CAUGHT BETWEEN STIGMA AND INEQUALITY

Butterfly by Brian Marks 2004. Part of the SCDMH Art of Recovery Series

Black & Minority Ethnic Communities and Mental Well-Being in Kensington & Chelsea and Westminster. Recommendations for improved service delivery and partnership with local communities

A Report by the BME Health Forum and
the Migrant & Refugee Communities' Forum

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Acknowledgments

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Acronyms

BME	Black & Minority Ethnic
CMHT	Community Mental Health Team
CPA	Care Programme Approach
CPN	Community Psychiatric Nurse
GP	General Practitioner
KCW	Kensington & Chelsea and Westminster
MH	Mental Health
MRCF	Migrant & Refugee Communities Forum
User	Someone who has received secondary mental health treatment

Summary

For members of many minority ethnic communities, the stigma attached to any suggestion of mental illness influences their decision when deciding whether to acknowledge the problem and seek treatment, or to conceal it.

The fear of being labelled "mad" or "crazy" and consequently shunned by family and friends leads some people to try to appear "normal" and untroubled. In these communities, psychological stress is seen as madness, and madness is seen as incurable. The implications of this are that there is little point in seeking treatment and mental distress must be endured as part of life in a minority situation within the UK.

Social exclusion can be both a source and a consequence of mental ill health. Members of BME communities often experience social exclusion, particularly poverty, unemployment and a lack of support from statutory services for which their own community groups may not be able to compensate. In addition, poor housing and isolation often lead to depression and can be compounded by an inability to communicate because of language barriers. This can adversely affect many aspects of the lives of people from BME communities – from accessing statutory services to arranging schooling for their children - and they were particularly ill-informed about the availability of mental health care services. The cumulative effect of this range of problems can cause severe mental distress.

When asked what would improve their mental well-being, people cited community-based activities of all kinds, from sports to social events, along with advice and improved access to health services. GPs are usually the first port of call for those with mental as well as physical health problems. However, many participants in the study have difficulty communicating with their doctors, not just because of linguistic and cultural barriers, but also because of the time constraints set on individual patient consultations.

Consequently, deteriorating mental health often goes undetected until it has become severe and as a result, BME patients are over-represented in acute care but under-represented at the counselling or psychiatric therapy stage. In other words, their treatment tends to be via by medication rather than by "talking therapy". In addition, they may often be mis-diagnosed at this stage and are not informed of the diagnosis that is applied to them.

Experiences described by users who had been admitted to mental health wards are often very negative and include isolation, boredom, staff insensitivity and unpleasant side effects from prescribed medication. If there were any therapeutic activities, they are generally in English since most of the occupational therapists are English speaking and interpreters are rarely available.

There is a widespread feeling that the treatments offered reflect the needs of the system, not those of the individual patient; and that doctors do not listen properly to their patients or take sufficient time on explanations. There is a shortage of interpreters and if the provision of interpreting were improved, this would transform services for minority groups. At the moment, they feel that doctors' perceptions of their state of mind and needs are seriously limited.

The most significant feeling that came from BME participants in this consultation is one of pervasive isolation, of "being on the outside". This in turn fuelled deep-seated depression because their many and diverse needs are not being adequately met. Better communication is needed at all levels through the assistance of professionally trained interpreters and the allocation of sufficient time to enable patients or clients to express their needs, understand their diagnosis and have full information about the help – including medication – that is available to them.

Culturally appropriate day centres could play a large part in alleviating mental distress, particularly if well staffed by trained workers; but so also can access to sporting activities, social events and faith-based meeting places. An active partnership needs to develop between statutory and voluntary services and the BME communities in order to break down social exclusion.

The BME communities themselves should participate in training professional staff about cultural diversity and minority needs, and an understanding and explanation of minority group approaches to mental health should be included in this training. This will aid professionals in their understanding of mental illness and stigma within BMA communities.

Greater access to bi- and multi-lingual advocacy in mental health care settings, including in-patient care, will also do much to reduce feelings of isolation and help doctors and nurses to offer effective care to individual patients; and much greater attention must be given to after-care services to aid continuing rehabilitation and better integration into the community at large.

Some Statistics

- Twenty consultations with BME community groups took place over a period of 9 months (see page 8).
- Over 300 individuals from different BME communities took part in these consultations.
- Eleven community facilitators were trained.
- Thirty-two people from the community, voluntary and statutory sectors attended the two plenary meetings and fifty six people attended the public meeting in May 2004.

Summary of Recommendations

1. **Stigma and all the negative perceptions** that circumscribe mental health issues within BME communities must constantly be challenged.
2. **Mental health link workers** are needed to work closely with those community and faith groups that already play a significant role in fostering mental well-being amongst BME communities. Link workers have a crucial role in promoting mental health and challenging stigma. In KCW there is a need for at least one part-time link worker to work with community and faith centres and liaise with local GP practices.
3. **Information about mental health and access to services** must be available in different formats, including audio and video, in various community languages. This information should be disseminated through mainstream and supplementary schools, faith groups, social venues, community radios and other local media. This way, information about mental health services can be mainstreamed and de-mystified; and community groups can then support and signpost those in need.
4. **Interpreters should receive training in mental health issues.** This will help to detect symptoms before people are forced into secondary care; and only professionally trained interpreters should be used in both primary and secondary care settings.
5. **Bilingual befriending schemes** can work within local communities and faith groups. Such schemes can also assist in secondary care settings to help combat users' sense of isolation and loneliness in hospital wards.
6. **There should be more support for community based activities and projects.** Community and faith centres play a very important role in the mental well-being of their members. In addition to their traditional role, many centres provide both direct and indirect support to people with mental health difficulties and would therefore benefit from additional financial and professional support with this work.
7. **Recognising, understanding and appreciating the role of faith** are vital for the provision of more culturally sensitive services. This can be done by creating better links with faith groups.
8. **More referrals should be made to therapeutic services**, such as psychology and counselling; and the waiting times for these therapies must be reduced.
9. **Assessment should focus on the individuals and their interests.** This should form the centre of the assessment process, not the process itself.
10. **Staff training should include cultural diversity** so that BME user voices are heard, understood and supported by the mental health care system. It is equally important that BME users and carers are involved in the planning and delivery of this training.
11. **Communication between staff and service users must be improved.** There should be regular meetings for service-users, where they are encouraged and given enough time to express their views about their treatment and medication in a comfortable atmosphere.
12. **In-patient ward activities should be more diverse**, to appeal to all users, including BME users. BME users should be continually involved and consulted to get these activities right.
13. **Full information about medication, its effects and side effects** must be provided in a way that can be understood by all users.
14. **More day centres, like the Oremi Centre, should be provided,** with more workers, including bilingual support workers, to meet the cultural needs of users.
15. **CPA plans must take proper account of culture and diversity,** especially when users are referred to day centres that offer therapeutic activities. Key workers must be allowed the time and opportunity to hear and get to know users, so that they can offer flexible support to meet individual needs.
16. **Action to improve social inclusion,** for example, through providing better access to social and leisure activities, housing services and employment opportunities in deprived areas, is essential to the mental health and well-being of the BME communities who live in those areas.

Introduction

The *BME Communities and Mental Well-Being in KCW* Task Group was launched in October 2003 to obtain feedback from black and minority ethnic (BME) communities in Kensington & Chelsea and Westminster (KCW) on issues related to mental health and well-being, including access to, and use of, local mental health care services. The project embraced migrant communities in KCW including those from Africa, the Caribbean and Morocco as well as refugee and asylum seeker groups from the Middle East, Africa and South Asia.

The project was co-ordinated by the KCW BME Health Forum (BME Health Forum) and the Migrant and Refugee Communities' Forum (MRCF). Representatives from the communities, with voluntary and statutory agencies, were also involved in the project from the outset.

The aim of the project was to assess community experiences and perceptions of local mental health care services, to identify unmet needs and to recommend improvements that will better serve the needs of local BME communities. With the new obligations on service providers in the *Race Relations (Amendment) Act 2000* and Section 11 of the *Health and Social Care Act 2001*, this project sought to facilitate better consultation with, and engagement of, KCW BME communities in the planning, commissioning and delivery of local mental health care services.

The task group included the following activities:

- Two initial meetings attended by representatives from community groups, mental health care professionals from the NHS and local authorities and stakeholders from the voluntary and community sectors. These two meetings were held to launch and publicise the task group; to involve all stakeholders from the beginning; to establish collective ownership of the project; to provide an overall direction for the project; to invite community groups to participate in the consultations; and to produce a pro forma questionnaire.
- Twenty consultation events run in partnership with BME community groups to obtain feedback from their members on concerns related to mental health in the local communities, including access to services and how local services can better meet people's needs.
- One public meeting with speakers on specific issues related to mental health and well-being.

This final report sets out the findings from the consultations and proposes some recommendations to service providers and commissioners on how services may be improved.

It is important to highlight that the information this task group collected is qualitative and not quantitative, since not all BME communities in KCW participated in the project. And as much as the project workers are confidant that the findings of the task group reflect the reality of mental health issues for BME communities in KCW, more work is needed to include those communities that – for whatever reason - have not given their feedback.

The intention in undertaking this piece of work is to lay the foundations for a progressive process of dialogue and discussion between service providers and KCW BME communities about all the issues affecting mental health and well-being; and the best way to meet the mental well-being and social care needs of BME communities is by working closely with them. The MRCF and BME HF hope that this project will encourage more consultations and co-operative work between users and providers to discover more about this important issue.

In the meantime, MRCF and the BME Health Forum will continue working with service providers and local BME communities to ensure that the findings and recommendations of this task group are taken forward.

Methodology

The task group comprised representatives of BME voluntary and community groups as well as the statutory agencies, since one of the aims of the BME Health Forum is to lobby for greater involvement of BME communities in policy-making and planning, commissioning and delivering services.

For this project, the BME Health Forum funded and enabled community organisations to run consultation sessions within their own communities. There were at least seven participants in each group and each group provided a written account that has been used to inform the findings and recommendations in this report. This is the same approach adopted by previous task groups that the BME Health Forum has co-ordinated to ensure the active involvement of BME communities from the very start of the project.

The selection of groups

More than 35 BME community groups in KCW were invited to join in the consultation. Over 15 groups participated and 20 community consultations took place. Including representatives from the statutory and voluntary sectors, as well as people who took part in the community consultations, many of whom have used mental health care services at all levels, well **over 300 people** took part in this project.

Community Consultation Training

The community representatives who facilitated the consultations attended a two-day training event organised by the BME Health Forum, with an experienced trainer, on *How to Run Community Consultations*. Attendance on this course was a requirement to run the consultations. A feedback session followed after all the consultations were completed to obtain feedback from the facilitators on the process used for the project. This session was an integral part of the training programme provided to the community facilitators. In addition, several groups that joined the project after the initial training were provided with facilitators to help run their consultations.

Developing the Pro Forma

Representatives from the BME Health Forum, MRCF and mental health professionals from the voluntary and statutory sectors met before the start of the training to develop a pro forma to guide the group consultations. (**Appendix A**) The pro forma was not a questionnaire, but rather a tool to be used by the facilitator to prompt questions and comments about mental health and well-being issues. The groups had the choice of using it or adopting their own methodology to make it more appropriate for their community group. Some groups, such as the Oremi Centre, did not follow the suggested pro forma; instead, their consultation covered the issues they thought had the most relevance for their users.

The process

The project was launched at a public meeting attended by local community groups, the statutory agencies and local and national voluntary organisations in KCW. As well as launching the project, the meeting also discussed its aims and objectives and the issues that needed to be addressed. A number of other events were organised throughout the life of the task group, including a second public meeting, a consultation on race equality and mental health in partnership with Westminster Social Services and a third public meeting with speakers.

The BME Health Forum and MRCF co-ordinated the task group and had overall responsibility for running the project. The project itself was funded by the BME Health Forum, which in turn is funded by Kensington & Chelsea and Westminster Primary Care Trusts.

The process adopted by the task group proved to be a successful mechanism for obtaining feedback from a range of BME communities. The task group was successful because BME community groups, the statutory agencies and local and national voluntary organisations were engaged on an equal basis from the very start of the project.

Throughout the duration of the project the BME Health Forum and MRCF provided community groups with extra capacity support, including the provision of a note-taker. Both the project co-ordinators and the note-taker also attended most of the consultations.

Comments on the methodology

Strengths of the methodology

- It was an empowering process for the BME communities, as they were involved in the project from the outset and were funded to run the consultations themselves.
- The training helped community facilitators both to run the consultations and to develop their own personal skills.
- Developing the pro forma helped facilitators raise important issues that they felt should be raised in the consultations.
- Funding community groups to run the consultations themselves enabled them to create the right environment in which to hold the sessions.

Limitations of the methodology

- The groups that participated are not representative of the full spectrum of BME communities in KCW.
- Only the views of individuals who have access to local community-based organisations have been voiced.

Completed consultations

Twenty consultations took place over a period of 9 months and almost 300 individuals from different BME communities participated (see below).

	Name of organisation/group	**Number of participants**
1	Advocates for Mental Health	3 users plus one MH advocate
2	African People's Link	11 people
3	Al-Hasaniya Moroccan Women's Centre	10 women
4	Arab Women's Voice	17 women
5	Black Unity Forum (jointly with K&C Mind)	6 people (5 users and a carer)
6	Earls Court Drop-in Centre	12 people
7	Egyptian Community	15 women
8	Eritrean Elders Welfare Association (Fifty Plus)	21 people (18 men, 3 women)
9	Islamic Cultural Centre and Mosque at Regent's Park	13 people (7 men, 6 women)
10	K&C Mind (jointly with Black Unity Forum)	6 people (5 users and a carer)
11	Muslim Cultural Heritage Centre	26 women
12	New Roots (Bangladeshi women's group)	14 women
13	New Roots (African-Caribbean group)	18 people (14 men, 4 women)
14	Oremi Centre	43 users of African and Caribbean origins

15	Persian Day Centre	12 women
16	Race Equality & Mental Health consultation (BME Health Forum & Westminster Social Services)	24 people from all sectors
17	St Antonio Eritrean Refugee Women's Group	14 women
18	Sudanese Community Information Centre	15 people
19	Umoja Pamoja (women's group)	10 women
20	Umoja Pamoja (young people)	8 young people

Caught between stigma and inequality public meeting held in March 2004 and organised by the BME Health Forum and MRCF.

Findings and Recommendations

Findings

As the next pages reveal in more detail, the core findings of this task group revolve mainly around health promotion and access to primary mental health care. The task group has identified that, for BME communities in KCW, the issues raised most often are about stigma, a lack of information and knowledge of mental health care services and high levels of stress, anxiety and depression related to a complex set of factors including social exclusion and linguistic and cultural barriers.

It is not surprising to note, therefore, that other recent local reports have come to the same conclusion. The Westminster Ethnic Minority Needs Audit (WEMNA) states, *"by far the most prominent health issues reported by those we recruited through the qualitative interview study were those of mental health, stress and depression"*[1].

Indeed, mental health problems in BME communities have been on the increase in recent years and so has the level of attention paid to them at a national level. However, what this report also shows is that there are still huge gaps in mental health services, particularly around health promotion that specifically tackles stigma in BME communities. The provision of education, awareness and information materials and access to primary care are also in need of improvement.

Whilst this report makes recommendations for action to promote mental health and address these gaps in services, it is important to underline that these recommendations are suggestions and ideas whose main intention is to instigate dialogue, discussion and co-operation between service providers and BME communities.

Although the recommendations in this report may provide some answers to current problems, service providers should ensure that they do not confine their responses to these recommendations only. The long term solution lies in maintaining an on-going partnership with local BME communities that is based on realistic participation and involvement by those communities.

1 Understandings and perceptions

1.1 Understanding mental health and well-being

Participants' answers to the question "what does mental well-being mean to you?" included: *"having peace of mind"; "being balanced mentally, not having extreme emotions and coping with day-to-day activities and events with peace"; "the ability to cope with life without feeling overwhelmed and stressed"; "being active and having things to do" and "not having depression or suicidal tendencies, socialising and being comfortable in yourself".*

Many participants also stated that having poor mental health was part of their life in the UK as a minority, as refugees or asylum seekers. A refugee man explained that *"for us, trying to survive makes for a lot of mental pressure. To get work one must have references, speak the language and have the right qualifications. Without these things it's impossible to get the right job."*

This notion of mental health and well-being is likely to be a contributing factor to the reality that many people of BME origin do not seek help if they feel down, depressed or isolated. *"If we are mentally sick we never go to the doctor - we just repress it",* a young man said.

This also highlights the fact that different communities have different coping mechanisms. These mechanisms may not necessarily be the familiar 'Western' methods, such as

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[1] Westminster Ethnic Minority Needs Audit, Health section, p18 – published in 2004

counselling. It is therefore very important for mental health professionals to bear that in mind if they are to ensure that the care they provide is culturally appropriate.

1.2 Perception of mental health and well-being within the community

Mental health problems within BME communities are highly associated with **stigma and shame**. *"Crazy"* and *"mad"* are some of the terms used to refer to people with mental illness. *"If you see a psychiatrist, you are messed up in the head"*, one man said. The majority of participants stated that they would not tell their friends, relatives or neighbours about their mental health problems for **fear of being labelled, isolated or alienated** by their friends and community. Some participants stated that they would keep their mental problems secret even from their own families, because they did not want to shame their families or be distanced from them.

Mental ill health within BME communities is understood as a **sign of failure and something to be feared**. It is described as **madness rather than psychological stress – incurable, serious and not to be mentioned**. And even when it is cured, the stigma remains – ***"once mad, always mad"***.

There is also a perception that **all mentally ill people are violent**, cannot understand things and are unable to take control of their lives, even when they are back in the community.

All these perceptions of people with mental health problems contribute to their social exclusion and the discrimination against them.

Recommendations

- **Stigma and all the negative perceptions** that circumscribe mental health issues within BME communities must constantly be challenged.
- **Mental health link workers** are needed to work closely with those community and faith groups that already play a significant role in fostering mental well-being amongst BME communities. Link workers have a crucial role in promoting mental health and challenging stigma. In KCW there is a need for at least one part-time link worker to work with community and faith centres and liaise with local GP practices.
- **Information about mental health and access to services** must be available in different formats, including audio and video, in various community languages. This information should be disseminated through mainstream and supplementary schools, faith groups, social venues, community radios and other local media. This way, information about mental health services can be mainstreamed and de-mystified; and community groups can then support and signpost those in need.

2 Mental Health Promotion

2.1 Social exclusion

Mental health problems can be caused by social exclusion and can also be the cause of social exclusion. Hence, the likelihood of people from BME backgrounds, who are amongst the most isolated groups in KCW, developing a mental health problem is greater in comparison to the wider community. Add to that the complications, anxiety and distress associated with being from a minority and/or refugee group and the risk is even greater.

But depression and anxiety can affect up to one in six of the population at any one time, with the highest rates occurring in the most deprived neighbourhoods. The RBKC Overview and Scrutiny Committee on Social Services, Health and Housing recently published an *In Depth Study of Health Inequalities*, in which it states that *"admission rates for all mental health-related issues suggest overall levels comparable to London but great inequality in mental well-being within the borough, with six of the more deprived (old) wards (Golborne, St*

Charles, Avondale, Colville, Kelfield and Pembridge) falling into the highest quarter in all London"[2]*.*

This link between mental health and social exclusion is also highlighted in the WEMNA Report: *"several interviewees attributed high rates of mental illness among their communities to the multiple problems of poverty, poor housing, unemployment or low paid work and lack of self-esteem that they experienced"*[3]*.*

2.1.1 Factors that affect mental well-being negatively

When asked *"what would negatively affect your mental well-being",* participants' answers included:

- **Poor accommodation and housing standards**
  Poor housing was considered to have a major impact on the mental well-being of BME communities in KCW.
- **Isolation**
  Isolation from the community and society, especially in the case of the elderly and single mothers, was seen as one of the main causes of depression. Likewise, mental health service users felt that isolation in hospital wards caused their mental health to deteriorate.
- **Unemployment**
  Participants highlighted that having no job contributed greatly to isolation, poverty and eventually mental health problems.
- **Drugs and/or alcohol misuse**
  Many participants described these as serious problems, especially for young people.
- **Language barrier**
  The language barrier, including lack of information in various community languages and how to access certain services, was a problem. A participant said *"if you know nobody, where can you go? People feel lost, and as though they do not belong, just because there is no information for them".*
- **Poverty and financial insecurity**
  Poverty and financial insecurity were considered by the majority of participants as having a negative impact on the mental well-being of BME communities in KCW. According to the National Service Framework *Mental Health: Modern Standards and Service* Model (NSF): *"children in the poorest households are three times more likely to have mental health problems than children in well-off households."*[4]
- **Being a refugee or an asylum seeker**
  Asylum seekers' uncertainty about the outcome of their application for asylum and their future and worrying about the situation back home in their "countries of origin" were some of the main causes of anxiety and distress for refugees and asylum seekers. An Iraqi user said "*bad news from my country, people dying there and a lot of victims. These things affect my family as well and make everyone sad. And I get upset."*
- **Lack of support**
  Lack of support, or discontinued support, for users of mental health services after discharge was a problem. Once users are discharged from hospital, no proper plans are made for continuity of support in the community. And when and if such plans are made, no proper follow up happens, especially around taking medication. In addition, little consideration is given to securing referrals to culturally sensitive services, such as day centres.
- **Lack of activities for users of MH services**
  As one user put it, *"how can I get better when there is nowhere to go or nothing to do during the day"?*
- **General political climate and its effects on relations between communities**
  Participants from the Muslim community in particular felt that the political atmosphere after 11 September and the war on Iraq were putting them under additional pressure and distress.

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[2] In Depths Study of Health Inequalities, Final Report, p12 – published 2004

[3] Westminster Ethnic Minority Needs Audit, Health section, p18 – published 2004

[4] National Service Framework – Mental Health: Modern Standards & Service Models, 1999.

These same issues were also highlighted in the King's Fund's inquiry into mental health in 2003, *London's State of Mind* - "*employment and housing are crucial issues in promoting and maintaining good mental health, yet the inquiry heard that service users found enormous problems in securing these necessities. Regeneration and other urban renewal schemes could tackle these issues with greater vigour, but few are prioritising mental health promotion. At a national level, while some policy initiatives (such as attempting to reduce child poverty) may be expected to promote better mental health, other policies (such as those relating to asylum seekers) may contribute to increased stress and exacerbate mental health problems among vulnerable people.*"[5]

2.1.2 Factors that affect mental well-being positively

In their answers to the question *"what would boost your mental well-being?"* participants provided the following suggestions:

- **Community based activities**
  Social gatherings and events, organised by local community centres, were highly praised and recommended by participants as a means to combat loneliness.
- **Projects and initiatives aimed at improving the community's mental well- being**
  Projects such as the *Over 55 Initiative* at the Muslim Cultural Heritage Centre, which involves outings and sports activities for the elderly, were praised for helping to combat isolation.
- **Sports activities and culturally appropriate sports facilities**
  Affordable and culturally appropriate leisure services, such as women only sessions, are key issues in accessing sports centres.
- **Support and advice**
  Community-based as well as professional support and advice on dealing with stress, anxiety and loneliness are thought to be necessary to improve the mental well-being of BME communities.
- **Improved health services for BME communities**
  Participants considered that good health provision, including efficient interpreting and culturally sensitive services at GP practices and hospitals are crucial to the mental well-being of individuals and communities.
- **Family and friends' support**
  Participants, including users, attached a lot of importance and value to the support they receive from their families and friends**.** As one Arabic-speaking user put it in his answer to a question about what would boost his mental well-being, he said *"talking to friends and family…I get on well with everyone. We discuss problems."*
- **Medication and drugs with fewer negative side effects**
  For users and non-users alike, the need for *'medication that works'* and *'medication without nasty side effects'* was considered important for better physical and mental health. Some users also stated that they prefer to have treatments other than drugs.
- **Stability and Security**
  A sense of stability and security, including financial security and meaningful work and employment
- **Faith**
  Faith was often mentioned, by users and non-users alike, as an important factor in people's mental well-being.

2.2 Knowledge of mental health services

In general, people who had not used mental health care services had **poor knowledge of the services available.** When asked if they knew what is available for people with mental health problems in KCW, the majority of participants were not aware of most of the services. However, the vast majority of participants said that their **GP** would be the main point of contact should they need to use mental health care services.

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[5] London's State of Mind, King's Fund 2003

They also stated that their **community groups** played a central role in fighting off isolation and in helping them to *"unload"* and release some of their anxieties. For many people within the community, the elderly and single mothers in particular, community centres are the only places where they can meet and socialise with others from the same community. The social and cultural activities organised by community groups are perceived as indispensable to the most vulnerable within the community.

Very few participants, on the other hand, have used **counselling services**, and when asked about their experiences of these, they did not find them helpful. A Moroccan woman who had used counselling services for a number of years said, *"I tried counselling but did not find it helpful at all. They keep asking you questions about your childhood. I had a happy childhood and all my problems started when I became a migrant in this country".*

When asked about where they would go if they had a mental health problem, some participants said they would not try to seek help because, as one Egyptian woman put it, *"if we have mental problems we don't seek help because we consider it as part of our way of life"*. However, if the situation deteriorated, they said they would contact their GP, A&E Services or the police, if necessary.

Participants who have used secondary mental health care, on the other hand, had a good knowledge of the range of services such as GPs, day centres, Community Mental Health Teams (CMHT), mental health advocates, community groups, counselling services, crisis services, hospitals and the emergency services (police, A&E, ambulance). **Hospitals, crisis teams, GPs and mental health advocates** are the services most used by members of BME communities. The least used, on the other hand, are **counselling and therapeutic services.**

In addition, it is important to note that the vast majority of participants have never taken part in any consultation or research on mental health issues. This indicates that **research and consultation on mental health and well-being issues have not been effective in reaching BME communities in KCW.**

Recommendations

- **Action to improve social inclusion,** for example, through providing better access to social and leisure activities, housing services and employment opportunities in deprived areas, is essential to the mental health and well-being of the BME communities who live in those areas.
- **Interpreters should receive training in mental health issues.** This will help to detect symptoms before people are forced into secondary care; and only professionally trained interpreters should be used in both primary and secondary care settings.
- **Bilingual befriending schemes** can work within local communities and faith groups. Such schemes can also assist in secondary care settings to help combat users' sense of isolation and loneliness in hospital wards.
- **There should be more support for community based activities and projects.** Community and faith centres play a very important role in the mental well-being of their members. In addition to their traditional role, many centres provide both direct and indirect support to people with mental health difficulties and would therefore benefit from additional financial and professional support with this work.
- **Recognising, understanding and appreciating the role of faith** is vital for the provision of more culturally sensitive services. This can be done by creating better links with faith groups**.**

3 Primary care and access to services

3.1 Barriers to accessing mental health services

This task group has shown that the majority of mental health service users from BME communities in KCW are sectioned and/or admitted to hospitals without going through primary mental health care. In other words, most BME users' first encounter with mental health services is when they are admitted or sectioned. This is partly due to the under-development and shortage of primary care services. In a recent report the King's Fund states "*London appears to remain locked into using high levels of acute inpatient beds for people with mental health problems, with vitally important community and primary care services remaining underdeveloped in many areas.*"[6]

There are also barriers that particularly affect people from BME communities, including refugees and asylum seekers. **These barriers** can be summarised as:

- **The stigma** attached to mental health problems and the shame that they bring to the patients and their families. Also, the perception that all mentally ill people are violent, out of control and cannot understand things reinforces their unwillingness to access mental health care.
- **A lack of knowledge** or awareness of the signs of mental illness, of what help is available and how to access it are major barriers for the vast majority of people who have not used mental health services before.
- **The role of GPs.** Many participants stated that they did not have proper communication with their GPs, not only because of the cultural and language barriers, but also because GPs themselves are very busy and overstretched by having to cope with an ever increasing number of patients. Therefore they do not have the time to listen to their patients properly. To those participants, many of whom had depression, this lack of communication can result in mental health problems going undetected and necessary referrals not being made at the right time.
- **Mistrust and fear of mental health services**. This is the fear of losing control over one's own life and handing it over to mental health care services.
- Uncertainty about the adequacy of **interpreting services** and its responsiveness to the language and cultural needs of highly diverse communities.
- **Childcare support**. Most women, even though they may need to access mental health services, would suppress their condition and try to cope without doing so, as they lack adequate and affordable childcare for times when they would like to use the services.
- **Confidentiality**. With all the stigma and shame that is attached to mental health problems, confidentiality is a major concern for many participants, especially younger people: *"I am very worried that if I see a mental health professional, they might breach confidentiality and inform my parents, something that I would not wish to happen".*
- Many participants stated that as **refugees or asylum seekers** they would not seek help because they are the main supporters of their families and *"could not afford being ill. My family would not be able to manage without me. I am the only breadwinner in the house and we do not know many people here. I am very worried about my asylum application and the pressure is draining me mentally and physically; but I have to deny it and continue as if I am OK, to protect my family"*.
- **Assumptions and lack of understanding of the needs of BME communities**. *"People make assumptions about me because I am black. People don't understand my behaviour and interpret it in a negative way"*

3.2 Referrals

People's general response to questions about referrals is that they would not mind seeing a therapist if this was their GP's advice. However, this project has identified that BME users in KCW make little use of therapeutic services such as therapists, counsellors and psychologists. It has also shown that BME users often start their mental health treatment at

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[6] London's State of Mind, King's Fund 2003

hospital level, when their mental health has deteriorated and things have got out of hand, rather than at the primary care level.

This indicates an absence of referrals to counsellors and psychologists from primary care. One of the issues often raised during the consultation is that people are given medication instead of a referral to a therapist. This conclusion was also arrived at in the Sainsbury Centre for Mental Health's *Breaking the Cycles of Fear* report, which states that *"the pathways by which black people come to the attention of psychiatric services often do not involve primary care or community-based alternatives to hospital*"[7]. And even if referrals are made, people have to wait a very long time before they can see a therapist. In one case, a BME user had to wait six months to see a psychologist.

Recommendation

More referrals should be made to therapeutic services, such as psychology and counselling; and the **waiting times** for these therapies must be reduced.

3.3 Assessment

Most users expressed dissatisfaction with the way in which assessments are conducted. The issues that were raised are:

- **Environment and patient assessment:** There were comments that the **environment** plays a very important role in the assessment process and therefore those being assessed need to be in a **friendly, familiar and comfortable setting**; and there was a consensus amongst users that there is a need for more choice over how assessments are conducted.
- **An advocate of their choice** to offer support during assessment. When people are being assessed, they are at their most vulnerable and can easily lose their confidence and the ability to think clearly and express themselves properly.
- **Trained interpreters**: There are concerns that interpreters are not properly trained in mental health issues. The lack of such training means that body language and some cultural signs are not interpreted properly, which can have serious consequences in terms of the results of the assessment. Mental health professionals also need to bear in mind that those whose first language is not English can lose their ability to speak English at an assessment, even if they are known to speak it. A distressed person is likely to lose the ability to speak any language when surrounded by professionals. At assessment, people have to understand perfectly what is said to them, so that they can give accurate answers; moreover, people in this situation might lose the confidence to ask for clarification if they don't understand a question. Their ' wrong' answers could be seen as a symptom of 'hallucinations', for example.
- **Cultures, attitudes and behaviours:** Members of the medical staff may often not understand the cultures, attitudes and behaviours of BME people or the way they express themselves, which means they are less likely to make an accurate assessment.
- **Poor communication** by mental health professionals and an unwillingness to get to know service users is perceived as controlling and oppressive. Treating users *'like numbers'* and having a different attitude towards patients with a mental illness to those with a physical illness are perceived to enforce discrimination against and a lack of respect for people with mental health problems. As one black user put it, "*I remember silence. No staff talked to me."*
- **Lack of explanation:** Another concern commonly expressed by users is that mental health professionals do not make the effort to explain things to service users. For example, people are not informed why they are being assessed; what the assessment procedure is; what their rights are; what their diagnosis is; what the diagnosis means; the nature of their illness and how it affects their life; and advice on how they can be helped and help themselves.

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[7] The Sainsbury Centre for Mental Health (SCMH), Breaking the Cycles of Fear 2002

- **Wrong diagnoses:** Some users raised concerns about wrong diagnoses leading to inappropriate treatment. As one participant put it, *“substance misuse was treated with mental health medication”.* There is a sense that over-emphasis on overt expressions of frustration are often misinterpreted as aggression or potentially threatening or violent behaviour.

Recommendations

- **Assessment should focus on the individuals and their interests.** This should form the centre of the assessment process, not the process itself.
- **Staff training should include cultural diversity** so that BME user voices are heard, understood and supported by the mental health care system. It is equally important to involve BME users and carers are involved in the planning and delivery of this training.
- **Communication between staff and service users must be improved.** There should be regular meetings for service-users, where they are encouraged and given enough time to express their views about their treatment and medication in a comfortable atmosphere.

4 Secondary Mental Health Care

4.1 Experiences during admission

The experiences of BME users of secondary mental health care services (in-patient hospital care) were highlighted when users were asked about what they thought was bad and what was good about those services.

Participants who have used secondary mental health care services reported the following **bad and negative experiences of the services:**

- **Isolation** and boredom on the wards. A great sense of isolation and loneliness is felt by BME patients, described thus by one user *“with no one to speak to in your own language”.* Another user stated, *“you get spoken to only when you are given your medication.”*
- **Staff insensitivity**, the impersonal service they provide, an unwillingness to explain things to patients and their lack of communication with patients. One participant said *“staff don’t interact with us apart from when telling us what to do”*.
- **A lack of culturally appropriate activities** in mental health hospitals: for example, music and art groups are run by English-speaking occupational therapists (interpreters are available only at some crucial meetings like ward rounds, mental health assessments and Care Programme Approach plans).
- **Treatment and medication:** There are a number of issues surrounding treatment and medication. These include:
  - ❖ A major concern that **medication has nasty side effects.** A number of service users complained that the side effects of medication are worse than the symptoms it is supposed to treat. There is a sense of mistrust that treatment is often about making service users ***‘easy to deal with’***, rather than improving their condition.
  - ❖ Another concern is that the **treatments reflect the needs of the system**, not the individual, and **medication is the only treatment offered**. Many users stated that treatment must involve more communication between staff and service users and their carers, counselling, time for talking and sharing ideas on the most appropriate treatment. Some also noted that treatment should involve preparation for the outside world, including more visits into the community.
  - ❖ People are **not properly informed about their medication and its side effects**. As one black user put it, “*you’re not given enough information on medication. You have to read up the information on medication yourself. How do you do that if you’re illiterate? No-one even tells you that information if you can’t read.*”
- Another common theme that arose is the **low expectation placed on a person’s recovery**, particularly as a black service-user.

- Many participants complain that **doctors do not pay attention or listen to patients whose advocates are not present** at crucial meetings. Nor do they allow enough time for those using interpreters.
- **TV channels, videotapes and newspapers are all in English**. Patients whose first language is not English have no access to satellite channels in their own languages. In addition, they could only get newspapers in their language if they were told that they could ask for them.
- **Halal and Kosher food** is not available in sufficient quantities, and in some instances not all meals have the Halal and Kosher option.
- **Multi-faith prayer rooms** are not available at all hospitals.

On the other hand, they consider **services to be good and positive when:**

- Staff members are sensitive to their cultural needs.
- Their medication works.
- Their medication is discussed with them.
- Some of their problems (such as accommodation and benefits) are sorted out by social workers,(if they are allocated one).
- The crisis team is tailored to individual needs.
- They receive counselling, advice and therapeutic training.

Recommendations

Working closely with local communities and faith groups, service providers should consider:

- **Bilingual befriending schemes** to combat users' isolation and loneliness on wards.
- **More diverse activities on hospital wards**. It is important to involve and consult BME users on an on-going basis about appropriate activities.
- **Providing complementary therapy**
- **Using only professional and trained interpreters**. Friends and relatives should be used only in a dire emergency, while a professional interpreter is being arranged.
- **Improving communication** between mental health staff and service-users. There should be regular meetings for service users, where they are encouraged and given time to express their views about their treatment and medication in a comfortable atmosphere.
- **Providing sufficient information about medication and its effects and side effects** in a way that can be understood by users.
- **Employing more bilingual advocates** to cover all community languages.
- Professional staff need to have higher **expectations of the potential and ability of black service-users to recover.**
- Treatment must include all areas of a person's life. This may include more time spent outside hospital and more emphasis on rehabilitation (life skills, improved living conditions, employment opportunities and coping strategies).
- **Developing better links with community groups and faith centres**. Faith plays a significant role in the lives of many people from BME communities, and work with religious leaders can be beneficial to both users and service-providers.

5 Aftercare

The following issues were raised about continuity of care and support after discharge:

- **Care Programme Approach (CPA) Plans**. There are concerns that care plans are just a formality, as no proper plans are made for continued support in the community. "*Once you are discharged, you are on your own*", one user said. And where there are care plans, only some parts of the plans are followed up, especially medication. Little consideration is given to securing referrals to culturally sensitive services such as day centres.

- **Day Centres**. Participants talk about the need for day centres as places where they can be listened to and understood. "*Somewhere I come to forget about my problems and socialise with staff and other members",* one black user said.
  For many users, the importance of community day centres is that they provide culturally sensitive services and offer advice and direction in a non-judgmental way.
- **Faith** was also stressed by many users. There is a sense of appreciation amongst many participants of the role that faith has in their lives.

Recommendations

- **CPA plans need to take into account cultural and diversity issues:**
  - ❖ When referring users to day centres and the kind of activities available.
  - ❖ Key workers need to have time to listen and get to know users so they can offer flexible support that meets varying individual needs.
- **More resources** are needed to provide:
  - ❖ **More day centres, such as the Oremi Centre.**
  - ❖ **More day-centre workers, including bilingual support workers,** to meet the cultural and linguistic needs of users.
- **Role of faith:** for more culturally sensitive aftercare support and to provide stimulating, challenging and direction-led activities, it is important to recognise and appreciate the importance of the role of faith and improve links with faith groups.

Next steps

The aim of this project is to improve mental health care service provision for BME communities in KCW. It also aims to promote mental health and well-being issues amongst BME communities and to challenge many of the misconceptions relating to mental health problems, but to make a positive change, there must be a mutual commitment to address the key findings of this project on the part of both the statutory and the voluntary sectors. Moreover, a solution for the long term can only be realised by working towards and maintaining partnership work and co-operation with BME communities themselves.

Community organisations have always played an important role in health promotion and disseminating information about different health services and as this report demonstrates very clearly, community centres have become providers of mental health services to their community. For many BME people, the elderly and single mothers in particular, community centres are the only place where they can meet and socialise with others from the same community. The most vulnerable people within BME communities perceive social and cultural activities organised by community groups as indispensable. In other words, for many people, community centres are the “treatment” for their isolation, depression and anxiety.

However, for community organisations to continue this vital role in addition to their other responsibilities, they need to be provided with the necessary support. They need to be empowered through active partnership with statutory service-providers: a partnership that is based on structured working relationships rather than just a passive provider-user relationship.

The mental health needs of the hugely diverse BME community in KCW are complex, varied, can be overwhelming and do not always fit within the existing statutory framework. In addition, statutory service-providers are often pressured by national and local priorities and targets; restrictions and reductions in funding; a lack of awareness of the needs of other cultures; and an institutional work culture that does not provide space for complex needs. So, by developing a meaningful partnership with community organisations, statutory agencies can maintain and develop a second-tier of mental health service-provision that will take some of the pressure off statutory mental health services. However, given the lack of resources available to community groups and also the lack of professional expertise to deal with mental health issues, community organisations fulfil this role inadequately. Consequently, the support of statutory agencies is vital.

The launch of this report marks a new stage of this project - that of work with the PCTs, the CNWL Mental Health Trust, other providers of in-patient care and statutory and voluntary bodies to take forward its findings and recommendations. The BME Health Forum and MRCF will continue to disseminate these findings and recommendations through presentations at different meetings. They will also seek to have the key findings addressed and incorporated into the Equality and Diversity Strategies, the Race Equality Schemes and the action plans of the NHS Trusts in both boroughs.

The BME Health Forum and MRCF will also feed back to the communities the development of work on these issues on a regular basis. Through their public meetings and events, newsletters, e-mail and mailing lists, they will ensure that progress will be communicated to all the BME communities in KCW.

For more information on this report and/or on how its findings and recommendations will be taken forward, please contact:

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APPENDIX A

Pro Forma for Mental Well-Being Task group

The following are issues that have been suggested by the Steering Group for this Task Group to be used during the community consultations run by community groups. They have been grouped together under headings to help give a structure to the discussion.

Note to facilitators:
Please make sure that all comments made during the consultation session are recorded by a note taker or noted on flip chart paper during the session.

We are aware that not all issues will be relevant to some groups and settings- so please feel free to focus on those subjects that are relevant to the people in your group.

1. Understanding of mental well-being.

- What does mental well-being mean to you?
- What would boost your mental well-being?
- What would negatively affect your mental well-being?

2. Perception of mental health within the community

- How is mental health perceived in your community?

3. Knowledge and experience of mental health services

- Do you know what services are available for people with mental health problems?
- Would you know how to contact mental health services if someone needed help, or if you did yourself – where would you go?
- Has anyone ever used any of the following mental health services? If so, which ones?
    - GPs
    - Day centres
    - Community Mental Health Team
    - MH advocates
    - Community groups
    - Counselling services
    - Crisis services
    - Hospitals
- What was good about the services you have used?
- What was bad about the services you have used?
- What were the difficulties you encountered, if any, in ***using*** these services?
    - Getting referrals
    - Appointments
    - Interpreting services
    - Nurses and MH professionals
    - Continuity of care
    - Completing forms
    - Gender/ sensitivity
- How do you think the services can be improved?

4. What barriers are there likely to be for users in *accessing* MH services?

- Culture/language
- Confidentiality
- Gender sensitivity/ compatibility
- Transportation
- Family and children needs
- Other barriers

5. How can MH service providers help overcome these barriers?

6. Specific issues related to the experience of the following user groups

- What are the experiences of ***women*** in accessing and using MH services?

- What are the experiences of ***elderly people*** in accessing and using MH services?

- What are the experiences of ***young people*** (up to the age of 35) in accessing and using MH services?

- What are the experiences of ***refugees and asylum-seekers*** in accessing and using MH services?

- What are the experiences of ***people with learning difficulties*** in accessing and using MH services?

- What are the experiences of ***disabled people*** in accessing and using MH services?

7. The experience of other alternative services

- Spiritual / religious healers
- Community support groups

8. What do you think of the information available on MH services? How do you think it should be presented?

9. Have you ever taken part in a consultation regarding MH/local health services planning and delivery? If not, why do you think this was, and how would you like to be consulted?

10. How would you like to strengthen/improve MH in your community?

11. What could you do if you had the resources?