

# UCE Birmingham and AFCAR

## Being understood, being respected:

*An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities*

Funded by the Department of Health

## A Report

Produced by

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## Executive summary

### Introduction

This report presents the process, and results of an evaluative piece of research into mental health service provision for black African and African Caribbean people in Birmingham. Previous studies indicated that black service users who have mental health problems are more likely than white service users to be diagnosed as schizophrenic, to be prescribed psychotropic medication, to be sectioned under the Mental Health Act or regarded as violent and in need of detention in secure accommodation. They are less likely than white service users to be offered social and psychological interventions. In addition, deaths among black detainees mean that black people have come to distrust and even fear mental health services that fail to meet their needs.

The research set out to address these issues by examining current statutory and NGO provision for African and African Caribbean communities in relation to a range of factors including its accessibility, cultural appropriateness, the extent to which it meets the needs of service users, the impact of factors such as racism, discrimination, culture and religion and issues relating to funding. The research also aimed to explore the views and experiences of service users and carers in relation to these issues, and examined the extent to which the current services are meeting the government directive on Delivering Race Equality (DRE).

A range of methods and data sources were used including a structured telephone survey of 15 non-governmental organisations (NGOs) and statutory providers; nine focus groups and four semi-structured individual interviews with a total of 25 service users and 24 carers; and three focus groups (involving 15 people in total) and 16 semi-structured individual interviews with a range of professionals from statutory providers, commissioners and independent sector providers (see section 3.1- 3.3). A range of methodological issues were encountered and resolved during the process of data collection (see section 3.4)

Findings are reported in section 4 by each phase of data collection. **Mapping voluntary sector provision** indicated that there was huge variety among the 15 organisations surveyed in terms of the range of services provided; the mix of staffing; opening hours and advertising. Sustainability is a major issue for NGOs and turnover is high. The majority of organisations surveyed rely on volunteers.

For the majority of NGOs, the focus of their work is broader than mental illness. This is particularly true of NGOs working with African communities, they tend to be supporting all members of communities, not just people with

mental illness and their carers, and taking a holistic approach recognising the complexity of people's lives and the multiple issues they are facing.

Wider concerns highlighted in this phase of the research include concerns about misdiagnosis and over-representation of black people in the system; the need for services to be geared up to respond to post traumatic stress disorder; and perceived insufficient collaboration between statutory services and NGOs.

**Findings from focus groups and interviews with service users and carers** are broken down by different stakeholder groups: African Caribbean service users; African service users; African carers/community leaders and African Caribbean carers. The range of issues highlighted is rich and complex and it is recommended that the **section 4.2 in particular**, is read in full. Themes arising from this phase of the research focus on the range of mental health services used; different ways that mental health is understood; experiences of using mental health services; how accessible, responsive and culturally appropriate services are; issues relating to the targeting of service provision to the specific needs of African and African Caribbean people; actions required to improve services for black people and roles for service users and carers in improving those services.

**Similar themes were identified from phase three:** interviews and focus groups with commissioners and providers from statutory agencies and the independent sector. Additional themes include cultural factors that affect the way services are provided; perceptions relating to culture including recognition that culture can include the culture of service users, service providers and the wider host culture. Culture determines what is considered to be normal and abnormal behaviour and within the wider "host" culture, African Caribbean communities are more likely to be labelled as deviant. Again the data here is rich and it is worth reading **section 4.3 in full**.

Summary of findings (**see section 5**) from the analysis of data from the three phases of data collection indicate some clear overall themes. They include:

- The role of non-governmental organisations (NGOs)
- Understanding mental health
- Accessibility of services
- Experiences of using services
- Facilitators and barriers to developing culturally appropriate services
- The need for mental health service provision that is targeted to African and African Caribbean people
- Roles for service users and carers
- Actions that should be taken to improve services
- Acknowledging the stress of working in mental health services
- The role of social and family support

In addition, the findings highlight issues of health in equality in the provision of services for Black and minority population, particularly in relation to use of psychosocial therapies. It also raises concerns about the impact of the socio-political issues on mental health status of refugees and asylum seekers and their use of health and social care services.

The main findings and themes are discussed in relation to the national, regional and local reports and papers, and the implications of the findings for the providers and commissioners of the mental health services are highlighted, **see section 6 for details**. This section also discusses ways of redressing this problem by better use of NGO and understanding issues involved in promoting mental health amongst the BME population. In addition it also argues the importance of investing in mental health promotion, environmental and family support for early intervention and recognition of signs of mental distress, as well as better communications and trust between all parties involved in the use and delivery of mental health services.

Facilitators and constraints to meeting service users' needs are also identified and include commitment of the Trust and commissioners to meeting the diverse needs of mental health service users as evidenced through backing from the Executive and the Board; staff champions and a Diversity Directorate; an emerging commissioning strategy and service redesign process. Constraints acknowledged and highlighted as; financial and human resources under the current health economy to support the implementations of the Delivering Race Equality and the Trust's service re design, and the lack of a clear lead from the Department of Health.

The report concludes that mental health services are at a crossroads. There are many opportunities for mental health services to develop and achieve the vision of responsive, culturally appropriate services including national and local policy frameworks (see **section 7 for details**). The reports advocate investment in public health promotion for de-stigmatising mental health, and influencing the wider determinants of health through working with parents, schools, policy makers and service providers in order to strengthen community relationship, create supportive environment and networking for the management and prevention of mental health problem. It proposes a move away from what currently appears to be an either/or approach to developing targeted services and mainstreaming. It recommends more funding to support Delivering Race Equality, building capacity and creating a sustainable NGO sector, and empowering users and carers to be involved and take lead in the path way to care plan, safe management and recovery.



## 1.0 Introduction

This research focuses on mental health service provision for black African and African-Caribbean people. The 2001 census data shows that 47,831 people in Birmingham described themselves as black Caribbean, accounting for approximately 4.9% of the population and forming the third largest black minority group in the city. It is possible that, if the additional 6.1% of people who described themselves as black or black British is taken into account, the black Caribbean population of Birmingham is nearer 10% with numbers closer to those of the Pakistani community ([www.statistics.gov.uk](http://www.statistics.gov.uk)). There is little census data about other black communities in Birmingham. Black African people comprise about 0.6% of the population ([www.statistics.gov.uk](http://www.statistics.gov.uk)). The data does not clarify the countries of origin but these are likely to include Somalia, Sudan, Rwanda, Sierra Leone, Nigeria, Congo, and Algeria.

Previous studies have demonstrated that black service users who have mental health problems are:

- More likely than white service users to be diagnosed as schizophrenic (Nazroo, 1997).
- More likely than white service users to be prescribed psychotropic medication (The Sainsbury Centre for Mental Health, 2002).
- Less likely than white service users to be offered social and psychological help through counselling, psychotherapy and other interactive interventions (DOH, 2003a; DOH, 2003b).

In addition, black people with mental health problems are more likely than white people with mental health problems to be sectioned under the Mental Health Act (Churchill *et al.* 2000, DOH 2003a) or be regarded as violent and, thus, in need of detention in secure accommodation (Bhui, 2001).

In response to this situation, which has been compounded by the number of deaths that have occurred among black detainees (Norfolk, Suffolk and Cambridgeshire Strategic Health Authority, 2003), black people have come to distrust or even fear the mental health services that, in their view, fail to meet their needs (The Sainsbury Centre for Mental Health, 2002; Keating and Robertson, 2004).

Alongside this climate of fear and distrust is a perceived disparity in service provision, which is attributed to a lack of sustainable funding. There have been many projects and initiatives but these tend to depend on short, fixed-term funding. This is not a situation confined to mental health. Husband (1996, p37) argues that, *"successive governments have sought to diffuse and defocus the formulation of policy by minority ethnic communities through promoting ever-changing, but ambiguous policies for minority ethnic communities"*. The provision of fixed term funding for short-term projects in mental health is

consistent with Husband's argument about ambiguity in giving the appearance of investment without any prospect of real progress (McGee, 2000).

Numerous reports have identified shortcomings in mental health services that have contributed to the poor quality of care and treatment provided for many black people. Stereotypical beliefs, lack of understanding among staff about culturally-based issues, lack of culturally-competent practices, language barriers, and institutional racism have all been cited as reasons why black people frequently receive less appropriate interventions, and experience less satisfaction with service provision than white people (The Sainsbury Centre for Mental Health, 2002; Parkman *et al.* 1997). As the inquiry into the death of David Bennett (Norfolk, Suffolk and Cambridgeshire Strategic Health Authority, 2003 p62) noted,

*"...time and again regrets at the existing state of affairs have been expressed. Time and again, promises of improvement have been made. While it would be unfair to say that nothing has happened, it is true to say that not very much and certainly not enough has happened. Unless there are sufficient resources and sustained management, which is both dedicated and committed, these problems cannot be solved. At present people from the black and minority ethnic communities, who are involved in the mental health services, are not getting the service they are entitled to. Putting it bluntly, this is a disgrace."*

This research attempts to address the current issues faced by African and African Caribbean people by drawing on their own experiences as mental health service users, and carers as well as those of service providers and commissioners. The report is presented in the following seven chapters:

- Chapter one sets out the background to the research;
- Chapter two sets out the aims and objectives of the research;
- Chapter three sets out the methodology for the research and methodological challenges encountered during the research and how they were addressed;
- Chapter four presents the main findings from each phase of data collection: a telephone survey to map voluntary sector provision; findings from focus groups with service users and carers analysed by stakeholder group (African Caribbean service users, African service users; African carers and African Caribbean carers); and findings from semi-structured interviews with service providers and commissioners;
- Chapter five summarises the main overall findings;
- Chapter six discusses the findings in the light of the literature;
- Chapter seven presents the conclusions and recommendations.

## 2.0 Aims and objectives

The research, on which this report is based, aims to provide an evaluative account of the extent to which current statutory and voluntary mental health services in Birmingham are meeting the needs of members of African and African Caribbean communities.

The objectives of the research were:

1. To examine the range of current statutory and voluntary provision for members of African and African Caribbean communities in Birmingham, identifying:
  - the target groups for whom services are intended, the need for and the functions of services;
  - the accessibility and cultural appropriateness of services and the extent to which current provision successfully addresses the needs of service users;
  - sources of funding and other support; factors that affect the ease or difficulty with which sustainable finances and support may be obtained;
  - the extent to which factors such as racism and discrimination, culture, religion and language, etc. facilitate or hinder meeting clients' needs;
  - the extent to which factors such as racism and discrimination, culture, religion and language facilitate or hinder working with other agencies;
  - specific factors that positively or negatively affect the function of services.
2. To explore the views and experiences of service users and carers to identify perceptions about the extent to which current provision is able to meet clients' needs, what helps or hinders this process and why, with reference to:
  - the nature of the services available and whether they are regarded as fulfilling perceived needs;
  - the accessibility and cultural appropriateness of services and the extent to which current provision successfully addresses the needs of service users;
  - the extent to which factors such as racism and discrimination, culture, religion and language are thought to facilitate or hinder meeting clients' needs;
  - specific factors that service users and carers may regard as important.



## 3.0 Methodology

The research focused on the locality covered by the Heart of Birmingham Teaching Primary Care Trust, as most of the African and African Caribbean population of Birmingham are resident in this area.

### 3.1 Research design

The theoretical design of the research was informed by the following principles:

**The use of multiple social research methods and sources of data:** The complex nature of the subject matter means that no single approach would be likely to provide sufficient data to meet the aims of the project. Consequently the design was based on using multiple social research methods and sources of data (triangulation) (Denzin, 1989) to facilitate the development of a comprehensive picture of current service provision in Birmingham and the extent to which this meet the needs of African and African Caribbean service users.

**Development of a research team, including co-researchers to engage service users, carers, and providers:** One consequence of exclusion is distrust or even hostility towards members of the dominant majority, especially where there is a history of negative experiences of research or where previous studies have failed to produce promised improvements (see, for example, Whitmore, 1994). Lack of trust in researchers is likely to be exacerbated by the legacies of oppression and persecution. For members of the black African Caribbean population these legacies arise from current and past experiences of racism and discrimination since the era of slavery. Some, though not all, individuals of black African origin may have immigrated to the UK as refugees and bring with them experiences of war, lack of human rights, torture and fear. Engagement with service providers and service users as part of the development and conduct of the project was a key part of the research process, to create champions who could overcome distrust.

**Consideration of the investigators' ethnicity:** several recent studies have demonstrated the importance of considering investigators' ethnicity when researching sensitive topics (McGee, 2000; Klem and Notter, 2002; Notter and Hepburn, 2004) and consequently the active participation of African and African Caribbean people in all stages of the project was seen as an essential pre-requisite to its success. From the outset, it was envisaged that the research team would include members of the communities to be studied, and the team would spend time preparing for the project through, for example, meetings, and presentations in community-based locations. Attempts were made to recruit African Caribbean researchers and there have been several

changes of research personnel from different ethnic groups, including African Caribbean.

Whilst the two key researchers were Asian and White British respectively, they co-opted African and African Caribbean co-researchers with particular expertise such as interpreting or skills in research methods to provide advice, support, or training. The two key researchers also worked with a steering group comprising mainly African and African Caribbean professionals and service users of mental health services.

### 3.2 Ethics

A number of ethical issues were identified in the project design. These concerned respect for autonomy, honesty, beneficence, non-maleficence, and justice (Beauchamp and Childress 2001). Consequently, an ethical review was deemed necessary before work commenced. The first phase of the project was reviewed by the Ethics Committee in the Faculty of Health, University of Central England in Birmingham, and favourable opinion obtained. Phases two and three were reviewed by the Heart of Birmingham Primary Care Trust's Research Ethics Committee, which also issued a favourable opinion. All potential participants were given letters of invitation to take part and written information about the nature of the project. All those who agreed to take part were asked to sign a consent form (appendices 1 and 2).

### 3.3 Data collection, analysis and sampling

The project had three phases;

Phase one: mapping the voluntary sector provision through a telephone survey and using a structured questionnaire (appendix 3). After piloting it was decided to record the telephone interviews for transparency and ease of analysis. Permission for recording was obtained and fifteen organisations were surveyed. To analyse the data, each organisation was given a number and an indication of the main target group was provided such as African, African Caribbean or *not targeted*. The **organisations surveyed were extremely varied** and so did not easily lend themselves to mapping via the telephone survey. For all questions, responses were not simply a case of ticking the relevant box and were often accompanied by explanations.

The nature of the responses therefore, meant that the data was best analysed and interpreted qualitatively, using Krueger's framework and Rabiee's guidelines (Krueger and Casey, 2000; Rabiee, 2004) to identify themes. Some quantitative analysis was also carried out by counting total responses in relation to the frequency, range and types of services provided, route of referral, source of funding, etc

Phase two: nine focus groups and four semi-structured individual interviews were carried out with 25 service users and 24 carers (appendix 4 & 5). Some of these interviews were undertaken with help from co-researchers and interpreters.

Phase three: focus groups and semi-structured individual interviews (appendix 6) with statutory providers, commissioners, and independent sector providers. Sixteen individual interviews were carried out with strategic and service managers, psychologists, social workers, consultant psychiatrists, mental health nurses. These include people working in primary care liaison teams, home treatment, rehabilitation and recovery, assertive outreach, psychology services, inpatient units, community psychiatric nurses, an independent sector provider and commissioners. In addition, after the first stage of data analysis, three further focus group discussions were set up with key members of the provider and commissioners (n=15) with the aim of filling the gap in data generated through earlier stages; checking interpretation of data; and assessing the feasibilities and constraints relating to emerging conclusions and recommendations.

Permission was obtained to digitally record all interviews and focus groups, where possible. However, some difficulties arose in data collection because the digital recorders were not always sufficiently sensitive to pick up comments from group discussions. This meant that the quality of transcripts was sometimes poor. In addition, some participants refused, or were unhappy about being recorded, therefore detailed notes were made to record the content. All recorded interviews and focus groups were transcribed verbatim.

Transcripts were analysed using Krueger's framework and Rabiee's guidelines (Krueger and Casey, 2000; Rabiee, 2004) to identify themes; data was interpreted considering the actual words used and their meaning, the context within which the comments are made, the frequency and extensiveness of comments, the intensity of comments, internal consistency, specificity of responses and the emergent picture with implications for larger trends or concepts that emerge from an accumulation of evidence which cut across the various discussions.

To ensure anonymity all interviews, organisations mentioned and focus group data was coded. In phase two each focus group was given a number (e.g. 1, 2, 3 etc). Each participant in each focus group or interview set was given a letter. Thus, 1B refers to participant B in focus group 1. The gender of respondents is indicated as M (male) or F (female) but not ethnicity as this would have made some respondents identifiable. In addition, an indication of the role of each respondent was included for example Service User, Carer, or Other for focus group respondents who considered themselves neither carers nor service users). In phase three, each interview was coded by gender and professional role (e.g. Psychologist, Social Worker).

### 3.4 Methodological issues

A range of **methodological issues** were encountered and resolved as part of the research process including:

**Difficulties identifying non-governmental organisations (NGOs) meeting the inclusion criteria**, that is to say working with African and African Caribbean communities, and providing mental health services. Identifying organisations and obtaining an up-to-date list, to use as a sampling frame, turned out to be a huge task. Various lists were provided by Birmingham Voluntary Service Council (BVSC), Birmingham City Council, AFCAR, and the African Community Council for the Regions. An internet search, networking, and use of personal contacts were also used. However, lists and contacts went out of date very quickly and there was a high turnover of NGOs. One third of the sixty-three letters initially sent to all organisations on the list were returned unopened and marked '*organisation or addressee not known*'. The main NGO partner in the research suggested and arranged an open day with other NGOs, service users, and carers to launch the project; however, this was only attended by a small number of people.

**A limited infrastructure and under-investment in NGOs working with African and African-Caribbean communities meant that taking part in the research was a low priority for people struggling to provide a service on very limited resources.** There was therefore a need for the research team to invest considerable amounts of time to engage NGOs in the research and to obtain their written consent to do so. For example, various stages were followed in obtaining informed consent from participants including initial posting of a letter setting out full details of the project and a consent form with a postage paid envelope for its return (appendix 2); and then following this up with reminder letters. Of the 63 organisations receiving letters, eight replied and returned consent forms. Further telephone calls were required to arrange mutually convenient times to carry out the telephone survey and to bring the total number of organisations returning consent forms to 15. On a number of occasions, although a mutually convenient time was fixed for the telephone survey, when contacted, the participants were not available, so the process of re-arranging yet another convenient time took further time and effort and delayed the process of data collection.

**Lack of trust meant that in addition to initial difficulties identifying and engaging NGOs, there was a further need to invest time in establishing relationships and trust before people were willing to take part.** This entailed taking time to set out face-to-face meetings, with individuals and NGOs and discuss the benefits of taking part in this research. One of the main areas of concern was the perception on the part of NGOs that black people were over-researched and received little benefit from research. These issues were addressed through:

**Providing basic training in research**, on a first-come-first served basis, for individuals from NGOs working with African and African-Caribbean communities. This was a two-day training course. Senior staff at UCE Birmingham provided input. All attendees were given a certificate of attendance. The training was free and hugely over-subscribed. In addition to providing participants with an introduction to the University, including a tour of the campus and library and basic research skills, the training was useful as a means of piloting research instruments and recruiting people who might be willing to act as co-researchers in setting up and running focus groups.

**Paying travel and child-care expenses, providing refreshments and in some cases "thank-you" payments to participants.** The latter were not offered to all participants, only to participants in the three Somali focus groups as we were advised that people would not take part in the research if they did not receive some form of payment.

**Investing time in visiting contacts from different organisations and groups**, which helped to generate goodwill even though many of these visits did not produce any tangible or direct outcome for the research.

**Providing relevant information to participants and contacts.** This included information about sources of support, locally, that people might wish to access and invitations to events of possible interest. A technique for managing flashbacks was provided for translation by the interpreter for dissemination to women taking part in one focus group who reported experiencing difficulty coping with flashbacks.

**At the time of the research, UCE Birmingham financial systems were not set up to facilitate the involvement of carers and service users**, and consequently payment procedures were often slow and complicated. An outcome of this experience was that the key researchers contributed a paper on the problems experienced and recommendations to a UCE Birmingham review of payments to service users and carers.

**Difficulties identifying carers groups for African and African-Caribbean people.** Few NGOs provided support to African and African-Caribbean carers via carers groups at the time of the research and at least one of the groups in existence had had its funding stopped. Furthermore, the concept of a carer was not relevant across communities. For example, within the African focus groups the term "*other*" is used to refer to participants including community leaders and young people involved in peer education, as many service users had no family or friends to care for them.

**Difficulties recruiting from a wide range of African countries.** Attempts were made to recruit participants from Nigeria, Algeria, Sudan, Sierra Leone, Cameroon, Congo, and Somalia. These attempts included direct contact by the researchers with groups and their representatives and indirect contact via members of the steering group or via co-researcher training participants.

Some contacts said that there was limited mental illness within a particular community. After a considerable investment of time, a decision was made to focus on areas where it was possible to set up focus groups with participants from Congo and Somalia.

**Difficulties in recruiting from the gay community.** An email focus group was established via a contact working with gay men from African and African-Caribbean communities, to provide an opportunity for them to submit their comments on mental health services. However, no comments were actually submitted.

**Issues in working with interpreters.** Three different interpreters supported participants at four different focus groups. Meetings with interpreters were held and written information provided for briefing purposes, including a request that focus group participants' comments should be translated using their exact words. In reality, some of the pronouns (he, she, I etc) were mixed up in translation and, in many cases, the interpreter reported participant's comments (She says this, she says that) rather than translating them directly. On several occasions, interpreters and co-researchers contributed to the discussion, making it difficult to identify participant's views.

**Constraints on time with service users and different conceptualisations of mental health meant that only a limited number of questions could be asked.** Piloting of the interview schedules with co-researchers and with service users highlighted the following points.

**The term "mental illness" is problematic.** For some languages, there is no literal translation, also for some communities, stigma meant that people were reluctant to talk about mental illness. Furthermore, some communities were not accessing statutory mental health services in the traditional sense, but were getting support from communities, faith groups, and GPs.

**The topic guide had to be used flexibly.** A set of core questions was identified including an introductory question, inviting people to start by telling their story about how they came to be using mental health services; or about the person they cared for; or what mental health meant to them. The scene for the research had to be set with certain groups, including providing an introduction, expanding the concept of mental illness to include anxiety, depression, peace of mind as well as crisis and expanding the concept of mental health services to include faith based support, support from friends and family, as well as other sources. However, the nature of the discussion often meant that it was not possible to cover all these questions due to lack of time and reflecting the ways in which participants' stories unfolded.

**Ethical factors influencing the scope of the research.** As researchers, we were advised by the ethics committee and the steering group that it might not always be ethical to hold focus groups with service users for a period longer

than one hour and within that, time had to be provided for breaks, if required.

In addition, research governance requirements to provide sufficient information about the project to provide informed consent and our own equality monitoring forms took a considerable amount of time, particularly when people were dropping into the focus group discussion and were not all present at the time when the project was explained. This meant that the time available to hear participants' stories was severely constrained. Attempts were made to distribute information about the project including consent forms and monitoring forms for circulation and completion in advance of the discussion. However, often groups only met occasionally and the only time that people were available was on the date of the focus group or staff did not have the time – with all their other work – to go through the forms with individuals. Consequently, the schedule was shortened to take account of these issues but there was still insufficient time to cover all questions with all participants.



## 4.0 Findings

This section presents the findings from the three phases of data collection.

### 4.1 Phase one: mapping voluntary sector provision

Fifteen organisations were surveyed. Of these, 12 described themselves as voluntary, two as statutory and one described itself as a mixture of both. Organisations had been established for a variety of periods – three for 20 years or more – but the majority had been established for less than 5 years.

The **organisations surveyed were extremely varied** and were providing a wide range of services. More than 10 organisations were providing each of the following: social events, support groups, support for carers, advocacy, training opportunities including life skills, a wide range of other services such as advice about benefits. Services provided less frequently by less than five organisations were clothing, furniture, shower facilities, and laundry facilities. Comments indicated that the nature of service provision tends to include sign-posting, for example, to financial or legal advice, support such as accompanying people to visits to the doctor or nurse and referral to a GP, CPN or other source of help.

In terms of **staffing**, the majority of agencies included a mix of staff; that is to say, paid/unpaid, professional/non-professional. Twelve of the fifteen organisations relied on volunteers.

**Opening hours also varied** and were not always limited to normal office hours. Several organisations opened in the evenings and at weekends. Some opened when there was an event or when the service was needed.

Although between one and two-thirds of the organisations surveyed were **advertising** via GP surgeries, out-patient clinics, local libraries and local shops **the main mechanisms for advertising** were via community centres and "other" which includes word of mouth, radio advertising, leaflets, email, in newspapers, on the internet and through churches, schools and other NGOs.

Of the organisations surveyed, 12 indicated that their organisation was **not primarily focused on people with mental illness and their carers**. This is particularly true of organisations working with African communities, which tend to be set up to **support all members of communities from specific countries**. The focus was on creating a centre for people to access to get support with a wide range of issues. Where discussed, mental health was defined far more broadly than mental illness. As one respondent said *"people have complicated lives and people are feeling very bad, their concentration is bad ...The main issue many people are struggling with is housing problems and also dealing with community language problems, not serious mental illness"*

(15, African).

**The route for referral** to these organisations was mainly self-referral (in 14 of 15 organisations), referral by a GP (in 11 of 15 organisations), or other source of referral (for example via schools, job centres, health visitors and community organisations).

Organisations were asked about **factors that might inhibit or prevent access to their services**. Several said that there were none; some indicated that lack of funds for instance for advertising or to extend opening hours was a major factor. A minority referred to stigma relating to mental illness and fear that other members in the community will hear that people have a problem.

The **main source of funding** for the majority of organisations (11 out of 15) was statutory funding although many organisations indicated more than one main source of funding. A small number, mainly African organisations, relied on voluntary donations. Where funding was from a source other than voluntary donations, it tended to be on a three yearly basis with an annual review.

**Statutory funding was perceived to be the most successful source of funding** for 7 of the 12 organisations who responded to this question. Organisations were not always clear about the reasons that funding applications were successful. Where responses were offered they were very varied and included: being a credible, long-established organisation; having patience; providing a project that meets the needs of all African communities, not just one section; providing a project that meets a need, as perceived by a funding body.

A variety of other agencies – statutory and charitable – were cited as the **least successful sources of funding**. Several organisations did not know why they had not been successful. Perceived reasons for lack of success included funding timescales and requirements such as bureaucracy and tight deadlines.

Organisations were asked whether there were any **agencies that they would never approach for funding**. Many said no, but others said that lack of time and the huge number of agencies limited capacity to approach a range of agencies. When prompted, some organisations cited ethical reasons.

Eleven organisations have someone who is **responsible for securing funding**. These people held a wide range of positions for example Chairperson, Secretary/Treasurer, and Service Manager and have been in post for anything from 7 months to more than five years, with the majority being 3-5 years.

Factors that have had the most positive influence on organisations obtaining funding were cited as meeting/being able to evidence a need; having someone who knows your organisation; being a low-cost provider; having capacity to meet the need; and providing services specific to minority ethnic groups and refugees which, according to one respondent, makes it easier to compete

against other organisations:

*"To put yourself into direct competition with another organisation, this I have experienced, with people who know how to raise funds – it's very difficult to compete with them. But when they [the funding bodies] specify it is funding for this group you will know your chance of getting that funding and then you can apply" (6, African).*

Two organisations raised concerns about factors that negatively influenced the process including racism, lack of a track record, lack of awareness of what the organisation does or stands for, short timescales for applying for funding and issues relating to research. On this latter point, one respondent commented that research expertise could be a positive and a negative factor:

*"In the main it's about research, because we have, over the years, have developed some credibility around action-based research we have been able to attract funds ... some of the agencies that hire us to do the work aren't always happy about the findings so that sometimes restricts repeat work" (7, African and African Caribbean).*

Six of the 15 organisations were asked for any comments on mental health services for African and African Caribbean communities. Their comments included:

- Concerns about **misdiagnosis and the over-representation of black people in the psychiatric system**, which has led to **stigma** and *"has made people wary of getting in and wanting to get out as soon as possible. With African communities, a lot of work needs to be done to encourage people to come forward"* (3, African and African Caribbean).  
*"People are still labelled and not properly assessed – this impacts on the services they can get and how they are perceived in their own community and society as a whole [e.g. the portrayal in the media of the black man with mental health problems who was arrested by the police and ended up dying]"* (3, African and African Caribbean)
- **The need for services to be geared up to respond to post traumatic stress disorder.**
- **Insufficient collaboration between NGOs and statutory services**, including a failure to recognise the role NGOs can play and to invest in them.

*"We don't call our services mental health, but contribute a lot to the well being of our client groups through counselling, community building, helping them to develop life skills, find job etc. There should be a better links with mental health services and our organisation. People trust us & know we can help them overcome their anxiety and emotional problem which could lead to mental health" (8, African Caribbean).*

*"There are not many Nigerians with mental illness. Every community has depression and anxiety ... community groups are put under pressure to do without resources and staff end up depressed because they can't help people" (14, African).*

- The need for a balance between **respecting and challenging cultural belief systems and practices.**

*"Also there is the balance between respecting cultural and historic practices/belief systems – we have to respect and challenge as well – communities have ways of dealing with things that could be a coping mechanism. For example, Asian families talk about mental illness as retribution/a curse on the family. We have developed a way to respect and challenge that view at the same time – to support the belief and try to get the person well" (8, African Caribbean).*

## 4.2 Phase two: focus groups with service users and carers

Phase two comprised of focus groups and interviews with 25 service users and 24 carers/others including 25 men and 24 women. Data was sought on ethnicity but not supplied by all participants. Twenty-one service users and 17 carers provided information on their ethnicity/nationality (table 1).

Table 1- Self-identification of participants Ethnicity

Service users (n=21)		Carers (n=17)	
British	9	Somali	5
Jamaican	4	British	4
Somali	5	Jamaican	3
Congolese	2	Black British	1
Black British	1	Congolese	1
		British Somali	1
		Dutch	1
		Muslim and British	1

An important issue to consider is that the self-identification of ethnicity raises an issue about the validity and reliability of ethnic monitoring data, and indicates the possibility of underestimation of the available data on ethnicity. Based on observation, the information provided by participants corresponds with the current census category (table 2).

Table 2- Ethnicity of participants based on observation & self-identification

Service users (n=21)		Carers (n=17)	
African Caribbean British	9	African	7
African Caribbean	4	African British	3
African	7	African Caribbean British	7
African British	1		

Findings are presented using the following thematic framework, generated from the data and by revisiting the original proposal:

- The range of mental health services used
- Understanding mental health
- Experiences of using mental health services
- How accessible and responsive services are to service users and carers
- Culturally appropriate services
- Targeted service provision
- Improving mental health services for black people
- Roles for service users in improving mental health services for black people
- Other comments

Where applicable, findings are presented under the thematic headings by each of four stakeholder groups:

- African-Caribbean service users
- African service users
- African carers
- African-Caribbean carers

#### 4.2.1 The range of mental health services used

Interviewees were asked about the range of mental health services used. Mental health services were defined by the interviewer as including any services and support that people access either for themselves, or for/by the person they care for, to support them with their mental health needs.

**African Caribbean service users** tended to mention services provided by NGOs excluding housing support, hospital and community and day care services including support from home treatment and, assertive outreach on a relatively equal basis. They tended to mention support from GPs and family less frequently.

**African service users** tended to mention support from family, friends, NGOs, which were mainly faith based, and GPs more frequently than statutory services. When prompted about specific examples of mental health services such as community psychiatric nurses, community mental health teams, and hospitals, several focus group participants agreed, *"these organisations you talk about are not publicly known"* (9A, Male Other). Comments by participants in a focus group for Somali women indicate that the main services used were GP and hospital services. Generally, there was a feeling that for specific issues faced by the women, *"There is no help"* (Focus Group 10, all participants).

**African Caribbean carers** tended to mention community-based mental health services and support including early intervention and to a lesser extent

inpatient services and GPs. They talked more than their African counterparts, about the support they accessed for themselves: carers groups were felt to be important.

**African carers** tended to talk about the importance of faith and faith-based support. One focus group was held with Somali Sheikhs. They were asked about the services that people within the Somali community use in relation to mental health. The discussion focused on different ways of understanding mental health. Where mental illness has a spiritual cause, for example, possession by entities or djin, then, Somali Sheikhs argued the cure should also be a spiritual one administered by exorcists and spiritual leaders. Somali Sheikhs reported that people with mental health problems come to them, as spiritual leaders, for help. One Sheikh said that he had two or three people coming to him every week. He commented that in spite of not being medically educated, he was collecting information about people's symptoms, and where appropriate, was referring people to the GP. One of the Somali Sheikhs talked about knowing two people whose mental illness had been helped by the NHS but was not able to identify the specific services used.

## 4.2.2 Understanding mental health

Focus group participants were invited to offer accounts of how they came to be using mental health services. These accounts, and other comments, provide insights into the ways in which different stakeholder groups understand mental health.

### African Caribbean service users

At least four participants talked about **loss** in their accounts of their experience of mental illness. Two participants had had children taken into care:

*"He was taken into care; white man put him into care"* (3B, Male, Service User).

A second participant talked about the start of her journey into mental illness is being **when her children were taken from her**:

*"That was when my children, as I said, was taken off me ... It was when my children had left me and then it's like I didn't know what to do with myself, you know? I was homeless at that time and everything like that and then ... my social worker that I had suggested ... a place where I could go and get shelter and be accommodated at that time... [a mental health] hospital and stay there for a while"* (6D, Female, Service User).

In a different set of interviews, one participant talked about **having a breakdown at the age of 20 after both her parents died within a year of each other**. She had been living in Leeds at the time and took herself to Accident

and Emergency because she was feeling mentally unwell.

*"I don't mean physically I mean mentally, I wasn't mentally well, so I took myself to Accident and Emergency in S Hospital in Leeds and they referred me to a psychiatric unit that they've got there at S Hospital and I was there for about two months, two or three months and I received medication. I wasn't offered any counselling at all even though I was bereaved, I wasn't offered any counselling; the only thing that they did give me was pump me with drugs and that was about it. Now I'm dependent on the drugs, you know?" (6A, Female, Service User)*

This was the start of a journey across different parts of the country and in and out of mental health services, which included a period in an inpatient ward in Birmingham. At this point, she realised that she needed to get out of the system. She described her experiences of being in the unit with many men who were exposing themselves and masturbating in front of her.

*"That was horrible and you know and I thought to myself if I don't try and behave myself; that's the terms that they used 'I wasn't behaving myself'; if I don't try to behave myself I'll probably be in here in [this inpatient ward], with all these men doing whatever they want to do, for God knows how long" (6A, Female, Service User).*

Getting out of the system **meant learning to play by the rules**. However, her comments indicate that she found the interpretation of the rules confusing. For example, another service user was reported to pull down her underwear and urinate if she did not get her own way.

*"So I sort of got my act together, tried to comply with whatever rules and regulations the staff, you know, put on us, put on me or whatever so I didn't play up and then after that I was sent to [another inpatient ward]... I was still very, very confused because ... there was a service user there in the hospital, a patient, and what she would do is, whenever she didn't get her own way she'd literally go into the hall, pull down her underwear and pee. You know? And I thought what the hell's going on? Is this the ward they put me on?" (6A, Female, Service User)*

On the other hand, the participant's 'misbehaviour' was a response to people going in to her room and stealing from her. Although she reported this to staff, no action was taken and she became angry as a result and caused some vandalism.

*"I told them about it, nothing was done about it. So I got vexed and I must've smashed up whatever it was on the ward, I smashed up, and then, you know, they'd give me the injections, pin you down and give you the injections and send you back to the ward to rest or whatever or get back to yourself or whatever. That was what happened but I thought to myself even if they're stealing my clothes, even if they're whatever, try not to get angry;*

*that was what I was telling myself whilst I was there, you'll never get out of this place if you keep on getting angry with these people" (6A, Female, Service User).*

Another focus group participant talked about the events that led to her being arrested. She had been in a relationship with a man who subsequently turned out to be married. She was pregnant by this man and had expected that they would get married (she was a Christian) and when she found out that he was already married, in her words, something in her head snapped. She had a fight with him and had ended up being injured herself. At the hospital, she told staff what had happened and was arrested but felt that the police had not handled the situation appropriately. Her account is not completely clear but she talked about getting rid of the baby and having a stench in her nose like rotten flesh that she could not get rid of.

Two focus group participants talked about **mental health as being linked to stress**. One commented:

*"Mental illness is a social problem, I don't think it's necessarily an individual problem, it's a social problem. I mean there's lots of things that can make people go off their head; if they haven't got proper accommodation, if their house is leaking or if their partner's gone off or if there's a bereavement or divorce; all those issues can make people just flip, you know what I mean?" (6A, Female, Service User).*

Another talked about her experience of mental illness as being linked to a series of stressful events. She saw her problems as being to do with her life situation – having problems with her flat, losing her job, being in financial difficulties, etc. All of these things were having an effect on her and one day she had boarded a train and realised she didn't have a ticket. The reaction of the ticket inspector was one of a series of events where people around her did not appear to recognise what she was going through:

*"I was having difficulty describing what happened ... Anyway, he wasn't listening to me, and I got scared so I ran off the train. And he seized me and he rugby-tackled me to the floor and I bit him and the police were called. There was a bystander who saw the incident and asked him what happened and he said that I had not paid the fare. He asked how much was it, it was .... pounds and he said here's the money and I thought that was going to be the end of it but it wasn't. He [ticket inspector] wouldn't accept the fare. And the police were called and they kept me in the cells overnight and then I went to court....Anyway, when I got to court ...instead of telling the magistrate and explaining to him my circumstances that I was out of work, I was having problems with my accommodation; he turned round to the magistrate and said I was clinically depressed" (2E, Female, Service User).*

In response to whether she agreed that she was clinically depressed, the

participant mentioned that:

*"No. More than anything, I was financially depressed because I hadn't any money at all. I could see that I'd been ill for a while but I didn't think I was clinically depressed. So I've been under the mental health services ever since ..... I keep thinking if only I hadn't caught that train" (2E, Female, Service User).*

**African-Caribbean service users** talked about their mental health in different ways. In one focus group, the discussion focused on **the impact of television images of war** on mental health: *"Just watch the TV. TV seems so violent. ... it sort of gets into my mind; the violence on the TV"* (3B, Male, Service User). When prompted about how this made him feel, the respondent said that it:

*"Makes me feel that I'm scared of going to war and things like that" (3B, Male, Service User).*

*Interviewer: The world's getting more scary, is that what you're saying?*

*"Yeah. It's the gun man, gun man out there" (3B, Male, Service User).*

As part of the same focus group, two participants talked about Britain having an,

*"Experimental culture – it's like we're all fighting in hospitals and different religions. Different religions are fighting over who is God and is there a God, all part of a religion" (3B, Male, Service User).*

One participant was trying to make sense of this for himself, drawing on the spiritual beliefs of his family and another participant. These include **the belief that there is a list of names of people who are "saved"; beliefs that mental illness is related to witchcraft; and beliefs about mental illness and drug use.** He commented that he had self-harmed because he was confused about whether or not his name was on the list of people saved. He also talked about how he had been a successful musician but had become mentally ill as soon as he achieved a level of success. His mum had told him that this was to do with magic but he himself didn't believe in magic. He also talked about smoking cannabis and how it had felt wrong to him and that he was trying to stay away from it but that this was getting harder rather than easier.

In one focus group, one of the participants talked about her experience of **mental illness as a symptom of lupus.** This sparked a discussion between participants in the group as to what mental illness is. There were a variety of views. Two talked in terms of the medical model of illness that is to say as a chemical imbalance in the brain, which requires medication to restore the balance. A third talked about mental illness in terms of **emotional, social, and financial problems:**

*"Sometimes you get a number of problems, a number of urgent problems*

*...in that kind of situation I need someone to talk to more than anything else. You can take tablets but the tablets kind of just dampen you down so that you can't deal with any of the things that are causing the problems in the first place ... if you can have help early on that can actually get help each other express what the problems are, emotional thing that is tearing you to pieces whether it is social problems, money problems, relationship problems" (1A, Female, Service User).*

Two focus group participants talked **about the role of medical staff**, in particular, but also from staff working in voluntary organisations, **in helping them to determine their state of mental health**.

*"Yeah and the doctors will tell you straight out if he thinks you're not well or if he thinks you do need some kind of medication, you know?" (6E, Male, Service User)*

*"Them here [at the NGO] will tell you plain out and straight away like that" (6D, Female, Service User).*

*Interviewer: And how do you feel when the doctor says that? Is it ok?*

*"Sometime you wonder why the doctor say that, you know what I mean? What does he see in you personally that he thinks that you do need medication or you might be sick, that you do need some kind of medication, things like that. It makes you think straightaway and wonder straightaway why he would want to say that to you. But that's it; he's the doctor, innit? So if he thinks something is wrong he's gonna tell straight out and there and then" (6D, Female, Service User).*

### **African service users**

For African Service Users, from both Congo and Somalia, accounts centred on **the circumstances that had led them to come to England**. In addition to the trauma that they may have suffered and/or witnessed before coming to England, there were also issues related to **the experiences of being an asylum seeker in England**.

Two reported that they were suffering from depression and one said that she felt suicidal. One person commented that it was very difficult to have a good life in England as an asylum seeker because of the constraints on being able to work and living in poverty. For example, one focus group participant was very unhappy in England. She reported that she had been arrested in Africa and had come to England, where she was struggling to cope with the loss of a baby, conceived after being raped, in an asylum seekers' centre in England. She was in physical and mental pain following a caesarean section. She was also struggling to cope with physical survival. Her housing support had been withdrawn; she was living on food vouchers, which could not be used to purchase the food that she was used to eating in her own country and she was

extremely depressed:

*"They've asked her to leave the house and she is feeling very depressed and she's feeling that with ... mental health except to kill herself. ... Before, she was ok, fine, happy, but since she was arrested and arrived here it goes from bad to worse ... When she came here it was to find help. But when she was here she had been raped, it's how she become pregnant. .... could have had at least her baby, but the baby died. She said her life ... She doesn't sleep and all look bad to her and her housing provider they are now after her cos they ask her to leave the house and give her nowhere to go" (4C, Female, Service User).*

A second focus group participant from the Congo talked about having previously been happy in Congo, but then having to flee to England. She thought she would find peace in England. However, although she had received some counselling, she was still experiencing **difficulties with memories of traumatic experiences**.

Similar themes arose from a focus group with Somali young people. One person described himself as having mental illness. He talked about his experiences in Somalia, seeing his family murdered - *"I have mental health problems. Because in 1991 I saw my mother and sister killed in front of me, I had their blood on my face"* (9C, Male, Service User) - about coming to England, leaving family members, including his children, behind, and not knowing if they were dead or alive. Having been refused refugee status, he was now homeless and unable to access any support. NASS had told him that if he agreed to go back to Somalia they would support him but going back for him meant death.

*"...then I come here, I have more problems than in Somalia. My previous problems compare. The weather here is very cool when sometime I am sleeping outside, sometime in Mosque. All this help me remember my mother and father in Somalia. I am here no living myself. It is very hard. When I am walking around the city, I am just talking myself. ... Sometime I think it's better to die than live in this situation. Its 15 years of it" (9C, Male, Service User).*

*"For him, coming abroad on top of everything else has given him more problems" (9A, Male, Other).*

*"NASS says if I agree to go home to Somalia, we'll support you, but if I go back I'll be killed because of the tribal oppressors. The refugee council say that this decision is by the government so they can't do anything. I have all the letters that show I'm not well" (9C, Male, Service User).*

This man was struggling to cope with the processes related to seeking asylum, day-to-day survival and the lack of support and willingness to accept that he was mentally ill, all of which were making him feel suicidal. This was

on top of the trauma he experienced in Somalia. He had tried to get help, but had been told there was nothing anyone could do to help him, because of his immigration status.

Two other focus group participants also had direct experience of the **violence in Somalia**. They did not see themselves as having mental illness and felt that **surviving trauma and maintaining mental health is dependent on having resources such as the support of family and friends, religion or a strong will:**

*"When I was six or seven, I witnessed the war in Somalia. As soon as you step over your door, you used to see dead people. As a child, it didn't affect me like the adults. I used to collect the shells and sell them for money. It never hurt at that time but after adolescence, it comes back to you. It depends on how strong you are. Weak-minded people get punished. [My mental health, my peace of mind] ... is the only thing I have. You think with your mind, that's how we've been brought up. Some people, because of their life situation and problems [have bad mental health]. My mental health status is good. Only yourself can make yourself mad. I've been living on my own since I was 14 years old. That makes you stronger or [brings you] down. I used to live in Bolton. It was the first place I came to in England. I never knew the culture in England. I came from abroad. It was very stressful. I was also finding it hard to mix with people. It was quite stressful. I had relationships problems. I had to keep strong, do activities. I believe that if you are too stressed, you just jump up and down in your room and that will help" (9A, Male, Other).*

Similar themes arose in the focus group for Somali Women. All the women in the focus group commented that they experienced **flashbacks relating to the war in Somalia**; several knew women who had been raped, and had lost friends in the war; one had been shot in the back and had seen "a dead person".

For others, the focus was on **depression and stress related to the experience of being a refugee** including the loss of the home and family that has been left behind and feelings of not belonging and not being welcome in England:

*"The problem is for the stress. If you are lonely you have depress [depression] and stress. I came from Somalia because of the war. When I come hear and my family were there and there was fighting there, you feel crying inside, sadness, you remember where you used to be and you can't be with family, you are here. ...When I was in Somalia, I had a lot of friends. Especially on Friday, I go to the beach or eat fruits. When I came here, I look like person who never eat one banana, because I was too lonely. I don't know how to work this country" (10C, Female, Service User).*

As a group, the women recounted the impact of an incident on this woman. She had been shopping for fruit and the market trader asked her if she had

ever eaten an apple before. The incident and the subsequent reaction of the market trader made her feel angry and misunderstood.

*"I was thinking, we came from the Horn of Africa, we have fruit, but can't say because no one believe me. ... [The market trader said] the country you was crying to come [to], why you not happy, You're in England now? .... I start arguing with him say how do you know, are you on inside of my mind? He was telling me I was a refugee because I was crying to come to Europe" (10C, Female, Service User).*

*"The day he said it, she kept talking about it, repeating it." (10B, Female, Service User).*

*"There's many ways to feel stress" (10E, Female, Interpreter).*

When asked how the word "a refugee" makes you feel, one woman responded:

*"Lots of things. It remind me I'm lonely here, I don't have rights, reminds me what I lost, what I used to be and what they think I am at the moment. They have the same name for refugee/asylum seeker. They ask you if you are citizen, refugee, asylum seeker" (10C, Female, Service User).*

This woman's story illustrates how her daily experience is a constant reminder of what she has lost and that she does not belong in England.

A further theme highlighted by Somali focus group participants was **the effect of drugs on mental health**. Somali women believed that the use of khat and illegal drugs causes mental illness.

*"The khat makes people mentally ill" (10A, Female, Service User).*

They felt that it is difficult to stop their children from using drugs in the UK:

*"Boys come here, use different drugs. In Africa, we respect our mothers, here the kids won't listen to the parent, and the parents know that. In our religion, it is a bad thing to take drugs. A girl I know, someone gave her son drugs. He was perfect, fine before, now he's mad, talking, saying when are people coming" (10E, Female, Interpreter).*

*"That's what they use, all the children [from Somalia] in the UK. The parent can't be there all the time when he's 17, he's free. If God help you to be straight, they'll be straight" (10B, Female, Service User).*

*"When I came here, I was teenage. If you don't use drug, they call you geek, you African, try it. If your mind not clever, they make you take drugs" (10E, Female, Interpreter).*

They also commented that combining khat and medication for mental illness makes people worse: *"there's many mad guys [from] Somalia eat khat and take medication [for mental illness] but they are not working together and*

*they don't sleep at night"* (10C, Female, Service User).

### **African carers**

Themes arising from African Carers' discussions about mental illness include the following.

Participants emphasised **the resources that help to maintain mental health** including inner strength. One carer from the Congo said that she had had similar experiences to her friends, but believed that she had to hold herself together, for the benefit of others. Her account suggests a belief that **people can suffer mental illness in response to extreme stress and trauma and those internal and external resources help to keep them mentally well**. These resources were similar to those mentioned by young Somali people – **support from friends, spiritual beliefs, and resilience**. However, even with these resources, she was still exhibiting signs of post-traumatic stress disorder, such as flashbacks.

Linked to this were comments from Somali focus groups about the effect of **not having resources such as family support. Family breakdown** was a further issue affecting mental health. Material deprivation and unemployment were causing stress, which was impacting on the whole family. For example, reliance on benefits meant that men were not fulfilling the traditional role of providing for the family. Furthermore, any spare cash was sent to family in Somalia:

*"I personally believe all this mental health thing starts from material deprivation. Kids grow up in a house with overcrowding, there are no computers, no place to do their homework, they grow up in poverty. This is basically how it is in Somali communities"* (9D, Female, Other).

*"Within Somali community there is overcrowding in the house. People are sending money home so the immediate priority may be the family at home who are dodging bullets, not their kid"* (9E, Male, Other).

*"And this child may do poor in education. They won't achieve"* (9D, Female, Other).

The resources that existed for Somali people before coming to live in England such as having family and social support close by were being eroded and this in turn was eroding their mental resilience. One person summed up the link between the erosion of resources such as family and social support systems and mental illness as follows:

*"Here [in Sparkbrook] every few months you see a new mad person walking down the street. The reason why he is mad is family break-up. He's missing the emotional support. If we had an organisation that could help them, we could help. If you're down emotionally, you are mentally*

*down; it's all connected" (9A, Male, Other).*

*"In our religion it says you cannot put yourself above anyone, you have to be equal, if someone is felt to be outcast, they are lower than someone else, that gives problem" (9B, Male, Other).*

There were concerns that **western medicine does not recognise different causes of mental illness and is therefore not equipped to diagnose or treat some kinds of mental illness** such as those caused by demonic possession or magic, which requires a spiritual cure. Participants in a focus group for Somali Sheikhs (**faith-based community leaders**) commented that there is no exact translation for the term mental health and tried to map aspects of mental illness. One person stressed that there is not one single cause of mental illness, nor one single way of experiencing this. Their accounts identify **ways of experiencing mental illness such as madness and paranoia, which were emphasised as being very different from each other. The accounts also distinguished between different causes such as possession by an entity or "djinn", magic or curses, extreme stress and despair.**

The concept of "dismoral" or **despair: when expectations are not fulfilled.**

*[To sheikhs] "As you may be aware we have a lot of people with [Somali word – albijab]. Can you explain that?" (8F, Male, Co-Researcher).*

*"It is a kind of mental failure. Its literal meaning is heart failure and in this meaning the heart is [the mind]" (8C, Male, Other).*

*"What the sheikh said, I agree. It is – we call it – dismoral, distress" (8B, Male, Other).*

When asked whether "dismoral" was similar to despair, participants responded as follows:

*"Yes, despair, dismoral – when you were expecting something and you couldn't find it, every day" (8D, Male, Other).*

*"Dismoral, distress, and despair are the same, when people come here with no status and no way out, no solution" (8B, Male, Other).*

*"Most of dismoral is caused by something you expect but couldn't find – you need what you need. With the civil war in Somalia, so many people were frustrated with one reconciliation after another [failing] and they were in despair" (8D, Male, Other).*

*"Some people come here to seek asylum. When they don't get asylum, this damages them, they are not entitled to a job, a house, university – all this causes problem. This all comes under mental health" (8B, Male, Other).*

With all these categories, one Sheikh concluded that **making a diagnosis requires specific expertise.** However, not all parties are sufficiently equipped

to make this diagnosis. For example, the medical profession do not have a sufficient understanding of possession, nor is this included as part of their training.

*"When you go to hospital and you are a doctor, you can't understand whether I have a djin. I agree [with what he says about] the case of modern technology – there's a lack of technology but at the same time I disagree with [what he says about] doctors who give people tablets. Somali doctors specialise in the case of magic. Other people who know about the tradition of magic, he knows how to, he did his own traditional medicine so can't ignore these things. There a lot of lack of medical culture. In European countries they don't know about djin and evil eye, they don't know they need to recite the Koran" (8B, Male, Other).*

There was general agreement among Sheikhs that for problems caused by djin, magic or curses, that the cure is spiritual, not medical.

*"If a person is paranoid he can be treated with tablets but if a man is magicked [or cursed] he needs to be treated differently" (8A, Male, Other).*

*"But magic and evil eye may affect [a person] in the mind or maybe not, it may affect them physically. So, every mad person cannot be evil eye. The cure is spiritual" (8D, Male, Other).*

However, Somali Sheikhs themselves had no access within the UK to specialist exorcists. There was concern that difficulties with diagnosis and the lack of availability of appropriate experts, whether these were experts from Somalia or medically trained doctors with expertise in djin were leading to experimentation. Sometimes experimentation, for example, treating someone with mental illness with spiritual help and someone with djin with medication was successful. Generally, there were different views among Sheikhs on whether such experimentation was desirable. One Sheikh believed that **different treatment options should not be combined**. Another felt that spiritual approaches were always appropriate but that there were also occasions when medical care was essential:

*"In every respect, we advise to recite the Koran in every disease, that will help everything. So this is giving us, we Muslim, to trust. This is the way of us. But at the same time, if someone has blood coming out, he needs to stop the blood and recite the Koran" (8D, Male, Other).*

There was **stigma related to mental illness**. Focus group participants were also asked about stigma related to mental illness within the Somali community. One Sheikh talked about people approaching him about mental illness in secret. Others talked about the reasons for stigma being to do with a lack of status or shame connected with mental illness; to do with fear of being permanently labelled as mentally ill; and about the impact of mental illness on marriage prospects. Examples were offered of people trying to hide

mental illness or explain it in more favourable terms, such as about people becoming mad through studying too hard.

There were issues about **the psychological impact of trying to integrate within the wider culture**. Participants in a focus group for Somali young people echoed some of the comments made by participants in other focus groups. Generally, however there was less emphasis on demonic possession; and more on the **mental impact of trying to integrate within the wider culture**. There was a feeling that this was impacting on young women (more than on young men) who were struggling to balance traditional Somali values with the desire to fit in with Western culture and

*"they end up in dilemmas and may do things that are worse for them (9D, Female Other).*

The struggle to balance different cultures was leaving them in a position of not being able to get help from anywhere:

*"Somali girls go to the doctor, they don't get proper information, they have an abortion, and they can't tell their family. They are using drugs. That is not highlighted at all" (9E, Male, Other).*

**Drug abuse** was highlighted as a strategy that some people adopt to try to cope with the inner conflict they are experiencing. One person commented that counselling was not part of Somali culture but chewing khat was something people saw as an aspect of their culture, something that their forefathers did. However, the psychological effects of khat were further compounding their difficulties:

*"Somali people, youngsters, have suffered mental health in the UK. In the UK, Somali people immigrate, a lot are from Holland or Sweden where they had a social life, they used to go to schools, they knew a way of life there, then they come here. Some may be living on their own. Some chew khat; they see it as their cultural imports from Somalia and still hold on to it. They start chewing" (9E, Male, Other).*

In addition, some people were reported to be combining chewing khat with Diazepam. On its own, the psychological effects of khat are damaging. They are likened to the effects of cocaine: a stimulant, euphoric effect. There are further issues for people who become addicted and spend all their money on khat. These effects are worsened when khat is combined with Diazepam. Focus group participants reported that they have been campaigning to de-legalise khat in England.

*"They say it is part of their culture [but when they are addicted] it is responsible for family breakdown, they spend all their money on khat, they chew, chew, and get kicked out" (9E, Male, Other).*

*"Our forefathers used to chew it and introduced it to us but the way they used it was different. Some people are addicted, they do it all day. It was illegal in Somalia, when there was a government" (9A, Male, Other).*

One person described his cousin's experience both in terms of the **stress of cultural integration and fighting demons**. He commented that his cousin had only been in the UK for one year and had not settled. He ended up in prison and came out on medication and with a diagnosis of mental illness:

*"My cousin was diagnosed with mental health – it means a person's personality changes. The person you knew and grew up with change, the way he speaks to you, talks about normal life, he's not himself, he's fighting demons, there are two people in the same mind. ....When he came out, I was happy for him, to see him, but he started discussing things beyond him – wars in the Middle East, things on the news, when he should have been living his own life. And mental health can make you become more aggressive" (9E, Male, Other).*

### **African Caribbean Carers**

African-Caribbean carers' accounts of mental illness varied. For some, there was a **triggering trauma and an inappropriate treatment response**. One particularly poignant situation related to one carer's daughter who had experienced racism and abuse but instead of being given any emotional and psychological support such as counselling, was simply put on medication and into the mental health system. She has never come out.

*"My daughter has been ill from when she was 17 and when she was in the Duke of Edinburgh scheme. They sent her to Aberdovey on an Outward Bound course. She was the youngest person there and the only black and they made her life hell. When she came back, I didn't recognise her. She said everyday they would harass her. If they went out for a walk they would leave her lagging behind and stop and wait for her, when she'd caught up, they'd go off, make a joke of it. She lost loads of weight. She wouldn't get out of bed. I talked to the doctor. He said come up and gave her tablets. I didn't know what they were. He put her in X.... place, I didn't know I was putting her in the system. I asked what she did while she was there, she said drawing, she never had no counselling at all. To this day, she's still in the system. ...Then she got really ill. She was getting in fights. Then I went to Y....place and they gave me [another] prescription. She threw the tablets down the toilet. She seemed to get worse" (5D, Female, Carer).*

Another focus group participant talked about how her son had been worried about whether or not he was gay and that this was associated with behavioural problems, which eventually led to him entering the mental health system. She herself suffered from mental illness and was unable to cope or to provide the support he needed.

Like some of the Somali focus group participants, one carer saw her daughter's problems in terms of *"being weak willed"* (7A, Female, Carer).

*"I am not caring for my daughter now. She's in Z Centre. She became ill when she was 18. She was brilliant before. She went to university and she becomes ill. When she become ill, there was not much help about. She was taken in hospital. She's in and out at Z centre. Sometimes at A Centre, she'd be alright. Other times she'd just go funny. That's what I was made to understand. She goes out in the day and gets in with people with drugs, and medication and drugs don't agree. I don't know if anymore needs to be done. She needs willpower and she doesn't have it. I wonder about hypnotism and whether she could go back to her past at the time she became ill and remember what it was. I wonder if the medication has a side effect that throws her back into being weak willed. When she's on medication, she just tends to sleep and she's always drowsy. She's 35 now"* (7A, Female, Carer).

### 4.2.3 Experiences of using mental health services

Participants were asked about positive and negative experiences of using mental health services.

#### African Caribbean Service Users

When talking about **positive experiences of services**, the following services and aspects of services were highlighted:

Two participants talked in positive terms about the help they had received from **statutory services** such as W House, T House and N Hospital.

*"I was [at W House] about three years, it helped in my recovery ... There's psychiatrists based on both sites, both campuses, and they used to help me through what I was going through in life at the time, helped me to get over it ... I appreciate what W and H House's have done for me in recovery"* (1C, Male, Service User).

Several participants highlighted **support from specific NGOs** and valued approaches which are seen as supportive and person-centred and which maintain people's independence. The advocacy role played by specific NGOs was highlighted. Being able to attend NGOs where participants can meet other people with mental illness helped them to feel less isolated; being supported, advised, encouraged and cared about was also important. One participant emphasised the important role of NGOs in helping them to cope with everyday activities. The participant talked about being mistrustful of the NGO at first, about being worried about being labelled *"as a person who can't cope, a person who has problems that can't deal with this, that and the other"* (1A, Female, Service User) even though she recognised that *"in reality that was my*

*situation*" (1A, Female, Service User). However the approach taken by the NGO which was about not about pushing but supporting and visiting her at home and helping her to deal with practical matters such as letters, but not taking away her independence; this helped her to gain trust and the NGO had been very supportive.

Three focus group participants singled out different members of staff at a specific NGO, commenting of one in particular, that his caring attitudes were very important to them. When asked what it was about his behaviour that they valued they made the following comments:

*"He's my friend, my number one friend ..."* (3C, Female, Service User).

*"Yeah he's good friend, a friend ... do you see why he's a good man? He takes you to the cafe, he helps you ... things like that. Seriously, ... he's a very nice man ... ah sure"* (3A, Male, Service User).

*"He talks to me. ...gives me confidence and so on"* (3C, Female, Service User).

*"That's true he makes you feel worthy"* (3A, Male, Service User).

In addition to advocacy, staff attitudes and encouragement, other aspects of support that were highlighted as being important were **financial advice and support; social activities** – three focus group participants talked about the role of their social worker in helping them to get out of the house and have a social life. Social activities were also provided by voluntary organisations – and **practical support**, such as the provision of food, shelter (in inpatient services) and re-housing within the community.

### African Service Users

Positive experiences of services and support highlighted by African Service Users include **support from faith** based groups (e.g. a Congolese Church) and spiritual beliefs and practices (e.g. prayer); **practical support** – housing, food; social support and socialising; support from **named mental health services** and medication.

Generally, Congolese service users did not provide detailed responses about the support they had received. When prompted, they **clearly valued the support** they had received both from family and friends and from mental health services. However, their day-to-day situations generally seemed very hopeless and as one person was reported as saying in an earlier section, it is fine when you are with friends in a supportive environment, but when you come back to your living accommodation, the memories are still there. Congolese service users talked about **medication as a positive** because it helped them sleep.

Somali women also emphasised medication as a positive aspect of the support

they received. However, they also expressed concerns about medication [outlined in subsequent sections].

### African carers

Only one African carer answered this question and her comments were **not positive**, focusing rather on the lack of understanding from the mental health services for the person she cares for and their inability to see what she can see: that her friend needs help.

### African Caribbean carers

African-Caribbean carers offered the following positive comments about their experience of mental health services and other sources of support, both for the person cared for and for themselves as carers:

At least four focus group participants talked about the support they received. This included examples of support from **mental health services and carers support staff**. Carers valued the offer of support even if they were not ready to take it up:

*"The doctor did say if I was finding it too hard, they could send someone to sit in with me. They offered. At some later date, I will take him up" (7D, Female, Carer).*

They valued having someone to think about their needs:

*"I care for my sister who was diagnosed with manic depression. They are introducing support workers for carers; I meet the worker every fortnight. They were really supportive. It was nice as well. Sometimes the family can be divided on my sister. Some say she knows what she's doing. Some should be more sympathetic. He got a carers weekend for me. It's good to have someone outside of the family" (7G, Female, Carer).*

At least two carers felt that the support provided was exemplary: *"There are lots of positives ... Going beyond caring, coming to my house" (7B, Female, Carer).*

*"Sometimes it comes down to your expectations. I was intrigued by someone talking about partnership. I look after my mum; I have done for 15 years, since I was a young man in shorts. My experience of partnership is positive. My mum's key worker is a CPN; I have her mobile phone and can call her 24 hours a day. I'm the only one here looking after a parent. I don't have any negative aspects towards it. ...My mum can tell the consultants everything they need to know and more. My mum's a chatterbox. She's had negative experiences, who doesn't, but it's mainly positive ... They've always been there for me. They have stage managed any times that she goes into hospital ... It's how many days she's going to*

*imprison herself, I shouldn't use that word, it's too strong. The doctors don't want to send for the police ... Having a named person, a named social worker, a named CPN. They respect mum. They see her every week. There are lots of positives" (7E, Male, Carer).*

All four carers were part of a carers group run by a statutory agency. During the focus group the member of staff supporting the group from the statutory team, did offer advice and support to carers on what to expect. It may be that having someone from a statutory team playing this role within the carers groups is essential to helping carers to access support. Also mentioned, but to a lesser extent, was the support provided by voluntary organisations to both the person cared for and the carer such as social and other activities, and being there in times of crisis.

Focus group participants were also asked about **any negative experiences of mental health services and support**. In talking about **less positive experiences of services**, African Caribbean service users highlighted a range of issues. These included **financial difficulties** experienced by service users generally (including costs to participants of taking part in social activities organised by NGOs) and concerns that there was insufficient funding for NGOs supporting people with mental health problems.

The **lack of continuity of care** was also an issue. This included not being able to see the same doctor and concerns about rumours about the closure of the Frantz Fanon Centre.

**The attitude of staff**, for example, in supported housing and in hospitals was an issue that included lack of care, lack of respect, and a perception that staff did not take sufficiently seriously; incidents that participants had found distressing. One participant had strong feelings about the **attitudes of staff working in supported housing**. He felt that staff had **insufficient compassion and respect for residents**, that they looked down on them, and that they didn't care. He also commented that the staff themselves were bringing their own problems into the work place and taking them out on residents. At least four participants offered examples of racism and discrimination. One commented that he had been discriminated and victimised by supported housing providers and had been unable to resolve the issues without the support of a NGO advocate. Another commented that her experience of services in Halesowen where she lived was different to her experience of support received from an NGO based in Birmingham. She commented that her CPN who visited her at home was

*"... racist ... very nosy ... her eyes will be wandering all over my paperwork on the floor; very nosy ..." (3C, Female, Service User).*

When asked whether there are any other things that her CPN does that are racist, the respondent said:

*"She'll say I can come off my tablets or injections; I can discuss it with a psychiatrist and so on" (3C, Female, Service User).*

Her comments appeared to indicate a conflict of interest in relation to **coming off injections** and **losing disability living allowance** rather than **discrimination and racism**. Nevertheless she felt and perceived that this suggestion was motivated by racism and may not have been made to a "deserving" person in that way.

Other experiences cited by the same respondent related to experiences in the B Hospital. The respondent talked about feeling uncomfortable in there and commented that there had been a tense atmosphere, and to cope with this she had tried to keep herself to herself and not mix with other service users. In response to a question from the interviewer about whether there had been any racism one of the male participants said that staff were not *"really nasty ... you can learn to live with that"* (3A Male Service User) but the female participant had a different experience and felt that this was to do with **being a black woman**. She also talked about racism in community care and an experience she described as degrading when she was given an injection by a male staff member who pulled her underwear right down to her ankles.

*"They treated me terrible, treated me terrible. I never want to see a nurse again, as long as I live" (3C, Female, Service User).*

Two focus group participants, when asked about examples of racism, said that people are beaten up in hospital by staff and patients.

A fifth participant from a different focus group felt that *"being black and being female, you know, I don't really stand a chance"* (6A, Female, Service User). She illustrated this by talking about her experiences of being put on the contraceptive pill, which had resulted in a blood clot. She was very angry about the way she had been treated:

*"But the thing is whilst I was in hospital the doctor; they put me on some contraceptive pills, right? And she never even asked, she never even tested my blood to see whether, if that medication she's given me is compatible with my system. So she gave me this pill and I'd be taking it and when I was discharged from hospital I got a blood clot. Yeah, I got a blood clot, in this leg, deep vein thrombosis and I mentioned it to the doctor, Dr M, but he said that you asked to be put on the pill. So it was my word against theirs so there's nothing I can do about it. I thought to myself even if I asked to be put on the pill they could've checked ... you know, at my age; cos I'm not a young woman anymore, I'm in my forties, at that age they should be more, you know, they could've checked, it could've killed me, the blood clot could've killed me" (6A, Female, Service User).*

As a black woman, she felt she also had no right of redress because:

*"... even if I do complain who will I complain to? It's like complaining to the government about the government ... I mean, how many black females are there in the government; do you know what I'm saying? So what I'm saying is even if I tried to voice my opinion I wouldn't stand a chance because I'd need a very, very, good lawyer to be on my side, so I thought, [to myself] just forget about it" (6A, Female, Service User).*

For this service user, the issue about representation of black people was more than simply having black staff in hospitals, or in the staff team because some of the black members of staff were also perceived not to care:

*"I think a lot of them had burned out, to be quite honest. They're weren't doing the job for compassion or passion or whatever they were just doing it because at the end of the day they're paying their mortgages and that's it; you know that's all they were bothered about. The amount of times I'd been in there and people had attacked me and whatever and you know the staff really, what did they do? They were doing nothing very much to help" (6A, Female, Service User).*

At least six focus group participants talked about **medication**. One person commented that it was only when she went to the Frantz Fanon Centre that she was made aware of alternatives to medication such as psychotherapy. She would have preferred to have been offered psychotherapy, as she felt that her problems were related to being adopted.

Another commented that she had been offered no counselling, even though she felt that her mental health problems were related to losing both of her parents within a year when she was 20 years old. However two different participants both talked positively about medication and how it had helped to relax them or stop them from getting into trouble. A further participant was more ambivalent about medication saying that on the one hand it had helped him to cope with anxiety and depression but that it was also making him feel more aggressive.

Two people talked about the impact of medication on getting on with their lives. One woman stopped taking her medication because she felt it interfered with her ability to do her job as a bus driver. Another woman talked about the negative impact of medication on her concentration and her ability to complete an Access to Education course.

One participant had lupus and commented that the mental health services at T House had **insufficient understanding of lupus** and as a result she had stopped attending and had gone to her GP, who was better equipped to help her. It had taken her a considerable amount of time to be diagnosed correctly and to get the correct treatment.

## **African Service Users**

African service users also highlighted issues about **continuity of care**, meaning that one asylum seeker had to talk about traumatic experiences over and over again, as she was seen by different staff. Her experience, which included being raped and losing a baby, was particularly distressing and difficult to talk about. When she was unable to talk about it anymore, it was viewed as uncooperative.

When talking about the experiences of people within the Somali community, participants in the focus group for Somali young people talked about the lack of support or recognition of **the difficulties of coming to live in England**, faced by people from other cultures. One person talked about coming to England and ending up in Bolton and how stressful it was to mix with people because he did not understand the culture in England. He coped with this by keeping active. Another focus group participant commented that his cousin had not had the same resources and ended up in prison within a year of coming to England.

**Specific issues faced by asylum seekers included concerns about insecurity of housing provision and having to use vouchers to buy food.** The voucher scheme was an issue for two focus group participants. Asylum seekers are given vouchers, rather than money, to buy food which can only be used in one shop where they have little choice and are unable to purchase foods that they would usually eat. The amount of money available on the voucher scheme is also limited.

Two people talked about issues relating to housing provision. One, whose application for asylum was rejected, had become homeless and isolated as a result. He was sleeping rough or in the Mosque and being in this situation and not being able to get any support made him reflect more on his situation and think about traumatic experiences.

Although he had been given medication and counselling, which had helped him to cope; he believed that being able to cope had resulted in him being kicked out of his accommodation.

Somali women expressed **concerns relating to medication** for mental illness. They believed that the medication provided is too strong for people from Somalia who are not used to taking anything stronger than Diazepam. The problems are believed to be exacerbated by people taking medication and khat at the same time. Some service users are reported to not be taking their medication, due to the side effects of combining this with khat. Somali women felt strongly that people with mental illness needed to be supervised to ensure that they take their drugs and are admitted as inpatients.

*"The khat is more important for them than the medication. Sometimes they don't take [their medication because of khat]. Is good idea to suggest*

*that if a person had a mental problem and if the doctor sees this person is not OK, they need to keep them somewhere because they need to take their medication, they can't look after themselves. Her [my] sister's son, her [my] nephew, he call one night and said auntie I want to come to see [you]. ... He said he needed money and I gave him £20 and he buy khat. When he went she checked his bag and asked why he didn't take the medication. He said if I take the medication I go mad, want to kill somebody, so I don't take it and now I'm normal. When she saw he start eating khat, she take it away, beg him to take his medication, when he took it he slept 5 days continually without doing anything. He's her sister's only child. She try to give him medication, he say no, no, no. She would ask the Government to send him back, when he went to Somalia, he was okay" (10A, Female, Service User).*

Somali women tended to access GPs and hospitals for care, rather than specialist mental health services, and reported experiencing **poor standards of care and racist attitudes from GP and hospital staff**.

*"Because we are having problems with a GP. He doesn't listen properly, he writes a medication without checking what's wrong ...When you go to the GP, you say you sick, not feeling OK, they say, don't think about it" (10D, Female, Service User).*

*"Most Somali people have TBs [Tuberculosis]. When they go to the GP they explain they have a high fever and are given paracetamol without send to hospital, they have to keep coming back" (10D, Female, Service User).*

One person talked about how her right to receive care had been questioned by staff in hospital on the grounds of her immigration status. This woman had been shot in the back and had had an operation to remove the bullet. In winter she has problems with breathing, relating to this wound.

When she went to hospital, she was vomiting and having trouble breathing and commented that one staff member *"started talking about ... saying they're looking for documents, then another doctor say that's not your business, you have to treat"* (10C, Female, Service User). When the interviewer suggested that she should make a complaint, comments by four of the women suggested that racism was part of their everyday experience – both from service providers and more widely – and that this had left them feeling that there was little to be done. For example two women commented that their GPs had asked her what they were doing in this country and one had said *"Why are all you Somalians in the UK, why don't you go?"* (10C, Female, Service User). Another commented that her GP had been rude to her in front of other patients:

*"My last born son was normal. When he was a few months he gained weight. I went to the GP. The doctor came out in front of all the people and*

*said he's overweight, sickness, no good, you have 5 children, you don't have time to hold him, so you put the bottle in his mouth, that's why he's fat" (10A, Female, Service User).*

### **African carers**

Issues highlighted by African carers included the lack of support for carers themselves, when they were tired and needed help. Linked to this, one carer commented that mental health services had not recognised that the person she cared for was mentally ill, even though to her it was obvious. Or, where they did recognise it, constraints, within UK law, meant that they were unable to help, because of the immigration status of the person cared for.

*"My point of view is they don't understand 4C because I am there every day I can see, all this year I've been with her since last year. So I am going there to explain because sometimes 4C don't talk and I know what 4C, she is suffering, but they said they don't find anything bad about 4C; but I know I can't leave 4C alone. They have to do something for her. Sometimes when they said bad things, I can't say that to 4C because I know what will happen next" (4B, Female, Carer).*

When questioned whether health professionals accepted the carer's observation, as she lives with and supports the service user, her response was:

*"Some of them do accept, do understand but sometimes they said that is the law; or their boss or their responsible said there is nothing wrong. For example when 4C take off all her clothes and they can see everything but they say there is nothing wrong with 4C so I don't understand that" (4B, Female, Carer).*

For carers from the Somali focus groups, there was **a belief that the Somali community is being overlooked**, with people being left to support themselves, without resources and without understanding.

One person commented that only six out of ten people within the community make it but no organisation is taking responsibility for the other four people with mental health problems and families are trying to deal with the problems themselves via religious support or if they can afford it, they send the person back to Somalia. Another commented that when Somali families can't cope with a person with mental illness, they call the police but the *"police don't know how to deal with it so they go to mental health and then they gets in prison"* (9E, Male, Other).

*"We don't ask ourselves why they've gone mad. There is no intelligence [intelligent] conversation between the community and mental health services. Every individual family solve its own problems. I seen one place*

*in Alum Rock, a community centre where you can get lunch – it's a Day Centre for Bangladeshis. Its not being racist but all the other communities have organisations that do something, provide shelter etc, rather than just handing them over to mental health which has only one solution – pills and injections ... I've visited Winson Green prison. There are Somali men there with mental illness – the guard don't care, the people who run the prison don't care. They say they have problems getting translated. We are being overlooked. There's too much overlooking, a lack of opportunity" (9A, Male, Other).*

### **African Caribbean carers**

Aspects highlighted by African-Caribbean carers in relation to negative experiences of mental health services include **feelings of guilt and inadequacy among carers, some of which are exacerbated by the way that mental health services operate**. One carer talked about how she had gone to the GP for help, after her 17 year old daughter became ill following harassment and abuse on an outward bound course. In telling her story, it was clear that she had been expecting counselling; instead her daughter was put into the mental health system. She only found out by chance at a later stage that an alternative approach could have been taken. This was when she had been back to the practice and had seen a different doctor there who had asked about her daughter. She commented that when she had told this doctor what had happened, the doctor had been angry and had said that her daughter should have been given counselling.

Another carer, herself suffering from poor physical and mental health, simply did not feel able to cope with her son's behaviour, and ended up telling him to leave the house. She talked about feeling guilty for not understanding that his problems were to do with mental illness. She also talked about having help from mental health services in coping with her son. However on one occasion, she had called for support and had been told that her son had to be admitted to hospital and that she needed to sign papers to allow this to happen. However she wasn't told that the police would be called and the way in which they responded felt inappropriate to her, left her feeling disempowered and exacerbated existing feelings of guilt.

*"He's not a criminal at the end of the day and the way they handled him when they were taking him out, you know, his hands up his back and all that, I says hold on go easy on him, he's not a criminal, at the end of the day he's sick and they told me to get inside cos I was making the situation worse, you know? And all I could hear was him calling me, you know, 'Mum! Mum!' you know and that really caught me up cos I couldn't do nothing, you know, and I just broke down and cried, just broke down and cried, you know? ... afterwards ... I spoke to his support worker and I spoke to my friend, yeah. And they said I hadn't done anything wrong, you know,*

*cos I kept saying I feel guilty cos I put him into hospital you know and they said I hadn't done anything wrong, you know? It's for the best, you know. .... I mean it's the way they just come in and take over, you know? They didn't explain what was, they'd just gone into the bedroom and they talked to him and it was like I wasn't in the house you know? That really, I felt out of place cos I didn't feel like it was my house, you know what I mean? All of these people coming from nowhere, they seemed to take over the house and I was thinking do I, is this my house?! ... I can understand that they had to focus on [my son] or they could at least at the same time explain to me what was going on. All they told me was that they need to get him into hospital and they were going to get someone else to assess him but they didn't tell me the police were coming and all them things, you know?" (6B, Female, Service User and Carer).*

Other carers also commented negatively on the way that **mental health services are perceived to criminalise black people** offering examples to illustrate this. One talked about how the police had tried to handcuff her daughter; another talked about a neighbour who had been dragged out of the bath with no clothes on.

A further issue highlighted by African Caribbean carers was that **support from mental health services often breaks down in a crisis**. At least two carers from different focus groups talked about difficulties getting help from mental health services in a crisis, particularly out of hours, weekends and holidays.

At least two carers felt that the level of care for the person cared for was inadequate. One carer felt that the staff were very lazy and were poor at addressing cultural needs. Two carers were concerned about the poor physical state in which their children were living and the lack of appropriate activities for them to do.

At least three carers from different focus group talked in terms of black people being used as guinea pigs in terms of treatment with **medication**:

*"He reacts badly to all medication. He's been a real guinea pig – would they have experimented on him so much if he wasn't black? ... If they're finding that none of the medication is helping, surely they could try other therapies but they're always saying: it's the cost, the cost" (5C, Female, Carer).*

In addition, several carers talked directly about their own concerns about side effects of medication and several reported that the person they cared for had voiced concerns about taking medication.

At least two carers indicated that they were themselves suffering from poor health and that they were receiving little or no support for the impact of mental illness on them as carers

*"When he became ill, there was no help, no social worker, there wasn't*

*anything to back you up" (7A, Female, Carer).*

*"It's killing me. I'm on sleeping tablets and anti-depressants. He's not my only child. I've got five children and my whole life seems to revolve around him. I'm hiding from him today. The only benefits I can get from him being in hospital, if you can call it a reward, is I don't have to worry about him wandering the streets" (5C, Female, Carer).*

#### 4.2.4 The accessibility and responsiveness of services to service users and carers

This section focuses on particular issues and any positive examples relating to how accessible and responsive services are to service users and carers.

##### African Caribbean service users

There were different views on how easy it was for service users to get their needs met. Two people commented that it was difficult to know where to go for **advice on a mental health problem**. Another commented that the advocacy and support provided by a NGO made it very easy to get help and advice from the doctor.

Three focus group participants commented that **to access services it was increasingly necessary to have a referral** rather than just drop in and this was the case for NGOs as well as statutory organisations. One person commented that there is limited flexibility in appointment times and it was difficult to get an appointment when it was needed, as opposed to when a doctor thinks it is necessary.

Three focus group participants talked about **the extent to which the police were responsive to their needs**. One person talked about her experiences of being put in a police cell describing it as "terrible" and commenting that the police had no understanding that she was mentally ill. Two others commented that they had found the police to be quite helpful. One talked about having *"[I] burnt me house down and they come in and helped me out of that situation"* (2C, Male Service User). Another talked about being treated well by the police:

*"Yeah, yeah. I've had dealings with the police. When me came over from Jamaica in 1963 ..... me stab a lady .... they treat me good, yeah, they treat me good" (2D, Male, Service User).*

##### African Service Users

The main barrier to accessing services highlighted by service users is **the lack of interpreters or the lack of willingness of GPs to use interpreters**. One service user from the Congo identified language as a barrier to accessing services via the GP. This service user tended to take her carer with her to

interpret for her, but reported that she had asked for an interpreter but this was refused. A Somali service user *had* been referred to mental health services by the GP and was able to be seen at the surgery by mental health staff, but he had also experienced the lack of interpreters as a barrier to access. He was also referred to a counselling group provided by the Refugee Council although this had now been closed down. The main comment about the responsiveness of services for Somali women related to the **dismissive attitudes of GPs**:

*"When you go to the GP, you say you sick, not feeling OK, they say, don't think about it" (10D, Female, Service User).*

### **African carers**

The main issue highlighted by African carers from Somali focus groups was a perception that **racism is a significant barrier for the Somali community**. Different people within the focus group emphasised different things. In one group there was a feeling by at least one participant that racism was a big subject and that it could not be covered in sufficient detail in one session. At least three focus group participants from different focus groups commented that there are targeted services for other communities but not for the Somali community and that targeted services are needed. Also mentioned was the perceived failure of services to live up to expectations.

*"When Somalians came to this country, they feel racism – they came because they thought they would have opportunity – but there is not enough budget. All of these things need to be tackled. Otherwise we can see our adolescents, teenagers; they don't have what they expected. There's other communities who want to dominate the budget the Government has, like Yemenis, Asians, even the black Caribbean's because if you say black African, we are differences [different]. Even you [to interviewer] we want you to say Somalians, because we are Somalis' [rather than African] ... The racism and discrimination is of a kind that causes mental health and you see other people dominating and taking part of you" (8B, Male, Other).*

Several participants in the focus group for Somali young people talked about the Somali community being overlooked. There were suggestions as to what was needed to address these experiences. At least two participants from two of the Somali focus groups commented that Somali people need more information about existing service provision. Young people felt strongly that Somali people will not access services that are not specifically targeted for Somali people. They were concerned that the research should highlight this need. Somali Sheikhs also felt that there was a need for a centre for Somali people.

The interpreter and co-researcher wanted the research to highlight that there

is a need for Somali organisations, but accepted that their role might need to be to signpost to existing agencies. Faith-based community leaders felt that culturally appropriate health education was essential for bringing about further engagement.

Faith based community leaders and young people also talked about **Somalis' experience of coming to live in the UK**. There was a view that there was something about being in the UK and having to cope with aspects of the culture here that causes mental health problems which are not experienced in Somalia. Specific aspects of the experience include frustration, for example, that expectations are not being met; loneliness and isolation; and having to cope with paying the wide range of different bills.

The case for targeted services was made by young Somali people in relation to the needs of women and girls, some of whom had experienced rape and trauma; others who were struggling to manage the desire to fit in with Western culture and cope with the traditional views of their parents. As a result they were getting into trouble, using drugs, getting pregnant and having abortions and having to cope with all these things on their own because they are unable to talk to their families. At least two interviewees suggested that there is a need for confidential advice centres. Some Somali young women were reported to be aware of services such as Brook Advisory Centres but a sense of shame hindered them from using these services.

*"They feel ashamed, they see themselves as Muslims and they are doing wrong stuff. In our community there is the Muslim issue, the shame [you feel from the] Muslim community – getting pregnant outside of marriage is shameful. And we Somalis, we do like to talk, so [you worry that people will find out]. If you go to Brook [Advisory Centre], you don't feel comfortable because it is not correct" (9D, Female, Other).*

In response to whether she feels judged by the Brook Advisory Centre, the respondent said:

*"By the [Somali] community. Also we find it hard to relate to any community outside the Somali community. These people are newcomers. The trust is missing for any other community – it needs to be our own culture. Afro-Caribbean's, Indians have been here for a long time. They've integrated. We have not" (9A, Male, Other).*

When prompted about whether they feel they are already facing too many obstacles, with all the things they have to cope with and manage, the participants responded:

*"Yes, to have to face coping with other cultures etc. But we will get there in the future" (9A, Male, Other).*

*"There are so many Somali communities. They have no idea how these*

*services are provided. So they need help to access services – signposting by Somali advice centres” (9H, Male, Interpreter).*

### **African Caribbean carers**

African-Caribbean carers highlighted a number of issues. Whilst some carers experienced services as supportive and responsive, it was clear that when there was a crisis and especially when this was out of hours, the service could break down. In addition one carer commented that attitudes towards carers were not always helpful: *“They think because you care for someone who’s mentally ill, you are too” (5C, Female, Carer).*

However, at least three carers talked about **feeling supported as a carer** by NGOs and the support they received from statutory services which were specifically designed to support them. For one, it was the sense of having people to care about him and help him to cope:

*“I understand more yeah, I understand more of how the illness comes along and things like that. The things I want to do is look about the medications and things like that and how the side effects and things like that and how can you get help when you’ve got a loved one who’s sick in hospital; can it be, could it be people that can, could come out, and help and to talk and support me in that way, in that field, cos, first time I seen 6B got ill to me it was like a gob-smack, it was like I didn’t know what to do, I was walking round the house like a zombie basically. At the time I could have had somebody who experienced in that field come in and just talk to me about it and if they been in situation with somebody that they know and that, just to encourage me like, sometimes people do encourage me. Cos when she was sick I came here all the time, the centre cos I’m a member here and the staff talked to me and they said you know cheer up, she’ll be back, she’ll be back home and things like that. You know, [the centre manager] she’s been good to me, cos she been ringing me up, when 6B was sick she rang me up a couple of times to see if I was alright and things like that, yeah. Everybody was running round; it’s like a family here, like a family unit here, you know, you can feel that love and that support with people, that supporting. It’s when you don’t have that support and that networking, it’s just like you’re going downhill, it’s like you don’t know what to do about it basically and you just feel like you’re going to collapse and breakdown, you feel like breaking down in front of that person and you don’t want to do that all the time. Yeah but basically I’m alright! I’m still surviving, yeah I’m still surviving!” (6C, Male, Carer).*

### **4.2.5 Culturally-appropriate services**

Focus group participants were asked whether or not they felt that services were culturally appropriate. Where necessary, specific examples were offered

as prompts to illustrate ideas about what culturally appropriate services might look like.

### **African Caribbean service users**

Focus group participants expressed a wide range of views about what culturally appropriate mental health services would look like:

Two people talked about the things that were important to them, culturally:

*"Well for me, culturally, I think if I'm able to have a laugh and a joke and speak a bit of patois to my friends, whatever, that's alright. I do try to read books and things but my concentration at the moment's not too jolly so I can't really get into books at the moment. I do like black issues and you know things concerning black people" (6A, Female, Service User).*

*"I read books most of the time, Afro-Caribbean, I read a lot of books, I read a lot of magazines, what's happening in the world you know, black people, Africa and ... sometimes a paper to keep up to date with what's happening" (6E, Male, Service User).*

Other issues highlighted included:

**Not making assumptions about the ways in which people express themselves.** One focus group participant commented that she had heard other service users say that when black people with mental health problems express themselves, this is misinterpreted as aggression. However, she had no direct personal experience of this.

**The need for black male and female psychiatrists and therapists.** At least four focus group participants talked about the importance of having psychiatrists and therapists who are African or African-Caribbean. One person commented that it had taken a considerable amount of time for him to get the medication that suited him. He had suffered side effects from previous medication and it was only when he met with a Jamaican doctor, that he was able to get the right medication. Another felt that access to a range of treatment options would be facilitated by having black psychiatrists.

*"I'm not racist or anything, as regarding white or Asian, but I think at the end of the day I think that black people have been under, unrepresented, whatever the word is, in the mental health system because they still tend to put more black women on all these high, strong medication, you know what I mean, whereas Asian women sometimes get a bit of support especially if they've got an Asian doctor, an Asian psychiatrist. They get more, sort of, help to cope and then their family would be counselled as well, the whole family. But black people, you know, it's either hospital or prison, you know, and I mean that's with black men as well but I'm speaking about black women, you're asking about my experience, it's*

*either hospital or prison. And to me that's not going to solve the problems in life"* (6A, Female, Service User).

Furthermore there was a need not just for black doctors and therapists, but also for more women and for people with an understanding of experiences that are wider than those of the middle classes:

*"There are quite a few changes that need to be addressed. One thing, a lot of the psychologists [psychiatrists] are men, usually middle class. They're set in their ways. ... how can I put it? I mean they should stop acting as Gods. Because I mean a lot of doctors especially psychologists [psychiatrists] they think that they are Gods, they can just dish out medication, put you on these things and you get so used to them that you can't really come off. And that's playing God. And at the same time it's helping the flipping multi-national pharmaceutical companies to make money you know and it's just an abuse, its abuse really"* (6A, Female, Service User).

Linked to this, a further focus group participant commented that it was very important for service users to feel comfortable with the people looking after them, to have the confidence that they understand your circumstances. The sorts of things that generate this confidence include being treated with respect and understanding. Cultural understanding is an integral part of this.

- **Appropriate models of mental illness (e.g. a social model) and treatment options (e.g. counselling).** It is clear that many service users understand mental illness in terms of a social model, rather than a medical model. As one person commented:

*"Mental illness is a social problem, I don't think it's necessarily an individual problem, it's a social problem. I mean there's lots of things that can make people go off their head; if they haven't got proper accommodation, if their house is leaking or if their partner's gone off or if there's a bereavement or divorce; all those issues can make people just flip, you know what I mean?"* (6A, Female, Service User).

One service user felt very strongly that mental health services do not understand mental health in terms of a social model. The same person also commented that the model of counselling used also needed to be appropriate. Although she had seen a black counsellor, the counsellor hadn't provided any feedback and it was the service user who was doing most of the talking. This made her feel that the counsellor did not understand. The same person commented that recognising mental illness in terms of a social model requires a response based on seeking to understand people, their personal circumstances, their culture, and their beliefs – not simply dishing out medication.

- **Feeling accepted in Britain.** For at least two focus group participants, the issue of belonging within the wider culture, of racism, needed to be addressed. However, in other focus groups, including those with African-Caribbean carers, there was at least one person in each group who questioned the need for research focusing on the experience of black people, or who talked about themselves as being British, Black British, rather than African-Caribbean, about being born here. At least two focus group participants' accounts emphasised their similarity to white people.

It may be that the need to be accepted, for some people, shaped the way they viewed their experiences. For one person this was about describing behaviour by other patients in an inpatient ward that made her feel excluded as being down to medication. For another focus group participant, when asked about whether or not the services he had used were culturally appropriate, he talked about the wider culture in Britain as being "*acceptable*" (3A, Male Service user). However, the same service user had commented that this wider culture is "*an experimental culture*" and also stated, when another focus group participant started to talk about her experiences of racism within hospital services: "*They wouldn't be really nasty, ... they wouldn't be racist .... I mean you can learn to live with that, ah sure*" (3A, Male, Service User).

- **Not being exposed to unacceptable behaviour within mental health inpatient services.** At least three people, all women, talked about the experience of being in hospital. One person's account focused on the behaviour of other inpatients including being exposed to male inpatients' masturbation and a female patient urinating in public places. She commented that she found this behaviour distressing and couldn't believe why she was in the same place as them. Another woman, also reported earlier, talked about not wanting to mix with other inpatients whom she described as "nutters".
- **Spiritual beliefs.** At least two focus group participants talked directly or indirectly about their spiritual beliefs (including obeah, juju, spirits, magic, curses). One person commented that these beliefs were neither understood, nor respected by mental health services staff, who would think that a person who talked about spirits was mad.
- **Clothes and hair.** One service user specifically mentioned that having black nurses help her to plait her hair was an example of culturally appropriate services. This wasn't something she asked for; it was something the nurses themselves offered. When asked how this had helped her she said that it had helped her to take pride in her appearance again, which was something she used to do when she was well. In turn she also helped other patients with their appearance because she recognised that when she was not feeling like herself; her appearance would be more extravagant than usual, suggesting that she recognised the importance of clothes, hygiene,

and hair care for the mental well-being of other people.

### African service users and carers

Comments by African service users relating to whether or not services were culturally appropriate focused on the following:

- Having culturally appropriate activities including culturally appropriate health education. It was mentioned that activities offered by housing providers for asylum seekers such as playing cards and going to the library are not the sorts of things asylum seekers do in their own country.
- The need for service providers to be sensitive to the needs of people who may be suffering from post traumatic stress disorder.
- Lack of provision for speakers of languages other than English.
- Providing medication in appropriate dosages. Issues relating to culturally appropriate services highlighted by Somali women were that medication was being administered in dosages that were too high for Somali people, who are not used to taking strong medication.

### African Caribbean carers

African Caribbean carers commented that **racism affects mental health service provision for black people**. Several different examples were offered including the way in which black people communicate, for instance in **pigeon English**, meaning that they can be put in situations where they are misrepresented. Also an issue was that black people's communication and gestures can be misinterpreted (e.g. by police) as aggression or being uncooperative; some talked about the normal pitch of voice for black people as being interpreted by medics as shouting. In one focus group, all the participants agreed that there is prejudice against black people within mental health services.

Several focus group participants, from more than one group, were concerned about the lack of alternatives to medication, the side-effects of medication and their view that black people were being used as guinea pigs in trying out different kinds of medication.

One person was particularly concerned about the lack of humanity in the medical approach. He commented that although there is a place for medication, for instance, to help people to be calm, too often GPs failed to take the time to listen to the person in front them, dismissing them with a prescription for drugs.

*"Because I know in the day care centre, what we have here now, I see a lot of them, who's got talents in there, they got mentally health [bad mental health] but they bright enough; just all they need is the doctors to sit down and listen to the people who've got mentally health and get to know them*

*properly. Don't rip them off with paper and with prescriptions all the time; that's not gonna help! Just to have somebody to sit down for five minutes, the doctors to sit down and let them know and let they talk to the doctor and the doctor sit down and listen cos sometimes this is what's missing in this basically"* (6C, Male, Carer).

However, the same carer also commented that a human exchange between patient and doctor relies on black people themselves being willing to talk but that black people are often reticent about their mental health problems because of personal experiences and knowledge of black individuals with mental illness who have died as a result of inappropriate care and insufficient understanding. He talked about a friend with mental health problems, who died at the hands of the police:

*"...the way the police handled him, wasn't nice. Even the police need to sit down and they need to listen and know what mentally health [bad mental health] is about and help. It doesn't help having cuffs on them and things like that, that's not right and killed an innocent, innocent, black man that was sick, right? Michael Powell [African Caribbean man from Birmingham who died in police custody] was sick and the way the police treat them ... the police shouldn't get away with that. They should understand where we're coming from, we're all human beings, we're not like dogs and things. They got illnesses, got illnesses. What they could've done, they could've taken him to L Hospital, they could've take him to Winson Green, to Z Centre; not have to spray, spray gas on him and kill him on the way to arrival at hospital. That's what made me angry when I seen that and he got mentally ill problem, right? If they can do that to him, they can go and do that to anybody who sick"* (6C, Male, Carer).

Other carers also talked about the ways in which their experiences of racism as a community shaped their expectations. One carer's children went to school with the family of a boy who had *"died in the hands of the police"* (7C, Female, Carer).

There were some positive experiences but, in one case this was seen as unusual enough to prompt a thank you letter:

*"When my son became unwell and we had to call the police, in my mind, you think, anything could happen, death of a young man in Handsworth, and in fairness to them, they did listen to me and I could say, and I write a thank you letter. But are they looking at us and thinking are we a cultural group and differ in this way/that way"* (7D, Female, Carer).

Two carers talked about assumptions that are made about black people. These included assumptions by members of the medical profession that a black man, young or old, is a drug taker when this may not always be the case.

One carer commented that it had been difficult to get some of her son's

cultural needs met. For example, he was not consistently offered a diet that he was unused to. She also commented that when she had complained she was treated as a troublemaker even though there had been previous complaints about the same issue.

*"I think the attitude that they say you can voice your concerns – if you do they treat you as a troublemaker – one nurse referred to me as the miserable one who's always complaining. My son put in a complaint about a member of staff who was teasing him. They've moved her to another ward and they claim they're going to send her on a training course. Apparently they've had a lot of complaints about her. I saw her on the street and she said I always come across as abrupt. Someone more cultural he can talk to would be nice. Yesterday he sat in his room all day. I phone him to see what he's done all day. It's just somewhere to keep him out of the way. The doctor says he's too vulnerable to survive in the community at the moment. The consultant describes him as acutely ill, not able to survive. So are they going to leave him here?" (5C, Female, Carer).*

Two African Caribbean carers from different focus groups talked about the need to break down **stigma relating to mental illness within the black community**. Linked to this, they commented on assumptions that black families will look after their own may be inappropriate as some families may not have the resources to do this or may be unwilling to do so, because of stigma.

#### 4.2.6 Targeted service provision

Time constraints meant that it was not possible to ask all the questions to all focus group participants. Participants at the pilot focus group carried out with **African-Caribbean service users** were asked whether or not they felt that mental health services were sufficiently targeted for black people. Two focus group participants felt funding for targeted services such as the Frantz Fanon Centre needed to be maintained and even expanded because the level of service was perceived to have been constrained by lack of funding. In the same focus group, one of these participants also commented that there needed to be more funding for mental health promotion, to help reduce the stigma associated with mental health, but also to help service users and carers find out what help is available and about the factors that can impact on mental health.

**African carers** from the Somali focus groups commented that there was a need for targeted service provision for people with mental health needs. The case for targeted service provision focused on the need for a service that people feel they can trust; the barriers that Somali people are already facing struggling to cope with life in multi-cultural Britain, which make it difficult for them to access mainstream services; that currently many mainstream services are not being accessed by Somali people; and on the grounds that

other communities have targeted provision.

**African-Caribbean Carers** in one focus group talked about the limited support available to them as carers. One of the carers groups had been running for two and a half years and was specifically targeted for African Caribbean people and all nineteen members of the group were carers of people with some form of mental illness.

The funding from Birmingham City Council for the project to support African Caribbean carers was due to finish at the time of the focus group and was not being renewed. The project officer was signposting carers to other support but the only group she was aware of was run by Axis. Carers were just being made aware of the news:

*"And things don't change. This is the first place I've come to and get support" (5B, Male, Carer).*

*"And they take off the funding – why is it with everything the first thing they cut is the African Caribbean. They say they're not using it, let's scrap it, how can we use it if we don't know about it?" (5C, Female, Carer)*

## 4.2.7 Improving mental health services for black people

Focus group participants were asked what changes should be made to improve mental health services for black people.

### African Caribbean service users

Focus group participants made the following suggestions about changes that should be made to improve mental health services for black people:

- Three participants stated that there should be **more funding targeted to maintaining and expanding mental health services for black people**, including advocacy, support, drop-in facilities, befriending and social and other activities.
- Another three focus group participants talked about **staff attitudes need to change**. One focused on care staff (e.g. in supported housing) needing to have a more caring attitude and more trust (e.g. not locking doors). Two others talked about the need for doctors to start listening to people, rather than just dispensing medication.
- Two participants stated that **action should be focused on addressing racism, discrimination and conflict within society as a whole**:
- **Service users need to be supported to live a useful life**. One focus group participant talked about this; about wanting to be independent and to have a suitable job.

### African service users and carers

For asylum seekers the lack of basic support such as food and shelter, a job or education meant that people who were already coping with trauma had additional worries which undermined their mental health.

The two asylum seekers from Congo commented that not being able to work, having to buy food with vouchers and find new accommodation just added to the worries that people had brought with them: *"they already have their own problems but with this system just make things worse"* (4A, Female, Service User).

In addition, the lack of understanding within society as a whole was adding to problems:

*"Just imagine you in Africa, you know? You don't know anyone and you want to get safe; change your life, because where you come from it was danger for you and [if] you go [back] there, you are stressing again. So if everyone knew that and understand that I think things would not be like now because they don't understand. I am reading the newspaper; if you never drink you will not know what is happening after drinking too much beer. You think people are mad, because you never tried, but when you are there you'll know because they never and there are people here they never heard about Congo, Africa so they can just say what they think. It is very, very, painful. I don't understand that because they don't know. If they knew that, I think things would be perfect. Unfortunately that is not the case"* (4B, Female, Carer).

For Somali focus group participants, the main areas for improvement are the need to address racism; to reduce the dosage in medication; to provide inpatient care to keep mentally ill people safe and to provide services to meet the needs of Somali people through, for example, targeted services, culturally appropriate health education or interpreters.

### African Caribbean carers

African-Caribbean carers felt that the following changes needed to be made:

- Listening to black people to understand their needs better.
- **Better out of hours contact and more inpatient beds to help prevent people with mental illness ending up in police custody.**
- **Less rigidity in service eligibility and access criteria.**
- **More direct contact between carers and staff and more information for carers and families.** At least four carers talked about the difficulties they faced in getting information about the person they cared for, particularly when relationships with that person were strained.

*"I'd like to see more regular information, briefing from the psychologist. Of late, I've heard my son talking about suicide. At one time I could not meet with my son and the psychologist and he's said he [my son] doesn't want me there. I haven't heard anything since. I want up-to-date details in my son's life. He tried to keep himself away from me of late. The door is open but it's become rare that I've seen him.*

*A couple of Sundays ago he came for dinner. He said there was nothing wrong with him. He feels his medication is not helping. He said about it's time to end it. I'd like to get information on what's happening. I promised myself I would ring up the CPN. Everyone's circumstances are different – it maybe can be worse than for me if the person live at home. I want a one to-one with the psychologist" (7F, Male, Carer).*

- **Better funding for mental health** and more prioritisation of mental health by the Government including, for one carer, funding for respite and holidays.

#### 4.2.8 The roles for services users and carers in improving mental health services for black and minority ethnic people

There was insufficient time to ask focus group participants, who were service users, whether they feel they have a role to play in improving mental health services for black and minority ethnic people. However, the question of the role that carers may have to play was covered with some carers, where time allowed for it. Young people from the Somali focus group who had already been involved in carrying out their own research and peer education were keen to be involved in the ongoing debate and discussions about mental health policy.

**African-Caribbean carers** felt that they could play a role in shaping service provision talking about their own experiences and being more vocal about their needs. They also talked about the issue of confidentiality and the need for health professionals to involve carers in the care plan as well as communicate with family members with inpatient/user concerns about health issues. They mention that sometimes respecting patient confidentiality cuts off the family members to provide support to their loved ones, especially if the patient is admitted against their will.

#### 4.2.9 Other comments

All focus group participants were given the opportunity to make any additional comments. The following additional comments were made by African Caribbean service users and carers:

There is a need for **practical help and support for service users which is appropriate and non-threatening**. It was stated that this should not be

provided by statutory agencies such as social services and it should not be provided in a way that means accepting it is deemed to be a sign that people can't cope. Such support includes things like opening letters, answering phone calls and help with housework. One additional aspect of practical support highlighted by one service user is help with childcare for children over the age of five, along the lines of programmes such as Home Start and Sure Start. Two focus group participants had had their children taken into care and a further participant said this was a constant fear for her.

**Stigma associated with mental illness** makes it difficult for service users to get the help they need from their families. One focus group participant commented that when she became mentally ill her family would not talk to her, or visit her in hospital. They do not approve of her going to a day centre, where she gets support.

### 4.3 Phase three: interviews and focus groups with commissioners and service providers

Sixteen interviews were carried out with individuals from the statutory sector (mainly providers from the Mental Health Trust but also included one commissioner and one interviewee within the Independent NGO sector). Interviewees included psychologists, strategic and service managers, social workers, consultant psychiatrists, ward managers of inpatient units and community psychiatric nurses (CPNs). In addition, after the initial data analysis, three focus group discussions were set up with key members of the Mental Health Trust, Local Implementation Task (LIT) group and the Joint Commissioners Board to present the findings, and engage in further discussions around the feasibilities and constraints relating to emerging conclusions and recommendations.

Participants were professionals from a wide range of ethnic backgrounds, however to ensure anonymity, the ethnicity of participants are not provided.

The findings are presented using a thematic framework generated from the data and by revisiting the original proposal. The thematic headings are:

- An overview of mental health services and client groups served
- Cultural factors that affect the way services are provided.
- Culturally sensitive mental health service provision.
  - ♦ Views of individuals.
  - ♦ Perceptions of what it means to the Mental Health Trust.
- The ability of the Mental Health Trust to meet clients' needs.
- Targeted provision for people from African or African-Caribbean communities.
- The role for NGOs in mental health service provision including any required changes.

- The role for service users in improving mental health services.
- The role for carers in improving mental health services.
- Other comments.

### 4.3.1 An overview of mental health services and the client groups served

Interviewees were asked to provide a brief overview of mental health services and client groups served. Their accounts included:

- **Background data on previous and current configurations of services.** At least three interviewees emphasised that the current Mental Health Trust was configured from a merger of two previous Mental Health Trusts in April 2003, one in the North of the city and one in the South, each with their own structures and approaches to service development. One person suggested that the merger was a work in progress. Another commented that there had been different patterns of progress, **in relation to the development of culturally appropriate services**; reflecting the greater ethnic diversity in the north of the city. In the north the focus was reported to have been more on service delivery than on workforce development relating to diversity. There were two services specifically aimed at the needs of minority ethnic communities (The Frantz Fanon Centre and Asian Services). The merger was perceived by one interviewee as providing a focus for reviewing the work of the Mental Health Trust on equality and diversity, including the future roles of targeted services.
- **References to national mental health policy.** One interviewee talked about the findings of a national census of in-patients in mental health facilities in England and Wales (Commission for Healthcare Audit and Inspection, 2005) and the report on delivering race equality in mental health care (Department of Health, 2005a), known as the DRE, as providing an important national policy framework with visionary outcomes that services are expected to deliver against including: *"increased levels of satisfaction with mental health services; less fear; reduction in the number of deaths; reduction in the rates of seclusion; reductions in the number of control and restraints"* (Service Manager 1, Female). The same interviewee commented that this framework was a driver for the redesign of mental health services to deliver and embed race equality in mainstream services.
- **An overview of mental health services.** Accounts emphasised that the Mental Health Trust provided **services for people with severe and enduring mental illness**, whereas the more common mental illnesses like anxiety and mild depression are to be dealt with by GPs and primary care. A partnership arrangement between Birmingham City Council and the Mental Health Trust had been formalised under a Section 31 Agreement and there were integrated management arrangements so services

traditionally provided by the City Council including social work services and day services are now managed by the Mental Health Trust on the City Council's behalf.

Services provided by the Mental Health Trust include:

**Home Treatment teams** to support service users in the home/community in the event of a crisis. They are on call around the clock and provide out of hours services, and respond by going into the person's home, when necessary, to help them with crisis resolution.

- **In-patient services** for service users who cannot be supported in the community. The research focused on two in-patient units.

In one, the ward manager estimated that a third of patients are from African and African Caribbean communities although she commented that it was difficult to be sure of exact numbers. In the other, the ward manager indicated that the proportion of patients from African and African-Caribbean communities was 50% or more.

- **Primary Care and Primary Care Liaison (PCL) Teams** to support people who need help via a multi-disciplinary team including CPNs, psychiatrists, psychologists, occupational therapists and social workers, until they can be referred back to the GP. One psychologist working within primary care (Psychologist 3, Female) commented that 10% of her client base is African Caribbean but was unable to comment on whether or not that was reflective of the area. She commented that currently referrals could include people with a whole range of mental health problems including anxiety and depression through to more severe mental illness. However, changes had been proposed which would ensure that the more common mental health problems would be dealt with by GP practices or other primary care agencies with the team focusing more on severe mental illness.

A CPN commented that the proportion of people of African and African Caribbean origin served by her team was less than 50% and that the population served was "*absolutely multi-cultural now ... with refugees and things ... [from] African countries and Middle-Eastern countries and things*" (CPN 2, Female). However a Consultant Psychiatrist working in the same team commented that the majority population and a large proportion of clients are African Caribbean (mainly African Caribbean, rather than African).

Within the Handsworth and Ladywood PCL teams psychology services were being provided for refugees and asylum seekers. The majority of people using the service were reported to be from Albania and Montenegro or Africa. The main source of referral for psychological support was GPs, but referrals were also received from consultant psychiatrists and PCL

team members.

- **Assertive Outreach Teams** for people with complex needs, who may be difficult to engage via PCL teams. One interviewee, from an assertive outreach team, commented that more than 80-90% of the clients are African-Caribbean and of these, the majority are male. Assertive Outreach was perceived by one interviewee to have *"evolved to meet the needs of people who didn't want services, who found Mental Health Services oppressive. We have had to learn that if the service is to work, we have to engage with communities. The service developed out of the review into Christopher Clunis [schizophrenic patient who was discharged and later committed murder] because the services let him down"* (Social Worker 2, Female).
- **Rehabilitation and Recovery Teams** for people who have been supported for many years but nevertheless have a high degree of debilitation but who are compliant with their medication to help them rebuild their lives.
- **Primary Care Psychology Services**, which at the time of the research was only available in the south of the city and included contracts between the Psychology Services of the Mental Health Trust and certain GP surgeries to provide GP based services to service users.
- **Specialist teams** such as Early Intervention, which specialises in the early intervention and treatment of young people in the initial stages of the development of psychosis; the Bi-Polar Service working with people with Bi-Polar Disorder and the Substance Abuse Service.

Two interviewees talked explicitly about the need for **mental health promotion**. One commented that mental health is often used as a euphemism for mental illness and that there is a need to look at the whole picture and focus on mental well-being. To this end, a Mental Health Commissioning Strategy is being developed.

The other interviewee talked about **services being developed in the NGO sector for African and African Caribbean people** aged 18-55, regardless of diagnosis (as long as they are not under a current section – although they can have previously been sectioned). The service includes acute psychiatric services, day services, counselling and therapy, training and consultancy (e.g. around governance, African-Centred and other psychological models); and cultural competencies for both statutory and voluntary organisations including *"black on black cultural competencies ... black people are not taught how to work with black people, it's just assumed that they automatically know, so we like to do cultural competency for black staff who are working with black people"* (Independent Sector 1, Female). There was also a mental health promotion element focusing on changing the attitudes of the black community towards mental health.

*"We need to change ... the black community's attitudes towards mental health, so that they're not so afraid of it, so we're not running from it and that we're not getting ourselves confused with the propaganda around misdiagnosis ... and around our level of mental stability ... Actually, we have to acknowledge that we are suffering and it is a lot about being here ... it happens here, it happens in America, doesn't happen in the Caribbean, doesn't happen in Africa ... we need to know that some of our experiences here, but also some of our lifestyle things are not conducive to good mental health. So we need to go back to some of our original concepts of that and support systems. We've given up on church, we've given up on extended family, all that kind of thing, which held us ... So mental health promotion is about looking at redeveloping strategies, building strategies around mental health rather than mental illness, so we don't go down there in the first place" (Independent Sector 1, Female).*

### 4.3.2 Cultural factors that affect service provision

In discussing cultural factors, interviewees identified a range of issues including:

- **What is meant by culture?** Two interviewees talked about this. One commented that culture can mean many different things: the cultural identity of service users, of service providers and the wider host culture. Another talked about the notion of an **ideal culture** and the importance of people being supported to find their own identity, drawing on different experiences and reflecting, for example, the large number of different Caribbean islands and mixes. This ideal culture could include conceptualisations of what it means to be black and middle class, because current notions of culture, particularly for African Caribbean people, are rooted in slavery and colonisation.
- **Why culture is important.** Interviewees commented that it is culture that determines what is considered to be normal behaviour and what is considered to be abnormal behaviour. At least three interviewees talked about the need to recognise differences between a black person's culture and the wider "host" culture. The experiences of black people within the wider "host" culture need to be taken into account. The phrase "host" culture itself, indicates issues relating to a sense of not belonging. The experience of not belonging, which starts long before people arrive in the mental health system, is internalised. In addition, experiences often include being seen, and treated, as a threat:

*"A lot of stuff goes on that people aren't aware of. People have got into hospital by being dragged in by the police. It is very restrictive. When you're there, you can't get the food you want – you think everyone else has got what they want, and you internalise it. People say black people don't*

*complain, on the surface it looks like it's going smoothly, only one or two are complaining about the food, or that there is no black key worker. But if people only see doctors and managers from a white background, some people are OK with it, but it can make you feel, how can they possibly understand me? The team doesn't reflect the service users we have. ... As I grew up, I couldn't relate to things. That sense of relating, belonging, getting better, you need a good education, people are disadvantaged from here. We need to give young black boys self-esteem through the school system, if we don't, we will have crime, they need extra mentoring sessions" (Social Worker 2, Female).*

When asked whether she thinks racism is a triggering factor, she responded:

*"As long as there are issues of racism and discrimination, black people are not part of a community. Mental health services need to look at things differently. It is not a straight line. If you don't physically fit in, and you talk to yourself, you're mad. If you're black, you are seen as a threat, you don't belong. Anything you do out of the ordinary will be pounced on. Mental health can be a way of decreasing stigma. Just because you talk to yourself or dress differently, that's acceptable, we need to teach that; but society is not good at accepting difference. We need to break down perceptions of mental illness at school" (Social Worker 2, Female).*

**Within the wider "host" culture, African-Caribbean communities are more likely to be labelled as "deviant" and are more likely to be regarded as violent and treated accordingly.** A failure to take into account what is normal culturally-based behaviour such as gestures, dress, communication, spiritual beliefs, can have a major impact on somebody's life. It can lead to a misdiagnosis of psychosis. It can lead to someone being sectioned or to a person being prescribed powerful medication.

One psychiatrist explained that when he had first started work, he himself had misinterpreted gestures and dress but he had had the benefit of working with an African Caribbean consultant who explained that particular ways of talking and dressing were not evidence of hypomania, as text books suggested, but was the norm for the people being seen. A further example he offered was of the difficulty of diagnosing depression.

*"I see loads and loads of psychosis among African Caribbean compared to neurosis and depression. I think that is another cultural thing I observe when they are presenting their symptoms, there is a difference. I see that 'whites' and Asians if they are depressed, right, suppose they know the terminology of depression, but Asians they really don't know how to express the depression but they know the way that the term that, you can see and read their emotions and also either somatising ... but I think African Caribbean's; when they are depressed I think it is very difficult to*

*diagnose it, difficult to detect it. I think they are very well tuned to hide if they want to. It's very difficult for me in a snapshot to say that they are depressed but you can say that for Asians and 'whites' I think ...You need to straightly ask. What I am saying is that if you don't ask they may not come out. If you ask, they will say how you feel; I think they are more honest in that sense. What I mean is even though you don't see features of depression still I think you need to ask, 'Do you feel sad?' 'Do you think that there is some problem going on in your mind?'" (Consultant Psychiatrist 1, Male).*

Interviewees highlighted the following cultural factors that affect the way that services are provided:

- **The cultural background of staff within the Mental Health Trust.** For example the majority of service providers in the Mental Health Trust were reported to come from a European background. Several interviewees commented that the teams they worked in were not representative of the population served. For example, one person commented on an Assertive Outreach Team that 40% of patients were black but less than 7% of the staff is African Caribbean. However in another team (Rehabilitation and Recovery) 40% of the team were African Caribbean.
- **The wider host culture.** The medical model, which dominates mental health service provision, was also recognised by at least one interviewee as the *"Eurocentric or the Western view of health and illness"* (Psychologist 1, Male). Within this model, concerns were raised by service users and carers in relation to the side effects of medication, which can be seen as non-compliance. One interviewee commented that there was a need to explain to families and service users about side effects but also commented that part of the dominance of the medical model may mean that families lack confidence to have this dialogue:

*"We need to come together and explain about the side effects, we need to explain how medication is seen within the medical model, that it provides people with a chance to get on with housing, training, life. There are different ways of taking medication and times – we need to explain that and work with the family. One psychiatrist I know said I never prescribe Clozaril [used to treat some forms of schizophrenia], it kills people. Other people just give them more if it is not working. The family need to have that confidence to talk to the psychiatrist, but there's deference to the psychiatrist; calling them doctor"* (Social Worker 2, Female).

- **Knowledge of services.** One interviewee questioned whether people with mental health problems have sufficient knowledge of services to get the help they need.
- **Belief systems of service users and their families.** Relevant beliefs include **stigma** relating to mental illness that may stop people from seeking help

for a loved one because they are worried about their community finding out; beliefs about the most **appropriate ways to treat mental illness** – *"Do they prefer to seek religious answers to their problems, do they accept the illness model"* (Psychologist 1, Male); beliefs and experiences that may influence whether or not people feel that they will be understood by or safe in the hands of the mental health system. *"There was a case recently of a man being picked up for his first offence, wearing his ceremonial sword, but the court over-reacted and sent him to Reaside-high security [clinic]"* (Social Worker 2, Female).

- **The origins of disassociation.** Interviewees offered multi-layered explanations of the way that cultural factors impact on mental health and the origins of black people's disassociation which began long before they reach mental health services. They commented that cultural sensitivity had to include an understanding of such issues and of a historical journey that may span several generations. Black people are more likely to live in areas where there is social deprivation, where primary care services and the range of mental health support available is limited; their experiences of alienation, not belonging and under-achievement, may start at school and their journey to disassociation may span several generations. One interviewee talked about the links between social deprivation, stress and psychosis, arguing that black people are more likely to be experiencing life-stresses that, if not dealt with, can escalate into problems such as psychosis.

However, they are less likely to get help to cope with *"...pathological degrees of stress. You help the person with the life-stress and they don't have to go down that pathway ... all poor people (whatever your ethnicity) tend to be the last ones whose needs get met. Most poor people, most minority ethnic people tend to be poor"* (Psychologist 1, Male).

- **Links between social deprivation, crime and "drug cultures".** Interviewees argued that there are links between social deprivation, criminal activity and drug cultures and that there is a high level of drug use among service users. The increasingly sophisticated make-up of these drugs was perceived to be having a direct detrimental effect on the mental well-being of those using them; on their likelihood of being perceived and diagnosed as delusional; and in one account, their likelihood of being treated with high doses of anti-psychotic drugs.

*"We see a lot of patients with psychosis in our area and, as you are aware, in this area several people are misusing illicit substances. Also probably due to using illicit substances and mental illness they are, most of my patients are having their forensic history; involved in various offences and involved with the police, you know? And cannabis is, I don't know if this is the right statement, but cannabis is more or less the norm in this area. I'm*

*aware that they have done a study and found that between 16 to 24 age group around 30-40% are using cannabis. That's a big number and using in the sense or have used at least, but lots of our patients they use cannabis a lot. Either they are having a misunderstanding that cannabis is good for health or they are self-medicating; one or the other. So tend to use, they recently did a survey, tend to use more the high anti psychotic doses compared to other areas, I think, because we need to use high doses because of their drug habit; that is my general way of working in this area"* (Consultant Psychiatrist 1, Male).

- **The role of families.** A further issue highlighted was the role of family and family breakdown and its impact on mental health. Family support was felt to be an important resource for identifying health problems and seeking help at an early stage and supporting the recovery progress. One interviewee believed, in contrast to comments by some focus group participants, that there was a strong sense of community support within the Somali population who *"do generally live in an extended family kind of way ... you can exert the pressures of extended family living onto the individual and you can get them, basically, to fall in line with what's in everybody's best interest. So if you're smoking, chewing or doing whatever you're doing with khat or if there are issue to do with drugs or indeed issues to do with your asylum status here, you can address it with the family"* (Independent Sector 1, Female).

In contrast, the African-Caribbean community was perceived to have experienced an erosion of both the extended and the nuclear family, and an absence of father figures all of which meant that single African Caribbean men and women were experiencing high levels of dependence with limited community and family support.

Generally, interviewees were positive or offered specific positive examples about the **way in which the Mental Health Trust takes cultural factors into account**. Many of the examples focused on asking about dietary requirements, religious needs, social and housing needs. Also mentioned was considering the need to provide translators and paying attention to diversity within the staff team. One interviewee described all these things in terms of learning to engage with communities. Addressing issues such as the origins or disassociation or the links between social deprivation, family support etc, tended to be mentioned less frequently. **Specific ways in which the Mental Health Trust takes culture into account are through:**

- **Assessment processes.** Four interviewees talked about the importance of the assessment process. In one part of the service assessment clinics were provided with up to an hour allocated for assessment with scope for further appointments if necessary. The assessment process provided scope for capturing issues that are important to how people live such as their

spiritual and belief systems; their normal daily routine, what they like to eat, social groups they like to be with and how they spend their leisure time.

One interviewee commented that the assessment process was used to find out about needs but that some staff were uncomfortable about asking people about specific cultural needs and that some service users themselves had experienced aspects of this as stereotypical: *"we ask at assessment about how people view themselves e.g. some people see themselves as British and might say "why do you assume I'm from the Caribbean". There are also sometimes issues about staff being scared of asking people about their needs ... it's always do people ask or just go with assumptions e.g. what is your ethnicity?"* (Mental Health Nurse 2, Female).

It was clear that the assessment process itself was not always sufficient to enable service users to make their needs known. Another interviewee commented that the system for meeting needs is reactive: if people do not complain, or ask for specific services, they don't get them.

- **By learning from other staff or service users themselves and from other organisations working with African Caribbean and African communities.** This was highlighted by at least four interviewees although there were other interviewees that recognised the importance of having staff who were representative of the population served. Some of this learning was formal and involved feedback by staff nominated to have a lead role on diversity from cultural awareness training and study days. Some was informal and involved African Caribbean staff championing issues relating to diversity and sharing their own perspectives on cultural sensitivity.

*"Staff are aware of the Bennett report [Independent enquiry into the death, at a clinic, of an African Caribbean man] and issues about being aware of people's cultural backgrounds and finding out issues, e.g. about hair care, stuff that promotes self-esteem. A couple of young guys here are into how they look. One guy got one of the domestic staff to do his hair. Also things people might eat or attitudes that might be different to small things"* (Mental Health Nurse 2, Female).

Also important were links with NGOs, including awareness of specific projects, such as housing projects targeted for African Caribbean people; and inviting staff from such projects to attend team meetings to talk about their work and about different models (e.g. *"the social model of mental distress"* (Social Worker 1, Female)).

- **Celebrating diversity.** Celebrating and promoting cultural events such as Black Awareness Week and *"various Asian events that go on ... [are] an attempt to show that value is attached to one's culture"* (Psychologist 1, Male).

- **Trying to ensure that the staff team is representative of the community served.** Six interviewees highlighted the importance of this.
- **Understanding religious beliefs and providing spiritual support.** The Mental Health Trust was reported to have funded a post focusing on meeting the spiritual needs of service users and staff and, within different teams, religious leaders could be involved in joint visits *"I've heard of the getting spiritualists to come into hospital"* (Social Worker 2, Female). One interviewee emphasised the need for sufficient sophistication to recognise that *"when somebody from a particular background talks about the spirit of God speaking to them, it doesn't necessarily mean they are hearing voices. Or they could be hearing voices and really being able to understand when somebody who believes that the spirit of God normally speaks to them has actually crossed over into psychosis"* (Psychologist 1, Male).

When asked if there were any examples of **how cultural factors are not being taken into account, or where cultural factors impact negatively on service provision**, interviewees identified a series of challenges or issues including:

- **The need to avoid over-simplifying complex issues and the dangers of stereotyping.** At least two interviewees commented that cultural competency and cultural sensitivity were often addressed over-simplistically: *"Where the interesting complexity is, that it is not enough to stick, for example, a black person in Handsworth and think that you've solved the problem because that black person doesn't necessarily come from the same background as the black people that they are going to be working with. You know, where in the Caribbean is the person from? Is the person from Africa and therefore just hasn't a clue about what black people from the Caribbean are like? An Asian doctor, you know, India is such a vast place, just sticking an Indian doctor in there to treat Indian clients. It's incredibly complicated. With the best will in the world you can think you're doing it right and you could just be creating or committing blunder after blunder and not even know that you're doing it. So yeah, I'm not even talking about instances of racism ... I wish I could say, that it was just white people but it's not. It's, I mean, across the board, it's, black people who have expectations based on their experience of being black; of what it is to be black and how black people behave and how black men behave, and what is normal and all of that. ... But I guess what I'm trying to say is it's across the board; it's everybody doing it to everybody where you know assumptions are being made about the other"* (Psychologist 1, Male).
- **Assessment processes, resources and workload issues can be a barrier to developing person centred care.** One person commented that, *"if we can just focus on it being person-centred actually we can get everything right. And if we're talking about cultural competency and cultural factors; for me, it's as simple as asking the questions. If you don't*

*ask the questions you don't know. So, for me, it's about asking whether somebody feels racism is an issue for them. Do they feel satisfied with services? Are there any issues about fearing contact with mental health services? What can we do to support them through that? What are the social networks we need to go out and develop for individuals? What would people like to see in their care plan? Now, if we can ask the most basic questions and we can do it from a person-centred approach for everybody we can get it right for BME communities"* (Service Manager 1, Female).

However, there was recognition by at least two interviewees that developing person-centred care could be time-consuming and that teams needed to be resourced to deliver person-centred care. Furthermore, the rigidity of assessment processes might also make this difficult and even where needs were identified, voluntary or community based organisations able to meet those needs, might not exist.

- **The need for greater trust between staff, service users and their families.** At least two interviewees talked about the need for staff to acknowledge that there are significant problems to be dealt with. However, there was also a feeling that continually criticising them was not going to work either. There was also a need service users, their families and NGOs to accept that change would not happen overnight.
- **Insufficient diversity training.** Several interviewees commented on having to learn on the job, from colleagues and from service users themselves. Some saw this process as valuable. Others felt that learning on the job should not be the main source of learning and that the lack of training was an issue for staff and service users. For example, one consultant psychiatrist talked about having had to learn the hard way that Muslim women don't like to shake hands with men and having given offence in the process. He also commented that understanding culture is an important way of establishing rapport and that having an understanding of culture is essential to establish rapport.

*"Because I think people, when you first meet them, whatever culture it is, the first three, four five minutes are the most important minutes, time, when you establish a rapport ....If you go wrong there it is very difficult to correct it"* (Consultant Psychiatrist 1, Male).

- **Language and interpreting services:** Language and specifically, the absence of interpretation, was perceived to be a significant barrier. One interviewee commented that supporting asylum seekers and refugees to overcome language barriers, in a range of settings, is an essential part of developing trust and facilitating therapy: *"I often do things outside the traditional role of clinical psychologist: I will write to the Benefits Office, Housing People, Home Office ... in the context of, you know, that it's important for engagement and building trust and all of these things are key*

*components of therapy ... it's really important to do those things so that when therapy is then relevant, we can then engage in those tasks, the tasks of therapy but I still, I think its therapeutic to assist on practical matters in order to build the relationship, build trust, create a sense of, an environment of safety"* (Psychologist 3, Female).

There were different views on whether or not it was appropriate to work with interpreters in delivering psychological therapies. Several interviewees felt that it was not appropriate. One was working with interpreters but had developed ways of checking with the client whether they were happy with the interpreter through hand signals and basic English.

### 4.3.3 Culturally-sensitive mental health service provision

Interviewees were asked about culturally sensitive mental health services – what they understood this to mean, from a personal point of view, and from an organisational point of view.

For individuals the following were important:

- **Treating people as individuals and not stereotyping.** This was highlighted by at least three interviewees – all psychologists who talked about the dangers of making assumptions. One person commented that being culturally sensitive is not having a drum in the corner of the room, a picture of Martin Luther King on the wall and having rice and peas for dinner. Another talked about the importance of not making assumptions about spiritual beliefs. For example, if someone says they are a Christian, she recognises that this could entail a range of different Christian view points and rather than assuming she knows what it mean, she checks this out with the person.
- **Having a more diverse workforce.**
- **Moving away from traditional approaches** towards a holistic approach – seeing the whole person. At least four interviewees talked about this, although their accounts had slightly different emphasis.

One talked about the need to work with the person to understand them and for the understanding not to just be limited to a medical focus but also to find out the outcomes people wanted for themselves. The following extract illustrates a perception that the way professionals understand mental health and mental illness can be very different to how service users understand it.

*"Very frequently we think in terms of diagnosis and symptoms and having interventions that would deal with and focus on symptoms but a lot of times if you ask service users what they want they are talking about totally different things. They don't mind hearing the voices, sometimes, as*

*long as they can have decent accommodation and that kind of thing. ... a lot of times the way that people understand why they feel uncomfortable or why they feel unwell is quite different to how professionals understand it"* (Psychiatrist 2, Male).

For this person, culturally sensitive services take account of these different understandings *and* the implications they have for how the person should be treated, for example, not just focusing on medication but also on relationships with family, community etc, which themselves should be culturally sensitive.

Several accounts focused on the notion of difference and the fear of difference. Comments by two statutory interviews and by several participants in focus groups indicated that some people were uncomfortable by the focus of the research on African and African Caribbean people. This discomfort was expressed in different ways. One person felt that *"we look too much at differences rather than the similarities between people and it keeps people separate"* (CPN 2, Female). Another interviewee commented that as a black person, he didn't want to be the person who is always asking for things (CPN 1, Male).

One interviewee explained this discomfort in terms of issues relating to assimilation and the pressure within the host culture on black people to assimilate. As a black woman, she talked about her own journey taking pains to emphasise similarities between herself and her white therapist years before, but now recognising and being comfortable with difference. She went on to talk about the implications of the pressure to assimilate. Some people identify more strongly with *"the oppressor, with white people and the white community than they do with themselves"* (Independent Sector 1, Female) or with the black community. At least two other interviewees (both black) talked about their own personal experience of wanting to belong. This pressure to assimilate creates a psychic split which deepens in periods of stress and this is *"part of the reason why we have so many psychotic breakdowns is because we had to, we had to create a kind of psychic split"* (Independent Sector 1, Female). She also argues that the pressures to assimilate are actually based on a lie because there is racism – that's a reality for black people – and society is not equal or fair.

To deny this, she argues, is *"one of the symptoms you can have and so on. So that just spreads across to other parts of your life; there you go, you know, even before you know what, you're as mad as ..., you're as psychotic as ...,"* (Independent Sector 1, Female).

Echoing comments by other interviewees, this interviewee commented that recognising these issues entails a different and holistic, African-Centred model of mental health and mental illness. She argued that this model allows people to explore some of the reasons why they find

themselves suffering with mental health problems. It is clear from the following comments that in contrast to the medical model, the African-Centred model takes account of history, deprivation, racism and pressures of assimilation.

*"...the African Centred Model ... allows us the opportunity to be able to explore why it is we're in the positions that we are and do something about it, so we have choices. If you're functioning from unconscious processes and you don't know that you're doing that, then you don't have a choice about not doing it. ... so, really its about educating people to understand, you know, you have to know there's, this place, it's stressful, that you don't do that, you're on dodgy ground, your defence mechanisms are going to break down. We all have defence mechanisms, they, are under particular sort of strains because of particular set of circumstances, our history, our experience, our poverty, all kinds of stuff or education so we need to be particularly mindful and we need to know that that's our reality so we can then choose how we handle that, but if we deny that ...Assimilation; the whole issue of why black people say, 'I don't wanna work with black people' or 'I'm not totally different, we're all the same'. We're not all the same and even if we were all the same we're treated differently and that and we have been for a long time, that makes a difference, yeah?" (Independent Sector 1, Female).*

Another reported aspect of African Centred services is that they are not afraid of black people and black people aren't afraid of them. Traditional models are reported to see black people as *"big, bad and dangerous"* (Independent Sector 1, Female) whereas services which are not looking at black people through that lens are not defensive in relation to risk management. To illustrate this, one interviewee offered examples of how black people in crisis will voluntarily approach services based on African-Centred models:

*"We've had situations whereby we've had to change the codes on our locks because we had a few people that come, they got to know us, they've done the counselling, they start to break down in the community, we come in, in the morning, and they're tucked up in bed! To get them into the statutory service they have to be sectioned, yeah, but they'll come and put themselves in our bed, yeah?" (Independent Sector 1, Female).*

Another interviewee commented that in order to provide culturally appropriate services, there does need to be a range of providers and choice. Choice is more than simply having a diverse workforce, it is about having services that are not based on *"dominant white assumptions"* (Commissioner 1, Female). However, there was recognition by this interviewee that there were challenges in commissioning services that offer alternative models and approaches. The challenges that

understanding why services do not work for some people requires a change of mindset within commissioning and this is not always easy.

Perceptions relating to what culturally sensitive mental health services mean to the Mental Health Trust were as follows:

- **Understanding the needs of people from different cultural groups.** Three interviewees made comments relating to the need for an understanding going beyond the factors such as diet, food and festivals; towards incorporating anti-oppressive practice and understanding of how people have come to the Mental Health Trust, the impacts of alienation and why people might present as being angry.
- **Avoiding a simplistic approach which does not recognise the complexities of identity,** of which race is only one element.
- **Mainstreaming race equality** through strategic actions such as race equality action planning; diversity training, developing a diversity network; and launching a diversity handbook. At least three interviewees felt that having a **Diversity Directorate and a Diversity Strategy** was indicative of the Mental Health Trust's commitment to the development of cultural sensitivity. However, limitations of the role of the Diversity Directorate were recognised including the dangers that race equality is perceived to be the business of the Diversity Directorate and so not the mainstream. Other limitations cited included historical under-investment in equality. One person talked about a lack of connection between the Directorate and other parts of the Mental Health Trust and was sceptical about its ability to make a difference:

*"Because of the size, we have a Diversity Director but we just don't feel any connection. There was a discussion about having a diversity team, one person from each area to meet up, that would be beneficial but I don't know if that will happen. Probably a classic in the Mental Health Trust was that they did a calendar for certain religious groups and then forgot others – so it was, are we providing a service for specific groups or for everyone – they left out Christian. It had the major Asian faiths but the majority of African Caribbean service users refer to themselves as Christian. It is a feeling of being disjointed; there is no real kind of direction. The study days e.g. with NIMHE/CSIP are useful, but that is the extent of it" (Mental Health Nurse 2, Female).*

Service re-design processes were also felt to be an important part of mainstreaming race equality and involved joint processes involving the Mental Health Trust, PCT's and NGO's.

*"There is also, [Mental Health Trust] ... a service redesign process that is in conjunction with the PCTs and NGOs and so on and so forth. That too is attempting to look at developing culturally-sensitive programmes*

*through the involvement of non-governmental organisations which will, of course enrich the array of community organisations that will be able to work with us as partners in dealing with service users and so on"* (Consultant Psychiatrist 2, Male).

More negatively, there was a feeling that culturally-sensitive mental health services within the Mental Health Trust were **characterised by talk that is not backed up by action or which is not resourced or monitored to facilitate implementation**. At least three interviewees talked about this. They mentioned about the need for resources to be assigned to ensure that outcomes required by national policy could be achieved; one commented that the current financial climate was a major threat to such policy. The lack of adequate investment in BME activities and programmes to back up the rhetoric was reported by at least two interviewees to be as much about the Department of Health as it is about the Mental Health Trust. One person commented that funding was often tokenistic:

*"Yeah, granted they have assigned some funds to Community Development Workers but that's a mere pittance compared to what is required to really develop meaningful community resources. So again, you have to wonder whether it's just a matter of the authorities responding to the various reports that have come out after tragedies that have happened so they can say they have done something. But when you really look at what, in fact, has actually been achieved it is really not very much"* (Consultant Psychiatrist 2, Male).

In addition to the need for resources, there was a perception that further incentives, in the form of targets to drive the race equality agenda, needed to be developed. One interviewee commented that he was not aware of any hard targets in relation to the outcomes in the DRE.

At least three interviewees talked about **conflicting policies**. For example there was a conflict between standardisation and efficiency versus flexibility: one person commented that there needed to be a better *local* understanding but that other priorities such as the need for standardisation and efficiency could get in the way of this.

Another example of policy conflict highlighted was a perception that *"the function of a hospital has changed significantly as well ... it's a more custodial form of care"* (Service Manager 2, Male). At the same time as managers were trying to meet the needs of service users – *"we've got policies in relation to giving users as much autonomy as we can. There's an introduction of an 'open door' policy. I mean Open-Units are meant to be open"* (Service Manager 2, Male).

They also had to balance issues of safety for staff, at least two interviewees talked about the difficulties for staff working in in-patient units, often in a

climate of under-resourcing: *"But you know those are difficult areas to manage. I mean for somebody who, I don't know whether you've spent any time in the In-Patient Units, but it's a difficult thing to comprehend because more often than not you're working on minimum staff. Secure psychiatric hospitals, even medium-secure or even Open-Units are not the most popular places in the world to be. And even within the psychiatric domain they're not the most popular places to work either"* (Service Manager 2, Male).

A third example of conflicting policies was the tension between the emphasis on reducing suicides and Government policy towards asylum seekers. One person commented that,

*"As the Government or the Home Office ... are stamping down on numbers [of asylum seekers] that they're accepting, then a lot of people that I work with who are asylum seekers would rather kill themselves, commit suicide than go back to the country they fled. That's a far more dignified way of dying; they don't have to put up with the shame and, you know, all these other issues, so potentially the risk of suicide could go up, but ... what resources, what financial support, are they giving to individual Mental Health Trusts to develop services to help reduce things like that, you know? So, there's a lot of really well intentioned aims and targets which, you know, all sound really good if only we could actually, on the ground level, implement them and that's why I call it rhetoric"* (Psychologist 2, Female).

#### 4.3.4 The ability of the Mental Health Trust to meet clients needs

Interviewees were asked about the ability and willingness of the Mental Health Trust to meet clients' needs and constraints and opportunities in providing mental health services for people from African and African Caribbean communities.

Three interviewees felt that there was a lot of willingness within the Mental Health Trust. Four interviewees offered **the existence of the Diversity Directorate as evidence of that the Mental Health Trust was willing and trying to meet clients' needs**, although two commented that **information from and about the Directorate did not always filter through**:

Two interviewees felt that **ability and willingness varied** (e.g. across teams; geographical areas of Birmingham; according to the perspectives of different stakeholders; reflecting constraints on resources; and the "goodwill" of managers). One person commented that even in the same week as a major event was held, as a tangible demonstration of willingness and commitment to improving mental health services for people from minority ethnic communities, the practicalities of this were severely constrained in the form

of identifying resources to produce materials in different community languages.

One interviewee felt that **the Mental Health Trust needed to do more** and be seen to be doing more especially with the closure of the Frantz Fanon Centre. One interviewee commented that at middle-management level *"people don't necessarily understand what it is that they have to change in practice"* (Service Manager 1, Female). Another commented that managers are not always very good at responding to issues raised, or of developing approaches to coordinate finding solutions to problems (Psychologist 2, Female)

**Constraints on the ability of the Mental Health Trust to meet clients' needs** included the following:

- **The scale of the problem and the size of the organisation meant that turning the situation around could take time.** One interviewee commented that *"We employ just under four thousand staff; we cover a population of 1.2 million. And it's like turning round a tanker. And what we're dealing with is a legacy of deeply-imbedded inequality that's been developing since the onset of the NHS. So, this isn't something we're going to be able to achieve over twelve months or two years, it's going to be a long hard slog of building blocks in order to turn that round"* (Service Manager 1, Female).

For others, the scale of the problem incorporated recognition of the links between mental health, social deprivation, racism and alienation.

- **Staff attitudes.** Several interviewees commented that there were issues about the level of awareness of race equality issues among staff and their willingness to address these issues. Two interviewees commented that some staff did not always have the understanding of the worlds in which service users live. One talked in terms of senior managers. Another commented that it was not enough to recruit people, particular in recruiting staff from overseas, with technical qualifications – they needed also to understand what it is like to be black, living in inner city Birmingham.
- **The absence of incentives or a clear lead from the Department of Health.**
- **Inadequate resources.** Five interviewees commented that **the successful implementation of policy objectives requires sufficient resources and incentives.** Two further interviewees commented that it was not simply a case of new resources not being forthcoming but existing services were being cut. Resources needed to be made available to enable teams to provide culturally appropriate services; to support people in the community; and to address the lack of psychological services for black people.
- **The complex nature of Birmingham and the large number of different communities living in Birmingham.** One interviewee commented that the

large number of different communities living in Birmingham makes it difficult to know where to focus.

- **Constraints on working with other agencies** due, for example, to restructuring and the loss of the Frantz Fanon Centre as a resource that different teams could work with; or the nature of the in-patient wards and concerns about risks involved in bringing people in from the outside.

**Opportunities for the Mental Health Trust in meeting the needs of people from African and African Caribbean communities** were identified by interviewees as follows:

- Backing from the Executive and the Mental Health Trust Board.
- Having robust organisational procedures, and policies and processes.
- Champions within the staff team who are themselves from minority ethnic groups.
- Being part of the Birmingham and Black Country Strategic Health Authority Focused Implementation Site for the DRE.
- Opportunities for working with NGOs. At least two interviewees commented on opportunities in working with specialist groups and for staff within the Mental Health Trust to develop their own expertise. One assertive outreach team had employed a member of staff to work with people to help them sort out their money. This was reported to build rapport. They were also trying to think creatively about housing, such as direct payments to support people to buy their own home (Social Worker 2, Female).
- Developing commissioning at a district level. The move to District Based Commissioning as mentioned by one of the interviewee was part of the national "Going Local" initiative designed to enable local areas to fund services specific to local needs.
- An emerging acceptance of diversity within wider society according to one interviewee.

#### **4.3.5 Targeted provision for people from African or African-Caribbean communities**

Interviewees were asked if they were aware of any targeted provision for people from African or African-Caribbean communities and their views on this. Seven interviewees cited the Frantz Fanon Centre as an example of specific provision for members of African-Caribbean communities; three interviewees spontaneously reported having used it as a resource and found it helpful. There was a lack of clarity at the time of the interviews about the status of the Centre. Some interviewees were unaware that there was uncertainty over whether it was going to continue; others were unsure of the reasons why its future was in doubt. Two interviewees commented that the service was no longer in existence

PattiGift (Voluntary African and African Caribbean Mental Health Service) was mentioned by two interviewees as another service targeted to meet the needs of African and African-Caribbean people. Also mentioned by one of those interviewees was a Black and Minority Ethnic Steering Group, possibly the steering group for this research project, and targeted psychological support for refugees and asylum seekers.

Another interviewee talked about Axis and a more general perception that targeted provision tended to come through the voluntary sector, with the exception of the Frantz Fanon Centre, which was part of the statutory service.

Reasons offered for the reconfiguration of the Frantz Fanon Centre included:

- A lack of understanding about its role among service providers and, according to one interviewee, among the black community.
- A suggestion that the Centre had not achieved what it was set up to do due to insufficient funding and isolation from the rest of the Mental Health Trust.
- A belief that having targeted services would not achieve changes that are required in the mainstream and that there are other drivers and organisations that are better placed to facilitate these. A variety of views were expressed by interviewees about issues relating to targeted services and mainstreaming race equality. Some of these were offered as an explanation for the reconfiguration of the Centre but other comments were made more generally in relation to this issue.

Two interviewees commented that providing services for African and African Caribbean people, or people from black and minority ethnic communities more generally, as a specialist service, tended to create division, make services more segregated, prevent mainstreaming and emphasise the notion of difference for specific groups, when difference is everywhere.

*"I guess what I'm trying to say is that even with all my English clients there's differences and, you know, we have to engage with those differences and we also recognise that there's a commonality and a uniqueness and I think that is also true for asylum seekers and refugees. [Having a separate service] takes away the responsibility from clinicians to engage with those differences and you know I kind of have a bit of an issue with that. It's down to everybody; clinicians should foster and cultivate the skills to work generically with different populations and when it becomes a specialism, as I said, you know, there's something quite isolating about that, 'well, they can do that then, you know we don't have to worry about that' and it takes away their responsibility to learn"* (Psychologist 2, Female).

There was a suggestion that targeted work should be carried out by agencies

outside of the Mental Health Trust such as voluntary organisations, such as the Race Equality Unit in CSIP, and that frameworks were in place such as the DRE and the Service Redesign Process that meant that there was no longer a need for the Mental Health Trust to have its own targeted services.

In response to the question of whether there is any specialist provision, one interviewee commented that although the Frantz Fanon Centre was the only “discrete” service, increasingly local arrangements were being developed to meet specific needs.

Examples offered included employing staff who speak specific community languages; employing a counsellor to work with the Bangladeshi population in Sparkhill and Sparkbrook; joint working between Handsworth PCL and a local church in Handsworth with specific expertise in “*counselling African Caribbean people within a spiritual kind of context*” (Consultant Psychiatrist 2, Male).

Several interviewees felt that similar arrangements needed to be developed locally, building on existing NGO provision such as the housing projects for African Caribbean people run by Servol and Mind, the national association for mental health). One commented that local providers (e.g. housing providers) have “*a kind of local knowledge that is very difficult for the professionals to come by, and every now and then that pays major dividends in relation to something that is happening that we need to involve them with*” (Consultant Psychiatrist 2, Male).

However, sustainability was perceived to be an issue for NGOs and at least two interviewees offered examples of NGOs folding or being under threat due to lack of funding. Another interviewee commented that although there is a need for targeted provision, when it came to specialist acute provision (hospitals) “*It doesn’t feel as if the voluntary sector is allowed to develop specialised hospitals*” (Social Worker 2, Female).

In addition to the general question about specialist provision, interviewees were prompted about any **provision for refugees and asylum seekers**. The main findings in relation to provision for asylum seekers and refugees were as follows:

- **Limited services or awareness of services for asylum seekers and refugees.** Few interviewees were aware of any specialist expertise within the Mental Health Trust for meeting the needs of asylum seekers. One person commented that there was a team funded by the local authority, working with asylum seekers in Aston, but another suggested that this funding had been cut. Two interviewees commented that there were services including support on a part-time basis from one psychologist and Refugee Services for people with housing and money problems. One interviewee commented that there was recognition within the Psychology

Service that the Mental Health Trust needed to be better equipped to meet the needs of refugees and asylum seekers, of which it was also recognised there was a steady flow through the Mental Health Trust.

Two interviewees commented that there was a need for services equipped to meet the steady increase in people with Post Traumatic Stress Disorder and to address particular experiences faced by refugees and asylum seekers, for example in relation to torture. One felt this was not likely to change because services were already struggling to cope with *"what they already have on their slate ... [and] the repertoire of interventions and the complexity of interventions available to you increases every day"* (Consultant Psychiatrist 2, Male).

In addition, there were new guidelines from NICE [National Institute of Clinical Excellence] in relation to schizophrenia to be implemented and there were insufficient resources to meet the current requirements, let alone the needs of a new group, such as asylum seekers.

A further issue highlighted by one of the focus groups, with participants from statutory agencies, was that the legal position was contributing to asylum seekers falling through the net. Those who lose their appeals also lost their legal right to mental health services. Consequently, 'failed' asylum seekers with severe mental health problems are falling through the net because no agency is taking responsibility for them.

**Barriers facing asylum seekers** included:

- **A view within the Mental Health Trust that asylum seekers will falsely claim mental illness as a route to getting refugee status** and two interviewees stated that they themselves had witnessed this. A third reported that she worked extensively with asylum seekers and commented that *"99.9 % of people I've come across, I've experienced working with, are not bogus and are not feigning their needs"* (Psychologist 2, Female)". However she herself had been asked to assess people judged by colleagues as not having mental health needs. The basis on which this judgement was made was that the person was reported to be very articulate, well-presented and with no signs of self-neglect. *"And I've seen people for a second opinion and it's slapped me in the face how obvious there are mental health problems. But it's the culture, whether it's an African culture; to present yourself in a scruffy un-maintained way to them is unheard of, you know I'm working with someone who ... attends his sessions immaculate, he smells nice, you know, he wears suits. On the face of it you'd think there was nothing wrong with him, you know, if he can look so good then there's no signs of mental health. That might be the case in the West, but that doesn't necessarily mean, you know, that those signs are applicable for people from different cultures"* (Psychologist 2, Female).

The same interviewee commented that the system creates dependency and that *"asylum seekers learn very quickly about the system that they're in and the system that is actually partly responsible for maintaining them in a certain level of distress. ... If I went to a country and I was uprooted and lost everything from the country I spent most of my life with, went to another country, found out I'm not gonna get any help unless I feign my needs; if that's the only way to get help then I'm gonna feign my needs, I don't think there's anything wrong with that ... if that is the only way of them getting some help then, my remit in the helping profession is to help.*

*I mean, you know, there is an issue of whether people are wasting, taking up services that they shouldn't be as we're so tightly resourced; I've never come across somebody where it's so obvious to me that they're an economic migrant and it'll somehow do their case a favour if they're seen to be, I've never come across that"* (Psychologist 2, Female).

- **Eligibility criteria and the definition of severe and enduring mental illness**

One interviewee commented that *"people have to have severe enduring mental illness, which usually means psychosis, for us to deal with them – if they are things like depression; we shouldn't be dealing with them. So people are being denied a service, or kept in primary care because their problems are not seen as being that severe"* (Social Worker 1, Female).

A second interviewee suggested that Western diagnoses of severe and enduring mental illness could exclude people in distress. She suggested that the focus should be on the severity of the symptoms that people present with including anxiety, trauma, nightmares, sleep disturbance and psychosomatic symptoms:

*"... if somebody's presenting with severe symptoms of distress then there's a remit to work with them. If their distress levels are not severe then they will probably be better served from a voluntary sector service or, you know, another service ... The person might not have SMI [Severe Mental Illness], they might not have schizophrenia or this or that but if their levels of distress are severe then I'll see them and I think that, as professionals, there's a moral and ethical obligation to use one's professional skills to help somebody in severe distress. I won't say, 'no sorry, you don't fit our definition of' but yes I guess some people are more rigid"* (Psychologist 2, Female).

Somatisation was only just starting to be understood, according to one interviewee. For example, it was reported that research has indicated that South Asian people *"are not psychologically-minded, they somatise"* (Psychologist 2, Female), and traditionally this has not been recognised. For example, GPs are reported to tend to treat Asians pharmacologically rather than recognising that physical ailments might be a manifestation of

mental distress.

**Difficulties for asylum seekers in obtaining psychological support.** Two interviewees commented that it was difficult to provide psychological therapies, described as the treatment of choice for Post Traumatic Stress Disorder, because psychologists were not prepared to work with people via interpreters. One psychologist interviewed was an exception. She routinely worked with interpreters. Another interviewee suggested that, *"It could be seen as easier to treat people with medication than with talking therapies – it's been hard to get psychological support - that is a general problem"* (Social Worker 1, Female).

- **Racist attitudes** of some staff, mainly GPs but also from consultant psychiatrists or key workers. Examples of racism included GPs being reported to have said that they don't like asylum seekers and refugees. This adds a further dimension to the trauma already experienced.

#### 4.3.6 The role of NGOs in mental health service provision

Interviewees were asked whether they felt that NGOs had a role to play in providing mental health services, and if so, what type of role. At least seven interviewees envisaged a role for NGOs. Three offered specific examples of the roles NGOs could play, for example, in debt and benefits advice, housing and supported housing, groups with specialist expertise in issues such as rape or sudden infant death syndrome. One interviewee offered examples of NGOs attending at the beginning of multi-disciplinary team meetings to talk about their work. Other teams had similar arrangements. One interviewee commented that NGOs have a role to play because they are trusted by their communities. They are outside of the statutory services; they don't carry stigma; and they have met needs when nobody else has been picking these up. At least three interviewees commented that the role for NGOs in mental health service provision is constrained. The constraints cited include:

- **Limited knowledge** about the roles that NGOs can play or about the services available. This was highlighted by two interviewees
- **Insufficient training and skills development.** At least five interviewees, of whom three were psychologists, commented that NGOs were neither always sufficiently skilled nor had guidelines or protocols that were followed in their work. There was a perceived lack of professionalism and governance within NGOs and also insufficient communication between them and statutory services. A couple of participants also commented that statutory and voluntary organisations are not always clear about the rules that each organisation is actually working to. They believed commissioners need to ensure new services are on a **"level playing field"** and are clear in terms of expected standards of the performance.
- **Funding constraints.** A number of key members of the Mental Health Trust

commented that NGOs are usually given funding for a specific project rather than the organisation as a whole. One interviewee commented that there was a need to invest in NGOs through strategic alliances, partnership working and sub-contracting, but that funding constraints within the wider health economy made this difficult.

- **The bureaucratic nature of the NHS, which makes it difficult for it to respond to the needs of NGOs.** A further aspect, highlighted by one person, was the need for the role of NGOs to be coordinated and a concern that the infrastructure for communication was not currently in place within the Mental Health Trust itself, let alone in relation to working with NGOs. One of the participants accepted the reality, explaining it as: *"An inherent difficulty between a large statutory organisation and a very not homogenous group of NGOs and that very fluid re-appearing/disappearing with funding"* (Consultant Psychiatrist 3, Male).
- **Staff within the Mental Health Trust feeling threatened by the NGO sector.** Two interviewees commented that staff within the organisation feeling threatened by NGOs is a constraint on working with the NGO sector. One talked generally, the other gave a specific example about staff feeling threatened in relation to delivery of psychological therapies by the NGO sector.

Interviewees were also asked about any **changes required to facilitate collaborative working between NGOs and statutory organisations**, to provide an appropriate mental health service. Comments included:

- **The need for more information about existing services:** concerns were raised about services being commissioned from the NGO sector without the wider statutory sector being consulted or even informed. One participant mentioned that as a result people in the NGO sector are struggling to **'bang on the door'** to get attention from the statutory sector and the statutory sector are completely unaware about the service.
- **The need to review grant funding:** one interviewee commented that this was included in the Commissioning Strategy for Mental Health and provided **an opportunity to work differently and be more creative in meeting cultural needs through support to NGOs**. This was also reported to be a theme within the Diversity Strategy for the Mental Health Mental Health Trust.
- **The need to address barriers to joint working between NGOs and statutory organisations.** This was highlighted by at least five interviewees. Central to this was the need to:
  - ♦ **Develop an understanding of the constraints that each sector works within** such as deadlines and financial and governance frameworks.
  - ♦ **Agree clear and shared priorities.**
  - ♦ **Move beyond mutual suspicion.** One manager commented that within the statutory sector managers feel threatened by NGOs. This

was partly caused by government policy, which focuses on promoting NGOs as a potential competitor to statutory agencies; and partly by managers within the Mental Health Trust using the NGO sector as a threat against staff:

*"... it does get stirred up, intentionally I don't know, politically and also by local managers [within mental health services] – ah, let's get the voluntary sector to do it" (Service Manager 3, Male).*

There was also a perception that *"The NGOs seem to be hostile, mistrustful and resentful towards the statutory sector. The service users tend to be caught up in the middle of this. There is a huge amount of work that needs to be done to bridge that gap"* (Service Director, Female).

Commissioners acknowledged this point and stated that all services commissioned will be within a clear and robust governance framework and commented that there is a challenge in ensuring that statutory and NGO sectors do work well together and services for patients are seamless. Currently, this is not always the case.

- **Change unhelpful attitudes.** From the statutory side, teams need to be more inclusive and more open to develop partnerships. Currently statutory organisations are reported to have an attitude where they feel they are the experts, the professionals, and are not receptive to the idea that NGOs may have more expertise with particular population groups. NGOs need to be willing to work alongside statutory organisations; to undertake training, where necessary; and recognise that they may not have the full picture in offering support for people with mental illness (e.g. they need the medical expertise of professionals). This highlighted by one of the interviewee "if somebody regularly visits a NGO but deteriorates they would go to the BSMHT rather than NGO" (Consultant Psychiatrist 3, Male). The development of partnership relationships needs to become more mature and more performance-orientated. One person commented that in the past, NGOs have been struggling to be noticed by the statutory sector, but now this is happening, the work of NGOs needs to evolve:

*"And then they take notice of you and then things need to evolve. You need to realise that you are in a different frame and now you need to really put your money where your mouth is and start to perform"* (Consultant Psychiatrist 2, Male).

Two interviewees suggested that **joint working was being facilitated** by having more regular dialogue; by being more professional about how things are done (e.g. asking for written submissions, having regular reviews and feedback from service users); and through the service re-design process. A major facilitator that is required is **the need adequately to fund the involvement of NGOs as a demonstration of commitment**. Three interviewees talked about

this. One talked about the need for commissioning to be carried out in a way that is sustainable for NGOs ; for monitoring to be “*reasonable and manageable*” and for NGOs to be supported to fulfil monitoring obligations (Commissioner 1, Female); and for funding processes to be accessible to a range of organisations.

#### 4.3.7 The role of service users in improving mental health services

Interviewees were asked whether they saw any role for service users in improving mental health services. There was general agreement that service users do have a role to play although most of the discussion focused on the mechanisms rather than the role itself. However one interviewee commented that the role of service users is to **provide information, as people on the receiving end of services, on what works and what does not.**

*“They have a perspective of what it is like to be on the receiving end of what we’re doing so that they bring to us information about the impact of what we do or don’t do, what we do well, as well as what we do badly. They also have ideas about how things can be improved on the basis of what they’ve been on the receiving end of. I suppose that’s kind of like the general statement of value that they being imbedded in the service brings”* (Psychologist 1, Male).

Commissioners taking part in focus groups commented that they recognise and value the contribution of service users and carers in planning and redesigning services. They stated that they have invested in extending User Voice and regular User Forums are held. Likewise, they have invested in Carer Support Workers and are expanding the roll out of Community Development Workers working across the BME communities. These developmental plans were welcome changes to mental health service provision, however, a lack of information about the existence or clear understanding of the role of Community Development Workers amongst a number of NGOs, service users, carers and even some statutory providers was a cause for concern, and an indication of lack of joint planning and working.

There were a range of views about how the role is to be fulfilled, including:

- **Service user groups/committees:** individual teams and service areas have their own forums. Some interviewees talked about the importance of User Voice although there was recognition that this is a predominantly white forum. One interviewee commented that lack of childcare support was a barrier to service users attending the user group (Psychologist 3, Female).
- **Involvement in recruitment processes:** in one Rehabilitation and Recovery Team interview panels have service user members.
- **Involvement in staff away days:** again this happened in one team, although

infrequently.

- **NGOs:** Rethink was singled out by one interviewee as facilitating greater **liaison between staff and service users groups.**
- **Informal arrangements** including “drop in” sessions for service users, places where service users and staff can eat together, or provision for taking service users on holiday. One of the interviewees talked about the value of informal mechanisms for bringing service users and staff together: *“Sometimes when we are going on holiday we go and drink with them and sleep [in the same room] with them; then they say that how comfortable they were in the drop-in centre”* (Consultant Psychiatrist 1, Male).

In addition, to providing a more comfortable, natural forum for interaction, one interviewee felt that informal mechanisms were valuable for persuading service users to comply with medication regimes:

*“Users group is more important because when I want to say somebody if they have no insight at all for their illness and don’t want to believe for medication I want to start some medication; I try to sell it when we are in the drop-in. With their permission I can call someone and say, ‘You had a similar problem, didn’t you? Don’t you feel different? Then they can talk to each other”* (Consultant Psychiatrist 1, Male).

#### 4.3.8 The role of carers in improving mental health services

Interviewees tended to focus on arrangements for working with service users rather than carers. There were **fewer arrangements, generally, for involving carers in mental health service provision.** One interviewee felt that this reflected the under-investment within adult mental health services, as opposed to services for older adults in support for carers. Another interviewee also commented that carers can be quite neglected and the provision that had existed to support carers in the past, including respite, was no longer available. She also commented on how important it was for carers to be able to meet with other people in similar situations:

*“I remember some years back there used to be a carers group that’s part of the, as an off-shoot of the Day Unit at L centre and I think it’s just if carers can meet other carers who are in similar situations it’s incredibly supportive really; even if it’s just to go to, sort of, offload but carers do not get that break as they used to when people who were acutely ill which, I mean, it is better than people being in hospital for months on end but it does have an impact on other things. We don’t seem to have the respite, as we did a little while back either”* (CPN 2, Female).

However another interviewee, working in an Assertive Outreach Team, commented that *“very few of our clients have families, they have very*

*isolated chaotic lives"* (Social Worker 2, Female).

Arrangements that were in place included:

- Carers' assessments as part of the Care Programme Approach.
- **A well attended and successful carers group** supported by staff from a Rehabilitation and Recovery team
- **Links between staff in a Rehabilitation and Recovery Team and a carers group**, mainly used by African Caribbean men.
- **Carer Support Worker posts** within the Heart of Birmingham area, funded as part of the National Service Framework for Carers. All four posts were focusing on supporting carers from minority ethnic groups; of those one was focusing on African and African Caribbean people.

One NGO provider was establishing **carer support forums** as part of its therapy programme to provide independent support and therapy for carers. The term 'member' is preferred to "carer". This forum was based on recognition that the extended family is extremely important for African and African-Caribbean people.

Various comments were made in relation to the role of carers and the constraints or issues in working with them including:

- **The need for more understanding between families and staff** and a mutual respect for views about mental illness: *"They need to understand the scientific view of mental health. We need their views – the spiritual, mystical thing – and we need to meet in the middle"* (Social Worker 2, Female).

Several interviewees talked about **difficulties in working with carers**. Views ranged from a feeling that *"it is very difficult to satisfy carers, I think"* (Consultant Psychiatrist 1, Male), to a view that families can be hostile towards staff and even abusive.

*"When families come here they can be quite hostile, e.g. always the focus is about the percentage of young black males that end up in hospital. That can be intimidating and it's about having the confidence to address this, say it is an anomaly, you need to talk to us, not shout at us ... We have had some abusive phone calls from families but it's really about speaking to people before a complaint arises. It can be difficult sometimes with families. We don't tend to do many carers' assessments, PCLs do those now. Occasionally, people don't have a carer's assessment"* (Mental Health Nurse 2, Female).

Two interviewees commented that some of the difficulties experienced relate to conflict between carers and the people they care for and that sometimes staff can be put in a difficult position in relation to visits from relatives.

*"We've now got a family room to manage visiting. It can cause issues if staff say that the person is a bit irritable: they may be irritable because of the visit - just because they're mentally ill, they can still make a choice"* (Mental Health Nurse 2, Female).

A further source of tension related to children visiting inpatient wards and staff concerns about *"having small children in a mental health hospital, the focus now is more about containment, in the old days we used to have children visit but it is useful to see how people respond to having children visit"* (Mental Health Nurse 2, Female).

- **Actively maintaining families as a resource for service users:** One NGO provider commented that working with families was vital to ensure that potential issues such as the stigma experienced by the family and the service users' sense of shame are addressed so that the family does not disappear as a resource in the event of a crisis. This work with families includes psychological therapies, complementary therapies; eating together; *"devotional time"* and keeping families *"'in the loop' because they're part of the process, yeah?"* (Independent Sector 1, Female).

*"Extended family is unbelievably important for an African-centred perspective"* (Independent Sector, 1, Female).

In one statutory team there was also recognition that relatives can get *"left out a bit"* (CPN 2, Female). The key worker or care coordinator is the person whose role it is to keep carers and families 'in the loop' by trying to do some family therapy, where appropriate; and trying to facilitate shared and open discussion. Confidentiality was important but one person commented that asking the service user about what can be shared often facilitated better communication.

- **The need to avoid stereotyping and racism** by not making assumptions that black families will or can support service users without help; and the need to create an environment where black families can be encouraged to get help early. This required more cultural competence within the police and the courts:

*"With black families, there are two categories. There's the stereotype - that they will either provide everything for themselves and childcare, but if things fall through, service users can fall into abusive situations. Or there are families who are at risk from the service user and we have left them there because of service users. A lot of people don't have faith in the education system but black people need to own up - say my child isn't right; people are not being picked up. That would reduce the way we come into the mental health system, it would be a choice, not because the person has been picked up off the street by the police. There was a case recently of a man being picked up for his first offence, wearing his*

*ceremonial sword, but the court over-reacted and sent him to Reaside - the high security clinic" (Social Worker 2, Female).*

- **The need to recognise the barriers faced by carers.** One interviewee commented that the very nature of the caring role means that opportunities for respite are limited and when they arrive, carers may choose to meet other needs such as sleep and social support, rather than attending carers groups: *"for the carers groups the very nature of caring means you can't get out. If you have any respite, are you attending a carers group, or sleeping, or having a life. The very nature of a carers group is defunct. Their own needs are basic. It's Maslow [Hierarchy of Human Needs theory]. It's hard to voice that. Carer's energies are so limited – the fight will be for the day to day stuff. So if I was running a carers group, I'd think what do they need – respite. When they're up and running they can be great, they have lobby potential of a group but getting in a position to lobby is so far removed from the day to day reality of caring" (Psychologist 3, Female).*
- **The recognition that, in working together, carers can be very influential.** One interviewee talked about the need for carers to come together as a group and to have an influence. There was recognition that the views of carers are important in shaping service provision and that carers can be a powerful group:  
*"we need their views ... As a group, if they come together, they can influence and say we need more beds etc. ... with carers, we can't ignore them anymore, with the NSF and Carers Assessments, their views are coming more to the fore, but whether they can influence the Mental Health Trust as a body, they can and do. One guy went to the press" (Social Worker 2, Female).*

#### 4.3.9 Other comments

Interviewees were given the opportunity to make "any other comments". This section highlights additional issues of importance to statutory interviewees. It also includes information from the pilot interviews that was not covered in subsequent interviews.

There were a wide range of other comments including:

- **There are staff working within mental health services, who themselves have mental illness. They are an untapped resource.**
- **Improving mental health services requires changes that are broader than cultural competency.** These include an emphasis on engaging people (e.g. through activities) and improving the quality of the physical environment.
- **Risks faced by staff working in mental health services and the impact on**

**staff recruitment and retention.** Three interviewees talked about the difficulties that staff face, focusing, in particular, on in-patient units.

*"Staff [at S house] are doing the best they can. Staff are beaten up; they have hot drinks thrown on them by patients. It is not a safe place overall"* (Social Worker 2, Female).

*"The issue is having staff stay. ICU [Intensive Care Unit] isn't for everybody. There are incidents and there have been incidents here. I hope every day I come in that I'll go home unharmed. Sometimes people become complacent about working on these wards. Although it is about containment and managing risk, it can get very wearing with clients who are very threatening to you. There are issues about recruiting and people going off sick"* (Mental Health Nurse 2, Female).

- **Issues relating to medication.** There were a series of issues relating to medication. Many of these arose in response to feedback to interviewees about issues highlighted by service users and carers. This feedback included a complaint by one service user who was given a Depot injection by a male nurse in a way that she described as abusive and degrading. One interviewee responded saying *"I've witnessed Depot's being done. If someone says they don't want a male nurse, we'll get a female in. This is routine and we will ask if they mind the gender of the person"* (Social Worker 2, Female).

Another issue arising from focus groups was concern voiced by carers about medication. Several service users said that **they valued having medication**, although a couple talked about it making them more aggressive. However some service users and carers in particular, were concerned about the side effects of medication, but reported that when they asked consultants about these effects they were told that their symptoms were unconnected to the medication. They also talked about feeling that the people they cared for were 'guinea pigs', being 'experimented on', in terms of medication with potentially serious side effects and that this happened because they were black.

These comments were fed back to interviewees from statutory organisation. One interviewee commented that alternatives to medication need to be available through an African Centred counselling services or by the NGO sector. Another commented that side effects were serious issues that need to be picked up and that there are **concerns about the influence of drug companies on mental health service provision.**

*"Weight gain as a side effect is a big issue – and it's massive weight gain, as much as four stone so it is a big issue for women clients – that's alanzipine and the big one is clozapine, where you need regular blood tests where the side effects can literally be death. ... The reason psychiatrists*

*may say that it is not drugs might be to do with the negative symptoms of schizophrenia – lethargy, etc. But there are big issues for me about the pernicious stranglehold of drug companies on mental health services – we have drug reps coming and providing a meal for the team and they sit around and eat food and hear about the drug ... in any other company it would be unacceptable. And nearly all the research is paid for by drug companies so that's why you won't find anything being researched that is not medication – research on counselling” (Social Worker 1, Female).*

- **Concerns about misdiagnosis.** Two interviewees raised concerns about diagnosis. One questioned the diagnosis of schizophrenia for one of her clients:

*“Enrol have done some research which showed that white patients had a range of diagnoses and all the black patients were diagnosed as schizophrenic. ... I have a client who would be sectioned every Christmas – I referred her for CBT [Cognitive Behavioural Therapy], she didn't go back into hospital for years. Her diagnosis was schizophrenia and she was being treated with Depot but, to me, it looked like bi-polar and I wondered why she was diagnosed with schizophrenia” (Social Worker 1, Female).*

Another suggested that there should be more comparative research focusing on the process of diagnosing illness between the UK and the Caribbean. He felt that drugs play a big part in diagnosis and commented that people who are under the influence of skunk and cannabis can appear to be delusional at the time they are taking the drugs. He felt that research comparing perceptions of drug use and mental illness between the UK and Caribbean islands would be useful (CPN 1, Male).

## 5.0 Summary of the overall findings

This section summarises the findings under major thematic headings as follows:

- The role of NGOs in service provision including barriers and facilitators to this role.
- Understanding mental health.
- Accessibility of services.
- Experiences of using services.
- Facilitators and barriers to developing culturally appropriate services.
- The need for mental health service provision that is targeted to African and African Caribbean people.
- Roles for service users and carers.
- Actions that should be taken to improve service provision.
- Acknowledging the stress of working in mental health services.
- The role of family & support network.
- Other comments.

### 5.1 The role of NGOs in service provision

There is general agreement that **NGOs have a role to play in mental health service provision**. There were examples where teams are already working successfully with NGOs and were aware of the roles that they are fulfilling. Furthermore, NGOs were perceived to be well equipped to play a part in mental health provision because traditionally they are the organisations that pick up unmet needs and are trusted by communities so there is less stigma for people wishing to access support via NGOs.

However the research highlighted various **barriers to joint working** including the following:

- Reports that some staff within the Mental Health Trust felt threatened by NGOs and that sometimes a sense of being in competition with each other is exacerbated by Government policy and managers.
- Perceptions by statutory organisations that in spite of the recognition of what NGOs do have to offer, in some areas they are under-skilled; they are often not governed by codes of conduct and protocols which inform professional practice.
- The Mental Health Trust itself may not be well-placed to co-ordinate partnership working with NGOs: in some cases communication within the Mental Health Trust itself is problematic, notwithstanding partners outside of the Mental Health Trust.
- There is insufficient up-to-date information about NGOs.

- Sustainability of NGOs; the insecurity of NGO funding is not perceived to be a good basis for partnership working and can be a distraction for NGOs themselves. **Sustainability is an issue.** The research indicates a **high turnover** of voluntary and community organisations working with African and African Caribbean communities; and a **reliance on volunteers**.

Changes which are required to facilitate and maximise opportunities for joint working could be maximised include:

- **A need for adequate funding and investment in NGOs.** The research indicates a lack of capacity in relation to funding (including having an understanding of what makes a successful funding application). The majority of organisations surveyed had a person within their organisation responsible for funding applications but this person often had another role. Tight timescales, the large number of funding sources and an emphasis on short-term (one-year) funding exacerbated the problem. Statutory funding was perceived to be the most important source of funding but many organisations were relying on more than one main funding source. One organisation was funded by six different agencies, each requiring funding to be renewed annually. A small number of mainly African NGOs relied on voluntary donations.
- Service re-design processes, the commissioning strategy for mental health, and opportunities to review grant funding, could provide scope for being more creative in meeting the mental health needs of people from African and African Caribbean communities.
- The need to address **communication barriers** and develop an understanding for joint working. NGOs need to be less suspicious of statutory agencies and recognise the constraints within which they work. There is a need to agree clear and shared priorities. Some managers in statutory agencies need to foster a more inclusive culture.
- The need to develop more up-to-date **information** on NGO services. The research found that NGOs tend to be **offering a broad range of activities/ services rather than focusing on mental health** and are often **not primarily focused on people with mental illness and their carers**. This is particularly true of NGOs working with African communities. Mental health is defined more broadly than mental illness, and services offered by more than half of the NGOs surveyed include advice about benefits, advocacy, accompanying people to visit a doctor/nurse, advice about housing and resettlement, support for carers, counselling, support groups, social events, support for children and young people through for example, youth groups, educational support, after school clubs and signposting to other services. Services are advertised mainly through community-based non-statutory venues, such as shops and community centres and through word of mouth and, to a far lesser extent, through GPs, and statutory organisations.

## 5.2. Understanding mental health

There are differing **understandings of mental health** between people working in commissioning, providers, voluntary and community organisations, carers and service users. Some providers talked about the importance of understanding beliefs about mental health and mental illness, but a medical model still prevails.

There were some common themes in the ways in which mental health was conceptualised by service users and carers. One was **the role of trauma, loss and significant stress and a treatment response that was perceived to be inappropriate**. For example, several service users and carers talked in terms of a significant event in their accounts of their own mental illness or of that of the person cared for. In addition, the response to this event by services was also seen to be significant. One example was the female service user whose parents died within a year of each other and who presented at accident and emergency services because she was feeling mentally unwell. She was not offered counselling, was hospitalised and had been dependent on medication ever since. Another example was of a mother who sought help from her GP after her daughter became withdrawn following a Duke of Edinburgh course at which she was systematically bullied. Again only medication was provided. The daughter was referred to mental health services and responded angrily and had also been in the mental health system ever since.

The focus within the Mental Health Trust on people with severe and enduring mental illness meant some people were falling 'through the gaps'. For example, there was reported to be a high incidence of post traumatic stress disorder within Heart of Birmingham which was not adequately being picked up. For example, although asylum seekers who had witnessed family members being murdered, or who had left their home country in search of peace, had been offered counselling and had found it useful, some were still experiencing flashbacks.

Furthermore, these experiences were being compounded by **the psychological impact of being a black person living in or coming to England including issues relating to identity, belonging, pressures to assimilate and status as a refugee or asylum seeker**. A wide range of issues were highlighted in connection with the pressure to assimilate, not just by asylum seekers and refugees but by other interviewees including carers, NGOs, and statutory service providers. This included racist attitudes with some GPs being highlighted as the main culprit by asylum seekers and refugees, although other service providers were also mentioned.

The pressures of trying to fit in or integrate were highlighted by a variety of respondents. One independent sector provider commented that the pressure to assimilate can lead to the development of proxy self and psychosis. Several service users and carers talked about the clash of cultures within England and

the difficulties of trying to fit in and maintain traditional values.

Particular stresses related to being an asylum seeker or refugee included feeling that they did not belong in England; losing your home; loss of status; not being able to work; only being able to buy food with vouchers; insecure housing and homelessness; and despair when expectations of a better life are not fulfilled.

**Links between mental illness and drug use, including khat, were highlighted by several carers** and a minority of service users. Illegal drugs and khat were widely held to impact on mental health. Chewing khat was identified as a strategy that some Somali's adopted to try to cope with inner conflict. The interaction between illegal drugs and medication was highlighted by many respondents. Some carers reported that the people they cared for refused to take their medication because of its effects when combined with khat and also felt that dosages were too high. One consultant psychiatrist commented that people who use illicit drugs tend to be prescribed high doses of anti-psychotic medication. Statutory interviewees also highlighted the links between mental illness and drug use, but extended the connections to include social deprivation and crime.

**Spiritual explanations for mental illness** were offered by several carers and a small number of service users **including possession by entities (or djin), magic and curses**. The importance of understanding spiritual beliefs was highlighted by many service providers, for example, understanding that when someone talks about the spirit of God speaking to them this does not necessarily mean that they are hearing voices. However faith-based leaders within the Somali community are concerned that in the UK, and within the health service, there is insufficient expertise to determine the cause of mental illness. Where this is due to djin (ghosts or spirits) or magic and curses then a spiritual cure is required. Somali people with mental illness are reported to be approaching spiritual leaders for help. One person talked about seeing two or three people every week. Amongst key members of the Mental Health Trust it was generally agreed that respecting service users and carers views **about spiritual beliefs**, especially if it facilitated health improvement should be encouraged. It was commented that *"Some people in Trinidad would go to the faith healer first and then the GP if that didn't work"* (Consultant Psychiatrist, Male 2).

Whilst agreeing with this approach one of the key member's of the Mental Health Trust expressed concerns about a lack of any model for this, and mentioned that there is a *"need to source the resources the Trust can use and support access to them"* ( Service Director, Female 2).

The Mental Health Trust's staff generally agreed that one of the main issues is how services outreach into places where service users feel comfortable, the Mental Health Trust could not provide those services but it could support

access for their spirituality.

**The importance of resources, both internal, such as resilience, faith, and external support from family and friends** was emphasised by carers who had faced similar pressures to those they cared for; and by NGOs emphasising the importance of extended family. In contrast, stigma associated with mental illness was reported to be an issue within the Somali and African Caribbean communities as is family breakdown linked to poverty, unemployment and the impact of these on male roles.

### 5.3 Accessibility of services

The resident population of the Heart of Birmingham Primary Care Trust comprises of the following: 51.7 % from Asian communities including Bangladeshi, Pakistani, Indian and other Asian; 11.8% who are African, Caribbean or other black communities; 0.6% from Chinese communities; 4% people describing themselves as mixed race; 29.2% white, including white British, Irish and other white; and 1.3% from other ethnic groups (Heart of Birmingham Primary Care Trust, 2005).

However, in terms of utilising the Mental Health Trust services proportionately, more white people, followed closely by people from Asian background than any other ethnic group were seen as in-patients, out-patients or attended day care at some stage during the data collection phase of this research (August 2005 - August 2006). Whether the high utilisation of the Mental Health Trust amongst the white and Asian communities in Heart of Birmingham Primary Care Trust (HOB PCT) are an indication of their higher morbidity rate or a different help seeking behaviour needs exploring. Table 3 provides detailed information.

Table 3: All service users who were seen as inpatients, contacts, outpatients or day care at some stage during Aug 05 to Aug 06			
Residents of HoB PCT by ethnic group	Accessed any Services by the Mental Health Trust		% HOB PCT population as a whole
	Total	Percentage	
Asian communities	2,573	31.2%	51.7%
African, Caribbean or other black communities	1251	15.2%	11.8%
Chinese communities	16	0.2%	0.6%
Mixed race	234	2.8%	4.0%
White	2,722	33.1%	29.2%
Any Other Ethnic Group	438	5.3%	1.3%
Not Known	704	8.5%	1.4%
Not Stated	298	3.6%	
Total	8,236	100%	100%
Source: Birmingham & Solihull Mental Health NHS Trust PAS system (ePEX)			

In terms of patients detained on admission, the picture is very different and is in line with national data, where African, African Caribbean or other black communities are disproportionately overrepresented.

Table 4 shows the ethnicity, total number of in-patients, number and proportion of all service users' resident in HoB PCT who are **detained** under the Mental Health Act at some stage during the data collection phase of this research (August 2005 - August 2006). Data from this table indicates that one third of in-patient populations are detained, and when compared with the total number of inpatients, the proportion of detained patients is highest amongst African, Caribbean or other black communities (39%), followed by Asians (36%), and any other ethnic group (35%), whilst white people are proportionately detained to a lesser extent (20%). The proportion of people detained on admission amongst Chinese communities and those who did not state their ethnicity was also very high, but due to the small number of patients, it should be interpreted with caution.

Such high rates of detention in African, African Caribbean and other black people compared to white or Asians population may in part be due to different patterns of help seeking behaviour, different presentation at early stage, late detection by GPs, and late intervention.

Table 4: Total number of inpatients, number and proportion of service users who were detained and inpatients at some stage during Aug 05 to Aug 06 in HoB PCT				
Ethnic Group	Detained and inpatients			Percentage of HoB residents
	Detained on admission(s)	Total inpatients	(%of total )	HOB PCT population
Asian communities	72	201	(36%)	51.7%
African, Caribbean or other black communities	82	207	(39%)	11.8%
Chinese communities	3	4	(75%)	0.6%
Mixed race	9	31	(29%)	4.0%
White	52	256	(20%)	29.2%
Any Other Ethnic Group	8	23	(35%)	1.3%
Not Known	1	4	(25%)	1.4%
Not Stated	5	8	(62.5%)	
Total	232	734	(31%)	100%
Source: Birmingham & Solihull Mental Health NHS Trust PAS system (ePEX)				

There were variations amongst African and African Caribbean service users and carers in the range and type of services accessed. For example **African Caribbean service users were accessing a wider range of services than African service users**. The former tended to emphasise services provided by NGOs (excluding housing support), hospital, community and day care services

including support from home treatment and assertive outreach on a relatively equal basis. They tended to mention support from GPs and family less frequently.

**African service users tended to make more use of support from family, friends, voluntary organisations (mainly faith based) and GPs** than statutory services. When prompted about statutory services, many were not aware of these.

**Similarly African Caribbean carers tended to emphasise a wider range of services than African carers.** The former focus on community-based mental health services and support including early intervention and, to a lesser extent, in-patient services and GPs. They talked more than their African counterparts about support they accessed for themselves: carers groups were felt to be important. African Carers tended to talk about the importance of faith and faith-based support and about the absence of support.

**Access to NGOs was mainly via self-referral** but there were also referrals from GPs or consultants, CPNs, social workers, therapists and other professionals.

**Barriers to access include:**

- **Limited awareness of services available**, for instance, in relation to statutory services, support for carers; services for asylum seekers and refugees among statutory providers.
- **Racism** and prior experiences of racism, alongside high profile media reporting of the experiences of black people together with the history of misdiagnosis and over-representation of black people in the psychiatric system which had made people wary of seeking help and/or wanting to get out of the system as soon as possible, according to one NGO.
- **Limited availability of interpreters** was identified by people from Congo and Somalia, along with a reported lack of willingness of some professionals to use interpreters. For example, some GPs are reported to be reluctant to arrange interpreters. There are also different views on whether or not interpreters should be used for psychological services, which means that people who can't speak English are often denied access to such services. However, there is at least one model where psychological services were being provided through an interpreter for asylum seekers.
- **For newly arrived communities there should be a bridge between statutory services and communities.** Young women within the Somali community are perceived to be particularly disadvantaged and isolated and are not accessing services.
- **Out of hours support** was a major barrier to accessing services, particularly in the event of a crisis.
- **Other specific barriers facing asylum seekers** include perceptions within the Mental Health Trust that asylum seekers may falsely claim mental

illness as a route to getting refugee status; and eligibility criteria, which emphasised the severity of a diagnosis (e.g. psychosis), rather than symptoms that are severe and enduring.

**Facilitators** include advocacy and other support for service users by NGOs.

## 5.4 Experiences of using services

**Service users tended to identify more positive aspects of using services than carers.** Aspects of services that tended to be valued by service users include:

- **Support from statutory services in helping people in their recovery**, for example counselling services for asylum seekers, and medication, as a means for some service users to feel more at ease with themselves, and in their words, better to cope with memories and emotional issues.
- **Support provided by NGOs with specialist expertise in working with black and minority communities** including supportive, person-centred approaches which maintain people's independence; providing encouragement, advice, care and places where people can meet other people with mental illness, which can help them to feel less isolated.
- **Practical support** such as help with post, financial advice, childcare, the provision of food, shelter including in in-patient services and re-housing within the community
- **Social support** through activities provided by NGOs, faith based groups and social workers, was felt by service users to be important in helping people to socialise and feel part of the community. This was also highlighted as important by African Caribbean carers.

No positive comments were offered by African carers. **African Caribbean carers**, who tended to have contact with a wider range of services (including statutory services) than African carers, **valued being treated as part of a care team and having other members of the care team (from mental health services) aware of and willing to offer support for the carer.** Several commented that the support provided went beyond caring and that there were lots of positive aspects.

Examples of negative aspects of mental health services tended to be more varied. Common themes included:

**Racism and discrimination.** This included specific examples of racism by GPs and other professionals, and how racism had become covert. More widely, it reflected the view that the involvement of the police in mental health services criminalises black people through the use of handcuffs or heavy-handedness when people are sectioned. Having said this, **service users offered mixed experiences of the police.** One female service user talked about being put in a police cell as a terrible experience; two male service users talked about being "treated good" by the police, one when he had burnt his house down and

another when he had “stab a lady”. There was also a sense of ethnic **communities being in competition** with each other and a concern that certain minority groups get an unfair share of resources. Staff debated the importance of “*the pre-cursor to a person’s mental illness*”, and factors already present prior to the onset of mental illness versus when “*they become ill and their negative experiences*” when they are in the system.

**Insufficient care and respect for individuals in service provision**, e.g. illustrated by attitudes of staff (for example, in supported housing, in hospitals); inadequate care; insufficient provision of activities for people in inpatient units; poor attention to personal appearance; not offering culturally-appropriate food.

Issues relating to **continuity of care** (e.g. for service users, this focused on having to talk to different members of staff and particularly when this means having to repeat distressing experiences; for carers it related to the breakdown of support in a crisis when this was ‘out of hours’).

**Concerns about medication** included a strongly held **belief by carers that some black people were ‘experimented on’ and used as ‘guinea pigs’** in terms of treatment with medication; **concerns about the side effects** of medication, some of which could be fatal, and the lack of willingness of clinicians to discuss approaches to dealing with these; **concerns that doses are too high** for people from Somalia who are not used to taking anything stronger than Diazepam; issues relating to side effects experienced **when people combine illicit drugs and medication** which may lead them to choose to only use the illicit drugs (e.g. khat) rather than medication; concerns about the **lack of available alternatives to medication**.

**Limited support for carers**, some of whom are, themselves, suffering from poor physical and mental health.

## 5.5 Facilitators and barriers to developing culturally appropriate services

Culture was widely recognised to be important. Culture determines what is considered to be normal, acceptable behaviour and what is considered to be strange behaviour. Misunderstandings relating to culture can lead to misdiagnosis of mental illness and presenting “symptoms”. However, there were different views about what culturally-sensitive services would look like, reflecting the multi-faceted nature of culture.

Culture can mean the cultures of service users, of staff within the Mental Health Trust (the majority of whom are white European) and the wider “host” culture. One independent sector provider suggested that there is a need to work towards an ideal culture because current notions of culture, particularly for African-Caribbean people were rooted in slavery and colonisation. Several

participants talked about the need to move away from the dominance of expert led, medical and custodial models of care. For some, the emphasis was on more dialogue between staff, service users and their families and a sharing of beliefs and cultures.

For others there was a need for alternatives (e.g. a social model of mental illness):

*"Mental illness is a social problem, I don't think it's necessarily an individual problem, it's a social problem. I mean there's lots of things that can make people go off their head; if they haven't got proper accommodation, if their house is leaking or if their partner's gone off, or if there's a bereavement or divorce; all those issues can make people just flip, you know what I mean?" (6A, Female Service User).*

One independent sector provider talked about African-Centred models of mental health and mental illness. Although the phrase "African-Centred" was not used by other participants, there was some agreement about the principles of the model. Several participants, including service users and black staff, talked about their experiences of wanting to feel accepted in Britain. Examples of racism were presented by many participants. The struggle to assimilate was widely described. Within an African Centred model, the pressure to assimilate can lead to psychosis. Statutory interviewees talked about this in terms of the origins of disassociation having their roots in experiences of alienation, social deprivation and pathological degrees of stress, which may span several generations. Several participants also commented that black people are often viewed as dangerous within the host culture and within mental health services. A number of key members of the Mental Health Trust stated that people want and need good healthcare and good services, not necessarily culturally-based. Where services are poor and short-staffed, where people are not respected, listened to and treated as an individual on the basis of their own merits etc, all communities will, as a result, not get a good service. One summed up this point as:

*"Matching skin colour to skin colour (like-to-like) is a crude attempt to try and provide people with exactly what they want. I can walk into a room of white people and am the only black person there it is uncomfortable. But like can be comfortable. Beyond that it is the communication. There are things in my culture (when growing up) that certain other cultures would not understand but people still need to be treated as an individual. It is the same with youth culture; they develop their own culture and language, such as texting, but it doesn't matter what colour they are" (Service Manager 3, Male).*

It was agreed by all key members of the Mental Health Trust that is more important that a staff member communicates and understands transparently what a person is saying and *"who the person 'is'; it doesn't have to be a black*

*person*". It is not particularly to do with language or colour, "*it is about the person*", whether they are white, black or Asian, etc, "*it is missed time and time again*".

Factors which facilitate the development of a culturally-sensitive service include:

- **Having a communication strategy to include mental health promotion.** A proper co-ordinated strategy between all parties involved in the provision of mental health services. A communication plan to provide information about factors effecting mental health, how to recognise early signs of mental health problem, what help is available, and how the services work. This should target the whole population and the NGO's, community settings including places of worship, work places, and schools could all play a part.
- **Having a diverse workforce.** Diversity includes having black psychiatrists and therapists; it includes having black female psychiatrists and therapists (as well as males) and it includes the need for staff with an understanding of the experiences of service users. Currently there is a perception that the majority of staff, particularly those staff responsible for decisions about diagnosis and treatment are white, male and middle class. However, several participants mentioned champions within the staff team (e.g. black consultant psychiatrists) and valued the contribution made by black staff within the workforce. The workforce profile of the Mental Health Trust (Appendix 7.1, 7.2 and 7.3) indicates that the proportion of African, African Caribbean and Mixed black population is well represented. In fact the percentage of the overall workforce from this community is twice as high as the total Black population in Birmingham (15.8% versus 7.86%) and 33% higher than the Black population in HoB PCT (15.8% versus 11.8%). However, In terms of professional breakdown about 21% the workforce within this group are nurses, 18% assistant nurses, 6% Managers, and only 3.6% are Medics, and 3.2% Psychologists.
- **The Mental Health Trust was widely perceived to be very willing to address cultural needs.** The existence of the Diversity Directorate and the Diversity Strategy were seen as evidence of this willingness. However, this willingness was sometimes constrained and needed to be backed up by investment and targets.
- There may be **opportunities provided by the national and local policy framework**, e.g. outcomes highlighted within the DRE; service re-design and race equality impact assessment processes.
- **Services are reported to be evolving to respond to cultural needs.** Several examples were offered. **Assessment processes** provide scope for culture to be taken into account including dietary requirements, religious needs, social and housing needs, language needs and belief systems. **New posts have been created**, e.g. a staff member had been recruited to ensure that

spiritual needs are met, and there were examples of spiritual practitioners being brought into hospital to work with service users; and one in-patient unit had recruited an activity nurse to provide opportunities to engage people. **Teams are trying to change the way they work** to be more responsive to the needs of service users and carers, e.g. one Rehabilitation and Recovery Team was regularly working with NGOs; one Assertive Outreach team was developing creative ways to engage people who traditionally have fallen through the 'gaps' - people who were reported to find mental health services oppressive - including helping them get housing; helping with decorating; going with them to relevant festivals, etc. Some African Caribbean carers talked about feeling that they were working in partnership with statutory agencies. These carers were part of a carers group supported by staff from one statutory team. Carers from a group without this direct link to statutory services were less positive.

- **NGOs, and the Frantz Fanon Centre were widely perceived to play an important advocacy role.**

Factors which hindered the development of a culturally sensitive service include:

- ♦ **The role of the police.** Although some positive comments were made about support provided by the police, by at least three participants, there were several examples offered of the way that the police role criminalises black people with mental health problems, particularly focusing on their behaviour when service users were sectioned. Carer's accounts indicate that they were unprepared for the ways in which police sometimes behaved or were even unaware that the police would be called. Witnessing heavy-handed police behaviour added to their own distress and the distress of the person being sectioned. Furthermore, examples of black people with mental illness dying in police custody were present in the minds of carers and the behaviour of the police, therefore, has the scope to reinforce or, in one case, change fearful attitudes.

Carers' concern about the involvement of police during sectioning was raised with the key members of the Mental Health Trust during one of the focus group discussions. Interviewees acknowledged the complexities of the process of sectioning, especially if the person was perceived by the family or health care professionals as being at risk of harming themselves or others. There was **a consensus view surrounding the involvement of the police at this stage**, and the fact that, in some cases, police involvement was inevitable.

A couple of participants stated that if the user/carer knows the police will be there it can be very distressing and it can become dangerous for all involved. They believed, however, that one should not generalise with

issues such as these, and *"A person is more likely to ask for less help if they knew this"* (Consultant Psychiatrist, Male 3). This view was challenged by another member of the group saying that the objection *"may not be that the police are in attendance, but that they were not told"* (Service Director 1, Female).

Acknowledging the last point, another member of the focus group stated, *"How are you supposed to deal with this; it is very complex. If you advise them the police will be present they could prevent you from coming in or they could leave. If you do liaise with the family, but not the service user, that is an impossible position to put the family in. If you tell the service user they either come to hospital or the police will be called, then that is coercion"* (Service Director 2, Female).

This was echoed by another member stating that *"I really don't know what the solution is. Also it is to be remembered that the Mental Health Trust deals only with severe and enduring mental illness"* (Consultant Psychiatrist 2, Male).

It was concluded that all that can be done is **to attempt to prevent it from getting to that stage.**

- ◆ **Constraints on the eligibility of psychological therapies.** These include limiting definitions of severe and enduring mental illness. The focus of the Mental Health Trust on severe and enduring mental illness does not sit easily with the way in which mental health is understood by service users and carers and can exclude people whose symptoms of mental distress are not classed as severe and enduring (e.g. people with Post Traumatic Stress Disorder). Several service users and carers provided examples of experiences that they felt should have been treated with psychological therapies (e.g. crisis linked to bereavement, racism, pathological stress) but were instead treated with medication. In addition, people who cannot speak English are excluded from some psychological therapies. However, there is at least one example where people whose symptoms are severe and enduring (e.g. asylum seekers) are getting psychological support which included the use of an interpreter. A view held amongst some Mental Health Trust staff that language was one barrier but the staff were not **equipped to deal with the experiences and suffering of refugees and asylum seekers.** However, in response to the constant debates about the inappropriateness of having an interpreter involved in therapeutic process, one of the service managers commented that there was also *"the issue of completely denying somebody a service as you can't speak their language and they can't speak yours"* (Service Manager 2, Female).

The service users and carers concerns about limited or lack of access to psychological services was raised with the key providers. One of the

interviewees stated that, *"A common perception amongst all service users was they didn't get enough psychological therapy. But it isn't just psychologists who provide psychological therapy"* (Service Director 1, Female). This point was challenged by one of the psychiatrists, saying that *"There is a lot of evidence that black people are "falling down the ladder" in terms of getting access to psychological services. A personal opinion of HoB was that there is more ability in HoB that is not being utilised"* (Consultant Psychiatrist 3, Male). He also referred to the racial element and added that there is an issue of **"psychologically-mindedness"** and a tendency to prescribe medication and hospitalisation rather than therapy. This was echoed by another interviewee commenting that *"I know of African Caribbean people who are capable of navigating their way through the system and they do know what's available but if they ask for it they are refused or given an excuse, and they know it is lies"* (Psychologist 1, Male).

A couple of interviewees however stated that this is a complicated issue, and is not just about services failing. An important point is that it should not be assumed that all African communities are the same and should not be perceived as such.

- ♦ **Insufficient diversity within the Mental Health Trust:** it is predominantly white and the dominant view of health and illness is a Western medical model.
- ♦ **Insufficient information about mental health services being provided for people with mental health problems and their families.** For example, service users and carers from African communities are less likely to be accessing community-based mental health services or to be aware of such services, than African-Caribbean service users and carers. However, simply providing information about services is not likely to be enough. There is a need for organisations to act as a bridge between communities (e.g. the Somali community) and mental health services.
- ♦ **Belief systems of service users and their families.** Stigma relating to mental illness; a lack of faith in the system; the fact that a lot of people do not enter the system by choice; and beliefs about the causes of mental illness and appropriate treatment (e.g. spiritual treatment for mental illness caused by djin) were all highlighted as factors which can act as barriers to access.
- ♦ **Models which do not take account sufficiently of the links between social deprivation, pathological stress, racism and disassociation,** which has its origins in deprivation, poverty, education and which can begin long before people arrive in mental health services.
- ♦ **The need to do more to maintain families, carers and communities as a resource.** Family breakdown is reported to be an issue for African and African Caribbean communities. Unemployment and the erosion of the traditional role of men in the family are impacting negatively on, for

instance, Somali families. Furthermore, some carers feel excluded from discussions about the person they care for. Family and extended family are a key resource for African and African Caribbean people and more attention needs to be paid to maintaining this resource. There were few carers groups and at least one carers group for African and African Caribbean people ceased to exist (because its funding wasn't renewed) during the research period.

- ♦ **An over-simplistic approach to culture and stereotyping people.**  
**Insufficient training.** Many staff are having to learn about diversity on the job or from colleagues. Furthermore, cultural competency training should not just be for white staff. There is an assumption that black people know how to work with black people; this is not always the case.  
**Insufficient funding.** A very small percentage of government's budget is set aside for mental health.
- ♦ **The absence of a clear lead from the Department of Health.** There is a lot of talk/rhetoric but it needs to be backed up with sufficient resources and targets (e.g. developing person-centred care can be time-consuming – teams need to be resourced to deliver person centred care). Furthermore, there are conflicting priorities (e.g. an emphasis on reducing suicides and a regressive policy on asylum).

## 5.6 The need for targeted mental health service provision for African and African Caribbean people

Comments by service users, carers and interviewees from statutory agencies tended to approach the issue of targeted services, in terms of either **targeted or mainstream services**. In other words, for some interviewees, from statutory agencies, the discussion focused on ways in which having targeted services was perceived negatively to impact on the scope for mainstream services to become more responsive to the needs of people from African and African communities. These were perceived to include reinforcing the idea that meeting the needs of people from black and minority ethnic communities is not everybody's business but the role of specialists.

For service users and carers there was often a perception that targeted services were vulnerable and that there was not enough of them. This perception was informed by the threatened closure of Frantz Fanon – widely perceived as an important resource by service users and statutory interviewees; and the removal of funding for one of the few carers groups for black carers.

Perhaps the way forward is not an 'either/or' approach, but 'both/and' – an emphasis on **both mainstreaming** through service redesign, links and partnerships with independent/voluntary sector **and targeted provision** for carers from African and African Caribbean communities; or for organisations

to act as a bridge between the Somali community and statutory services; or for services to meet the needs of asylum seekers and refugees.

## 5.7 Roles for service users and carers

There was general agreement that service users and carers have an important role to play in mental health service provision; particularly in terms of providing feedback on services and care. However, some staff from statutory agencies commented that carers can be difficult to work with and can be suspicious and difficult to satisfy.

Existing forums for service users (e.g. User Voice and Patient and Public Involvement Forums) are predominantly white and were not adequately engaging black people. There are some good models for service user involvement including involvement of service users in monthly staff team meetings; involving service users in recruitment; providing informal opportunities for staff and service users to engage with each other including drop-in sessions, opportunities for socialising and eating together.

Carers forums are very limited generally and particularly so for black people. One model that seems to work very well was a carers group, supported by staff from a mental health services team. There is a need for more forums, more publicity about forums and more respite to enable carers to attend.

## 5.8 Service provision improvement

The required actions that service users and carers identified to improve mental health service provision were wide ranging. They include changes that are not traditionally seen as being the responsibility of mental health services including:

- A need to tackle racism, discrimination and conflict within society as a whole.
- Asylum policy means that asylum seekers are struggling with the basics of survival (food, shelter): this is fundamentally linked to mental health and needs to be addressed.
- Better funding for mental health services (based on a social model of mental health – see below).
- The need for a social model of mental health which is less expert-led and which includes actively recognising that service users need support to live and work and be empowered; that they need advocacy, drop in, befriending, social and other activities. The balance of service provision needs to shift from being medically based and relying only on medication to including alternatives to medication and practical support (e.g. with housing, work etc).

Within the current model of service provision there is a need for:

- Better out-of-hours contact.
- More in-patient provision.
- Less rigidity in access/eligibility criteria.
- More direct contact between carers and staff, including more liaison with carers about the person they care for.
- More understanding and empathy for service users.
- Outreach work with recently arrived African communities to ensure people from these communities are involved in accessing appropriate services (e.g. with reference to this piece of research by employing Somali and Congolese outreach workers; by funding centres to act as a bridge between the community and services; by building on peer education work that is already going on).
- The need for culturally appropriate health promotion.

## 5.9 Acknowledging the stress of working in mental health services

In addition to the major challenges for mental health services in relation to developing culturally appropriate provision for people from African and African Caribbean communities, a further challenge is the impact of the difficulties that staff face, particularly those working in inpatient units, for staff recruitment and retention (see section 4.3.9).

## 5.10 The role of family & support network

One theme that has arisen from the research is the importance of social support (from families and communities) in maintaining mental health. Several interviewees highlighted the threats to family and social support including stigma relating to mental health and the impact of social deprivation on family cohesion. The need to invest in families as a resource for service users was recognised by some statutory and NGO providers. However, this sits alongside the limited support that exists for African and African Caribbean carers.

## 5.11 Other comments

A wide range of other issues were highlighted including the following:

- Stigma relating to mental illness was a barrier to service users getting support from their families and communities.
- Improving mental health services is about more than cultural-competency. At a basic level there is a need to fill posts and improve the physical environment.

- Difficulties in recruitment and retention of staff are a barrier to improving mental health services.
- There is a need for collaborative research learning from experiences in the Caribbean (or in Somalia) as many research participants (across the board) felt that mental health problems do not manifest in these countries in the same way as they do in England.

## 6.0 Interpretation and discussion of the main findings

This section of the report discusses the main themes set out in section five, in relation to a review of the literature including national, regional and local reports and papers. Where appropriate, it also incorporates feedback and comments received, and interpretation made by key members of the Birmingham and Solihull Mental Health Trust and PCT commissioners, in response to presentation of the initial findings and recommendations of this piece of research. The themes include:

- Models of mental health and illness.
- The role of NGOs.
- Accessibility of services.
- Limited support for carers.
- Issues relating to medication.
- The need for alternatives to medication, such as psychological therapies.
- The role of family support in early detection and health seeking behaviour
- Consistent policy about provision of mental health services for asylum seekers.
- Funding and support for BSMHT Action Plan on service re design.

### 6.1 Models of mental health and illness

A key theme arising from the research is **the need for a variety of models of mental health and illness**. A model is a framework and associated set of assumptions or perspectives that shape the way a particular issue is viewed (in this case mental health and illness). Mental health services have traditionally been shaped by a Euro-centric, expert-led, bio-medical model of mental health and illness. This model was criticised by many research participants.

Several research participants argued that there was a need for alternative models of mental health and illness, although some felt that the medical model still has a place, but needs to be informed by other models. The main requirement from research participants for an alternative model of mental health is for one that recognises the role that wider determinants of health (e.g. racism, social deprivation, crime, education etc) have to play and takes a whole system approach to dealing with these. It is also important that the model is not expert-led but focuses on being responsive and appropriate, and ensures that communities served by mental health services are involved in shaping the services that are commissioned and provided.

Locally, policy documents such as the mental health service re-design strategy, the draft commissioning statement for adult mental health services and the draft project plan for the Birmingham and Black Country Strategic

Health Authority 'focused implementation site' (see below) all set out visions of services that are responsive, appropriate and based on whole systems approaches. However, at the time of the research, this is something that mental health services in Birmingham are slowly moving towards, and they are not yet there.

The DRE (Department of Health, 2005) sets out an alternative model of mental health. Its vision for mental health services in 2010 is characterised by:

- Less fear of mental health care and services amongst BME [black and minority ethnic] communities and BME service users.
- Increased satisfaction with services.
- A reduction in the disproportionate rate of admission of people from BME communities to psychiatric inpatient units.
- A reduction in the rates of compulsory detention of BME service users in inpatient units.
- Fewer violent incidents that are secondary to inadequate treatment of mental illness.
- A reduction in the use of seclusion in BME groups.
- The prevention of deaths in mental health services following physical intervention.
- More BME service users reaching self-reported states of recovery.
- A reduction in the ethnic disparities found in prison populations.
- A more balanced range of effective therapies, such as peer support services and psychotherapeutic and counselling treatments, as well as pharmacological interventions that are culturally-appropriate and effective.
- A more active role for BME communities and BME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services;
- A workforce and organisation capable of delivering appropriate and responsive mental health services to BME communities (Department of Health, 2005, pp4-5).

Another key element of the DRE was the statement that "*providing equitable care pathways means offering diverse routes to recovery, not a single, pre-determined pathway*" (Department of Health, 2005, p46). To this effect CSIP (Care Services Improvement Partnership) has commissioned a project to develop best practice around addressing barriers to care (of which several are highlighted by this research); and involving NGOs in creating alternative pathways. CSIP is also developing community engagement projects including projects for refugees and asylum seekers, to ensure that specific barriers facing these groups are addressed.

The DRE vision and associated work picks up issues highlighted by the research, including fear of mental health services (reflecting over-representation of black people in the system; poor experiences within the system; and deaths of mental health service users); the expressed need for alternatives to medication; the need for a diverse and culturally competent workforce; and **the need for black communities (via NGOs), carers and service users to have a wider role in mental health service policy, planning and delivery.**

It provides a framework for issues to be addressed and mechanisms for progress to be monitored including an action plan to ensure that senior personnel take personal responsibility for achieving race equality; the requirement that Mental Health Trusts should make public declarations on performance against core standards (such as monitoring progress against race equality frameworks) which must be informed by the views of service users and which will be backed up by inspections by the Healthcare Commission). It states that a 'regular' census of mental health patients will be carried out and identifies new systems for reporting all patient safety incidents, including deaths.

The DRE also states that **Focused Implementation Sites** will be used to facilitate and guide a whole systems approach to change. Birmingham and the Black Country is a focused implementation site for delivering a **programme of developments to improve mental health services for BME people** and has as its three priorities for year one; to build capacity in the NGO sector in order to increase choice and address barriers to access; to improve the information that informs commissioning and service development; and to develop partnerships (e.g. with the criminal justice system) to improve the pathways (or routes by which people from black and minority ethnic communities come in) to care (Birmingham and the Black Country Strategic Health Authority, 2004).

The DRE states that targets should be set locally as part of the achievement of core standards. Several research participants felt that **targets are vital to ensure that the vision is achieved.** The results of the first census (Commission for Healthcare Audit and Inspection, 2005) indicate how vital such targets are as five years short of the 2010 date for the vision issues persist, such as those which prompted this research and which are highlighted in section one of the report. For example, African and African Caribbean people are three times more likely to be admitted to hospital, and up to 44% more likely to be detained under the Mental Health Act (Department of Health, 2005b).

Crucially, the DRE acknowledges the **impact of the following social exclusion on mental health:**

- **Social deprivation** (including financial insecurity, unemployment and a poor built environment);
- **Racism within society as a whole** (which should be addressed – although

this doesn't explicitly include addressing the current discourse on asylum which is driven at least in part by wider Government policy);

- **School exclusions and disaffection with the education system.**

It also comments that these issues *"have rarely been the target of mental health promotion activity ... [and] action to mitigate those factors may decrease disparities in mental health"* (Department of Health, 2005, p60). This is all important but doesn't go far enough towards providing a framework for how mental health services can address these wider determinants of health. Recruiting 500 community development workers by December 2007<sup>1</sup> (a revised target date, since the original target date of 2006 was not achieved) is an important commitment but will be insufficient to achieve the step-change that is required.

The census of inpatients in mental health services also acknowledges the association between social and economic factors and mental illness:

*"There are links between the risk of mental illness, access to appropriate care and outcomes and the social and economic disadvantages experienced by many of those from black and minority ethnic groups. For example many black and minority ethnic groups suffer disadvantages relating to housing, education, employment and social status, living in the inner city and social isolation. All of these factors could increase the risk of mental illness. These factors can also affect the nature of patients' contact with appropriate services"* (Commission for Healthcare Audit and Inspection, 2005, p11).

It does not refer to the role of trauma, bereavement or other loss which were issues highlighted within this research.

Within the literature, studies confirm that genetic and neurological development factors are insufficient to account for mental illness. For example, a study focusing on the increased incidence of schizophrenia amongst the African-Caribbean population in England suggested that schizophrenia research should focus on socio-environmental variables, especially the impact of unemployment and early separation from both parents (Mullet *et. al.*, 2002). **Socio-economic exclusion, as a key factor for understanding** experiences of African-Caribbean mental health service users, had also been highlighted by McLean and colleagues (McLean *et. al.*, 2003). Furthermore, Chakravorty and McKenzie (2002) argue that experience of racism, both as a chronic and acute stressor could lead to mental illness. These factors have been framed as *"mental illness is a social problem"* by a number of participants in the current research.

Other studies also call for research on differences in risk factors for mental illness to focus on a wider range of variables including *"high levels of lifetime exposure to adversity"* (Turner and Lloyd, 2004); racism, discrimination, and

feelings of alienation from the dominant culture (Castle et. al, 2004). McKenzie (2003) argues that there is *"a growing literature showing an association between racism morbidity and mortality. Racism may be important in causing the development of illness"* (McKenzie, 2003, p2). He indicates that racism is common, citing a United Kingdom national survey in which 25-40% of participants said they would discriminate against ethnic minorities; and cites figures from 1999 indicating that 282,000 UK crimes were racially motivated, and that a third of people from ethnic minorities constrain their lives through fear of racism.

He also indicates that **victims of racism in the United Kingdom are more likely to have respiratory illness, hypertension, a long term limiting illness, anxiety, depression and psychosis**. He cites a study of residents in Maastricht, indicating that discrimination affects psychological health and suggests that the mechanisms by which this happens are that racist acts, perceptions of society as racist, and the effects of racism may act as stressors impacting on neuro-endocrine and immune systems (although he also states that the literature on these mechanisms is sparse).

The implications of his analysis, he argues is the need for Government policy to acknowledge racism as a causative factor in illness and to move *"the discussion away from recruitment and access and towards prevention and the impact of societal structures on rates of illness"* (McKenzie, 2003, p2). This focus on prevention (of racism and its impacts) needs to be included in national and local approaches to mental health promotion. This is not explicitly addressed in either the service redesign strategy or the project plan for the focused implementation site.

African-centred models of mental illness directly address the impact of issues such as racism, discrimination and alienation reflecting a clear theme arising from the research on which this report is based; **the psychological impact of being a black person living in or coming to England including issues relating to identity, belonging, pressures to assimilate and status as a refugee or asylum seeker**.

One interviewee commented that a starting point within African-centred models is a recognition that racism exists. A recent conference held in Birmingham on "the use of African centred psychology in the liberation of people of the diaspora" organised by PattiGift African Centred Mental Health Care (2006) highlighted the following:

- The need to **acknowledge that racism exists**; that its impacts are wider than mental health services; and that **racism pervades a wide range of areas that determine health and well-being** including education, employment and lifestyle. For example:
  - ♦ Children from black and minority ethnic groups are three to four times more likely to be excluded from school. Boys from black and minority

ethnic groups comprise 83% of those permanently excluded.

- ♦ 35% of males from black and minority ethnic communities smoke compared to 27% of the general population.
- ♦ The number of women from black and minority ethnic groups who are unemployed is twice the national average (PattiGift African Centred Mental Health Care, 2006).
- **The vital importance of empowerment as a strategy to address the psychology of oppression.** The psychology of oppression is internalised, for example by creating a situation in which African and African Caribbean people believe that their physical survival depends on the oppressor (an example offered was the fear that black people have of the consequences of speaking out against racism – in the research, examples of this were offered by black staff who were reluctant to champion the needs of people from African and African Caribbean people for fear of being seen as partial). Other elements of the psychology of oppression include denying people access to their history and culture; promoting a negative image of their history and culture of black people compared with the elevation of the history and culture of the oppressor; and using division (of which social exclusion could be seen as one symptom) as a form of control, (within the research there were several examples of division), e.g. particular minority ethnic communities felt they have been overlooked in the distribution of resources.
- **The internalisation of oppression can lead to a psychic split in which there are two warring minds: one African and one Western.** This is a theme that was picked up by several research participants, particularly in discourses relating to newly arrived communities, asylum seekers and refugees.
- **The need to support people to develop culturally-sensitive coping strategies.**
- The need for a **unified model of health** which includes recognition of the importance of action, not just at the level of the individual, but incorporating community levels, social organisations and networks, social institutions and structures and society – both national and global. Western psychology is perceived to be individualistic – the person is a self-contained, independent unit in the social system. African psychology, in contrast, sees the individual as being joined with and constantly interacting within the social environment.

It is clear from the research that actions are being developed at a variety of levels (e.g. emerging partnerships between statutory teams and NGOs to address the needs for community and social support; and using mechanisms such as equality impact assessment and diversity training to change institutions). The mental health service redesign strategy (Heart of Birmingham Primary Care Trust, 2005) states that wider determinants of

health such as economic status, housing, employment and education are increasingly recognised for their impact on health and well-being.

Locally, the need for a more systematic approach is recognised. Currently partnerships with NGOs have been instigated by specific individuals within staff teams. There is also a need for the gaps at the structural and societal levels to be more explicitly addressed.

Within African centred psychology, the treatment agenda includes a discussion of social context, history and racism, etc. Although several research participants, including interviewees from statutory agencies, argued that culturally-appropriate mental health should include these wider issues, how they will be picked up in the proposed models is not explicit.

Finally, a key element of African centred psychology involves identifying cultural factors that motivate recovery. Recovery has to be reframed from an individualistic focus to one that incorporates the interaction between an individual, their family and the wider community and recognises that the collective is the most salient element for an individual's understanding of their identity: the African concept of self is based on the idea that *"I am because we are"* (PattiGift African Centred Mental Health Care, 2006). Supporting families and carers; community capacity building; addressing exclusion within the education system, and within the wider culture, all need to be included as key elements of the treatment approach. Commissioners were keen to work with the wider community in seeking to address issues around stigma, social isolation and lack of understanding of how to access mental health services. They mentioned that they are in the process of preparing a city-wide consultation document on Mental Health Promotion Strategy which addresses some of these issues.

## 6.2 The role of NGOs

In the light of section 6.1 the role of NGOs in the treatment agenda is clear. The DRE and other local frameworks all highlight the crucial importance of NGOs in achieving a new vision of mental health services – whether this is the 2010 vision set out above; the vision within the commissioning strategy for mental health services in Birmingham; commitments within the service re-design proposed by the Mental Health Trust; or the priorities in the draft proposal for the Birmingham and the Black Country Focused Implementation Site.

The existing service model was perceived to have many strengths (Heart of Birmingham Primary Care Trust, 2005) including specialised community mental health teams; new acute units (smaller in scale than the old institutional facilities and located close to where people live); a highly skilled workforce; the experience and commitment of NGOs, which includes strong

potential for further development; and a shared vision. This provides a strong foundation for a new model of care which is equitable, accessible, promotes recovery; focuses on positive health and well-being, rather than disease and symptom control; prioritises social inclusion; and ensures appropriate services for black and minority ethnic communities. Actions for ensuring that services are appropriate include:

- Staff training and development programmes to develop cultural awareness/sensitivity to the needs of people from minority ethnic groups. The research has highlighted several areas for inclusion in training and development programmes including training on the impact of racism on mental health; the impact of social deprivation; and the psychological impact of being black and living in/coming to England.
- Employing a diverse workforce.
- Supporting the needs of carers.
- Using assessment processes to ensure that cultural needs are addressed.
- Strengthening partnership working with the NGO sector and building capacity.
- Developing approaches to actively engage people from black and minority ethnic communities, including addressing issues relating to fear of mental health services.
- Ensuring that the views of black and minority service users and carers are heard.
- Using the opportunity of being part of a Focused Implementation Site (FIS) to "mainstream" black and minority mental health issues within general service provision. Within the FIS project plan there is a statement that explicit service plans should be developed with resources identified for local priorities and these should be owned at Board level.

The new model is crucially dependent on bringing together primary, secondary and community care where the role of NGOs is not marginal, but where the NGO sector is viewed as:

- The **preferred provider** for housing, day care, employment and vocational schemes, community based support, re-integration, counselling, advocacy and mental health promotion.
- A **channel for promoting healthy behaviour** (it is not clear why the phrase 'healthy behaviour' is used in preference to the usual 'healthy lifestyles').
- A **source of information about the experiences of carers and patients**.  
*"There is no aspect of mental health care from which external agencies such as NGOs should be excluded, provided the organisation has the capacity and capability to deliver high quality service interventions. Meaningful partnerships between the various agencies are a prerequisite to mainstreaming mental health and in achieving a whole system approach"* (Heart of Birmingham Primary Care Trust, 2005, p22).

These statements, together with the focus on social inclusion are all important. Also valuable is the statement that teams are to be evaluated in terms of their outcomes, relating to employment, accommodation and social participation. The statement that psychological interventions should be expanded with a role for NGOs in this area would be welcomed. The strategy also acknowledges the need for a comprehensive, coordinated approach based on whole system working to addressing race and culture within mental health services.

However there are significant issues to be addressed. The service re-design strategy (Heart of Birmingham Primary Care Trust, 2005) states that less than 5% of the mental health commissioning budget is currently spent on NGOs. Birmingham and Solihull Mental Health Trust has very few partnerships with community organisations and directs less than 4% of its investment in adult mental health services in the Heart of Birmingham Primary Care Trust locality to the NGO sector. Where funding is available, it is time-limited or on a year-to-year basis (although this is starting to change). The majority of services provided by NGOs focus on residential and day care support and counselling, with only 21 NGOs providing services to more than 10 clients. It was unclear how issues relating to the sustainability of NGOs would be picked up and how some of the communication barriers highlighted will be addressed.

The strategy also states that there is concern that existing services for black and minority communities *"are not sufficiently clinically orientated, to make a real difference to the clinical experience of black and minority client groups"* (Heart of Birmingham Primary Care Trust, 2005, p16). It was not clear what was meant by this, in light of the discussion in 6.1 about the need for alternative (i.e. not just clinical) models of mental illness. It also states that the main focus of primary care liaison teams should be on managing the care of people with complex and long term conditions; but as the research has highlighted the definition of severe and enduring mental illness can exclude people with severe and enduring symptoms of distress. Intentions to build capacity to identify and manage mental health problems in primary care through the introduction of primary care mental health workers are clearly important but will not be sufficient to ensure a whole systems approach that acknowledges and addresses some of the issues highlighted above (e.g. the impact of racism; the importance of social context, history, cultural and education systems etc).

Finally, several research participants, whilst welcoming the strategy, commented that they were concerned about the impact of the current financial climate within the NHS for its implementation. The following extract from one of the commissioner clearly sets the scene: *"It is unlikely that the levels of growth in funding that have been available to the NHS in recent years will continue and as you know there has been considerable financial*

*constraint in the last year and will be again next year as the NHS seeks to balance its finances across the country. In the circumstances we will need to identify the greatest need, potential costs benefits and to look to redesign services by making savings elsewhere and redeploying them".*

### 6.3 Accessibility of services

National policy frameworks (Department of Health, 2005) provide some scope for addressing **barriers to access highlighted within the research**. Barriers to access include the lack of interpreters, racism, out-of-hours support not being available, and specific barriers facing newly-arrived communities and asylum seekers.

Language barriers and wider communication problems (e.g. for people with learning disabilities) are to be addressed via a CSIP project to share examples of good practice about communication and knowledge sharing over the world wide web. In addition, NHS Direct will provide a national interpretation and translation service to enable all NHS Mental Health Trust to access a telephone based interpretation service; and a translation service and access to British Sign Language interpreters. No date for the implementation of this service was specified in the document.

One tool that could be used by commissioners and service providers to address barriers to access and inequalities in outcomes for African and African Caribbean communities is to look at how equitable services are. Health equity audits can be used to identify whether services are distributed fairly, in relation to need or inequalities in outcomes. The current priority within Government policy attached to tackling inequalities in health means that agencies are measured, not just on their general performance, but on their actions to 'close the gap' between those with the best health outcomes and those with the worst health outcomes. This means that agencies need to be targeting service provision more closely. Health equity audits can be used to identify actions required to 'close the gap' and these might include changing the distribution of resources to better reflect the needs of a target group.

In response to emerging conclusions and recommendations, commissioners commented that any health equity audit would need to address the whole community and not just one or two groups. The recommendations suggested that health equity audits should be carried out on the basis of the distribution of particular *services* (e.g. psychological services), relative to need (e.g. as measured by disparate outcomes), and that actions which will 'close the gap' in outcomes need to be identified and implemented.

Closely linked to a discussion about barriers to access is the need to understand existing pathways [or routes into mental health services] for African and African Caribbean service users. Bhui and Bhugra have revisited

a model of pathways into care developed by Goldberg and Huxley (1980, cited in Bhui and Bhugra, 2002). The original model illustrates that to reach specialist care, a patient needs to pass through a series of referral filters and that **GPs have a crucial role** in appraising people presenting for help and deciding whether to refer them to psychiatric services.

However, Bhui and Bhugra (2002) argue that patterns of health seeking vary across cultures and this needs to be recognised. There were also variations according to gender with black women being less likely to know what they want from their GP; to make multiple requests of their GP; to leave a primary care consultation without a follow-up appointment; to be less satisfied with the consultation; and to self-refer to accident and emergency departments compared to white women.

African and Caribbean people reportedly bypass the traditional GP filters and access psychiatric services and forensic services via accident and emergency departments, the police and criminal justice systems. The ways in which black people are brought into the service (e.g. the involvement of the police and the lack of proper communication about this at the point of section; the use of force and the criminalisation of black people) were all themes arising from the research.

Bhui and Bhugra (2002) argue that there is a need to strengthen care pathways by exploring the role of the NGO sector, traditional healers, and specialist mental health services/psychiatrists, in referring people to care through the traditional filters and not via the police and criminal justice systems.

Within the research there were different pathways to care for people from African and African-Caribbean communities (section 4.2.1 provides some insights into this, although its focus is more on the range of services used than on pathways to care). Within African communities, including people from Congo and Somalia, there are differences between asylum seekers and refugees and those with citizenship.

Comments indicate that the groups highlighted by Bhui and Bhugra (2002) – NGOs, traditional healers (faith groups) are important in pathways to care and could usefully be included in the model. There was use of some of the traditional pathways (i.e. GPs) particularly for asylum seekers, but comments indicate that these pathways were sometimes problematic. Presenting to the GP did not always lead to a satisfactory outcome for service users and carers. Racism amongst some GPs was a barrier reported by asylum seekers. Responses by GPs that were perceived to be inappropriate (e.g. to symptoms of mental distress following trauma) were also an issue.

Bhui and Bhugra (2002) highlight differences in rates of detection and referral of people with mental disorders across ethnic groups within primary care and suggest that these are likely to be influenced by variations in professional

practice and local service configurations, as well as by the culture of the presenting person. Asian GPs were reported to be poor detectors of morbidity among Asian patients and, they argue, the difficulties of assessment by Asian GPs may not be restricted to Asian patients. They argue that the cultural views of practitioners can influence assessment and clinical management of disorders, and has not been adequately addressed. The need for training for all GPs in cultural awareness and the introduction of cultural awareness and mental health training to GP training curricula was highlighted in an early policy document but it is unclear what action has been taken on this (Department of Health, 2003b).

The research found that people from Somali communities were not tending to access mental health services (and were not always aware of such services), but were accessing support from faith-based community leaders and NGOs. They were also accessing support via GPs and this raised questions as to how GPs were approaching detection of mental disorder among Somali communities. However the new training programme and financial incentives provided to GPs for mental health screening and the appointment of CPNs as gateway workers, as part of the implementation of the service redesign, is a welcome development. It is hoped that this new funding and pathway to care not only improves early detection, but also facilitates provision for treating people suffering from stress, anxiety, and mental health distress at primary level.

A number of actions are required to improve the accessibility of services including a whole system approach to cultural awareness training (including primary care); and an increased role for NGOs, not just in service delivery, but in referral.

Bhui and Bhugra (2002) cite Harrison et al (1988) as recording that 40% of African Caribbean people made contact with some voluntary and community agencies in the week preceding admission compared with 2% of the general population. They argue that mental health professionals need to pay greater attention to the role of schools, places of worship, traditional healers and NGOs. A role for NGOs in service provision, health promotion and dissemination of information is envisaged and this could be strengthened to include a role as *"the most appropriate and least stigmatising source of help for black patients"* (Bhui and Bhugra, 2002, p27).

This was a theme, within the research arising from focus groups with Somali people. Faith-based community leaders were arguing for more dialogue between themselves and statutory services and other participants argued that there is a need for organisations to act as a bridge, between the community and statutory services.

## 6.4 The role of family, friends, and network support in early detection and health-seeking behaviour

Bhui and Bhugra (2000) cite the work of Cole et al (1995) as having demonstrated that people who enter care in a way that is coercive (e.g. via compulsory admission, admission under section 136 of the Mental Health Act 1983, via the police rather than via the GP or other first contact with health services) tend to lack resources such as supportive friends or relatives, or relatives living close by, or are more likely to be single and that it is the absence of such resources that is significant in people who access care in this way, rather than ethnicity. Findings from this research echo Cole's findings particularly in relation to the need to enable families to maintain contact and creating a supportive environment. The following quotes from one of the focus group discussions also sums up the importance of family support for early detection

*"My experience of working both in Aston – a highly populated African Caribbean area and Small Heath – with high Pakistani population is that the pattern of mental health illness is the same in both of these inner city areas. However in Small Heath, most of our patients either live in an extended family set up or have close family network, so if the patient does not have insight about her or his illness, those living around him/her are able to see the changes and detect the problem and bring to the attention of GPs" (Nurse Manager 2, Male).*

The point raised above suggests early help seeking, either by self or by the family member, could, not only, help early detection at primary level, but also could facilitate management and the recovery process through having a supportive environment in the form of family. According to Singh and Burns (2006) this may partly explain the lower rate of section amongst Asian compared to African Caribbean patients.

Having said that, the complexity of help seeking behaviour needs to be acknowledged. Howerton and colleagues (Howerton, et al 2007) in their study of understanding help seeking behaviour amongst male offenders argue that despite greater need the main factors which inhibited help seeking behaviour were chaotic upbringing, distrust, and fear of a diagnosis of mental illness. A number of participants in their study feared being stigmatised by friends, family, or others if they are formally diagnosed as having a mental health problem. In addition there is enough evidence to suggest that men in general and young men in particular tend less likely to seek help from healthcare professionals, even when experiencing severe levels of distress (Richardson and Rabiee, 2001, Biddle, et al 2004). Furthermore, it is well known that many people consult their general practitioner or seek health professional help because a close friend or relative is concerned and encouraged them to do so (Gentzel, 2006, and Biddle et al 2004, Zola, 1973).

These findings therefore suggest a great potential and need to work towards de stigmatising mental health problem, also creating trust and cooperation between patient, family, friends and doctor. This type of development could also **empower** patients/ users of mental health services to help themselves and **take control in their path of safe management and recovery**. A model adapted successfully over the last 10 years by Gentzel (2006) – as a service user with more than 30 years experience of manic depressive illness in Sweden - provides a good example of a tool for recovery. Although the structure and access to mental health care support and services varies between Sweden and UK, the proposed model suggested by Gentzel based on her personal experience could be transferable. Gentzel suggests that developing a contract of care plan between the user and all parties involved, when the user is not suffering from an acute phase of illness, could help the process of recovery. The model enables service users to develop insights about their illness and take control and responsibility both in terms of adhering to medication and developing a network contract created between supportive family, friends and health professionals to help recovery.

**Mental illness as a social problem** has been highlighted by a number of participants in this research. Financial and social deprivation in the form of financial issues, being unemployed, family breakdown, bullying at school, racism, experience of trauma, being an asylum seeker, and adapting to the new culture were just a few examples mentioned.

Links between **mental illness and use of recreational drugs**, including khat, was highlighted by several professionals, carers and a minority of service users. Within the literature, studies confirm that cannabis not only increases the risk of psychosis, but cannabis use in people with mental health problems could worsen the symptoms, interfere with medication, and increase the chance of relapse (Degenhardt, 2003, Smit, et al 2004, Oz et al 2005 and CSIP 2007). This is a need therefore, for a wider dissemination of this information particularly to adolescents through health promotion programme activities via schools, other community and family settings.

In addition, it has been suggested by Oz and colleagues (2005) that minority status appears to be a risk factor for developing an increased rate of mental illness. They argue that this, in part, might be due to chronic exposure to discrimination. Linked with that and citing a number of different sources of evidence, Singh and Burns (2006) suggest that, regardless of ethnicity there is an increase rate of mental illness amongst immigrant community all over the world (e.g. Finish migrants to Sweden, Britons, Germans, poles and Italian immigrants to Australia). They further argue that *“any potential solutions must go beyond the health sector and involve statutory as well as voluntary and community agencies. The problem does not reside exclusively in psychiatry and hence the solutions cannot emerge from psychiatric services alone”* (Singh and Burns.2006, p:650).

Having mentioned that, African Caribbean groups are the least satisfied with secure services but the most likely to be held in them and one study has indicated that young black men's dissatisfaction with inpatient services was directly proportionate to the amount of contact they had with them (Bhui and Bhugra, 2002). Changing the focus of service provision to home-based care and early intervention is one way that statutory services are currently seeking to engage service users. However, also important is the need to maintain or build resources such as social support, support from families etc.

Linked to the whole discussion about pathways to care is the issue of crisis management. It is not simply the first contact with services that can be problematic, there were several examples arising from the research of how **the breakdown of out-of-hours support could also lead to problems for service users and their families.**

A survey of service users by the Healthcare Commission in 2006 (Centre for Public Scrutiny, 2006) explored satisfaction with crisis management services for the 49% of survey respondents who had an out-of- hours contact number. Of the 39% who had called it in the last 12 months, 62% had spoken to someone immediately (compared to 65% in 2005); 21% got through in an hour or less (compared to 22% in 2005) and 8% could not get through to anyone. Under half of the respondents (44%, compared to 48% in 2005) said that they had definitely received the help they wanted. These figures suggest that out-of-hours support needs sustained investment for standards to be raised.

## 6.5 Limited support for carers

The role that carers (including supportive friends and community support) play in maintaining mental health is clear from previous sections within the report. Although other local strategies acknowledge the important role of carers, supporting carers is an explicit priority in the draft commissioning strategy for working age mental health services, setting out the intentions of Birmingham City Council which included addressing the needs of carers from black and minority ethnic groups.

These statements are vital in the context of the research which highlighted the real lack of support for carers and that some existing groups for African and African Caribbean carers were no longer being funded. Also important within the research is the finding that carers groups that were supported by members of staff from community mental health teams tended to be more positive about their relationships with statutory agencies.

## 6.6 Medication issues

Although several service users made positive comments about medication (e.g. asylum seekers valued the effects it had on helping them to sleep and

switch off from bad memories), there were also concerns. These included a feeling, voiced by carers, that approaches to medication for black people are **experimental**, that there is insufficient attention paid by medics to concerns about side effects (which can be very serious); about the interaction between medication and illicit drugs; and about the dosage of medication.

Earlier research by Callan and Littlewood (1998) confirmed the above findings and suggested that approaches to prescribed medication for black people differ to those of the white population. Members of African-Caribbean communities in the UK receive medication more often, and in higher doses.

In addition, a survey of service users' experiences of community mental health services by the Healthcare Commission in 2006 (Centre for Public Scrutiny, 2006) found that of the 93% of respondents who had been prescribed medication, only 42% felt that they had definitely been involved in decisions about medication; 40% felt that they had been involved to some extent and 17% were not involved at all. Of those who had been prescribed new medication in the last 12 months (45%) only 38% were definitely told about the purpose and possible side effects of the new medication, 28% to some extent and 34% not told. Although all these figures represent an improvement on previous years, they indicate that there is still an expert-led model of mental health care when it comes to medication.

Interestingly, one of the interviewees commented that although it was very important to involve mental health service users in decision-making about medication, one also needs to question whether prescribing practices are different in other branches of medicine. If the practice is not different, there seems to be less concern expressed in research, and particularly in media, in relation to this issue. She argued *"suffering from mental health is very distressing both for the service users and the carers; at times mental health professionals seem to be the easy target for shifting the blame"* (Service Manager 1, Female).

Linking to "experimental approaches to medication", a question worth asking is why unlike psychiatric practice, frequent changes in the type and dosage of medication at early stages of treatment or management for other health conditions such as diabetes or blood pressure are not perceived as problematic by patients and their family.

It is plausible that both a better relationship, clear lines of communication and more trust exist between the patient/family and the practitioners of other branches of medicine, or as the above interviewee argued the nature and severity of mental health illness makes coping difficult for both service users and carers, hence a quick solution is expected.

However, concerns about the dosage of medication, raised by participants from Somali focus groups, were confirmed previously by a number of

trans-cultural psychiatrists (Rock, 1982; Andrade, 2005; Chen, 2006). It is well known that inter-racial differences exist in the way the body handles a drug; this is affected by processes of absorption, transport, metabolism, and excretion. It appears that people from Asian and African origin require lower doses of most psychotropic drugs. Andrade (2005) suggests that variations in drug prescription for different ethnic population, based on variation either in their genetic makeup, metabolic factors, or less previous exposure, should not be ruled out.

The report 'Inside Outside' (DoH report about improving services for black and ethnic minority communities in England), argued that annual audits should be undertaken of the use of psychotropic drugs for mental health problems by ethnic group. (Department of Health, 2003b).

The response of commissioners to medication issues raised by this research was positive. They suggested that *"there is a need to consider how best to address some of the general perceptions and /or misconceptions whilst also recognising and addressing the concerns about side effects, drug interactions and dosages"*, and agreed to discuss these issues with their prescribing advisors.

## 6.7 The need for alternatives to medication

Several research participants identified a need for psychological therapies to be more widely available. A report on psychology services for black and minority ethnic communities in Birmingham (Roberts, 2006) identifies psychological therapies as including specialist psychological assessment and psychological interventions for groups and individuals using therapy models such as cognitive behavioural therapy, systemic and psycho-dynamic psychotherapy. The report highlighted the following issues:

- In spite of a strong evidence base that psychological therapies work for black and minority ethnic communities; that they are wanted by such communities; and that the need for them is supported by Government policy and directives, **service users from black and minority ethnic communities are still unlikely to be referred for psychological therapies of any kind.**

*"Psychological therapies should be integral to what Birmingham and Solihull Mental Health Trust offers to service users and their carers and relatives. They are strongly supported by the evidence and are much wanted by service users. ... they are not an optional extra"* (cited in Roberts, 2006, p2).

- **Proposals for psychological services in Birmingham** include the employment of a full-time consultant clinical psychologist, leading a specialist service targeted to black and minority ethnic communities in the

Heart of Birmingham, focusing on inpatient units and possibly extending this to home treatment services; incorporating current work on personality disorder services; taking a strategic overview of services for asylum seekers; developing a curriculum for group based support; staff supervision and training and coordinating the development of partnerships and service level agreements for psychological therapies provided for the black community by NGOs. It was unclear how many of these proposals have been commissioned.

- **There are clearly barriers to the further development of psychological services.** These include a reported fear that developing psychological resources would open up flood gates of demand, and targeting those resources to African and African Caribbean people would lead to accusations of favouritism.

What is clear is that, generally, the availability of alternatives to medication in the form of psychological therapies is not being prioritised, notwithstanding specifically for people from minority ethnic communities. In a survey of service users' experiences of community mental health services by the Healthcare Commission in 2006 (Centre for Public Scrutiny, 2006) the percentage of all respondents reporting that they had received counselling services in the last 12 months has fallen slightly but consistently from 42% in 2004, to 40% in 2005, and 39% in 2006, despite the fact that 57% of respondents stated that they wanted counselling services. A further study by the Healthcare Commission found that only 50% of people with schizophrenia had access to counselling services, in contrast to new national guidance stating that all people with schizophrenia should be offered such access.

## 6.8 A consistent policy around mental health service provision for asylum seekers

Issues around inconsistencies of approach around the provision of care for asylum seekers was highlighted. It was apparent that when an asylum seeker loses their appeal and becomes a failed asylum seeker they legally have no access to mental health services. One of the interviewees commented that *"Work has been done around failed asylum seekers which gets referrals made through a GP which has put pressure onto the PCTs to provide a GP"* (Consultant Psychiatrist 4, Male). It was acknowledged, by a number of respondents, that there are many cases where there have been failed asylum seekers who are obviously extremely unwell but no-one seems to know what to do. It was believed that the tender for such a service was won by a black provider organisation, to provide an African Caribbean service, but according to a service manager *"it never got off the ground; unsure what the reasons were and who commissioned it. No one is taking responsibility for this failure; however the PCTs and Birmingham City Council are blaming the Trust"* (Service Manager 3, Female).

## 6.9 Funding and support for BSMHT Service Re-Design action plan

The Mental Health Trust has an implementation plan regarding the service re design for HOB, with an estimate timetable in place. It requires however to work in synchronisation with other Mental Health Trust plans, PCTs and NGOs. It was stated by at least four key members of the Mental Health Trust that there is determination to improve the services for people and "*The 'model of care' is BSMHT's attempt to create a partnership between itself, the PCTs and NGOs; this strategy doesn't exist anywhere else in the UK*". BSMHT expects the PCT to produce an implementation plan for strengthening and developing primary care services. A similar implementation plan is required for NGO's; these steps would help develop an overall strategy in relation to all mental health services.

At the time of this research, there was uncertainty and concerns about the funding to go with the implementation plans. It was mentioned by one of the service managers that much of the funding would need to go to primary care and NGO's to strengthen their capacity; "*the whole idea is to move, in the first instance, 5000 people from secondary care to primary care*" (Service Manager, 2, Male). To do this, resources need to be identified and pathways need to be transparently clear. Concerns were raised whether within the current health economy funding would be available. One of the service manager expressed frustration in terms of "*there does seem to be a shared vision but no progress or synchronisation*". This was echoed by another interviewee adding that, "*the changes in the last eighteen months have destabilised and the funding crisis has created major issues in mental health services*" (Service Director 2, Male).

There was a perception amongst some staff within the Mental Health Trust that the PCTs have exacerbated the mistrust between the NGO's and BSMHT. There was a concern that commissioners and PCTs have the real authority and are the source of funding, but BSMHT is the only real visible statutory sector that service users and carers see. Therefore, in order to implement DRE, a greater coordinated approach is required in relation to communication, funding and support for mental health service provision.



## 7.0 Conclusions and recommendations

Mental health services are at another crossroads. There are many opportunities for mental health services to develop to achieve the visions set out in earlier sections of the report. These opportunities are both national (e.g. the framework offered by the DRE) and local (the service re-design strategy, the work of the focused implementation site, commissioning priorities etc).

In addition, a number of positive comments were made by participants. For example, service users and carers acknowledged social and practical help they had received from NGOs, support and care from statutory services including; hospital, community and day care services, support from home treatment and assertive outreach teams. Furthermore, a number of positive actions are taking place, and there is a commitment from the Birmingham Mental Health Trust and Commissioners to improve mental health services for African and African Caribbean communities. However there is a need for more specificity and greater targeting of resources.

In particular, the recommendations arising from this research include the following:

- **Health equity audits (or audits based on health equity principles) should be carried out in relation to key elements of service provision** specifically the availability of psychological therapies; support for asylum seekers; funding for carers support; respite care; and NGO sector funding to assess the extent to which funding is targeted to needs (i.e. not equally but equitably).
- **Funding and resources should be targeted to re-providing the above services on the basis of need.** Carrying out health equity audits may be politically sensitive because they can highlight that the traditional allocation of resources does not always reflect current needs. Methodologically, health equity audits can also be time consuming and resource intensive. However, when there are severe constraints on funding, auditing services on health equity principles is vital. The outcome of the health equity audits for the service elements, specified above, may reveal a need to review the distribution of services. For example, the research has suggested that GP-based psychological services are currently only available in the south of Birmingham. African and African Caribbean communities tend to be concentrated in the north and central areas which means that there may be physical constraints on their ability to access psychological therapies within GP surgeries. It is not likely to be sufficient to address health equity issues only by targeting new funding to needs. With constraints on funding, it is likely to be necessary to re-orientate existing funding and services better to reflect need. One example where this has been carried out is in relation to cardiology services in West

Hertfordshire which included a £300,000 shift in recurrent resources to areas of highest need (see Tackling Health Inequalities: What Works, Department of Health, February 2005, [www.dh.gov.uk/healthinequalities](http://www.dh.gov.uk/healthinequalities))

- **There needs to be a move away from what currently appears to be an 'either/or' approach to developing targeted services and mainstreaming.** There is a need for both mainstreaming (e.g. of culturally competent practice) and targeted provision (e.g. to provide a bridge between excluded groups such as Somali and Congolese communities, African Caribbean and African carers and mainstream services).
- **Local targets need to be developed in relation to national policy drivers and outcomes in Delivering Race Equality and reflecting the outcomes of Health Equity Audits.** A monitoring and reporting strategy needs to be developed to mainstream responsibility for performance against Delivering Race Equality.
- **The role of partners in a 'whole system approach' to creating mentally healthy communities needs to be developed** to ensure that the strategies being pursued by the Mental Health Trust are actively understood as part of a whole system with the connections between different parts of system being clear. This could be carried out at different levels, e.g. along the lines of the resource pack Creating Healthier Communities (DoH resource pack for local partnerships) which brings together cross-government policies; and evidence based practice; and which also helps people to consider what currently happens on addressing the wide range of causes of mental health; such as deprivation, racism and other environmental stresses rather than just the bio-medical factors.
- **Linked with the above recommendation is the need to create supportive environments and develop personal skills** through working with partners to ensure that family and community links are strengthened, and social support is available for individuals within minority communities. **Supportive environments could also create trust, and respect between individuals and within communities** to foster better relationships and improve understanding of some of the general perceptions and/or misconceptions.
- **'Out of hours' support needs to be reviewed and strengthened.**
- **More funding should be made available from the Department of Health to support Delivering Race Equality.**
- **More funding should be made available from the Department of Health and other Government departments to create a sustainable NGO sector infrastructure** to enable NGOs to play the roles envisaged in service re-design and other strategies. The infrastructure should include the development of training, protocols and skills sharing between NGOs and

statutory agencies.

- **More respite care** should be developed or if additional resources are not available, existing respite care provision should be reviewed on the basis of a health equity audit.
- **Outreach work should be funded for** excluded groups such as **Somali, Congolese and other African communities** to raise awareness of existing services; providing mental health promotion building on existing voluntary work; and signposting/building bridges between the community and services, including faith-based community leaders.
- **Protocols should be developed for involving carers/families in the care of service users drawing on good practice.**
- **Protocols should be developed for the use of trained interpreters in psychological services** building on good practice and considering the provision of training for interpreters using the co-researcher model developed as part of this research by UCE Birmingham and adapting this for training mental health/health interpreters.

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## Appendices

### Appendix 1: Service user and carer participant information sheet and consent form

NAME

ADD1

ADD2

ADD3

POSTCODE

DATE

Dear NAME

#### **Re: An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities**

The Centre for Community Mental Health at the University of Central England is undertaking a project to identify the extent to which current statutory and voluntary mental health services in Birmingham meet the needs of members of the Black African and Black Caribbean communities. The Project has two stages, in this stage of the project we wish to ask a number of users and carers about their views and experiences of using mental health services. We enclose an information leaflet about the project that we hope you will find helpful.

The purpose of this letter is to invite you to contribute to this project by participating in a focus group interview at.....Centre\*

If you agree we will telephone or contact you at the centre and arrange a mutually convenient time.

We do hope that you will agree to take part. If you would like further information or have any queries please contact:

Paula Smith on 0121 777 8631 or e-mail: [paula\\_s@tiscali.co.uk](mailto:paula_s@tiscali.co.uk)

Professor Fatemeh Rabiee on: 0121 331 7754 or email: [fatemeh.rabiee@uce.ac.uk](mailto:fatemeh.rabiee@uce.ac.uk)

Thank you for taking time to read this letter. We look forward to hearing from you.

Yours sincerely,

**Paula Smith**, Research Fellow

**Professor Fatemeh Rabiee**, Project Leader

**Mervyn Morris**, Reader in Mental Health, Central for Community Mental Health

\*The centre where the interview will take place will be named for each participant. The named centre will be a place where the participant attends on a regular basis.

## **Information leaflet: An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities**

### **What is this project about?**

This is the second stage of a project aimed at identifying the extent to which current statutory and voluntary mental health services in Birmingham meet the needs of members of the Black African and Black Caribbean communities. In this project we wish to ask users of the mental health services and their carers to tell us their story about:

- the range of the services they use
- the number of years they have used each service
- the accessibility and cultural appropriateness of each service
- whether current provision successfully addresses the needs of users
- the positive aspects of the service
- the negative aspects of the service
- factors which facilitate or prevent meeting their needs
- The way forward for improving the services

### **Why you have been asked?**

As one of the user of mental health services or a carer, we would like to hear to hear your views and experiences of mental health services.

### **How will this project help people who are service users/carers?**

This project will give you a chance to:

- have your say about your experiences of services in Birmingham
- tell us about your experiences as a Black person who uses services or cares for some one who uses mental health services in Birmingham
- help to improve services for the future

### **What will taking part involve?**

You will be asked to take part in a focus group lasting approximately one hour. A member of the project team will arrange a convenient time for this and ask if you are happy for the interview to be tape recorded.

If you are a service user the focus group leader will ask you about:

- your experiences of using mental health services
- your experiences of how helpful the mental health services are to you as a Black person
- how culturally appropriate mental health services are
- what needs to be changed or improved
- the way forward for improving services

If you are a carer the focus group leader will ask you about:

- your experiences of how helpful the mental health services are in supporting you as a carer
- your experiences of how helpful the mental health services are to you as a Black person
- how culturally appropriate mental health services are
- what needs to be changed or improved
- the way forward for improving services

### **What will happen to the information that you provide?**

All information from focus group interview will be treated confidentially. No named person will be identified in the final report. Information will be used only for this project. Information will be stored securely separate to individual contact details. Interview tapes will be destroyed on completion of the project.

### **What will happen if I do not want to take part?**

You do not have to take part if you don't want to. Your decision will not affect the treatment, care or help you receive either now or in the future. If you agree to take part, but change your mind at any point, even during the interview you can withdraw if you wish.

### **Are there any disadvantages or risks in taking part in this project?**

There are no risks in taking part in this project. However, there is a possibility that remembering your experiences may become painful for you. We assure you that if such situations arise, we will make sure that you are able to get help.

The University of Central England also provides indemnity insurance for the project team for any non-negligent harm that may arise as a result of this project.

### **Has this project been approved by an ethics committee?**

The East Birmingham Research Ethics committee has given approval for this project.

### **Has the project been reviewed by an independent sponsor?**

Professor Uduak Archibong at Bradford University has reviewed the project and agreed to act as academic sponsor for this project.

### **Who will the results be made available to?**

We will organise a presentation to feedback to everyone. In addition we will compile a report to send to the service providers and to the Department of Health.

### **Will I be identified in any way?**

No, you will not be identified in any way in either in the presentation or the report. No one will know that you have taken part unless you decide to tell them.

To ensure confidentiality, you should also not repeat details of our discussion to anyone else outside the group.

### **What do I do if I need further information?**

Please contact Professor Fatemeh Rabiee or Paula Smith, c/o Centre for Community Mental Health, UCE Birmingham, Faculty of Health, Westbourne Campus, Birmingham B15 3TN

Fatemeh: Tel: 0121 331 7754 or email: [Fatemeh.Rabiee@uce.ac.uk](mailto:Fatemeh.Rabiee@uce.ac.uk)

Paula: Tel: 0121 777 8631 or email: [paula\\_s@tiscali.co.uk](mailto:paula_s@tiscali.co.uk)

### **What should I do next?**

Please sign the consent form and return it in the stamped addressed envelope provided. A member of the project team will get in touch with you as soon as possible after receiving your reply.

**Thank you for taking time to read this information sheet**

## CONSENT FORM FOR FOCUS GROUP INTERVIEW OR INDIVIDUAL INTERVIEW

**Title of Project:** An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities

**Name:**

**Address:**

**Please write initials in boxes below**

1. I confirm that I have read and understand the information sheet and have had the opportunity to ask questions.

☐

2. I understand that my participation in this interview is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

4. I agree to take part in the focus group

☐

5. The best day and time of the week to contact me is.....

6. My Telephone Number is.....

**Signed:**

**Date:**

**Interviewer:**

## Appendix 2: Professionals participant information sheet and consent form

NAME

ADD1

ADD2

ADD3

POSTCODE

DATE

Dear NAME

### **Re: An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities**

The Centre for Community Mental Health at University of Central England in Birmingham is undertaking a project to identify the extent to which current statutory and voluntary mental health services in Birmingham meet the needs of members of the Black African and Black Caribbean communities. The Project has two stages; in this stage of the project we wish to ask a range of professionals from statutory organisation about the types of services they provide for members of Black African and Black Caribbean communities, and factors such as culture, funding and language that may affect these services. We enclose an information leaflet about the project that we hope you will find helpful.

The purpose of this letter is to invite you to contribute to this project by taking part in a face to face or telephone interview. If you agree we will make arrangements to telephone you and arrange a mutually convenient time.

We do hope that you will agree to take part. If you would like further information or have any queries please contact:

Paula Smith on 0121 777 8631, e-mail: [paula\\_s@tiscali.co.uk](mailto:paula_s@tiscali.co.uk) or

Professor Fatemeh Rabiee on: 0121 331 7754, email: [fatemeh.rabiee@uce.ac.uk](mailto:fatemeh.rabiee@uce.ac.uk)

Thank you for taking time to read this letter.

We look forward to hearing from you.

Yours sincerely,

**Paula Smith**, Research Fellow

**Professor Fatemeh Rabiee**, Project Leader

**Mervyn Morris**, Reader in Mental Health, Centre for Community Mental Health

## **'An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities'**

### **What is this project about?**

This is the second stage of a project aimed at identifying the extent to which current statutory and voluntary mental health services in Birmingham meet the needs of members of the Black African and Black Caribbean communities. In this project we wish to ask a range of professionals within the statutory organisation about:

- the type of clients for whom each service is intended, the need for and the functions of each service;
- the accessibility and cultural appropriateness of each service and the extent to which current provision successfully addresses the needs of users;
- the extent to which factors such as racism and discrimination, culture, religion and language etc. facilitate or hinder meeting clients needs;
- the extent to which factors such as racism and discrimination, culture, religion and language facilitate or hinder working with other agencies;
- other factors that have positive or negative impact on the function of the service during the last five years.

### **Why you have been approached?**

As one of the team member of the provider of mental health services for Black African and Black African-Caribbean in Birmingham, we are interested to hear your views and experiences of provision of appropriate care and to hear your perspectives on the extent to which is feasible to respond to the needs identified by the users and carers of the services.

### **How will this project help people who are service users/carers?**

This project will help improve services for users, carers and professionals by

- helping to develop a directory of statutory and voluntary agencies available to Black mental health service users;
- providing an opportunity to examine experiences of Black African and Black African-Caribbean service users and carers in Birmingham;
- improving understanding of the factors that enhance or detract from the provision of sustainable funding to help agencies identify sources of long-term support;
- improving understanding of the impact of factors, such as culture, racism, language, and religion, on the provision of mental health services to Black people in Birmingham that will be of benefit to planners in developing future services.

### **What will taking part involve?**

You will be asked to take part in a face to face or telephone interview lasting approximately 45 minutes. A member of the project team will telephone to arrange a convenient time for this. The interview will be tape recorded and will ask questions about:

- the type of service(s) provided by your agency;
- which client group(s) these services are provided for;
- any factors that inhibit/prevent access to the agency's services;
- any factors that inhibit/prevent provision of culturally appropriate mental health services;
- feasibility of responding to the needs identified by users and carers of your services.

### **What will happen to the information that you provide?**

All other information from face to face or telephone interview and the interviews will be treated anonymously and in the strictest confidence. No named person will be identified in the final report. Information will be used only for the purposes of the project. Information will be stored securely separate to individual contact details. Interview tapes will be destroyed on completion of the project.

### **What will happen if I do not want to take part?**

There is no obligation to take part and the project team will not contact you again. If you agree to take part, but change your mind later you can withdraw at any time.

### **Are there any disadvantages or risks in taking part in this project?**

There are no risks in taking part in this project. UCE Birmingham provides indemnity insurance for the project team for negligent and non-negligent harm that may arise as a result of this project.

### **Has this project been approved by an ethics committee?**

The East Birmingham Research Ethics Committee has given approval for this project.

### **Has the project been reviewed by an independent sponsor?**

Professor Uduak Archibong at Bradford University has agreed to act as sponsor for this project.

### **Who will the results be made available to?**

A report based on the findings of this project will be available to all participating agencies. Papers based on the findings will be prepared for publication in professional journals.

### **What do I do if I need further information?**

Please contact Professor Fatemeh Rabiee or Paula Smith, c/o Centre for Community Mental Health, UCE Birmingham, Faculty of Health, Westbourne Campus, Birmingham. B15 3TN

Fatemeh: Tel: 0121 331 7754 or email: [Fatemeh.Rabiee@uce.ac.uk](mailto:Fatemeh.Rabiee@uce.ac.uk)

Paula: Tel: 0121 777 8631 or email: [paula\\_s@tiscali.co.uk](mailto:paula_s@tiscali.co.uk)

### **What should I do next?**

Please sign the consent form and return it in the stamped addressed envelope provided. A member of the project team will get in touch with you as soon as possible after receiving your reply.

**Thank you for taking time to read this information sheet**

## CONSENT FORM FOR FACE TO FACE/TELEPHONE INTERVIEW

Title of Project: 'An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities'

Name and address of agency:

Please initial each box

1. I confirm that I have read and understand the information sheet dated and have had the opportunity to ask questions.

☐

2. I understand that my participation in this interview is voluntary and that I am free to withdraw at any time, without giving any reason.

☐

4. I agree to take part in face to face interview\* or telephone interview\*

\*please delete as appropriate

☐

5. The best date and time of the week to contact me is.....

6. My Telephone Number is.....

Name:

Signed:

Date:

Interviewer:

### Appendix 3: Telephone Survey Tool

University of Central England, Centre for Community Mental Health/AFCAR

An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities

#### Audit tool

				Office use only	
Name of this agency					
1. Is this agency (please ✓ as appropriate)					
Statutory?					
Voluntary?					
A mixture of both?					
2. Are staff in the agency (please ✓ as appropriate)					
		Yes	No		
Mental health professionals?					
Social care professionals?					
Lay people?					
Volunteers?					
Paid staff?					
Other? (please specify)					
3. Which of the following services does your agency provide? (please ✓ as appropriate)					
	Yes	No		Yes	No
Advice about benefits?			Advocacy?		
Financial help?			Interpreters?		
Legal advice?			Help with literacy problems?		
Debt counselling?			Doctor/nurse?		
Advice about housing?			Dentist?		
Resettlement?			Chiropodist?		
Clothing?			Help with drug dependence?		
Furniture?			Help with alcohol dependence?		
Food?					

	Shower facilities?			Support for carers			
	Laundry facilities?			Therapy?			
	Befriending?			Counselling?			
	Social events?			Support groups?			
	Other? (please specify)			Holidays?			
				Other? (please specify)			

4. When are these services available? (please ✓ as appropriate)

	Yes	No
Daytime		
Evenings		
Weekends		
Bank holidays		
Seven days a week throughout the year (inc. bank holidays)		
Seven days a week throughout the year (exc. bank holidays)		
Friday only (inc. bank holidays)		
Monday – Friday only (exc. bank holidays)		
Other? (please specify)		

5. How are services advertised? (please ✓ as appropriate)

	Yes	No
GP surgeries?		
Local libraries?		
Local shops?		
Out patient clinics?		
Community centres?		
Other? (please specify)		

<p>6. What group(s) of clients are these services intended for? (please ✓ as appropriate)</p> <table border="1"> <thead> <tr> <th></th> <th>Yes</th> <th>No</th> </tr> </thead> <tbody> <tr> <td>Black Caribbean people with enduring mental illness?</td> <td></td> <td></td> </tr> <tr> <td>Black African people with enduring mental illness?</td> <td></td> <td></td> </tr> <tr> <td>Caribbean people caring for relatives with enduring mental illness?</td> <td></td> <td></td> </tr> <tr> <td>Black African people caring for relatives with enduring mental illness?</td> <td></td> <td></td> </tr> <tr> <td>Other? (please specify)</td> <td></td> <td></td> </tr> </tbody> </table>		Yes	No	Black Caribbean people with enduring mental illness?			Black African people with enduring mental illness?			Caribbean people caring for relatives with enduring mental illness?			Black African people caring for relatives with enduring mental illness?			Other? (please specify)												
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<p>8. How do clients access these services? (please ✓ as appropriate)</p> <table border="1"> <thead> <tr> <th></th> <th>Yes</th> <th>No</th> </tr> </thead> <tbody> <tr> <td>GP/Consultant referral?</td> <td></td> <td></td> </tr> <tr> <td>CPN referral?</td> <td></td> <td></td> </tr> <tr> <td>Referral from therapists?</td> <td></td> <td></td> </tr> <tr> <td>Self-referral?</td> <td></td> <td></td> </tr> <tr> <td>Carer brings client to you?</td> <td></td> <td></td> </tr> <tr> <td>Police?</td> <td></td> <td></td> </tr> <tr> <td>Social workers?</td> <td></td> <td></td> </tr> <tr> <td>Other? (please specify)</td> <td></td> <td></td> </tr> </tbody> </table>		Yes	No	GP/Consultant referral?			CPN referral?			Referral from therapists?			Self-referral?			Carer brings client to you?			Police?			Social workers?			Other? (please specify)			
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<p>9. Are you aware of any factors that inhibit/prevent access to your services? (please state)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> </table>																															
<p>10. a) What is the main source of funding for your organisation? (please ✓ as appropriate)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 70%;"></th> <th style="width: 15%; text-align: center;">Yes</th> <th style="width: 15%; text-align: center;">No</th> </tr> </thead> <tbody> <tr> <td>Statutory funding?</td> <td></td> <td></td> </tr> <tr> <td>Lottery?</td> <td></td> <td></td> </tr> <tr> <td>Grant from charitable trust?</td> <td></td> <td></td> </tr> <tr> <td>Other please state</td> <td></td> <td></td> </tr> </tbody> </table> <p>b) How often is this funding reviewed/renegotiated?</p>		Yes	No	Statutory funding?			Lottery?			Grant from charitable trust?			Other please state																		
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Lottery?																															
Grant from charitable trust?																															
Other please state																															
<p>11. What additional sources of funding does the organisation depend on? (please ✓ as appropriate)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 70%;"></th> <th style="width: 15%; text-align: center;">Yes</th> <th style="width: 15%; text-align: center;">No</th> </tr> </thead> <tbody> <tr> <td>Regular direct debits from supporters?</td> <td></td> <td></td> </tr> <tr> <td>In-house fund-raising events?</td> <td></td> <td></td> </tr> <tr> <td>Street collections?</td> <td></td> <td></td> </tr> <tr> <td>House-to-house collections?</td> <td></td> <td></td> </tr> <tr> <td>Collection boxes?</td> <td></td> <td></td> </tr> <tr> <td>Fund-raising events in partnership with other agencies? ? (please specify)</td> <td></td> <td></td> </tr> <tr> <td>Adverts in relevant publications?</td> <td></td> <td></td> </tr> <tr> <td>Church collections?</td> <td></td> <td></td> </tr> <tr> <td>Other? (please specify)</td> <td></td> <td></td> </tr> </tbody> </table>		Yes	No	Regular direct debits from supporters?			In-house fund-raising events?			Street collections?			House-to-house collections?			Collection boxes?			Fund-raising events in partnership with other agencies? ? (please specify)			Adverts in relevant publications?			Church collections?			Other? (please specify)			
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12. a) Which source(s) of funding have proved most successful in the last five years? (please ✓ as appropriate)

	Yes	No
Statutory funding?		
Lottery?		
Grant from charitable trust?		
Regular direct debits from supporters?		
In-house fund-raising events?		
Street collections?		
House-to-house collections?		
Collection boxes?		
Fund-raising events in partnership with other agencies (please specify)		
Adverts in relevant publications?		
Church collections?		
Other (please specify)		

b) Why do you think these have been successful?


<p>c) Which source(s) of funding have proved least successful in the last five years and why do you think this is so? (please ✓ as appropriate)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 60%;"></th> <th style="width: 10%;">Yes</th> <th style="width: 10%;">No</th> </tr> </thead> <tbody> <tr><td>Statutory funding?</td><td></td><td></td></tr> <tr><td>Lottery?</td><td></td><td></td></tr> <tr><td>Grant from charitable trust?</td><td></td><td></td></tr> <tr><td>Regular direct debits from supporters?</td><td></td><td></td></tr> <tr><td>In-house fund-raising events?</td><td></td><td></td></tr> <tr><td>Street collections?</td><td></td><td></td></tr> <tr><td>House-to-house collections?</td><td></td><td></td></tr> <tr><td>Collection boxes?</td><td></td><td></td></tr> <tr><td>Fund-raising events in partnership with other agencies (please specify)</td><td></td><td></td></tr> <tr><td>Adverts in relevant publications?</td><td></td><td></td></tr> <tr><td>Church collections?</td><td></td><td></td></tr> <tr><td>Other (please specify)</td><td></td><td></td></tr> </tbody> </table> <p>d) Why do you think these have been unsuccessful?</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> </table>		Yes	No	Statutory funding?			Lottery?			Grant from charitable trust?			Regular direct debits from supporters?			In-house fund-raising events?			Street collections?			House-to-house collections?			Collection boxes?			Fund-raising events in partnership with other agencies (please specify)			Adverts in relevant publications?			Church collections?			Other (please specify)								
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<p>13. Are there sources of funding that the organisation would never approach? (please give reasons for this)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> <tr><td style="height: 20px;"></td></tr> </table>																																													

<p>14. Has the organisation ever turned down a donation? (please give reasons for this)</p> <table border="1" data-bbox="395 398 1206 656"> <tr><td> </td></tr> <tr><td> </td></tr> <tr><td> </td></tr> <tr><td> </td></tr> <tr><td> </td></tr> </table>													
<p>15.a) Is someone in the organisation responsible for securing funding?</p> <p>Yes                      No                      Don't know</p> <p>b) If YES, what position do they hold?</p> <p>c) How long has this person been in post?</p> <table border="1" data-bbox="395 1003 1206 1305"> <tr><td>Up to six months?</td><td> </td></tr> <tr><td>7-12 months?</td><td> </td></tr> <tr><td>13-24 months?</td><td> </td></tr> <tr><td>25-36 months?</td><td> </td></tr> <tr><td>3-5 years?</td><td> </td></tr> <tr><td>More than 5 years?</td><td> </td></tr> </table>	Up to six months?		7-12 months?		13-24 months?		25-36 months?		3-5 years?		More than 5 years?		
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More than 5 years?													
<p>16. In your opinion, what factors have had the most influence on your obtaining funding in the last five years?</p>													
<p>17. Would you be happy to take part in an interview if I need to clarify things further?</p>													
<p>Thank you for answering these questions. The information you have provided will be treated in the strictest confidence and you will not be identified in any way in the report.</p>													

## Appendix 4: Interview Schedule for service users

An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities

### Interview schedule – Users\*

Greeting

Introduction

Setting Ground Rules

Ice Breaking Question:

Tell me about yourself

Main Questions:

Can you tell me about the range of mental health services you use (*Probes- types of service, number of years they have used, the place they access these services; voluntary/ statutory?*)

Can you tell me about your experience of using these services (*Probe- statutory? voluntary? Pick up any positive or negative aspect*)

Can you tell me about the positive aspects of using ... service (*Probe- statutory? Voluntary ask for an example*)

Can you tell me about the negative aspects of using ... service (*Probe- statutory? voluntary? Ask for an example*)

Can you tell me whether current provision of mental health addresses your needs as a user? (*Probe- if not in what way?*).

How easy is it for you to get help from this service? (*Probe- explore issues of language, religious belief, racism and discrimination. Ask for me some positive and negative examples*).

How culturally appropriate is this service for you as a Black person? (*Probe- explore issues of language, religious belief, racism and discrimination. Ask for me some positive and negative examples*).

In your opinion, is there any specific provision targeted for you as a Black African/ African Caribbean user? (*Probe, if yes what are they, if no why not?*)  
*In your opinion, what steps should be taken to provide a mental health service for Black people?*)

What changes, if any, do you feel are needed to improve provision of a good

mental health service for Black people? (***Probe**-Explore steps needs to be taken*)

In your opinion, what role could users play in improving mental health services for Black people?

Are there any other points that you would like to make about mental health services for Black people?

### **Thank you for giving us your time and views**

\* Please note that the interview schedule will be piloted amongst 2 users of mental health services, and data generated will be analysed prior to the main study. This step will be taken to ensure that the questions are clear, the timing proposed for the interview is sufficient, and the data generated are able to answer the aims and objectives set out for this study.

Also, please note that this is just a guide to remind us the type of issues needs exploring. Like any interview situations, not all questions set out in this schedule will be asked. Often participants' answers to some of the earlier questions covers the later questions.

## Appendix 5: Interview Schedule for carers

An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities

### Interview schedule – Carers\*

Greeting

Introduction

Setting Ground Rules

Ice Breaking Question:

Tell me about yourself

Main Questions:

Tell me about the range of mental health services used by the person for whom you provide care (*probes- types of service, number of years they have used, the place they access these services; voluntary/ statutory?*)

In your opinion how helpful are these services? (*Probe - statutory? voluntary? Pick up any positive or negative aspect*)

Tell me about the positive aspects of using ... service (*Probe - statutory? Voluntary ask for an example*)

Tell me about the negative aspects of using ... service (*Probe - statutory? voluntary? ask for an example*)

To what extent do these services meet you needs as a carer? (*Probe - if not in what way?*).

How easy is it to get help when you need it as a carer? (*Probe - explore issues of language, religious belief, racism and discrimination. Ask for me some positive and negative examples*).

As a Black person how culturally appropriate is the mental health service for you and the person for whom you provide care? (*Probe- explore issues of language, religious belief, racism and discrimination. Ask for me some positive and negative examples*).

Is there any specific provision targeted for you as a Black African/ African Caribbean Carer? (*Probe - if yes what are they, if no why not?*).

In your opinion, what steps should be taken to provide a mental health service for Black people?

What changes, if any, do you feel are needed to improve provision of an adequate mental health service for Black people? (***Probe**-Explore steps needs to be taken*)

In your opinion, what role could carers play in improving mental health services for Black people?

Are there any other points that you would like to make about mental health services for Black people?

Are there any other points that you would like to raise about mental health services for Black people?

### **Thank you for giving us your time and views**

\* Please note that the interview schedule will be piloted amongst 2 carers of people who use mental health services, and data generated will be analysed prior to the main study. This step will be taken to ensure that the questions are clear, the timing proposed for the interview is sufficient, and the data generated are able to answer the aims and objectives set out for this study.

Also, please note that this is just a guide to remind us the type of issues needs exploring. Like any interview situations, not all questions set out in this schedule will be asked. Often participants' answers to some of the earlier questions covers the later questions.

## Appendix 6: Interview Schedule for professionals

### An evaluation of the statutory and voluntary mental health service provision in Birmingham for members of the Black African and Black African-Caribbean communities

#### Interview schedule – Professionals within Statutory organisation\*

##### Greetings

##### Introduction

##### Main questions:

1. Can you give me an overview of the services that this organisation provides?
2. Which client group(s) does the organisation serve?
3. In your opinion, to what extent do cultural factors affect the ways in which this organisation provides services? Please can you give me some positive and negative examples?
4. What does “culturally sensitive” mental health service provision mean to you personally?
5. In your opinion, what does “culturally sensitive” mental health service provision mean to your organisation?
6. In considering the factors above, could you please describe the extent to which your organisation able/ willing (ability /willingness) in meeting the clients' needs?
7. Do you have any specific provision targeted for Black African and African Caribbean Communities? (*Probe, if yes what are they, if no why not?*)
8. In your opinion, what step should be taken to provide a “culturally sensitive” mental health service? Any opportunity & constraints?
9. In your experience what role does voluntary organisations play in providing mental health services? (*Probe- How closely do you liaise with them? If no liaison the reasons for that*)
10. In your opinion, what role, if any can User & Carer groups play to improve provision of an appropriate mental health services? (*Probe- How closely do you liaise with them? If no liaison the reasons for that*)
11. What changes, if any, do you feel are needed to facilitate collaborative working between Voluntary & Statutory organisations for provision of an appropriate mental health service?
12. Are there any other points that you would like to raise in connection with this research?

**Thank you for giving us your time and views.**

\* Please note that the interview schedule will be piloted amongst 2 professionals from mental health service, and data generated will be analysed prior to the main study. This step will be taken to ensure that the questions are clear, the timing proposed for the interview is sufficient, and the data generated are able to meet the aims and objectives set out for this study.

## Appendix 7: BSMHT Statistics

### Appendix 7.1: Number and percentage of BSMHT workforce, by ethnicity

Ethnic Group	Number		Percentage of HoB residents
	Total number	(%of total)	HOB PCT population
Asian communities	283	(7.4%)	51.7%
African, Caribbean or other black communities	584	(14.9%)	11.8%
Chinese communities	11	(0.3%)	0.6%
Mixed race	54	(1.4%)	4.0%
White (British, Irish, Other)	2312	(59.4%)	29.2%
Any Other Ethnic Group	34	(0.9%)	1.3%
Not Stated	616	(15.8%)	
Total	3894	(100%)	100%
Source: Birmingham & Solihull Mental Health NHS Trust. February 2007			

## Appendix 7.2: Workforce by ethnicity and selected professional breakdown/background

Ethnic Group	Staff Group			
	<i>Psychology</i>	<i>Medics</i>	<i>Nurses</i>	<i>Nassi</i>
White - British	49.68%	19.64%	51.06%	48.11%
White - Irish	3.87%	1.09%	4.80%	3.23%
White - Other	7.74%	4.36%	1.55%	0.81%
<b>White</b>	<b>61.29%</b>	<b>25.09%</b>	<b>57.42%</b>	<b>52.16%</b>
Mixed - White and Black Caribbean	1.29%	0.00%	0.56%	0.54%
Mixed - White and Black African	0.00%	0.00%	0.28%	0.27%
Mixed - White and Asian	0.65%	0.36%	0.07%	0.00%
Mixed - Other	1.29%	0.73%	0.14%	0.13%
<b>Mixed</b>	<b>3.23%</b>	<b>1.09%</b>	<b>1.06%</b>	<b>0.94%</b>
Asian / Asian British - Indian	4.52%	13.09%	2.33%	3.77%
Asian / Asian British - Pakistani	0.65%	6.55%	0.64%	1.62%
Asian / Asian British - Bangladeshi	0.00%	0.73%	0.21%	0.13%
Asian / Asian British - Other	0.00%	6.18%	1.41%	0.13%
<b>Asian</b>	<b>5.16%</b>	<b>26.55%</b>	<b>4.59%</b>	<b>5.66%</b>
Black / Black British - Caribbean	3.23%	1.09%	8.47%	13.88%
Black / Black British - African	0.00%	2.55%	11.02%	3.10%
Black / Black British - Other	0.00%	0.00%	1.20%	0.81%
<b>Black</b>	<b>3.23%</b>	<b>3.64%</b>	<b>20.69%</b>	<b>17.79%</b>
Chinese	0.65%	0.36%	0.21%	0.13%
Any other ethnic group	0.65%	2.91%	0.85%	1.08%
Not stated	25.81%	40.36%	15.18%	22.24%

Source: Birmingham & Solihull Mental Health NHS Trust. February 2007

### Appendix 7.3: Workforce by ethnicity and professional breakdown/ background Source:

Ethnic Group	Ancillary	Maintenance	Admin & Clerical	Medical	Qual Nursing	Nursing Assistants	Qual AHP's	AHP Assistants	Scientists	Technicians	Senior Mgrs	Drug Workers
White - British	5.48%	0.53%	17.02%	3.06%	36.42%	17.80%	3.83%	2.33%	4.80%	0.87%	6.16%	1.70%
White - Irish	8.57%	0.57%	12.57%	2.29%	44.00%	14.29%	1.14%	1.71%	4.00%	0.00%	6.86%	4.00%
White - Other	2.67%	0.00%	5.33%	20.00%	36.00%	8.00%	1.33%	1.33%	17.33%	1.33%	5.33%	1.33%
Mixed - White and Black Caribbean	0.00%	0.00%	17.39%	0.00%	34.78%	30.43%	0.00%	8.70%	8.70%	0.00%	0.00%	0.00%
Mixed - White and Black African	8.33%	0.00%	8.33%	0.00%	50.00%	16.67%	0.00%	0.00%	0.00%	0.00%	16.67%	0.00%
Mixed - White and Asian	0.00%	0.00%	22.22%	11.11%	11.11%	0.00%	0.00%	0.00%	33.33%	0.00%	11.11%	11.11%
Mixed - Other	0.00%	0.00%	20.00%	20.00%	20.00%	10.00%	0.00%	10.00%	20.00%	0.00%	0.00%	0.00%
Asian / Asian British - Indian	3.70%	0.00%	13.58%	29.63%	22.22%	17.28%	1.23%	0.62%	4.32%	2.47%	3.09%	1.85%
Asian / Asian British - Pakistani	3.08%	0.00%	13.85%	40.00%	15.38%	18.46%	0.00%	0.00%	4.62%	0.00%	4.62%	0.00%
Asian / Asian British - Bangladeshi	7.14%	0.00%	28.57%	21.43%	21.43%	14.29%	0.00%	0.00%	7.14%	0.00%	0.00%	0.00%
Asian / Asian British - Other	0.00%	0.00%	2.38%	38.10%	50.00%	7.14%	2.38%	0.00%	0.00%	0.00%	0.00%	0.00%
Black / Black British - Caribbean	2.99%	0.30%	15.82%	0.90%	38.21%	30.45%	0.60%	1.49%	1.79%	0.60%	3.28%	3.58%
Black / Black British - African	3.18%	0.00%	1.82%	4.09%	76.36%	13.64%	0.00%	0.00%	0.00%	0.00%	0.91%	0.00%
Black / Black British - Other	10.34%	0.00%	10.34%	3.45%	55.17%	17.24%	0.00%	0.00%	0.00%	0.00%	0.00%	3.45%
Chinese	18.18%	0.00%	18.18%	18.18%	27.27%	9.09%	0.00%	0.00%	9.09%	0.00%	0.00%	0.00%
Any Other Ethnic Group	2.94%	0.00%	8.82%	23.53%	35.29%	20.59%	0.00%	0.00%	2.94%	0.00%	2.94%	2.94%
Not Stated	9.53%	1.63%	33.57%	23.66%	50.33%	39.93%	5.69%	4.59%	16.82%	1.21%	10.45%	2.58%
Total	4.93%	0.46%	15.07%	6.93%	36.65%	18.64%	2.70%	1.95%	5.08%	0.74%	5.06%	1.77%

Source: Birmingham & Solihull Mental Health NHS Trust. February 2007

## Glossary

**AFCAR** - African & African Caribbean Voluntary Sector Providers.

**Axis** - NGO that supports black and minority ethnic people, families and carers.

**Bennett Report** - Independent inquiry into death of David Bennett, an African Caribbean man, diagnoses as schizophrenic who died in a mental health ward.

**Brook Advisory Centre** - national voluntary sector provider of free and confidential sexual health advice and services specifically for young people under 25.

**BSMHT** - Birmingham and Solihull Mental Health Trust.

**CPN** - Community Psychiatric Nurse.

**CSIP** - Care Services Improvement Partnership (formerly National Institute for Mental Health in England (NIMHE).

**Depot** - a special way of taking medicine as an injection which releases the drug slowly over several weeks.

**Diazepam** (T-Quil, Valium) - is a benzodiazepine, a sedative that is used to treat anxiety, depression, insomnia, seizures, and muscle spasms.

**DOH** - Department of Health.

**DRE** - 'Delivering Race Equality'; a Department of Health report.

**FIS** - Focused Implementation Site.

**Frantz Fanon Centre** - African and African Caribbean statutory mental health service.

**GP** - General Practitioner.

**HoB** - Heart of Birmingham.

**Khat** (quat, qat, qaadka, chat) - a herbal leaf that is chewed; giving stimulatory effects. Especially popular in Horn of Africa region and Arabian Peninsula.

**Mind** - National Association for Mental Health.

**NASS** - National Asylum Support Service.

**NGO** - Non-Governmental Organisation.


**NHS** - National Health Service.

**PCL** - Primary Care Liaison.

**PCT** - Primary Care Trust.

**Sheikh** - Somali faith-based community leader.

**User Voice** - Statutory organisation that promotes greater involvement of service users in the planning and delivery of mental health services.

The background is a solid light green. A large, dark green curved shape, resembling a thick arc or a partial circle, dominates the right side of the image. Within this dark green shape, there is a white crescent-shaped area on the right edge.

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