we can talk, we can share, we can express our feelings and ideas – that is the best way to get rid from depression.** You can follow some people, get inspirations from other people. it is the chance for people suffering from mental distress to come together."* [woman, NE – creative writing group]

Kindred Minds in Southwark hosted the women-only focus group in South London; the participants were very appreciative of what the group had to offer:

*"It's about what you don't have to say or explain."* [woman, Southwark]

*"I don't know where I would be now [without Kindred Minds]."* [woman, Southwark]

The women said it was safe to speak there, it *'takes into account all our different cultures, different foods'*; *it's like a family unit, you feel part of the world'*. Kindred Minds offers complementary therapies, which a couple of the women described as having an important role in improving their relationship with their bodies: *'it is the opportunity to allow yourself to be touched, to find out who you are, being at ease with yourself'*. Others mentioned the social activities, the workshops and the theatre group. Several people, both in this group and in others, mentioned the importance of coming together to share food.

*"Even when we're breaking bread, the different cultural meals, the beauty of it is that we share real experiences, and also we're not frightened of actually disclosing that, whereas before it's all hidden inside. You give us the time where we can open up and express ourselves and know that we're going to be safe so I quite like that.."*

[Woman, Southwark]

Asylum seekers in the NE focus group mentioned the group they were attending (developing partners cic) and the Asylum project as vital resources enabling them to connect with others in the same or in similar situations:

*“I went to the Asylum project, it is a good place.. so many people came there, we got the chance to talk to each other, people from the local area, from other countries, a real cultural mix in that place..” [Woman, NE]*

Other individual services, groups or projects mentioned include: Peckham Befrienders; Blackfriars; The Lorrimore day centre; Mosaic clubhouse; Phoenix women’s health organisation; Southwark women’s forum; Local Mind association – for information, and find out about Kindred Minds; Rethink Forresters respite place – like a country hotel; Women’s crisis house; Dragon café.

*“I could go there and sit on the sofa and not talk if I wanted to, be alone with other people around...” [Woman, Southwark – talking of a day centre]*

*“They bought a stupid little cake for my birthday, was the first time anyone had done this [in this country], made me feel I was a human being... that I could be cared for.” [woman, Southwark – talking of a day centre]*

### **What might be helpful? What would you like to see funded?**

From the survey responses to Question 11 (*What single service would you like to be funded in the future?*), the two main themes to arise were: specific (named) BME and other voluntary sector community groups and projects, and access to talking therapies. A third theme was peer support and peer or user-led groups and services. These themes were reflected and explored in more depth in the focus group discussions.

### ***Specific named services***

The participants named a range of voluntary sector projects and community groups that they would like to see funded. These services include many developed for and by particular BME communities as well as some with other individual needs or issues in mind.

#### ***Services, groups and projects named by survey respondents (Q11):***

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- Kindred Minds
- Peckham Befrienders
- Mosaic Clubhouse
- Solidarity in a Crisis
- Developing Partners cic
- Community Links
- Dial House
- Freedom from Torture (the Medical Foundation for the Care of Victims of Torture)

- Southend Mind
- Butterfly project
- NSUN
- Isis

For example, Peckham Befrienders (South London) aims to reduce the isolation experienced by black African/Caribbean people with mental health problems. Developing partners (Teesside in the North East) is a social enterprise organisation led and run by people with long term mental health needs working in partnership with diverse people who experience social exclusion. Kindred Minds (based in Southwark Mind in South London) is a BME user-led and user-run community project with the aim of ‘sharing common experiences, celebrating our different cultures, exploring ways to define and articulate our needs, looking at ways to campaign and improve services, build confidence, manage our own well-being, and achieve personal goals’ (taken from their website).

Dial House is a survivor-led crisis service in Leeds; the Butterfly project is for people who self-harm; Mosaic Clubhouse (South London) is a community centre that provides opportunities to people with mental illness; it is ‘organised to support people living with mental illness to re-join the worlds of friendship, family, employment and education’ (from their website).

It is perhaps important to note that several of the named groups and organisations were currently under threat due to funding issues. A significant reduction in funding and resources as a result of the economic downturn and the political response to that downturn, has undoubtedly had an impact on organisational capacity in the BME voluntary sector.

### **Talking therapies**

This was the most frequently mentioned individual service type the survey respondents said they would like to see funded; it included mentions of counselling, psychological therapy, talking therapy, CBT. One or two people mentioned the need for black counsellors or therapists, and some were specific about wanting the space to talk as against, for example, CBT or a limited numbers of sessions.

*“Talking Therapies - because when diagnosed it’s no good just medicating everyone, there has to be better understanding of the condition by the person experiencing a condition exclusive to how it affects them, and the best way is to talk about the problem(s) experienced and get professional help to cope and find strategies to cope better, for longer.”*

### **Peer support**

Many people mentioned peer support or user-led services, valuing the support of people with similar experiences to themselves, or those on parallel paths and journeys.

*“more peer support groups with access to clinical help when needed -- some facilitation by clinicians but not entirely run by them, rules agreed by group.. This could include some groups that are specific to a particular culture. It isn't discrimination if it gives people the security, support and confidence they need to make progress.”*

In one of the focus groups, participants showed a sophisticated understanding of what is meant by peer support: peer-led peer support, with training, trained by 'us' as against a professional-led peer support where the training brings the peer supporters 'up a level' such that they lose their equality or 'peer-ness' with others in the group. Not people getting together and 'moaning about their crap' but constructive, sharing ideas and strategies, supporting and signposting people to other sources of help.

### **Other supports and services**

A range of other supports and services were mentioned by both survey and focus group respondents, many of which reflect the social approach to mental health discussed at the start of this report: community groups / cultural clubs; exercise; practical advice and information (housing, benefits, debt, immigration, parenting support); support for children and young people; creative opportunities (e.g. creative writing, art); dietary and nutritional advice; alternative and complementary therapies.

In addition to the above themes, the focus group participants gave some more nuanced responses to the question of what services or supports people would like to see funded. There was the space here to consider ideal or imagined services that would meet their needs:

- **Retreat, sanctuary, opportunity to opt out** of life for a short time when you feel you can't function but don't want to be in hospital, somewhere where your principles and beliefs are upheld, you feel safe.
- **A BME support network** to provide support to people admitted to hospital:  
*“A BME network that is alerted to provide befriending, peer-support and ensure needs are being met. People from other countries may not have friend and family networks and not understand the system.” [quote needs completing]*
- **The opportunity to talk about racism** 'if people talked about it I could have shifted the blame thing out of myself' / opportunities to explore identity, what it's like to be black in this country. 'The opportunity to explore our identity as women in a safe space, we learn so much from each other.'
- **Something to mediate/ to assist you on your journey** as a refugee/asylum seeker

*“What is it that could be put in place so that we could cope with whatever situations that may arise as we go along this journey, because it’s really difficult. Not many would want to cope with this situation... If only something could be put in place, some mechanism, so that we could cope with this situation..”*

## Conclusions

It is impossible to understand what people find helpful without an appreciation of the context of their lives and the ways in which they understand their mental distress. For more detailed discussion about this theme, see: Kalathil, J. 'Recovery and Resilience: African, African-Caribbean and South Asian women's narratives of recovering from mental distress.' (Mental Health Foundation, 2011). A key theme from this study is that of people seeking alternatives to the conventional Western medicalised approach to mental health and mental illness. The people we talked to did not, generally, conceive of their distress in this way and explored it in relation to their identity, race and culture. Consequently a medical approach which starts with medication as the first treatment on offer is seen as irrelevant at best, and damaging at worst. Participants in one group explicitly discussed the social model of mental health, suggesting that it has more to offer people for whom race and culture are important issues in their lives.

The powerful effects of racism and the stigma and discrimination attached to refugee or asylum-seeker status were described as causing and contributing to distress, as well as serving as powerful disincentives to approaching services. Refugees and asylum seekers talked of being seen as 'rubbish', stereotyped as liars and scroungers, not believed and not trusted, of feeling shame. They were put off by the 'formality' of services, of their association with police and other officialdom. They were keen to hide their refugee status whenever they could, for fear of the stigma and discrimination surrounding them.

Closely related to this was the desire for the space and opportunities to acknowledge and talk about race and the effects of racism: a strong feeling that this is discouraged, not just within statutory mental health services but in many voluntary sector organisations as well. Professionals do not want to hear about it, people feel silenced and this further exacerbates their distress. In a similar way, LGBT people felt silenced by mental health professionals unable or unwilling to talk about sexuality or sexual identity. There is a real need for people to be able to see '*someone like me*' when they are in need of help; whether through dedicated peer support groups, counselling services or community groups where people can meet others who share something of their identity and life experiences.

Some distinct cultural differences discussed in the groups go some way towards explaining the reasons for people feeling misunderstood by mainstream services, and therefore as barriers to seeking help. For example, a couple of people brought up in Africa talked of the strangeness of finding so many people in this country living alone – the individualisation of society and, crucially, the individualised response of services to you as the person in distress; the strangeness of talking to a stranger about personal problems, the separation of the individual from their family and community through their contact with services.

People talked over and over again of the need for alternatives to medication and for more opportunities to talk and to be listened to without judgement – often, but not necessarily, within the context of wanting more and easier access to psychological therapies.

A holistic approach, that brings the support on offer closer to the community in terms of culture, language and approach, is more likely to encourage people to seek help when they need it. The Western medical model and medical approach towards mental health and illness renders mainstream mental health services irrelevant and inaccessible, even alien, to some of the communities we spoke to. This is not unique to black and minority ethnic communities; many white British service users also find a medical approach towards understanding mental distress profoundly inadequate. However, it is further compounded for some people and some communities, by being unfamiliar and by being supported by an inherently individualised culture where independence and autonomy are seen as desirable goals.

Some people in the study did find mainstream mental health services helpful; this was usually dependent on individual members of staff who had been able to offer a listening ear as well as, perhaps, refer people on for specialist help (particularly counselling or psychotherapy). There was some agreement about the value of mainstream services being dependent upon the individual nurse or doctor who had been able to listen and offer support to someone as a fellow human being.

Many individual groups, projects and services were named during the course of the focus groups and in the survey responses as having been helpful and deserving of future funding. Most of these services reflect a social model of mental health as discussed in the focus groups, offering a sense of belonging along with an holistic approach to mental health and wellbeing that includes: food, music, socialising, counselling, peer support, practical help and/or complementary therapies and shared strategies for dealing with different problems.

BME community groups and organisations suffer from a lack of visibility and voice and poor access to resources. A recent briefing paper based on research into the voice and influence of the BME voluntary and community sector (VCS) suggests that ‘the BME VCS voice was not strong and there were challenges facing the BME VCS both in relation to access to resources and political support’ (Ware, 2013). Kalathil (2011) has pointed out that many BME groups are founded on advocacy or community development models rather than on models recognisable as ‘user involvement’ nor, indeed, named as ‘peer support’ (Faulkner and Kalathil, 2012). Similarly, organisations serving refugees and asylum seekers may address mental health as part of their broader work around advocating for people’s rights (Sollé, 2009). In other words, it is important for funders to retain a broad concept of the groups and organisations that can offer support to people from BME communities who are experiencing mental distress. It is also important to bear in mind the broader context in which these groups exist: namely, a reliance on short-term funding and a lack of infrastructure to sustain them.

## Recommendations

The research leads us to make the following recommendations:

1. Funding is needed to strengthen those (often small) groups and organisations that serve BME and other marginalised communities, to build upon their expertise in responding to the needs of their communities and offering people acceptable routes into finding support when in distress. Many community groups and organisations offer people from black and minority ethnic communities and other marginalised communities an accessible and acceptable route into finding support when experiencing mental distress. This route can then be used to access additional information, advice and signposting if more specialist help required.
2. Funding needs to support groups and organisations that reflect a social model and a holistic approach to mental health and wellbeing, offering people an open door and a sense of belonging along with supports and services that include: food, music, socialising, counselling, peer support, practical help and/or complementary therapies and shared strategies for dealing with different problems.
3. Funding is needed to support the infrastructure that will enable these small groups and community organisations to build their capacity to access further funding. Several of the groups mentioned in the research were small and poorly funded and some were close to closing down due to lack of funds. Recent research from the Third Sector Research Centre has shown that, in the context of austerity and the 'big society' agenda, 'below the radar' activity (informal and semi-formal voluntary and charitable activity by an estimated 600,000 or more small community groups) has become crucially important (McCabe and Phillimore, 2012). This could be especially true for the BME voluntary and community sector. Groups that wish to expand or simply to continue to support people in a more sustainable way, will need the support to build capacity to access more substantial funding.
4. It is vital that any future funding takes into account the need for people from black and minority ethnic communities, refugees and asylum seekers, to acknowledge and discuss the effects of racism on their lives and as a potential cause of, or contributor to, their mental distress. Mainstream services, too, need to hear this message and overcome their fear and reluctance to acknowledge the profound effects of racism and discrimination on people's mental distress.
5. The research strongly indicates the need for greater access to psychological therapies for people from black and minority ethnic communities. However, opportunities to talk and to be listened to need to incorporate everything from informal occasions, such as meeting people over food in local groups and activities, through peer support and more structured group activities, to more formal access to counselling and psychotherapy.
6. Some people in our study talked of the need to see more black counsellors and psychotherapists, more black and minority ethnic people encouraged into these and other parallel vocations, and some talked of the need for training in cultural sensitivity.



However, it was also clear that the valued support of some individuals was not dependent on their race or culture. An individual yet holistic approach was advocated by some: the need for understanding an individual within the context of their lives.

7. We would strongly recommend that services be funded that offer refugees and asylum seekers the support they need to negotiate services when they are in distress. At present, many are fearful of seeking help from over-formal, seemingly alien, services that can compound rather than relieve their distress.
8. Although it goes beyond the remit of this piece of work, we would also recommend a complete overhaul of acute psychiatric care and the way in which it responds to people from black and minority ethnic communities. At the very least, mental health services and professionals need to acknowledge the role of overt and institutional racism in contributing to people's lives and distress; but also need to examine the ways in which they are treating people differentially. This is not a new observation (see, for example, 'Breaking the Circles of Fear', published by the Centre for Mental Health in 2002). Indeed, it has been further fuelled by recent findings from the CQC<sup>1</sup> that the use of the Mental Health Act continues to rise and that detention rates continue to be higher for Black African, Black Caribbean and other Black groups. Many service users in this research (particularly those in the Lambeth focus group) talked of traumatic experiences and fear. People from black and minority ethnic communities are not going to willingly seek help from mainstream services for their mental distress when they see those services to be more punitive than helpful.

The last word goes to a member of one of our focus groups who had a message for funders everywhere...

*"Listening to all of you, it sounds like [Kindred Minds] has had a really big impact on all of you. In terms of funders sometimes that gets lost, the depth of that, the importance of that gets lost because funders always want to know numbers. It's like, **why can't funders recognise that whole people's lives can be influenced**. And that is really, really, really important. It's not how many people you get through the door really - you can see why they've got to do it like that because there's no other way of how to assess that, but it just seems a crazy way, especially something like mental health.. who cares if five people come to a group and five people have a really, really positive experience. Or you get fifty people come in and they just come in and get a bit of food."* [Woman, Southwark]

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<sup>1</sup> Monitoring the Mental Health Act in 2012/13, CQC 2014

## References

*This is not a study reliant upon a literature search or the wide use of references; however, the following few have arisen in relation to the issues discussed:*

Care Quality Commission: Monitoring the Mental Health Act in 2012/13, London: CQC 2014.

Faulkner, A. and Kalathil, J. (2012) *The Freedom to be, the Chance to Dream'*: Preserving User-led Peer Support in Mental Health. London: Together for Mental Wellbeing.

Gould, D. (2013) *Service Users' Experiences of Recovery under the 2008 Care Programme Approach*. London: Mental Health Foundation/NSUN.

Kalathil, J. (2011) *Dancing to Our Own Tunes: Reassessing black and minority ethnic mental health service user involvement: Reprint of the 2008 report with a review of work undertaken to take the recommendations forward*. London: NSUN.

Kalathil, J. (2011) *'Recovery and Resilience: African, African-Caribbean and South Asian women's narratives of recovering from mental distress.'* London: Mental Health Foundation.

Sollé, D (2009) *'Improving Mental Health Support for Refugee Communities: An Advocacy Approach'* London: Mind.

## Appendix A: Topic Guide

### Ethnic Inequalities in Mental Health: Promoting Lasting Positive Change

As you know, there is an over-representation of some black and minority ethnic groups at the 'hard end' of the mental health system (i.e. entering services via the police or other emergency services, detained under the Mental Health Act or admitted to secure services). Some groups are not being reached at all and, amongst many, there is continuing dissatisfaction with existing mainstream services. The organisations Lankelly Chase Foundation, The Afiya Trust, the Centre for Mental Health and Mind, who have a long history of focussing on these issues, have come together as a partnership. Their aim is to take action to promote lasting positive change in the field of ethnic inequalities and mental health.

We have been talking to a range of people to find out where change is needed and what action the partnership might take in order to develop a programme of work. We are interested in existing mental health services, and in new responses developed within and by BAME communities.

You are central to this discussion and we hope you are able to take the time to provide your experience, views and insights so that we can find new ideas and responses so that everyone can get the right support when they need it.

#### The Impact of 'race', culture and ethnicity

1. Bearing in mind the context of your race and culture and the experience you have had of using services, do you have any thoughts or views about the experiences that you have had of mental health services...
2. Do you believe that your background ('race', culture, ethnicity, migration / refugee / asylum status) has had an impact on the kind of support you have received for your mental health needs?  
If yes, is there an example you'd like to share with the group?  
[Prompts: In assessment  
In the diagnosis you were given  
In the kind of service/support you were referred to  
In the kind of service/support you were not given]

#### What works

3. Where did you first go when you needed support?  
[Prompt: Keep this short, but to get a sense of: is it GP? A community group? Faith group? Family? Mental health services (voluntary/involuntary)?  
[if appropriate] What stopped you seeking support when you first experienced problems?

4. When you needed support, what are the kinds of support or service that helped you?
  - Within mental health services
  - Within the community
  - Within voluntary sector
  - From family and friends

[Prompt: We are looking for specific examples. There will be descriptions of people's humanity, empathy etc. but try to look for examples of specific kinds of services or structures where they might have received support, even if these are completely offbeat]
5. Why were these services/supports helpful?

[Prompt: Perceptions of what works – *how* does it help? We are looking here for specific examples of factors that enable the kind of support that people actually need and find useful]
6. Thinking back to the time when you were in need of help or support, was there anything that you thought would really help you but wasn't available to you?

[Prompt: Again looking for specific examples in all sectors, wider community and family - not just within mental health services]
7. Now when you need support, who/what service do you go to?

[Prompt: Are there examples of community and user-led initiatives that people are able to name?]
8. If you had one choice to name a particular kind of service or support that should be funded in the future, what would this be?

[Prompt: Generate ideas for what needs to be sustained, what needs to be scrapped. Will be interesting to see how this works across the whole consultation]
9. Is there anything else you would like to tell us about your hopes for the future in terms of better support around mental health and wellbeing?

## **Appendix B: Charter and Guidelines from ‘Dancing to Our Own Tunes’ (Kalathil, 2011)**

### **Charter and Guidelines for Partnership Working between Generic and Black and Minority Ethnic User/Survivor-led Organisations**

#### **Background**

This charter emerged from the work which was initiated to take forward the recommendations of the report *Dancing to Our Own Tunes: Reassessing Black and Minority Ethnic Mental Health Service User Involvement*. The report was jointly commissioned by the National Survivor User Network (NSUN) and Catch-a-Fiya National Forum for Service User and Survivors from black and minority ethnic communities<sup>2</sup>.

A steering group, TOOTS (To Our Own Tunes), was set up to take the recommendations of the report forward. The specific task was to set out ways for NSUN and Catch-a-Fiya to work in partnership, and more generally to suggest ways of partnership working between generic and black and minority ethnic user/survivor led organisations.

#### **Aims of the Charter and Guidelines**

1. The aims of the charter are:

- To assist organisations locally and nationally to work with service users/survivors from black and minority ethnic communities to identify and build upon the strengths and opportunities for developing innovative ways of partnership working
- To combat stigma and discrimination against and fear about mental health service users from black and minority ethnic communities
- To foster a robust, candid environment of trust in partnership working between generic and black and minority ethnic user/survivor-led organisations

2. The purpose of the guidelines is to suggest:

- What the charter means in practice
- Facilitative ways of partnership working

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<sup>2</sup> There is often a debate around the terminology used to refer to communities minoritised in relation to the local population on the basis of their “racial” or “ethnic” origin. No single term is fully capable of capturing the vast diversity, difference and similarity within these communities. Currently, “Black and minority ethnic” is the term consistently used in census, survey and routine administrative data. This term refers to a range of communities including established groups (e.g. African, Asian, African-Caribbean), new migrant communities (e.g. people from Eastern European countries), refugee and asylum seeker communities, transient communities (e.g. the traveller community), and groups often referred to as “invisible minorities” (e.g. the Irish community). Hence we have chosen to use this term for the purposes of this paper.

## The Charter

Partnership working with black and minority ethnic service user/survivor –led organisations involves the following:

- Showing a positive and enabling attitude to black and minority ethnic service user/survivor organisations
- Acknowledging the discriminatory experiences that people from black and minority ethnic communities face within society, mental health services and within generic user involvement initiatives.
- Recognising the role of these experiences in making individuals experts in their own right and in informing the nature of partnership working and the solutions to apparent challenges
- Empowering them to ascertain that there is confidence in them
- Making a genuine use of their knowledge, experiences and skills, one which stems from a fundamental value for them
- Creating a work environment that ensures mutual listening, hearing and understanding
- Ensuring that the partnership organisations have all the necessary information to work together
- Ensuring that there is openness and honesty within the relationship that will foster a competent and productive partnership
- Treating each other with respect and dignity, with outcomes that benefit all involved
- Supporting each other to achieve goals
- Having faith in each partner's ability to do the job to the standard required
- Providing non-judgemental and proactive support so as to enable each partner to work in their own ways to achieve their aims

## The Guidelines

Partnership working with service user/survivor led black and minority ethnic organisations is facilitated by the following:

### Values

- A genuine commitment from all partners to supporting race equality and changing organisational practices that may be discriminatory to service users/survivors from black and minority ethnic communities
- Mutual respect between partners and avoidance of competition
- Open mindedness towards ways of doing things that may stem from different and diverse backgrounds and experiences of people and communities. The fact that it is different does not mean it is bad or wrong, or will not work
- Honesty and openness. Each partner needs to feel comfortable about being honest and open and this honesty and openness should be respected by both sides
- Equality and fairness. Partners may come from unequal power structures.

- Therefore each partner needs to be aware of the power dynamics between them and work towards equality. Patronising and tokenism should be avoided and there should be a true sense of fairness.
- Sensitivity in language and actions. Each partner may have different ways of expressing and doing things. Respecting these will help determine the success of the partnership.

### *Setting up the partnership*

- Establish a shared vision: Each partner needs to agree on a shared vision for the partnership. The shared vision should be ironed out in detail so as to avoid confusion later
- Ensure equality in the partnership: Acknowledge the specific knowledge and expertise both of the black and minority ethnic and of the generic organisations.
- Be democratic in leadership and decision making: Ensure each partner is fully involved. This does not only mean shared tasks or consultation. Let each organisation take the lead in aspects of work for which they have particular skills.
- Agree clear roles: The roles of each partner should be well defined so as to avoid confusion. Each partner should then take full responsibility for their particular role
- Have realistic and clear expectations: Each partner should be agreed on the goals for the partnership and what is to be realistically expected of each partner
- Identify development needs: Ensure each partner has the necessary skills and capacity for the joint initiative. If gaps are identified, provide necessary training and development opportunities

### *On-going management of the partnership*

- Share responsibilities: Many tasks within a partnership can be carried out jointly. Know what each partner is capable of and use this to the advantage of the initiative and to furthering the partnership.
- Ensure accountability: There should be clear lines of accountability for the work. Each partner should be able to identify the individual responsible for any aspect of the work.
- Have continual information sharing: Each partner needs to be kept up-to-date about what is happening with the other in order to plan and have things running smoothly. Use appropriate languages and methods of communication to share the information
- Share learning and good practice: Promote opportunities to learn from each partner's work, highlight good practice extensively and use it to aid partnership working
- Acknowledge successes: Celebrate the successes along the way. This does not have to wait till the end of an initiative. All partners need to be acknowledged for their achievements and for successes in the initiative as a whole.
- Identify difficulties: Try to address these as they arise. Do not sit on a difficulty and hope that it will disappear; bring it out into the open and get it cleared up.

- Review the initiative regularly: There should be consistent opportunities to review the partnership and its work to make sure that things are going according to plan, are on target and on schedule. These occasions will also provide opportunities to iron out any difficulties, grievances etc.
- Provide on-going support for addressing race equality: Partners may need help with changing attitudes and practices or with dealing with personal experiences of discrimination. Be creative about the forms of support which are offered.
- Provide independent support for managers of organisations in the partnership. Staff can come to managers to talk through issues for them , managers also need someone whom they can approach.

### *Good Practice*

- Agree quality assurance standards for the partnership: these should be based on standards that respect and take into account each partner's definitions of quality and methods of measuring quality
- Be creative: There is usually more than one way to work in partnership. Explore imaginative ways of addressing the needs and concerns of users/survivors from black and minority ethnic communities even though these may seem different from generic organisational practices.
- Be flexible: Be prepared for change and difference. If usual ways of doing things are not working for users/survivors from black and minority ethnic communities, try something new. Real partnerships are built on the courage and willingness to change.