

Breaking the Circles of Fear

A review of the relationship between
mental health services and
African and Caribbean communities

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Photography: Errol Francis, Jennie Smith
Design: Jennie Smith

ISBN: 1 870480 55 4

Published by

The Sainsbury Centre for Mental Health
134-138 Borough High Street
London
SE1 1LB

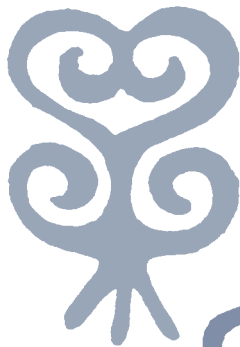
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A charitable company limited by guarantee no 4373019
Charity registration no 1091156



Adinkra symbols (below)
Found on hand-printed and hand-embroidered Adinkra textiles. The symbols originated in the 19th century with the Asante people of Ghana, and the Gyaman people of Cote d'Ivoire. From top: *Sankofa* (you can always undo your mistakes); *Nyame nwu na mawu* (perpetual existence); *Gye nyame* (accept God).



A NOTE ON TERMINOLOGY

In this review the term 'Black' refers to people of African descent and origin; people who may commonly be referred to as African or African Caribbean. We have used the term 'Black' throughout the report to indicate those communities, except when citing authors who use different terminology.



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Foreword

THERE IS A profound paradox at the centre of Black people's experience of mental health services in England. Young Black men, in particular, are heavily over-represented in the most restrictive parts of the service, including secure services. And Black people generally have an overwhelmingly negative experience of mental health services. Yet these same communities are not accessing the primary care, mental health promotion and specialist community services which might prevent or lessen their mental health problems. They are getting the mental health services they don't want but not the ones they do or might want.

We have reached a point in the relationship between the Black communities and mental health services where there are truly *Circles of Fear*. Black people mistrust and often fear services, and staff are often wary of the Black community, fearing criticism and not knowing how to respond, and fearful of young Black men. The cycle is fuelled by prejudice, misunderstanding, misconceptions and sometimes racism.

Yet the circles of fear do nothing for either staff or the Black community. We are delivering expensive, poor quality mental health services that do not match the needs and aspirations of the clients and their families. Whatever the reasons – and this report sheds light on many of them – we need to turn this around and *Break the Circles of Fear*.

I believe this report represents a major step forward in turning this problem around and creating solutions that are owned and led by the Black community itself. Already leadership has emerged and exciting and effective services have been created which can build bridges between the community and statutory services. But much more can be done and this report suggests how. It is right that we should reflect on the past and the history of oppression and neglect which is all too evident. This report acknowledges that past but is concerned first and foremost with the future. I commend it to you.

Dr Shirley Tate

Chair, West Yorkshire Metropolitan Ambulance Service NHS Trust
Chair, Breaking the Circles of Fear Steering Group



Acknowledgements

THE STEERING GROUP for the review and the Advisory Panel, which were chaired by Drs Shirley Tate and Andrew McCulloch respectively, are listed in Appendices 3 and 5. In addition, the Sainsbury Centre for Mental Health would like to thank:

The authors of this review:

Frank Keating
David Robertson
Andrew McCulloch
Errol Francis

Matt Muijen for editorial input to the final draft.

The organisations that participated in the review's site visit programme and all those who undertook the site visits. A full list of the services visited can be found in Appendix 6.

The team of focus group facilitators and Heather Vernon for her administrative support.

The Tizard Centre, University of Kent at Canterbury.

Special thanks to all those who took part in the focus group interviews and responded to the call for evidence in the press and professional journals.



Executive summary

The purpose and scope of this review

THE NEED FOR changes to the mental health care and treatment of Black people is widely recognised and long overdue. There is compelling research and statistical evidence which shows that Black and African Caribbean people are over-represented in mental health services and experience poorer outcomes than their White counterparts.

Stereotypical views of Black people, racism, cultural ignorance, and the stigma and anxiety associated with mental illness often combine to undermine the way in which mental health services assess and respond to the needs of Black and African Caribbean communities. When prejudice and the fear of violence influence risk assessments and decisions on treatment, responses are likely to be dominated by a heavy reliance on medication and restriction.

Service users become reluctant to ask for help or to comply with treatment, increasing the likelihood of a personal crisis, leading in some cases to self-harm or harm to others. In turn, prejudices are reinforced and provoke even more coercive responses, resulting in a downward spiral, which we call 'circles of fear', in which staff see service users as potentially dangerous and service users perceive services as harmful.

The review was focused on documenting the 'circles of fear' and impediments to change which lead to the poorer treatment of African and African Caribbean adults and to use this information to produce a strategy for *Breaking the Circles of Fear*.

How the review was conducted

The review took place in several interlinking stages, i.e., a call for evidence, regional launches, focus group interviews, site visits, follow-up focus groups, and the implementation and dissemination of the findings. It was chaired by Dr Shirley Tate and was led by a steering group representing key stakeholders. An advisory group provided expert advice on the operational and practical issues. It represents the largest and most ambitious piece of research on this subject to date.

The audience

This report is aimed at all those who are responsible for the planning, provision and delivery of services to this client group including central Government, the NHS, social services, the nursing and professional bodies, primary care, the Black voluntary sector and other partner organisations. It is also aimed at service users and carers.

The key findings from the research

Ten key themes emerged from the research:

1 There are circles of fear that stop Black people from engaging with services

These function in the way described above.

2 Mainstream services are experienced as inhumane, unhelpful and inappropriate

Black service users are not treated with respect and their voices are not heard. Services are not accessible, welcoming, relevant or well integrated with the community.

3 The care pathways of Black people are problematic and influence the nature and outcome of treatment and the willingness of these communities to engage with mainstream services

Black people come to services too late, when they are already in crisis, reinforcing the circles of fear.

4 Primary care involvement is limited and community-based crisis care is lacking

5 Acute care is perceived negatively and does not aid recovery

6 There is a divergence in professional and lay discourse on mental illness/distress

Different models and descriptions of ‘mental illness’ are used and other people’s philosophies or worldviews are not understood or even acknowledged.

7 Service user, family and carer involvement is lacking

8 Conflict between professionals and service users is not always addressed in the most beneficial way

The concept of ‘culture’ has been used to attempt to address some of these issues, but can divert professionals away from looking at individual histories, characteristics and needs.

9 Black-led community initiatives are not valued

Specifically, secure funding and long term capacity building initiatives are absent.

10 Stigma and social inclusion are important dimensions in the lives of service users.

The strategy

A wide ranging programme is needed to break the circles of fear addressed both to the statutory sector and to the Black communities. The main aims would be to:

- ❖ ensure that Black service users are treated with respect and that their voices are heard;
- ❖ deliver early intervention and early access to services to prevent escalation of crises;
- ❖ ensure that services are accessible, welcoming, relevant and well integrated with the community;
- ❖ increase understanding and effective communication on both sides including creating a culture which allows people to discuss race and mental health issues;
- ❖ deliver greater support and funding to services led by the Black community.

These aims will not be delivered through a top-down approach working mainly through statutory services. A much more promising approach is to empower the Black community to develop, or further develop, 'gateway organisations' which can build bridges between the community and services and between individuals.

The Recommendations

The review generated fifteen recommendations covering the six key elements of the strategy as follows:

Establishing the gateway function

Recommendation 1: Gateway organisations should be commissioned to develop bridge-building programmes to support reintegration of Black service users.

Recommendation 2: A national resource centre must be established to support the development of gateway organisations.

Supporting the community

Recommendation 3: The National Institute for Mental Health should create and fund a national programme of mental health promotion aimed at and owned by the Black community.

Improving access

Recommendation 4: All health and social care communities with significant populations of Black people should identify practical steps to encourage early access in non-stigmatising or generic community settings as part of the National Service Framework for Mental Health (NSF) implementation programmes.

Recommendation 5: Advocacy for service users and support for carers needs to be available early in the cycle.

Recommendation 6: Each health and social care community must ensure equal access to appropriate counselling and psychotherapy services.

- Creating sensitive services** **Recommendation 7:** Carers and advocates must be involved in care planning.
- Recommendation 8:** Acute inpatient care for Black people must be systematically reviewed.
- Workforce development** **Recommendation 9:** Training programmes in mental health should be developed and implemented for the relevant generic workers. Specifically, Black primary care staff are a key resource in bridge building. They need to be appropriately trained, supported and developed.
- Recommendation 10:** Staff development programmes must be implemented to support the overall strategy. The national resource centre should act as a central point for information about training and development programmes for NHS and gateway agency staff.
- Recommendation 11:** The leadership centre, which is part of the Department of Health's Modernisation Agency, should develop leadership programmes for Black staff in all relevant sectors, working with Black organisations and national partners.
- Capacity building** **Recommendation 12:** Government should create opportunities for national and local funding via mechanisms such as Section 64 and neighbourhood renewal grants to Black organisations.
- Recommendation 13:** The development of a national voice for the Black user movement should be facilitated.
- Other recommendations** **Recommendation 14:** The Department of Health should set relevant performance targets.
- Recommendation 15:** The National Institute for Mental Health should develop a research strategy to evaluate and underpin the development of service solutions and community involvement. ■





The client group

This chapter explains the need for a review of the treatment and care of African and African Caribbean adults with mental health problems and describes the process and methodology of the review.

Introduction

THIS REPORT PRESENTS new insights into the dynamics and dimensions of the treatment and care of Black people with mental health problems. The messages contained in it are consistent with previous findings, but this is the first large-scale qualitative inquiry into this field. Our evidence is that mental health services continue to fail to meet the basic needs of Black people. It is futile to seek strategic solutions for change which do not address these needs.

Why the focus on African Caribbeans? This report specifically focuses on the African Caribbean community because not only is this group the most over-represented minority ethnic group within mental health services, it is also the social group to which the greatest level of fear seems to be directed within society as a whole as well as within mental health services.

The care pathways of Black service users are problematic, and are often characterised by hospital admission under a Section of the Mental Health Act, involvement of the police, the forcible administration of medication and contentious staff-user interactions (Goater *et al.*, 1999; Thornicroft *et al.*, 1999). Unfortunately, the Black community associates mental illness with being detained in hospital and involuntary treatment in a confined and restrictive environment. There is a plethora of tragic experience that resides within the collective memory; stories about successes, innovative services and good practice are somewhat elusive or prove difficult to sustain. While acknowledging the obstacles faced by services the challenge is to make care more therapeutic and less restrictive. There are many instances of good practice and there are successes that we can build on. However, there is a deep lack of understanding and trust between the Black community and mental health services. Black service users remain the most disaffected of all groups using services (Sandamas & Hogman, 2000; Parkman *et al.*, 1997). Such is the level of disenchantment with services amongst service users, and their families and carers, that there is the feeling that services no longer have the best interests of clients at heart.

The need for the review

The need for change to the mental health care and treatment of Black people is widely recognised. This review took the position based on the literature and practical experience of the Sainsbury Centre for Mental Health (SCMH) staff, service users and networks, that little has changed over the last 15 years and proposed that there are circles of fear that interfere with the interaction between mental health services, service users and families and carers (Sandamas & Hogman, 2000). We discovered that these ‘circles of fear’ stop Black people from using services when they are needed and that they stop professionals from engaging with Black people in ways that are sensitive to their needs. The mutual lack of trust has to be broken before progress can be made.

The review was solution focused and specifically aimed to:

- ❖ identify service and community impediments to change and recommend solutions;
- ❖ identify the learning and training needs of clinicians and other professionals who work alongside mental health professionals, for example, the police;
- ❖ develop guidelines for best practice; and
- ❖ draw up an implementation and dissemination strategy.

Three sites with significant populations of individuals from African or Caribbean backgrounds were included in the review. Two inner London boroughs – Lambeth and Haringey – and a city outside London – Birmingham – were selected.

Characteristics and needs of the client group

Over-representation of Black people in the more restrictive components of mental health care is well documented. The lack of relevant and appropriate care for these communities has also been highlighted. The vexed question of mental health and ‘race’/ethnicity has been an issue of concern and debate for the past three decades. Numerous commentators, particularly within Black communities, have asked why is it that mental health services continue to fail Black people. In the face of an ever-increasing number of Black people entering mental health services and their negative experiences of services, the attitude of clinicians has been questioned. A study by Lewis *et al.*, (1990) found that psychiatrists were more likely to perceive Black people as violent, therefore racism or prejudice could account for the differential experience. A more recent study has found that particular stereotype to be no longer valid, yet the authors still recognised and acknowledged that racism remained evident within mental health services (Minnis *et al.*, 2001). However, Spector (2001) concludes that racial stereotyping and particularly perceptions of dangerousness do influence patient management.

Spector (2001) reviewed studies which looked at the relationship between race and coercion, in particular compulsory hospital admissions in the UK and the use of control and restraint in the US. The over-representation of Black people in psychiatric services has been said by some sources to be due to a hypothesised genetic predisposition to schizophrenia (Selten *et al.*, 2001). Genetic or biological explanations

might appear convincing but there is little evidence to support them (Fernando *et al.*, 1998; Jenkins, 1998; Sharpley *et al.*, 2001; Rose, 2001).

The evidence shows that Black people are more likely to be subject to:

- ❖ Compulsory admission under the Mental Health Act (Mental Health Act Commission, 1999; Davies *et al.*, 1996)
- ❖ Readmission (Glover, 1989)
- ❖ Over-diagnosis of schizophrenia and under-diagnosis of depression or affective disorder (Cochrane, *et al.*, 1977; Bebbington, 1981; Dean *et al.*, 1981; Harrison *et al.*, 1989; Cochrane *et al.*, 1989; Lloyd & Moodley, 1992)
- ❖ Involvement of police in hospital admission and use of Section 136/137 of the Mental Health Act (Turner *et al.*, 1992; Rogers & Faulkner, 1987)
- ❖ Over-use of psychotropic medication (Lloyd & Moodley, 1992)
- ❖ Admission to medium and high secure facilities (Jones & Berry, 1986)
- ❖ Physical treatments (Littlewood & Cross, 1980)
- ❖ Excessive admissions via the courts (Robertson *et al.*, 1996; Banerjee *et al.*, 1995; NACRO, 1990).

They are less likely to receive psychotherapy, psychological treatments, counselling or other alternative treatments.

On the other hand, service provision in the independent sector, particularly Black-led services, is perceived positively by the Black community.

The process of the review

A steering group and an advisory panel of external experts together with key staff in SCMH led the review. The terms of reference and memberships of these groups are set out in Appendices 2-5. The review comprised several interlinking stages.

In the first stage, regional launches to publicise the project, enlist local support and generate a network of contacts were held in each of the three review sites. A pool of facilitators with experience or in-depth knowledge of mental health services provided to Black people was recruited to do the interviews. Service users facilitated all the focus groups with service users and a carer co-facilitated all the family and carer interviews. Four training and briefing workshops were held to familiarise facilitators with the aims and objectives of the review, to devise interview schedules, and to achieve a common language for use in the interviews. In addition we held two debriefing sessions to reflect on the process of interviewing and to make contributions to data analysis.

Review methods

A range of methods was used to collect information on the care and treatment of Black people. First, we launched a national call for evidence in national and local newspapers, including the Black press and in professional magazines. A total of 124 responses were received and information from these was used to formulate the questions for the review.

Second, we used focus group interviews in two stages to elicit views on a) impediments to change and to unpack the concept of 'circles of fear', and b) to explore achievable solutions for change. In addition we

conducted individual interviews with psychiatrists to document their concerns about mental health services. Third, we visited services or projects to document examples of best practice and obtain further views on solutions. A more detailed description of the methods used can be found in Appendix 1.

A programme of site visits to mental health services was carried out to seek examples of best practice and obtain further views on solutions. Members from the steering group, advisory panel and staff from SCMH undertook the visits. These were planned using advice from within SCMH, the steering group, the advisory panel and the team of consultants.

Respondent profiles

Seventeen focus group interviews were conducted in the first round and fourteen in the second. The average number of respondents in the groups was six and there was a mix of men and women. In the interviews for professionals there was a mix of ethnicity and professional backgrounds. We were not able to engage fully with senior management, an area that needs further attention. Tables 1-2 and 3-4 gives a break down of the number of groups for the first and second rounds respectively. All individuals who attended the regional launches were invited to participate in the focus group interviews. A high response rate was achieved for mental health professionals, except for psychiatrists. Respondents were identified through gatekeepers who work with service users and carers. This approach may have limitations for generalising to the population of Black service users and carers as a whole, but the main purpose of this review was to explore impediments to change and to develop achievable solutions.

There was still a high degree of scepticism about the project, even after users and carers had agreed to participate in the interviews. Most of the concerns related to the purpose of the review and how data would be used, including a view that Black people are over-researched and that they never see the benefits of participating in research projects. Some respondents preferred not to be identified even though we gave assurances that the project would respect anonymity and confidentiality. Mistrust of this nature towards participating in research reflects the mistrust that Black people have towards mental health services in general, as a result of past experiences.

Feedback on the data collection process has been positive. Service users, families and carers, as well as professionals, welcomed the opportunity to talk about the issues at length. They reported that they derived a great deal of support from meeting others who were in similar positions to themselves. Professionals stated that the interviews provided them with opportunities to reflect on the issues in a safe environment as well as raise awareness about the shortcomings of services that they provided. ■

Table 1 Breakdown of focus groups (first round)

Categories	Total (n)
Service users	5
Families & carers	3
Professionals*	8
Police (multisite)	1
Total	17

* 2 Black professionals

Table 2 Gender breakdown (first round)

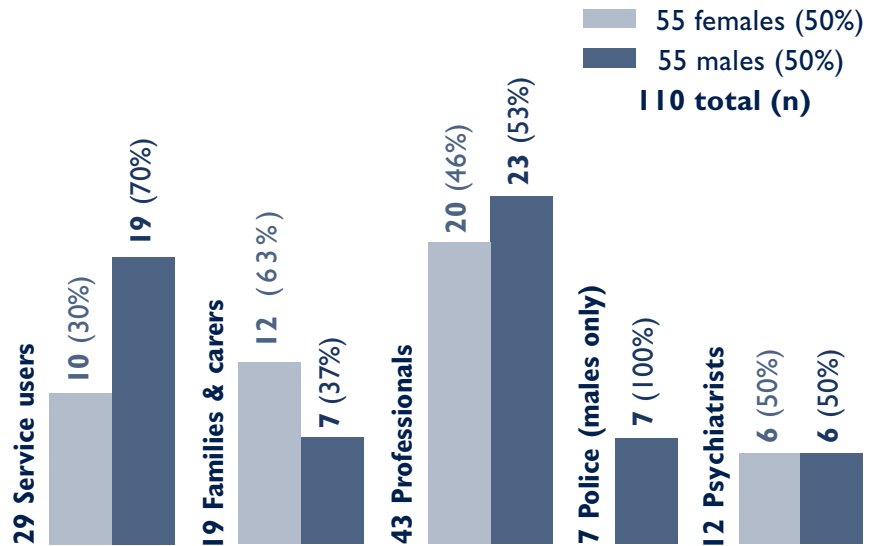
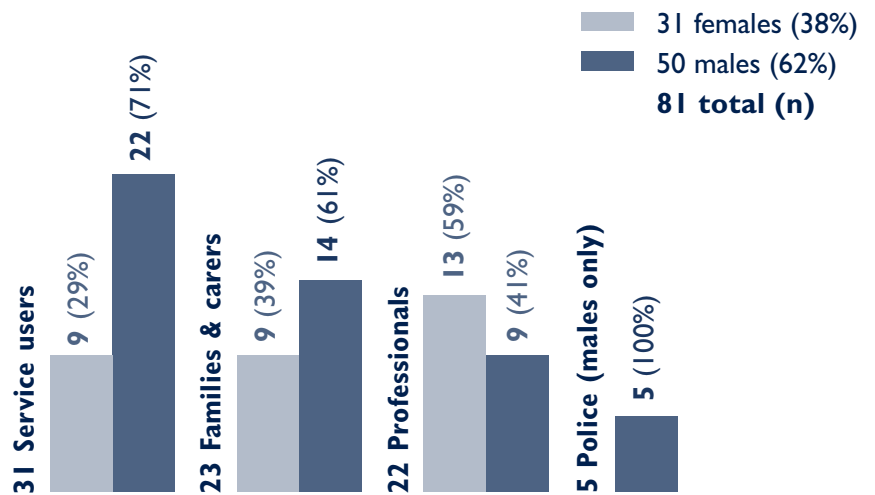


Table 3 Breakdown of focus groups (second round)

Categories	Total (n)
Service users	5
Families & carers	3
Professionals*	5
Police (multisite)	1
Total	14

* 2 Black professionals

Table 4 Gender breakdown (second round)



2

The Black community in context

This chapter will give a brief overview of the current state of affairs and provide profiles of the review sites. Background information is included to show where Black people live, what their patterns of service use are, what services they use, why and how the three sites were selected, and particular lessons that were learnt by using these sites.

The social context

BLACK COMMUNITIES HAVE a long history of inequity and disadvantage as a result of racism and discrimination. These negative experiences are reflected across all indices such as housing, employment and education, i.e. Black people experience poor housing, high levels of unemployment and low pay. Modood *et al.* (1998), for example, found that whereas 28% of White households have incomes below half the national average, the figure for African Caribbean families was 41%. They also found a clear association between high levels of unemployment and areas of high minority concentrations. For example, in Birmingham the electoral wards with a high concentration of minority communities also have high unemployment levels. The unemployment rate for Black people, currently 15%, is three times greater than that for White people (5%). Young Black men are particularly disadvantaged and have the highest levels of unemployment of all groups, nearly a third in the 20-24 age range being unemployed (Matherson & Babb, 2002). This is all the more important given the young age profile of the Black community.

Black people also face massive disadvantages within the education system, not only in terms of academic success but in terms of the risk of being excluded from school or being referred to specialist psychological services for children with learning difficulties or behavioural problems. Within the personal social services Black families are more likely to have their children taken into care, very often on the basis of detrimental mental health assessments, leading to wardship or adoption proceedings.

Standard of living is another area that illustrates high levels of inequity. Modood *et al.* (1998) assessed standard of living using a series of indicators, such as consumer durables, arrears and disposable income and devised a generalised measure of 'hardship'. They found that African Caribbeans were worse off in all measures and that they were more likely to experience financial 'hardship' than other groups.



There is evidence showing how the distress arising from experiences of racism can bring people into contact with mental health services (Sanders-Thompson, 2002). If we combine the inequalities and disparities that Black people experience in the wider society with those that are embedded in the mental health services, we are left with a rather bleak picture: one that reinforces the social exclusion of Black people. It therefore becomes clear that opportunities for re-engagement and participation in society after contact with mental health services are limited. A natural consequence of this is that mental health outcomes for these communities are likely to be negative.

The policy context

The care and treatment of Black people with mental health problems has been the subject of numerous policy initiatives at local and national levels. The 7th Annual Report (1997) of the Mental Health Act Commission sums up the policy concern:

“Provision for patients from minority ethnic communities often remains basic, insensitive and piecemeal leading to patients feeling alienated and isolated. It is dispiriting that the serious issues of inappropriate care and treatment of patients from Black and minority ethnic communities, which were raised in previous Biennial Reports, continue to cause concern and to be noted in the reports of the commission visits.”

More recently, the National Service Framework (NSF) for Mental Health (DoH, 1999) emphasises the poor sensitivity of existing services to African and Caribbean people. Table 5 adapted and updated from Olajide (1999) illustrates the attention given to the care needs of Black people in a number of policy documents.

Review site profiles

Haringey

Haringey is one of London’s 33 boroughs, located in the north of the capital, and roughly 11.5 square miles in area. Almost half of its 223,700 people come from ethnic minority backgrounds, including Greek and Turkish Cypriot, African and Caribbean, Indian, Pakistani and Bangladeshi, Irish and Chinese. Recently, Kurdish, Somali and Kosovan nationals have settled in Haringey, too. The people of Haringey speak a total of 193 different languages. 17% of the population are from Black groups, 6.1% from African Caribbean backgrounds.

It’s often said that Haringey is an outer London borough with inner London challenges. It ranks as one of the most deprived boroughs in the country, with 8.1% of the population unemployed in January 2001, double the national average.

Lambeth

The London Borough of Lambeth is the largest inner London Borough with a population of 272,500 (1999 mid year estimate). Between 1981 and 1991 the population fell by 11% – the second highest loss for a

Table 5 Recent reports and initiatives relating to mental health needs of Black and minority ethnic groups in Britain

1993: Mental Health & Britain's Black Communities report

Showed where Black and ethnic minority service users were dissatisfied with services.

1994: Ritchie report

Highlighted a series of errors and omissions in the care of Christopher Clunis, a Black man with schizophrenia who stabbed Jonathan Zito to death. (The report found that his ethnicity had affected the assessment and management of his care.)

1994: Mental health task force

(London project and regional race programmes.) Demonstrated dissatisfaction with services, as well as highlighting good practice.

1994: Black Mental Health: A Dialogue for Change

Advocated a new way of integrating voluntary and statutory sector practice. Voluntary sector seen as valuable in managing mental illness among Black and minority ethnic service users.

1994: NHS Executive letter EL (94) 77 on collecting ethnic group data

All service providers to collect data on service users' ethnic origins, to help assess which groups were using particular services and whether these groups' needs were being adequately considered.

1994: Ethnic health unit set up

Attempted to address the needs of Black and other minority ethnic users for physical and mental health care services. Unit had a short lifespan but initiated some important work.

1995: Learning the Lessons

(Zito Trust report) Looked at all the homicide inquiries where the perpetrator was mentally ill and attempted to identify common lessons. Emphasised role of race and ethnicity of mentally ill people and looked at service shortfalls for minority ethnic groups.

1995: Mental Health: Towards a Better Understanding

(Health of the Nation public information booklet for ethnic minorities and their carers.) Highlighted the plight of carers and their needs.

1998/9: A First Class Service

Advocated national service frameworks which set standards of care with best quality and fair access. Highlighted inequalities in health care.

1999: MacPherson report

(Following the murder of Black teenager Stephen Lawrence and the failure of the criminal justice system to bring his murderers to justice.) Highlighted institutionalised racism. The NHS (along with other public bodies) expected to examine its structures and services in the light of the report to eradicate racism.

1999: The National Service Framework for Mental Health

(Department of Health) Set out national standards of care and measures for monitoring performance. Gave special emphasis to the cultural sensitivity of services for African and Caribbean ethnic groups, the assessment of Asian ethnic groups and the plight of socially excluded groups, such as refugees.

2000: The NHS Plan

A key aim is to address inequalities in health, especially for people from minority ethnic communities.

2002: The Race Relations (Amendment) Act 2000 and the EC Article 13 Race Directive

The Act also places a general duty on public authorities to work towards the elimination of unlawful discrimination and promote equality of opportunity and good relations between persons of different racial groups.

Adapted and updated from Olajide (1999)

London borough. Socially and culturally Lambeth is one of the most diverse communities in Great Britain. 34% of Lambeth's population is from ethnic minorities – the seventh highest figure for a London borough. 25% are from Black groups and 4% from groups from the Indian Sub Continent. Lambeth has the highest proportion of African Caribbean residents of any London borough, and the third highest for Black Africans.

Lambeth also attracts refugees from many nations/countries such as Vietnam, Somalia, Eritrea, Angola, Azerbaijan, the Kurds and many other groups. Approximately 132 languages are spoken in the Borough. After English, the main languages spoken are Yoruba and Portuguese. Lambeth still has an acute unemployment problem with an official unemployment rate (Sept 2000) of 8.6%, compared to 7.5% for Inner London and 4.9% for Greater London as a whole. For men the figure is 11.6%, and women 5.0%.

Birmingham

The 1991 Census revealed that 78.5% of Birmingham's population is White. Ethnic minorities form 21.5% of the population, 6% are from Black groups, the majority from African Caribbean backgrounds.

Experience of services Fear

Fear is a phenomenon that is inextricably linked with both racism and mental illness. Fear is a component of race relations and racism. Black people are often cast as 'the Other' and therefore viewed with suspicion, hostility and anger. The basic fear of 'the Other' is a central aspect of racism in all parts of our society and affects relationships within mental health services between Black service users and professionals.

Sivanandan (1991) has argued that the fear with which most Black people regard mental health services seems to be grounded in an association with other, more obviously coercive, agencies such as the police or prisons. Evidence for this association is provided by Sivanandan's (1991) *Deadly Silence: Black Deaths in Custody*, in which the deaths of Black people held in police custody and in prisons are connected with deaths in psychiatric hospitals and are said to be caused by similar stereotypes – of Black males in particular.

In terms of mental illness, Corrigan, *et al.* (2001) proposed that fear of mental illness leads to those perceived as mentally ill being avoided. Such avoidance creates a social distance between people with mental health problems and the rest of society and leads to them being socially excluded (Sayce, 2000; Link *et al.*, 1999). Phelan & Link (1998) suggest that fear of mental illness and people with mental health problems can stop individuals from engaging with services.

If you combine these different layers of fear – fear of Black people, fear of mental illness and fear of mental health services – you arrive at a pernicious circle of fear: a circle that impacts negatively on the engagement of Black people with services and vice versa.

Conflict

Conflict is an inevitable dynamic in organisational life and should not necessarily be avoided. Smith, *et al.*, (2001) suggest that when properly addressed it can result in improved interpersonal relationships and a positive organisational culture. Furthermore, when conflict is managed effectively, such interventions can contribute to a safe environment and reduce the demands that conflict places on the institution (Shapiro & Tippet, 2002).

Evidence shows that conflict arises between professionals and service users due to the different explanatory models of mental illness that they use (Arcia, *et al.*, 2002). It can be argued that these conflicts, when not addressed appropriately, can lead to negative and undesirable outcomes for service users, families and carers.

Summary

This brief literature review has demonstrated that:

- ❖ Black people are disproportionately disadvantaged,
- ❖ Policy directives and initiatives have yet to yield positive outcomes for Black people, and
- ❖ Black people's experiences of mental health services are characterised by fear and conflict. ■





Exploring ‘circles of fear’

This chapter aims to:

- ❖ Identify the fears that were described in interviews with service users, families and carers, and professionals, and
- ❖ Illustrate how these fears impact on the interactions between services and mental health service users.

The findings reported here detail some of the fears that were described to us and shed greater light on the dynamics between Black people, their families, carers and mental health services. Some of the issues raised here may be similar for White people, but the distinguishing factor is that Black people experience these issues in a qualitatively different way because of their historical position in the UK, as discussed in Chapter 1.

What are these fears?

BLACK PEOPLE SEE using mental health services as a degrading and alienating experience: the last resort. They perceive that the way services respond to them mirror some of the controlling and oppressive dimensions of other institutions in their lives, e.g. exclusion from schools, contact with police and the criminal justice system. There is a perception that mental health services replicate the experiences of racism and discrimination of Black people in wider society, particularly instances where individuals have experienced the more controlling and restricting aspects of treatment. A service user talks about her experience of seeking help from mental health services as a Black person:

“...Coming to mental health services was like the last straw... you come to services disempowered already, they strip you of your dignity...you become the dregs of society” (Service User).

“I remember when I first went into hospital ... I feared that I was going to die”

Service users expressed fears about being admitted to hospital and most strikingly a fear that involvement with mental health services could eventually lead to their death. A service user comments:

“I remember when I first went into hospital ... I feared that I was going to die” (Service User).

Medication (over-use, disabling side effects, etc.) was cited as another

source of fear. This was compounded by lack of information about the benefits and possible side effects. Being labelled mentally ill invoked fears about the future and the stigma attached to mental illness. One respondent in talking about his diagnosis said:

“... When I heard the words schizophrenia I was so afraid of what was going to happen to me” (Service User).

Concerns about the unpredictable nature of ‘the illness’, loss of control and the overall impact on their quality of life were further sources of fear for service users. Respondents talked at length about their fears about managing their personal, social and economic affairs and the lack of adequate support to help them reintegrate into society.



Families and Carers also feared the unpredictable nature of emotional distress, but this appeared to be based on a lack of knowledge and understanding of the illness and the unresponsiveness of services to their pleas for help. One carer stated that when she saw how bloated and obese her friend’s son had become after receiving treatment, she feared that her own son would have a similar experience and therefore delayed seeking help until the situation reached critical proportions.

For carers, like service users, the fear was that the illness would eventually lead to their loved one’s death (due to police intervention) or confinement in one of the special (high security) hospitals:

“I’m a good citizen, I follow the law, I go to work and all the rest of it, I do that. But the point is that I’m aware, I’m much more aware of the potential of the police, I’m afraid of informing the police in the wrong kind of circumstances. I don’t want to know he’s dead, I don’t want to know he’s committed some serious crime and he’s ended up in Broadmoor or Rampton, I don’t want that, that’s what I’m trying to avoid. I can smell it on the horizon, but I’m trying my best to avoid it, that’s why I do what I do” (Carer).

Another source of fear was professional power and the difficulty families and carers experienced when they challenged assessments or decisions made by professionals. An extract from one of the interviews illustrates this when a carer talked about her efforts to have her husband’s medication reviewed,

“... nothing was done, even when my husband was vomiting, vomiting up the tablets because he didn’t want tablets. And I remember once I had to take a taxi to go to hospital, it was a Sunday because the consultant didn’t believe that he would vomit out the tablets. So we go there, give the tablets and show my husband vomit them out almost on his feet. And still that point didn’t go through. So what I have found all along the years is this, I am afraid to challenge them [professionals]... it is always a struggle to be taken seriously” (Carer).

Professionals' fears derived from perceptions about dangerousness and violence. However, views were expressed to indicate that this applied to any person who exhibited a certain type of behaviour. They did not make any references to any particular ethnic group or talk explicitly about having fears of Black people with mental health problems. Professionals talked about their fear of violence due to previous physical assaults by patients,

“To be honest, I think I’m more wary of size. If someone’s big, that actually worries me ... we tend to get out of the way, which I think is the best route, avoidance ...”

“Well, about things like violence and so on, because it’s of great concern to us because we’ve got a small team, we might have 20, 25 patients, some of whom have had psychotic episodes, and virtually all of whom will have had a diagnosis in some form of acute psychosis with personality disorders, because that’s what we specialise in. So violence is, we do have violence reported. To be honest, I think I’m more wary of size. If someone’s big, that actually worries me ... we tend to get out of the way, which I think is the best route, avoidance ... So we tend to keep out of the way. So I think size, I’m just trying to think, because I’ve been beaten up by a patient, and also we used our team response to assess the level of risk, so if the whole team are fearful for example of someone, we would put that as a greater risk than if somebody’s not. If someone says, ‘oh no, he’s fine with me’, we think that reduces the risk a bit, because it’s likely that that person might be able to talk to them if they’re so agitated they may become violent” (Professional).

Knowledge and information about services

There is much concern about violence in the NHS, not only in mental health but other settings, such as accident and emergency departments and primary care. This is reflected in the NHS zero tolerance policy which not only targets physical assault but also aggressive and threatening behaviour towards staff. The UKCC’s report by Wright *et al.* (2002) also highlighted the growing concern with violence in mental health settings and strategies for its prevention and management. Staff are rightly concerned about violence but it would appear that racial biases in perceptions of dangerousness influence patient management (Spector, 2001 cited in Wright *et al.* 2002; Barnes & Bowl, 2001). This is borne out by the fact that in a study comparing Black and White patients, despite having lower scores on aggressive behaviour, Black patients were perceived as being more dangerous (Bhui, 2001).

We believe that professionals have a particular fear of Black people but they were not able directly to acknowledge it. Even though this was not clearly addressed or openly discussed, we have to understand the generalised fear about dangerousness in the context of the stereotypes about Black people as ‘mad and/or bad and dangerous’ (cf. ‘big, Black and dangerous’, Prins *et al.*, 1993; Barnes & Bowl, 2001). Interestingly, when asked how they deal with individuals who are perceived as dangerous or violent it emerged that the use of restraint procedures to gain control over the situation were the most common solution. This should again be viewed in the context of known evidence that Black

people are more likely than their White counterparts to be subjected to more restrictive and punitive forms of treatment.

The relationship between the Black community and **the police** tends to be fraught at the best of times. A defining moment in relations with the police came with the publication of the MacPherson report and the steps taken to combat institutionalised racism. The police force is unique compared to other institutions in its admission that as an institution it has not treated Black people in a fair and just way. As far as mental health issues are concerned police involvement usually signalled that there was going to be a problem, as one officer commented,

“Whenever we are asked to assist, at the end of the day it’s because it’s probably going to be something quite unpleasant” (Police Officer).

There were instances which the officers found quite distressing and where they were not supported by mental health professionals:

“There was doctor – there must have been four or five other professionals there and they all stepped back. It was just automatically – the police will deal with that. I mean not only did they leave us to wrestle with the woman they didn’t even assist to take the baby”

“There is one thing that I’ve done that I’ve felt really uncomfortable about ... It was a pre-planned assessment on a woman who had given birth to a baby two or three weeks earlier. They knew she was at home. We went in forced entry. Myself, a sergeant and one of my female colleagues and I felt really uncomfortable. He [the psychiatrist] asked this lady several questions that she got right and he got wrong! General knowledge questions like, ‘What’s the date?’ and ‘Who’s the Prime Minister?’ And she was getting them right and he was going ‘Is that right?’ You know you sort of really felt quite awkward but at the end of it, it ended up in a free for all and I felt really quite awkward having to manhandle a female. ... [She was] quite vulnerable, quite large but she also had a babe in arms. So we had to not only manhandle her to remove the baby, which obviously at three weeks old [was] incredibly fragile and I felt quite awkward doing that. We found all the other professionals took one step back. As soon as it came to hands on. There must have been about eight people in that room and only three moved forward ... ASWs, two ambulance officers, staff psychiatrist, the social worker for the lady. There was doctor – there must have been four or five other professionals there and they all stepped back. It was just automatically – the police will deal with that. I mean not only did they leave us to wrestle with the woman they didn’t even assist to take the baby” (Police Officer).

One of the striking issues to emerge for professionals was that there seemed to be a fear of talking about issues of race and culture in a safe and honest manner. There is an air of secrecy about these issues illustrated by one person who recounted that he speaks to his manager behind closed doors and ‘off the record’ when he has concerns about racism, etc. This is worrying given that all respondents in the focus groups worked in areas where there were significant numbers of Black people present in their services. This perceived lack of safety in talking

publicly about race related issues may have been a factor contributing to the low number of psychiatrists participating in focus groups.

One can assume that if it is not safe for professionals to talk about issues of race and culture amongst themselves, then it must be even more difficult for service users, families and carers to talk to professionals about it. A further assumption that can be made is that when professionals do not have opportunities to talk about issues of race and culture then it is unlikely that they will be able to develop and build competence and confidence to incorporate these into their practice. It seems therefore that these fears could impair professional decision making particularly when it is evident that these are based on perceived risk and a potential lack of knowledge about issues of race, culture and ethnicity.

About political correctness

When staff say that they can't talk freely about race and culture issues, the implicit problem is often what has come to be called 'political correctness'. The term 'political correctness' is basically a pejorative term which applies to anti-discriminatory policies that are regarded as extreme, oppressive and somehow restrictive of 'free-speech' and behaviour. The term has complex origins and applications and, although it was probably first used in Europe in the 1920s (Blazquez, 2002) it has recently made a comeback in the US as part of a rightwing backlash against anti-discriminatory social policy (Bloom, 1987). Even radical left commentators, for example, Camille Paglia (1994) used the term to describe the 'fascist speech codes and puritanical ... regulations' which she claims has resulted from certain attempts to regulate racism and sexism in language, behaviour and social policy.

In the UK, it has also become customary for agencies or workers, whose services or practice has been criticised, to blame 'political correctness' for their inability to speak frankly about race issues, or for constraining their normal behaviour or professional practice. For example, following the publication of the MacPherson Report, the Police Federation, parts of the news media and certain politicians blamed the report for 'low morale' within the police force and for undermining their work with ethnic minorities (Dizaei, 2000). Some news editorials declared that, by using the phrase 'institutional racism' all police officers were being branded as racists and that they had 'lost the confidence to police the streets' (CARE, 1999).

It is certainly true that attempts to address racism and sexism in language, behaviour and policy have sometimes been ridiculous. For example Dale Spender's very useful (1980) text about the masculine biases present within our language was alleged by some people to have inspired absurd policies such as a reticence to ask for black coffee or the branding of the nursery rhyme Bah, Bah Black Sheep as racist! However, Will Hutton (2001) reminds us that "words are important" and goes on to say that "political correctness is one of the brilliant tools of the American right, developed in the mid-1980s as part of its demolition of American liberalism." Hutton goes on to say that,

“The sharpest figures on the American right soon realised ... that by using the term political correctness against its exponents – they could discredit the whole political project”

“The sharpest figures on the American right soon realised ... that by using the term political correctness against its exponents – they could discredit the whole political project.”

However, it has been demonstrated that some of the more outré policies reported by the opponents of political correctness never actually existed. In many of the examples where it has been alleged that political correctness has either stifled debate or constrained behaviour, it can be demonstrated that anti-discriminatory policies have actually encouraged debate where none formerly existed. As Will Hutton reminds us,

“It is an advance that it is no longer possible to call blacks niggers and that sexist banter in the workplace is understood to be oppressive and abusive.”

We should anticipate, therefore, that any initiative against racism or sexism is likely to be met with the charge of political correctness by those opposed to change. Surely it is necessary for there to be a rational balance between outlandish prohibitions on behaviour or language and reasonable criticism of racism – whether it is manifested in language, human behaviour or social policy. Our report seeks to achieve the latter.

Summary

This review showed that the fear has the following impact:

- ❖ Service users delay seeking help and therefore present to mental health services in serious states of crisis,
- ❖ Families and carers are reluctant to become involved in services because they fear the outcome for the person they care for, and
- ❖ Professionals do not have access to safe spaces to talk about issues of race and culture.

It is clear that these fears impact negatively on the interactions between Black people and mental health services. The challenge is to explore ways in which they can be addressed. We suggest that services need to be aware of how the structural position of Black people in society generates fear and anxiety. A starting point in exploring fears Black people have about mental illness and mental health services is to acknowledge that these are rooted in the legacy of racism and disadvantage. ■





Identifying impediments to change

The review aimed to explore why there has been little or no change over the last decade in how Black people experience and perceive mental health services. We were able to glean some insights into the impediments to change and identified four types. These will be described below (see Box 1).

Bureaucratic and hierarchical service arrangements

MOST RESPONDENTS OBSERVED that organisational structures are rigid and inflexible and influence the way in which professionals respond to service users, families and carers. Moreover, they affect how service users engage with services. Services were also perceived as fragmented and characterised by a lack of transparency and accountability. These were seen as variables that impacted negatively on an organisation's ability to change. A carer commented on the complaints procedure thus:

"I've got no faith in the local resolution stages because it doesn't operate impartially and there's no independence, and their professional manner is just not pleasant at all, you know? I got sent a report of the review, the same person who messed up the stage one of the complaint procedure was allowed now to scrutinise her work and send me a response, are you with me? You know what I mean, I sat down and thought, here we go, someone has messed up, I've complained against them, and they have been allowed to be a judge in their own court, you know?" (Carer).

A service user talks about her experience of services and says:

"You have to adhere to strict rules and regulations, you have to do as the doctor commands, as the nurse commands, as the occupational therapist demands – you have very little will of your own...you become like a vegetable. They [professionals] try to succeed in their way, that is to prescribe medication, and they don't take you seriously, so what is the point? They're not there to help me, so why should I talk to them?" (Service User).

Another factor that stops change is how power is dispersed within services. Black professionals, for example, are mainly employed in lower

paid positions and therefore perceived themselves as having limited roles in decision making. One professional talks about her frustration and the extent of powerlessness and isolation she experienced when attempting to change or challenge practice:

“Sometimes, when you want to do things, make it better for patients, you report what’s wrong in the ward, but because you are Black, it’s always brushed under the carpet, the next time it happens, you do nothing, just leave it. And even if sometimes you discuss this between the Black guys, what’s going on and what if you try to change things, someone will sneak behind your back and go and report ... so you think, will it ever work?” (Professional).

Material impediments

These refer to resources, staffing patterns, lack of treatment options, lack of support for Black voluntary sector agencies, and lack of support for user and carer groups. Staffing patterns on the wards and in the community affect the continuity of services and affect how service users perceive care. The use of agency staff on acute wards undermines professionals’ ability to provide quality care, but it also impacts negatively on the levels and nature of interaction between staff and service users. A service user offers his views on the frequent changes in staff:

“... and the next appointment was a different doctor, a different psychiatrist, and it kept on going like that. And all I was doing was repeating the same thing to each, each other of the psychiatrists. So I can’t go through that phase no more ...”

“I, when I’ve been up to see the psychiatrist – there’s a couple of times when the psychiatrist had his own office. Well in that office there was me, the psychiatrist and one of the staff who I used to live with, and I was telling him, giving him feedback on how I was doing back at home, and then in that time they arranged for a next appointment, and the next appointment was a different doctor, a different psychiatrist, and it kept on going like that. And all I was doing was repeating the same thing to each, each other of the psychiatrists. So I can’t go through that phase no more – this is why I’m frightened of the mental health system, because it doesn’t seem to work for me. I could be ill, I could be dying upstairs in bed and they, they will turn a blind eye” (Service User).

Respondents commented that the lack of a range of treatment options led to a perception that all that mental health services can offer is medication, control and restraint. Another material barrier is the perennial problem of time-limited funding for the Black voluntary sector, but more importantly, a lack of support for and guidance on applying for funding from mainstream budgets.

A serious material barrier is the lack of support and infrastructure for service user and carer groups. A representative from a user group described the difficulty they experienced in securing funding, but also to be taken seriously by staff and senior management. He reported that this lack of support made it difficult for them to develop organisationally and to build a secure resource base,

“We are several steps behind the White user movement, so we need to be encouraged, supported ... we need to be cherished and valued” (Service User).

Another user expresses her views on the attitudes of funding bodies to Black user groups:

“I mean they [funders] are actually saying ‘you get on with it, we’re not going to support you in this and if you fall down, that’s your problem, we’re not going to pick you up” (Service User).

There was also a suggestion that Black user groups should be supported to work in tandem with other groups, because working in isolation reinforces marginalisation and can lead to stereotypical views.

Psychological barriers

A significant barrier to change was the fear identified earlier. Professional cultures and staff attitudes were cited as a factor that hinders change. These were viewed as fixed, stereotypical and discriminatory. There was a perception that staff were not able to incorporate other belief systems and explanatory models into their understanding of mental health in Black communities. The challenge is to achieve a balance between drawing on Western models of care and incorporating healing strategies that are embedded in other belief systems (Barnes & Bowl, 2001).

Knowledge/educational barriers

These related to knowledge about mental health services (content, form and structure) from a user and carer perspective. This lack of knowledge has been referred to as mental health literacy, but that term often refers to a lack of knowledge about mental illness rather than mental health services. There was a perception that Black people do not have adequate knowledge about services, how they are structured, how they operate and how to access them. Such lack of knowledge therefore also meant that they did not always know how to negotiate access to services. Professionals on the other hand lacked knowledge and understanding of cultural traditions. More importantly, they lacked an appreciation for cultural traditions and the impact of racism on the lives of service users.

Summary

We were fairly optimistic that respondents would be able usefully to engage in discussions about change. But it was evident that they found it extremely difficult to talk about change and appeared more able to offer a diagnosis of the situation rather than identifying root causes of the problems. Possible explanations for this are, one, that we were asking respondents to talk about change in the abstract, or two (a more likely explanation), that we were asking individuals who are in relatively powerless positions to comment on matters that require knowledge and seniority to effect change. Another explanation may be that the issues

were so overwhelming that it was difficult for them to transcend those. Some barriers also affect staff. Bureaucratic structures left professionals with feelings of powerlessness to effect positive and lasting change. Psychological barriers are probably the most challenging areas for change because these impact significantly on the interaction between service users and professionals. We have identified obstacles to change at four levels that in combination create a powerful barrier between service users, families and carers and services. ■

Box 1 Impediments to change

Impediment	Indicator
Structural	<ul style="list-style-type: none"> ❖ Bureaucratic service arrangements ❖ Position of Black staff ❖ Service cultures
Material	<ul style="list-style-type: none"> ❖ Staffing patterns ❖ Support for Black Voluntary Sector ❖ Support for user & carer groups ❖ Range of treatment options
Psychological	<ul style="list-style-type: none"> ❖ Fear of services ❖ Stereotypical attitudes
Educational	<ul style="list-style-type: none"> ❖ Lack of information ❖ Lack of knowledge





Experiencing treatment and care

This chapter will describe the components of care and treatment offered to Black people and will use the care pathway as a framework within which to present the findings.

Access to care

THREE MAIN FACTORS emerged when analysing the ways in which respondents talked about access to care: knowledge and information about mental health services (discussed in the previous chapter), the nature of service responses to calls for help, and perceptions about the effects of treatment.

Knowledge and information about services

The nature of the response offered by services affected willingness to seek further assistance in the future. An important reference in relation to 'service responses to help-seeking' is to primary care services since it is known that Black people often fail to access appropriate mental health care from the primary care sector. This produces long delays in accessing treatment until worsening conditions can cause a public crisis in which police and compulsory procedures are eventually involved (Sathyamoorthy, G. *et al.*, 2001).

Service responses to help-seeking

A number of incidents were cited of individuals turning up at an accident and emergency (A & E) rather than contacting a GP to request an admission. However, carers' experience is often that they are told to go away. A carer talks about her efforts to have her son assessed for hospital admission and the devastating outcome:

'I keep going to the doctor until I'm blue in the face and the doctor won't do anything'

"You know, you have your child born, you know what kind of child he is, and I know when he's sick, when he's taken sick he sits down like that and shakes himself. I keep phoning the doctor all the time, I said 'M' is breaking down. He said, 'oh no, no, no, 'M' is all right.' I said, 'have you seen him?' He said 'no, he's fine'....I say, 'he needs to be back in the hospital because he is breaking up'. He said, 'oh no, no, no, let him come and see me next week.' Next week come, he smashed up the whole house. I keep going to the doctor until I'm blue in the face and the doctor won't do anything" (Carer).

Carers can experience great problems accessing GPs and primary care. The potential partnership between families and carers and mental

health services to identify problems early and assist better-planned admissions to hospital is neglected. Previous studies show that good communication and if necessary planned admissions lead to a decrease in the number of people being admitted under the Mental Health Act (MHA), but could also direct service users to more appropriate community-based care. This raises challenges in managing mental health problems in the home/community and in developing services that are not only user, but also family and carer centred.

Perceptions of staff

There was general agreement by staff that Black communities find it very difficult to contact and engage with mental health services, primarily because psychiatry is viewed by the community as intrusive. Therefore problems are kept within these communities. When asked to comment on some of these difficulties from their perspective, professionals felt that they are constrained by their roles and tasks, even though they are aware that this affects their ability to be creative or innovative. Moreover, interventions that are on offer are not always appropriate to individual need, and suitable interventions are not always available.

A comment by one professional illustrates this:

“...in some ways our format’s the same, I mean it doesn’t matter whether you’re Irish or whether you’re British or English, ... somehow there has to be a better match, and I don’t think we’re very good at shifting to match the psychological requirements and beliefs of sub-groups, if I can call them that, of different kinds, but equally, I’m not sure that we’ve got that much information to know how to do that” (Professional).

Perceptions about the effect of treatment

The negative and damaging side effects of medication was another factor that influenced the tendency to seek help. There were numerous comments from carers about the effects of medication on their loved ones, as the following comments illustrate:

“I don’t want you to give him that sort of medication, he’s like a zombie, I can’t talk to him, he don’t know where he is, plus he’s frightened, you know”

“I talked to the doctor in charge and I said, ‘I don’t want you to give him that sort of medication, he’s like a zombie, I can’t talk to him, he don’t know where he is, plus he’s frightened, you know” (Carer).

“I mean when you go to the ward, they’re like zombies, I mean they just drug them and they just sit there, and – you go there, you have to do things for them” (Carer).

“I believe if at the beginning of time they had given him counselling – if there was a counselling service set up, where they can send these young people to, and they counsel them and get out of them whatever is inside them that is, you know, getting them ill or whatever. But they don’t receive any counselling, and because of that they medicate them, they begin to give them drugs – and the drugs makes them mad. They say they’re

schizophrenic, it's the drugs – some of the bad drugs that they inject in those young people [that] causes them to be mentally ill” (Carer).

Given these views it is understandable that Black people will access services at the latest point in time, often beyond the point of potential therapeutic engagement via more formal routes and with greater police involvement, rather than using GP/primary care services as described elsewhere in this report. It is clear that the pathways by which Black people come to the attention of mental health services are not only different, but seem to influence the nature and outcome of treatment and the willingness of these communities to engage with mainstream services (Burnet *et al.*, 1999).

There were also innumerable stories about the difficulties that carers and families experienced in being taken seriously by professionals and the lengths that people had to go to get help.

“I got frustrated, I had to run about again, lie to them – before they actually got the psychiatrist to go and see him ...”

“... He got his relapse, and then I went running to the clinic, trying to see who could help. I had to lie, to say he was becoming aggressive and all that. I think they sent people on two occasions to his home to assess him. But they say, ‘Oh, he is alright, he is ok, we saw him, we asked him the time and the day of the week and he was alright’. I got frustrated, I had to run about again, lie to them – before they actually got the psychiatrist to go and see him” (Carer).

“I’ve been at my wits end now, but I’m willing to cooperate and be collaborative, supportive, you know, and now it’s like a battle. It doesn’t have to be this way, you know ... [But] if she wants to make this difficult for me, I’ll make it difficult for her. But it doesn’t have to be this way” (Carer).

Service user and family and carer involvement in all aspects of patient care, particularly the medication regime, could well have important therapeutic benefits.

Views of Black communities on mental health services

Respondents reported that problems of access and of creating an appropriate response to crisis were compounded by the large degree of stigma associated with mental illness in the Black community. This has implications for mental health promotion in these communities. The following comments highlight some of the experiences of families,

“There is no support. I mean they’re [Black community] mostly the first ones who tell you you’re mad, because if your children are mad, you’re obviously mad as well, and my sons are not mad. If ‘D’ is mad it is a result of how the system has treated him, ‘R’ has succumbed to depression because of things we’ve passed through” (Carer).

Another carer spoke about the difficulties within his family as they struggled to deal with mental illness,

“And the minute you fall to the wayside in terms of you start smoking ganja or you get locked up or you go to the police station, if that happens to you, you are cut off and are almost like, a severed limb ... even your own mother, your own father, your own brother, your own sister, don’t even talk to you anymore, they never see you in the street, that’s what it’s like, that’s the culture in my family”

“What has happened since quite simply has been first of all there is a lot of shame in the family. You know, whatever the hell’s going on inside your life? When you walk out on the street you’re going to look clean, respectable and you’re going to make sure that you hold the family name high. And the minute you fall to the wayside in terms of you start smoking ganja or you get locked up or you go to the police station, if that happens to you, you are cut off and are almost like, a severed limb ... even your own mother, your own father, your own brother, your own sister, don’t even talk to you anymore, they never see you in the street, that’s what it’s like, that’s the culture in my family. With my brother now, he knows that he grew up as part of that system, so he feels that sense of shame and that sense of isolation and it perpetuates his isolation even more” (Carer).

Although this view is not confined solely to Black families the sense of shame is more acute as a result of racism and pejorative ideas about Black families and individuals. Views on mental illness are also informed by the perception that mental health services are acting as a form of social control especially when, as Mercer (1984) points out, they are marshalled by the police, social workers, psychiatrists and family members. It is therefore not surprising that Black people resist or avoid using services as long as possible and come to the attention of services when they are in crisis. Mclean, *et al.*, (in press) suggest that this may also lead to stereotypes that Black people have more severe mental health problems than White people.

There was also a view that Black communities should take a more active campaigning role in relation to mental health issues to raise their profile. One respondent compared the response of the Black community to deaths in police custody to that to the deaths of people with mental health problems in hospital. He suggested that the former will always evoke outcries in the Black community, but the latter goes unnoticed. We would caution that this has to be understood in the context of media coverage about these issues.

Informal support

Support from families, the church, cultural groups, religious or spiritual practices, etc., was generally perceived positively. It has been recognised that religion plays a supportive role through the psychological and social support derived from the membership of faith communities. Yet, it has been found that spirituality or religion is not taken into account in psychiatric history taking (Ndegwa & Kilshaw, 2002). However, the support that is offered in church should not be accepted as always unproblematic. For example, some religious standpoints may obscure underlying mental health problems, by categorising some behaviour as demonic possession. A professional relates a discussion on the church with one of her clients:

“... actually, one of my personal clients here has said to me, he’s been to church, he talks about his voices, they told him that he’s full of demons and he needs to exorcise his demons” (Professional).

These concerns could be addressed through education and partnership within a mental health promotion programme. Black communities could benefit from an appreciation of the strengths and resources that are located in non-mental health specific activities.

Acute hospital care

In this review we were interested in people's experiences of acute or hospital care. There is strong consensus that hospital care is a negative experience and does not aid recovery. The traumatic experience of acute care by service users is well documented and has been a consistent finding of many studies (SCMH, 1998).

A striking feature of this review was the level of fear and apprehension expressed when acute care was discussed. This is an area that has attracted the most censure and it was evident that hospital care dominated people's thinking about mental health care as a whole. The ward culture in particular played a major role in the perception of the care that people received (Baker, 2000.). It was described as impersonal, regimented and closed. There was a system of rules that was not apparent to service users and carers.

Life on the wards

When respondents talked about experiences on the acute wards, interactions between service users and staff were characterised as being confrontational, with an autocratic use of power. Staff did not negotiate with service users if there were any disputes or challenges to their authority. Moreover, users reported that staff did not respond to demands or requests that required an effort. When service users were perceived as dangerous, aggressive or difficult to manage, staff were said to employ 'control and restraint' and seclusion in a rather arbitrary fashion, as the following illustrates,

“They didn't pin me down, they just grabbed me arms and legs and put me in seclusion”

“They didn't pin me down, they just grabbed me arms and legs and put me in seclusion. I mean I was able to talk with people, so they could have said to me, you know, you're not allowed in the kitchen or whatever. ... I wasn't doing anything as far as I know, but they just decided to put me in the lock up and that made me even worse, you know. Not understanding why they're taking me and putting me into the lock up. And I was in there for some time, when they could have kept me on the ward, but maybe I wasn't sitting down or whatever” (Service User).

The psychiatric ward can be viewed as a community, albeit one with role and power differentials between staff and users. The following service user comment is used to illustrate the problem,

“I was on [an] intensive ward and I really had bad treatment there, although I was getting the medications on time. One time, one nurse came in the evening and, you know, we have our smoking area where I was smoking, and the nurse tells me to go to my room, you know. Yeah,



say that to me, 'I have to go to my room.' And I say 'I'm not feeling sleepy, I don't wanna sleep – I wanna relax, sit down and smoke, or watch the telly'. And they said the telly time – the telly have to be switched off by 12 o'clock. I said: 'Fine, I just wanna sit, I don't wanna go to my room'. He said 'Go to your room – I'm not gonna say it again – if I say it that last time you're gonna get [an] injection'. You know what I'm saying, 'You're gonna get [an] injection'. And the guy and the other nurse gave me [an] injection. Well I was struggling with them but – you know what I mean – they pulled me down and gave me [an] injection – you know, all these psychiatric nurses have their own way of training whereby they can sort of pull you down" (Service User).

Respondents, both staff and service users commented on the general lack of structure on the wards and being left to their own devices. There also seemed to be a generational issue with older/mature service users getting more attention. Keeping young men on the wards occupied or distracted was simply not seen as a priority (Baker, 2000). As one user commented,

"No it didn't cater for your young ones at all, they used to treat the elderly Black patients better than they treated the young. We was like left, take the medication and left on our own, no structurebility [sic] – no goal to reach" (Service User).

Staff mainly saw the narrow role they had in patient care as a resource issue. High bed occupancy and staff shortages meant that they did not have the time for physical health and social care issues not directly related to mental health nursing care. They did not have the time to run groups or engage in one-to-one sessions with patients. In addition the regular use of agency staff hindered this type of staff-service user interaction, as agency staff tended not to know the patients. This only added to feelings of crisis management on the wards. Some staff admitted that the wards were not therapeutic and their roles were mainly about containment and the management of risk. As one professional told us,

"... they should have at least one member of staff, but quite often they don't and they're just relying on agency staff and don't really know what the care plans are, what's going on, and it can be quite hard I think"

"Wards are quite often operating in crisis, you know, they don't have the qualified staff, ... they should have at least one member of staff, but quite often they don't and they're just relying on agency staff and don't really know what the care plans are, what's going on, and it can be quite hard I think" (Professional).

Medication

Respondents cited medication as an area of major concern. The negative effects of medication and lack of alternatives, specifically counselling, were also cited. There was little information about medication, side effects, treatment regimes or outcomes. Carers reported the alarming effects of medication on the people in their care. Many carers reported feeling isolated and distressed at having to witness their children

entering a downward spiral of deteriorating mental and physical functioning and receiving increasingly coercive treatment and care. Carers wanted to know why despite the treatment offered they could see no discernible improvement in care. Professionals either seemed unwilling and/or unable to address carers' legitimate concerns and requests for information and dialogue.

For many it seemed impossible to distinguish between effects that were due to mental illness or effects due to the medication. For some carers the treatment merely aggravated the psychotic symptoms or in some cases was deemed to be causing the problems.

Service users also recognised and acknowledged the usefulness of medication and that it could be beneficial if used in the right context. That is with the consent, consultation and involvement of the user. The use of newer medication such as the atypical antipsychotics may lessen side effects and therefore improve concordance (Dolder *et al.*, 2002). There were some positive experiences regarding medication as the following service user comment shows,

“Now if you let the medication work, you know, and stabilize your mind right, then you can stay out of hospital right, then you know, maybe they'll start to consider your case more seriously ...”

“I think, the reason why I think, well the reason I'm in the situation I'm in right, I'm coming off the medication altogether right – is 'cause I stayed on the medication when they gave it to me right, and like the medication was my job to do, you know what I mean? It's there to stabilise your mind right, if you keep coming off of it all the time and that you're going to get sick again and like the more you end up going into hospital, if that's a regular occurrence like, they're not going to take you off the medication in the long term, so they keep you sedated right. Now if you let the medication work, you know, and stabilize your mind right, then you can stay out of hospital right, then you know, maybe they'll start to consider your case more seriously and they'll look at your situation and say well maybe we can reduce it gradually for him”
(Service User).

A recurring theme was that people were not informed about the process or the content of care. Service users also reported that they had little input into treatment regimes or found it very difficult to obtain reviews. A professional also commented that service users knew very little about the nature of treatment,

“...in terms of effects of medication, I run a woman's group here and one of the sessions I ran was asking people if they knew all the aspects of their situation... and almost all said no to every question, nobody knew what the effects were, they couldn't even tell you what medication they were taking you know, and I find that a lot with our clients”
(Professional).

Service users and carers reported that they experienced some difficulty in getting psychiatrists to consider reducing the dosages of medication or to take on board the views of service users and carers. However, in

instances where reviews were offered these were viewed positively. Although instances of the positive effects of using medication were mentioned such as reduction of symptoms or the stabilisation of individuals, on the whole medication was viewed negatively. Families and carers and service users used quite pejorative terms such as addiction and dependency when referring to medication. There was an element of fear in service user and carer accounts about the impact of psychotropic medication: people talked about it ‘poisoning their system’ and about the need for an ‘antidote’.

The concerns service users expressed about medication go much further than the psychotropic effects, respondents also commented on the use of intramuscular injections. The way in which medication was administered was seen to be coercive and punitive. This could also have an impact on concordance as service users may view the medication as simply a legacy of their confinement or as punitive.

When professionals were asked to give their views on medication and its over-use for Black people, it became clear that information on dosages prescribed to Black people was not always available at local level. Professionals talked at length about the fact that they did not know, for example, how many Black people in their locality were detained under the Mental Health Act, or how many of them were on acute wards. There was a divergent view from some psychiatrists that medication is all that psychiatry can offer, and that it is unrealistic to expect anything else from them. Although this might be an honest admission of therapeutic impotence from the perspective of a professional, from a Black person’s perspective it confirms exactly one of the major areas of concern, i.e. the dominance of medication as a treatment intervention ignoring alternatives.

Carer’s role

The role of carers in treatment adherence was not always acknowledged. Carers and families reported that they were viewed with hostility and suspicion by professionals, who felt that their involvement and interventions were unhelpful. This is likely to be particularly offensive to carers who provide the majority of care. As one carer stated,

“... but most of the time I have to fight and fight to get him to take a bath and change, he’s just so distressed, he don’t care”

“I give him his medication, yes, I see to it – that he takes it every evening, and – and I try to get him to have regular baths, part of his illness is that he will not bathe, so I have to use money, I say ‘well, if you don’t take a bath and change your clothes, then I don’t give you any money’, so that’s one way to get him to take a bath, I withhold money from him and he’ll change his clothes, but most of the time I have to fight and fight to get him to take a bath and change, he’s just so distressed, he don’t care” (Carer).

Treatment studies have shown the positive impact that carers can have on medication adherence (Olfson *et al.*, 2000). They possess specialist knowledge that can be used positively, for example, there were instances of families and carers having a key role in ensuring concordance. As the

“I’m not mocking the medication because I’m sure there’s a place for it, because initially I did need it, I needed some sort of medication initially ...”

following service user and carer comments illustrate,

“...the first time I was in hospital, my mum was around at the time, and she knew a little bit about mental illness because my older brother had been in hospital before me, and she wouldn’t let him off his medication, and she did the same for me, after my first admission. The second admission, you know, my mum happened to pass away, and I decided that I wasn’t having this medication anymore, because it wasn’t really doing anything for me. I’m not mocking the medication because I’m sure there’s a place for it, because initially I did need it, I needed some sort of medication initially...” (Service User).

Mental health assessments and misdiagnosis

Respondents commented that the psychiatric diagnosis had a major impact on the nature of treatment and care, particularly a diagnosis of schizophrenia. For carers it appeared to be a catch all term. It seemed to engender stereotyped or rigid responses and unimaginative forms of treatment: mainly medication with counselling seen as ineffective and unnecessary. It also meant that service users were fearful of the label and clinicians were pessimistic about outcomes.

The issue of diagnostic assessment is an area of much concern particularly for Black and minority ethnic communities. The epidemiological findings are beyond the scope of this report, and are reviewed elsewhere. The contradictory data found in various studies indicates the difficulty of making firm statements beyond the fact that the Black community is neither served well by over-diagnosis and over-treatment or under-diagnosis and under-treatment. For example, on the one hand many studies show that African Americans in the US and African Caribbeans in the UK have a high incidence of diagnosed schizophrenia and low incidence of affective disorders. It is argued that clinicians are misdiagnosing African Americans (Bell & Baker, 1999). But this problem is by no means restricted to the US or the UK: figures for the Netherlands are also similar for this group.

On the other hand, the study by Nazroo (1997) suggests that there is massive under-diagnosis of depression and anxiety in the African Caribbean community. This study is one of the few ‘community studies’ of this problem, going beyond the sampling frame of the hospital to look at the prevalence of schizophrenia and affective disorders within the African Caribbean community. The study claims that the level of schizophrenia in the African Caribbean community is similar to White British people and that Black people are more likely to be depressed or anxious than White people. The implication of this study is that misdiagnosis is happening on a massive scale and that there are many people with untreated mental health problems trying to cope in the community.

We do not know the correct conclusion, but what concerns us is that the debate about numbers and diagnostic classification of groups obstructs the need to concentrate on quality of care and empathy at an individual level. As one service user states,



“A lot of the White doctors don’t understand where the Black people are coming from, so they tend to over-medicate and all the rest of it. You know, if there are White doctors or whatever, they tend to like misdiagnose and tend to over-medicate or whatever, because they see the external things or whatever, and they’re probably misreading the signs or whatever, and that tends to lead to wrong diagnosing I think” (Service User).

Clinical perspectives

Our evidence showed that professionals have particular difficulties around making a diagnosis. There was a view that the relationship between professionals and Black people are adversarial from the start for various reasons, e.g., their past experiences with psychiatry, the police and other institutions. It is therefore difficult to take a full history in order to arrive at an accurate assessment of the situation. There is a perceived pressure to make a quick diagnosis that leaves no space or opportunity to make a tentative diagnosis. A psychiatrist talks about the issue of diagnosis:

“I think the difficulties in making a diagnosis for Black clients is the potential adversarial interaction in engaging them in the first place ... they’re not necessarily going to trust you and be able to tell you everything that’s going on”

“I think the difficulties in making a diagnosis for Black clients is the potential adversarial interaction in engaging them in the first place and therefore you’re not necessarily going to get a full assessment, they’re not necessarily going to trust you and be able to tell you everything that’s going on. And the same with family members as well, you won’t necessarily get a full view of what’s really going on within the family because they’ll be sceptical about the decisions that we’ll make. Therefore we might have more assumptions, that might lead to more assumptions being made with maybe lack of information. I’m sure the way we relate to Black people as well is part of that, one is likely to expect more of a difficulty in relating and therefore that’s more likely to happen ” (Psychiatrist).

It was suggested that the key to making an accurate assessment is building a relationship of trust and ‘working’ with what the service user perceives as the problem. Particular emphasis was placed on the responsibility of professionals to take the initiative to build a positive relationship. A psychiatrist talked about his attempt at this and the successful outcome that was achieved:

“In other words I think it’s me that has to go a little bit out of my way and make a particular effort, things like positive discrimination, in order to set the ball rolling”

“I actually think that the responsibility lies with people like me to make an effort to show willingness to engage in a way. In other words I think it’s me that has to go a little bit out of my way and make a particular effort, things like positive discrimination, in order to set the ball rolling. So in other words, I wouldn’t normally spend an hour and a half with a family justifying a treatment decision, I just haven’t got the time for it, but I spent the time the other week doing it because I thought it was worthwhile, so it’s a kind of form of positive discrimination. And actually people seem to quite like it, you know, Black patients who I’ve worked with that have successfully engaged, point to it as positive. So I think that helps ...” (Psychiatrist).

Sons and brothers, parents, police and the circles of fear

“Listen to carers, even if we are not professionals, in our way as parents, you know, we know what we are doing – we know what we are doing...”

The dissatisfaction with services reported by respondents, particularly families and carers, was palpable. They felt that when they challenged the treatment and care offered they were perceived as being aggressive and that professionals had a rather paternalistic or condescending attitude towards them. As one carer commented, professionals should,

“Listen to carers, even if we are not professionals, in our way as parents, you know, we know what we are doing – we know what we are doing, so they need to listen and they have to take that in consideration, and we need then – need to accept that even if we are not called professionals, we need to work in partnership with – each other for the best of the patients, that is why we are there, the best of the patients” (Carer).

Family and carers, very much like service users, were peripheral to the whole care process. Respondents commented on not being recognised or acknowledged by professionals, and not being supported in any meaningful way. This lack of support was particularly evident during staff and family and carer interactions such as at meetings. The unequal power relationships merely added to the continual sense of frustration and dissatisfaction. Carers struggled to be heard and to have some impact/involvement in the care and treatment that was being proffered. In many respects their treatment in terms of disempowerment, discrimination and lack of control mirrored that which was being experienced by the people they cared for. Information flow was said to be unidirectional and there was no sense of dialogue or attempt at some mutual understanding. As one carer commented,

“Yes, but they have tribunals, every so often they have these tribunals, but your views are not really taken into consideration, once you’re in the system and you’re assessed you’re in their power, and I would attend these meetings ... I would be the only mother there, and this little inquisitive Black woman with these views, and you have not training, you know – how do you come to speak like this, you know – and so you’re just classed as a nuisance” (Carer).

Sometimes carers were ignored by professionals with quite tragic consequences,

“It could have been stopped if the doctor listened to what I said ... because it’s me who looks after him and cook, wash, everything, is in the house everyday, so I know what’s going on”

“It could have been stopped if the doctor listened to what I said, because when I phoned him and told him that ‘P’ needed to go back in the hospital because he was breaking down, because it’s me who looks after him and cook, wash, everything, is in the house everyday, so I know what’s going on. He tells me that it’s me who needs to go into the mental home. In the morning a friend came and he said to me, ‘didn’t you hear that a madman kill a woman around here?’ I said, ‘no’. The news was coming on and he said, ‘see there!’ And I said, ‘oh no!’ He said, ‘you know him?’ I said ‘yes, it’s ‘P’. I want to go there’. I just shaking like that, he said, ‘I’ll take you.’ ‘I want to go there’, I said” (Carer).

There were also carers who felt that they wanted information and training regarding mental illness and mental health services. They sought support and also assurance that what they were doing was right. As one carer commented,

“... we do need training, you know, for such a serious thing as mental illness, to be just there and to be classed as carers, carers need some training, it’s a very draining and tiring thing”

“... My eldest son, ... I define him as a victim of the whole system, he’s been in the system now over six years, seven years. I haven’t cared for him all that time, but I’ve been there. I’m a single parent, and he’s been really treated very, very bad by the whole system. The treatment he has received has really marked him for life; he’s now defined as a chronic schizophrenic. And I have his younger brother, who I care for now, and – having no training, which I think is the essential issue, that we do need training, you know, for such a serious thing as mental illness, to be just there and to be classed as carers, carers need some training, it’s a very draining and tiring thing” (Carer).

There was a view that carers needed training to learn how to negotiate with mental health services to ensure that they receive the best and most appropriate level of care for their relative or friend. A professional talks about her experiences of providing support to families and carers and some of the difficulties they experience:

“... it’s kind of more than just information that’s needed, it’s also a kind of training on skills of negotiation with the system, you know, for people to be able to use the language that will get them the things they want ...”

“If their, if their child, or partner, or whoever has been admitted to the inpatient services, the relative seems to have a real battle on their hand to get the information that they want – you know, they’re seen as being interfering and sometimes they come to us asking us to negotiate on their behalf, or to help them to advocate for the person that’s in hospital. And it seems to me it’s kind of more than just information that’s needed, it’s also a kind of training on skills of negotiation with the system, you know, for people to be able to use the language that will get them the things they want, because as you rightly say, for an African-Caribbean person, if they start to kind of gesticulate or whatever, they’re suddenly, even as a carer or a relative, suddenly you get on the wrong side of the professionals and you’re on a losing battle really. So, you know, it’s about how they kind of negotiate within, within the system, and use that same language to get what they want” (Professional).

However, training alone is not going to ensure that carers are able to obtain an appropriate response from mental health services, even professionals encountered difficulties when they themselves had to go to services for help. It was quite sobering when it became apparent that they could fare no better than carers without their professional background and experience. As one respondent commented,

“I worked in the system and it was so surprising for me, it really was surprising, I thought because I’d worked in the system, a) I’d be able to cope with it a lot easier than I did and b) understanding the system

would mean that the appropriate support would be available at the appropriate time and I had no input to that system” (Carer).

In many instances carers were providing a high level of support and admitted to being drained by the whole experience. The combination of providing care and battling the ‘system’ was having a detrimental effect on their health. It was also particularly stressful for older carers or for people who had been caring for a long time. The carer organisations or support groups were mentioned as a useful source of support and solidarity. It was very enlightening and sometimes a humbling experience for carers to be able to share their experiences with other people in similar situations where they could also access information.

Professionals commented on the difficulties experienced by families and carers in accessing information about services and their training needs. In a quite literal sense families and carers are forced to adopt a kind of battle mode, they were engaged in a real struggle to get themselves heard and to access the merest bit of information from services. Communications with services are predicated on the belief that the individuality of the service user is paramount. This is likely to lead to conflict as Black families and carers tend to be much more involved in the early stages of contact with mental health services.

The involvement of families and carers is seen as encroaching on the rights of service users as individuals and the ensuing lack of disclosure as an issue about confidentiality. Involvement is not seen as an understandable and welcomed response. The burden of caring for someone with mental health problems, the lack of support and increasingly fractious relations with services, are significant factors in families and carers not engaging with services. In our review we found that families and carers were the most critical of all respondents. This is a very important finding as they are ‘powerful advocates’ with a major role to play in the process of care (Bates, 2002). That families and carers could be so disenchanted with the whole process of care points to a major failing of services.

Carers also reported major concerns about compulsory treatment and use of the Mental Health Act: police involvement was particularly distressing all the more so when it was carers themselves who had sought police intervention when all other avenues had failed. This was said to be due to the lack of alternative options in the community. Unfortunately, police involvement is associated with criminality rather than therapy, and this impacts negatively not only service users but on Black families and carers. The decision to involve the police or seek detention under the Mental Health Act was never taken lightly, as is illustrated by the following quotes:

“If my mother was right here and you asked her, ‘why did you ask for your son to be taken by the authorities and sectioned?’ Her answer is, she asked for help for him. She wanted to do the best for ‘C’. Those were

her exact words that she said to me yesterday. She wanted to do all she could, because it was the best thing that she saw for her son. She didn't want him to be picked up off the streets ... by the police, and beaten in the back of some van. And you read all about it in the South London Press, or The Sun, or even the Bulletin. She wanted to know that he's taken in a controlled manner and looked after. Now the reason why my mother was so upset when she spoke to me yesterday is because it appears that in the light of what's happening recently – his misbehaviour, his relapse – that she's been, if you like, let down by the services, by the system” (Carer).

“The most distressing part of it is when you had to call the police in, because people will be seeing police come in through your door and whatever and you don't know – they may be wondering ‘why police, why police’, you feel embarrassed and you feel, you know, excluded because you are alone. I used to be just crying my eyes out, because you can't go in the police van with them” (Carer).

We have already mentioned earlier the alarmingly high number of Black people in contact with the police as a result of mental health problems. One carer characterised their response to his brother's mental health crisis as being indicative of the police fears regarding Black people with mental health problems;

“But what I realise now, after learning about, over the past three, four years, I begin to understand now the culture and the fear, it is a circle of fear, because there's fear in the users and the victims and there's certainly fear in the amount of the police. Now they may be a lot bigger and a lot stronger, they may have CS gas, batons and the support of the Mental Health Act, but it appears that the police was as afraid of my brother as he was afraid of them”

“Now, I've asked my father this about 1,000 times, it's a misrepresentation or if he's totally mistaken, that as many police officers as that went to my brother's flat. Now my brother's flat, it's only a one bedroomed flat and I don't see how 38 officers could fit into the place, they must have been hanging outside the windows, you know? But he assured me that that was the case. But what I realise now, after learning about, over the past three, four years, I begin to understand now the culture and the fear, it is a circle of fear, because there's fear in the users and the victims and there's certainly fear in the amount of the police. Now they may be a lot bigger and a lot stronger, they may have CS gas, batons and the support of the Mental Health Act, but it appears that the police was as afraid of my brother as he was afraid of them” (Carer).

Service user accounts of police intervention were characterised by the unnecessary use of physical force and handcuffs:

“The police came and put me in handcuffs – the handcuffs [were] on so tight, man, ... four policemen ... I was crying man” (Service User).

“It took about seven of them to put the handcuffs on me and they had truncheons and they were whacking me about the head and they were kicking me in my stomach, [they] gave me a good kicking on the floor” (Service User).

That police intervention need not be such a negative experience goes without saying. There are ways in which proper handling can actually result in de-escalating a potentially volatile situation,

“... if you stay at a normal level and try and just talk to them, explain, why you have been called, what you want to do, how you are going to do it, then they start calming down ...”

“Talking from experience... not just the mental health. If you go to a situation doesn't matter what it is, you turn up and everyone's excited. Black people, certainly Black youths tend to be very much more excitable or act in an agitated state when you first talk to them as a police officer. And that can be misconstrued, if they are excited, even aggressive, agitated. Then your level of response goes up that much more. Your level of – the firmness, the way you deal with them actually the way you talk to them. If the person is highly agitated – then you become much firmer, show your authority. I mean ... when I was younger in the job that is the way I looked at it. Then because of the problems that caused, you begin to realise that if you stay at a normal level and try and just talk to them, explain, why you have been called, what you want to do, how you are going to do it, then they start calming down instead of you going around meeting them at their level and the only way it can go then is up – as opposed to dropping down” (Police Officer).

This issue of police involvement was a major dilemma for families and carers having to decide how to deal with someone in crisis. Hospital, even with all its associated problems, was seen as preferable than the unwarranted police attention,

“That is all our concern, we try to get our son in a safe environment so that the police don't pick him up” (Carer).

In addition families and carers also had to deal with the fact that the people they cared for would hold them responsible for getting them compulsorily admitted to hospital and the subsequent treatment they faced. The experience had a sobering effect and some carers were less inclined to seek compulsion subsequently,

“Yeah, the first time I had him [sectioned] and he said ‘you've done this to me’, so now this is why I prefer him to stay at home, because he feels that I've betrayed him really, you know, by sending him there [hospital]. An' this is why I've been trying to care for him at home but I don't know if I'm doing enough” (Carer).

In addition, the decision to have a family member sectioned can also have far reaching implications for relationships within the family, as the following carer's comments highlights,

“From that day I can tell you now, it's like he has never been able to forgive anybody. They informed my mum that they were going a few days before, but they didn't tell her exactly when they were going. That

experience has been so – I don't think it's fair, I mean he said, it appears that he's been so traumatised by that experience that he's never been able to forgive anybody in his family, that everyone in his family are, if you like, co-conspirators against him. But on the point of the effect on the family, there's a situation of blame going on right now where my mother is saying that everyone, all the family are blaming her for sectioning him, and also my brother has accused my mother and father of colluding having him sectioned. My brother blames us for all colluding and conspiring to keep him there, so there is a residual effect” (Carer).

Conflict We asked respondents to comment on their perceptions of the nature of care provided. It emerged that there were differences between the perceptions of service users, families and carers, and professionals. This divergence in perspectives often led to conflict. Conflict seemed chiefly to arise in two domains: the illness model and treatment.

Illness model Service users, families, and carers and staff differed in the way in which they talked about distress. Service users, families and carers invoked folk models of illness (Levkoff, 1999) by attributing symptoms to non-physiological causes, including psychosocial and/or supernatural ones. Professionals on the other hand engaged the language of disease, illness or pathology to describe distress. Extracts from the interviews illustrate how service users, families and carers talk about this.

“... my son fell on his head and turned funny ...” (Carer)

“... my spirit came out of my body and the night came ... and I had to run for it ...” (Service User)

“I was out of my head ...” (Service User)

“We went to ... [a country abroad] and something happened there and he [my son] became very frightened and there was a shock to his system. When he came back to England a few weeks later, he became funny in the head...” (Carer).

When asked to explain what was happening, there was agreement that something was wrong, but it was often not perceived as mental illness. Conflict arose when service users, families and carers were trying to have diagnoses changed. A carer described how his brother became withdrawn over a period of months and eventually locked himself in his room. All attempts to lure him out failed, so they were compelled to call in assistance from the police. His brother was taken away for psychiatric assessment and was diagnosed with schizophrenia. The family contested this – they felt their brother was ‘down’, because he had lost a job and was not making progress as opposed to the rest of his family who were. The family is still after a long struggle trying to change the diagnosis, because they feel the treatment currently offered is inappropriate and is doing more harm than good.

It has been argued that the reason why Black people are more sceptical of explanations offered by professionals may be because these

resemble arguments that have been used to judge Black behaviour negatively and to justify their disadvantaged position (Schnittker, *et al.*, 2000). It is clear that personal health beliefs and perceptions of illness will determine whether people will agree to undertake treatment prescribed. This finding suggests that it is important for professionals to negotiate shared understandings about the problem and to come to an agreement about how they will work together in defining and addressing symptoms.

Interestingly, internal conflict arose for professionals when they felt that they were obliged to make decisions about treatment that adhered to service culture and styles, rather than their personal beliefs. This was particularly true for Black professionals who stated that they felt their worldview was not valued in contexts that favoured standard (western) models of treatment.

Treatment

Generally, Black service users feel that they are offered a limited range of treatment options that revolve around coercion and restraint. Access to psychology, psychotherapy and counselling was extremely rare whilst many people complained of being compulsorily prescribed excessive amounts of medication. Disagreements about medication, dosages and reviews were another area of conflict. Respondents talked at length about the difficulties they have experienced in having medication changed or reviewed.

“You really have to run about, even if you know what your rights are, you go to the people, first of all they will think – ‘oh, she’s very pushy, she’s very bossy’, and they don’t like that – but you have to – you know – and you really have to fight” (Carer).

Strategies for working with conflict

There was an absence of any real strategies for working with conflict. A common tactic used by service users, families and carers in conflict situations was to disengage from services – in other words avoid it. In the example cited above, the young man’s family has given up trying to change the situation, but due to the visible deterioration in their relative, they have disengaged from him as well. Professionals seemed to resort to the use of professional power to resolve the situation and maintain control over it. Carers were very dissatisfied with the support they received from professionals.

“... but I can’t see how I’m being supported, I’m just being probed, you know, the contents of my life is laid open to people, and at the end of the day it isn’t helping me ...”

“... someone would come and say they’re there to support me, but I can’t see how I’m being supported, I’m just being probed, you know, the contents of my life is laid open to people, and at the end of the day it isn’t helping me, so I suppose they see me as being very uppity and stuck-up, or whatever, I don’t go here and there, but I just feel it – my wounds are too raw, and people just going over my wounds, and I’m – no-one is healing me, you know” (Carer).

In instances where carers were offered family therapy as a mode of

conflict resolution their experiences were quite negative and they were left feeling very dissatisfied with the whole process. It was viewed with suspicion and there were a number of respondents who saw it as intrusive and a tool for professionals to consolidate and exercise power over families and carers.

“I don’t trust them, I’m not going for family therapy again, it would have helped, the family therapy would have helped ...”

“This is what they do. It’s their policy. Alongside racism, divide family members” (Carer).

“I don’t trust them, I’m not going for family therapy again, it would have helped, the family therapy would have helped ... but you have so much confidence in them and you’re surprised that next they’re using that information to put you in trouble, without your knowledge” (Carer).

An important aspect of their frustration with services is that communication with professionals tends to be rather fraught. All too often effective involvement is stalled at this stage with both sides adopting entrenched positions and professionals seeing carers and families and or service users as belligerent and hostile and as people they are not able to work effectively with. There is evidence to suggest that this can have a major impact on the level of compulsory admissions of Black service users (Morley *et al.*, 1991).

Social inclusion and exclusion

Following the lead of Barnes & Bowl (2001), social exclusion was conceptualised as those varied routes and mechanisms by which people come to be regarded as effectively occupying a position of non-citizen. Black people therefore have to grapple within the constraints of being Black in Britain, being mentally ill in society, being mentally ill in the Black community and negotiating their relationships and interactions with the mental health service system.

As expected, most service users reported that they felt excluded from society and that they were not able to ‘escape’ the patient role,

“...it is always there with you ...” (Service User).

Similarly carers stated that they are living with the situation all the time:

“You are living with it all the time, you wake up, it is there, you go to sleep, it still is there ...” (Carer).

A comment from a service user captures this:

“... Well, I started somewhere 25 years ago and I’m still there and it’s almost like treading water and bashing your head up against the wall and nothing happening ... they’re putting up these walls where we can’t get through, and we can’t grow and we can’t develop ourselves ...” (Service User).

These viewpoints have been challenged in some of the interviews, by a suggestion that mental illness is only one dimension of an individual's life and that other dimensions such as family, work, education, etc., are equally significant. This particular worldview is embraced by a Black-led voluntary sector agency that was included in the site visits. They adhere to the motto that "there is life after mental illness". One service user captured the essence of this perspective in his adage: "I am passing through."

Respondents commented that exclusion had a major impact on Black service users. This was cited as one of the reasons why Black service users did not access services in the same way as White service users because they did not feel that services were open to them. Black service users were viewed as being unassertive, more unaware and less inclined to press for recognition of their rights.

"What I found with Black clients [is that] the service is there, but they don't feel that they have the same rights to use it"

"What I found with Black clients [is that] the service is there, but they don't feel that they have the same rights to use it. So in terms of my experience of working here, you know, that's one of the positive things I feel that I've initiated, to enable Black clients to feel like they are part of the service and we give them the encouragement in this room to go out there and use the other services that everyone else seems to have no problem of using" (Professional).

The exclusion service users experienced within mental health services was seen within the context of Black people's histories and experiences of discrimination and disadvantage: they simply did not expect the same standard of care as their White counterparts. It did not happen in the wider society so why should mental health services be any different. As one professional commented:

"So what tends to happen is the service users just settle for whatever is, you know, available. Not so much of what's available, but what's available for them as [an] ethnic minority" (Professional).

One of the respondents who had a dual role as both a professional and a carer spoke quite passionately about the impact of stigma and exclusion and lack of sensitivity to these issues. It appeared that professionals seemed unable to modify their behaviour or change their attitude, as one respondent commented:

"... why it is that the professionals still treat us like second class citizens, especially within mental health, you know? Why is it that you can never erase a label? Why does it stick for life?"

"Nobody treats you like a human being, you are treated like another commodity, you know, and yet you will have to go through dissecting a lot of your personal issues, and it goes nowhere, you know. I empathise, and that's why I ended up in this kind of work because I know what I have been through and I see how other people get treated, and I wonder why, with the amount of training that people have been given right across the board, why it is that the professionals still treat us like second class citizens, especially within mental

health, you know? Why is it that you can never erase a label? Why does it stick for life?” (Carer).

Service users reported a lack of support in community settings, particularly day centres, to assist them in re-engaging with economic and social activities. The employment and training expectations of some service users were not matched by what was on offer in day centres, where people expected real jobs or training opportunities. Programmes that were geared to employment, for example, the Transitional Employment Programme (TEP) offered mundane day-to-day rehabilitation tasks. This is all the more important when considering the positive impact that employment can have on quality of life and mental health (Evans & Repper, 2000). In addition not only did they fail user expectations in terms of employment, they also did not assist service users in dealing with their emotions, as one user commented,

“Well I’m not happy with what’s happened, you know. I’m happy out of the mental health institution, but I’m not as far as I’m concerned, here. I decided I’m not going to come back ’cause it’s not doing anything for me, you know, all they do is getting me angry and when I lose my temper they want to tell me that I’m behaving aggressively and this and that. I don’t get any support, they just call me and talk to me and say ‘Oh your behaviour’s not as we would like’ and so as far as I’m concerned, I thought I was coming here to find work you know, they can’t help me with that, in turn I’ll have to go and look for somewhere more supportive” (Service User). ■





Positive practice

THE PURPOSE OF the site visit programme was to look at schemes providing or facilitating the provision of services specifically addressed to African and Caribbean communities. The aim was to explore the ways in which services were supportive and sensitive to the needs of service users, to identify the practical difficulties they faced, and the ways in which they achieved change and innovation. It was not our intention or indeed within the scope of the project to evaluate schemes. However, where feasible we attempted to get feedback from service users in order to select and describe the projects for inclusion in the final report. Some of these services have been evaluated independently and we have gained some insight from these reports. In selecting projects to be visited note was taken of project type, geographical distribution and also ideas on ways forward.

There were a total of 11 sites visited from the voluntary and statutory sectors including one acute psychiatric ward. This report presents data from three sites based in inner city districts, all dealing with considerable diversity and with significant African and Caribbean communities. For a full list of sites see Appendix 6.

We have identified seven key variables by which data collected in the sites were analysed (see Box 2). We believe that these variables comprise the dimensions of a service that can meet the mental health needs of Black people.

Physical environment

A number of key characteristics of the physical environments of sites visited were observed. The style of decoration was important to users. One organisation reflected cultural diversity in the colours of the walls, cultural artefacts and posters. Most of the services were community based, a factor that was valued by service users. However, for many voluntary organisations obtaining suitable accommodation or purpose-built premises was problematic.

Service philosophy

All the services visited had clearly defined and explicit service philosophies that were reflected in their aims, objectives and activities. Central themes in these philosophies were:

- ❖ a 'whole-person' approach;
- ❖ a strong emphasis on developing and building a sense of identity;
- ❖ viewing mental illness as one aspect of human experience;
- ❖ reducing social exclusion and stigma through social and material support;

- ❖ less hierarchical service arrangements, and
- ❖ treating professional and inter-personal relationships as the most important therapeutic tools.

Interagency relationships

Well-developed interagency relationships were perceived as an effective way of providing and building effective services. One organisation, for example, reported that they have good relationships with other services and can therefore make a valuable input to activities. Their staff are invited to MHA assessments for Black service users to provide a community perspective. This was an area that was not always well developed elsewhere. Voluntary sector agencies, in particular, talked about working in isolation and their struggles to have their services recognised and valued by mainstream services. Staff in the voluntary sector organisations reported that they are not being valued, recognised or respected by professionals in the statutory sector. A major issue is their struggle to get statutory services to acknowledge their expertise and professionalism and to establish credibility (particularly with psychiatrists).

Box 2 Key service variables

❖ Physical environment

This includes the layout of the building, the general appearance, amenities and issues around access for people with disabilities, and cultural appropriateness.

❖ Service philosophy

The overall vision and guiding principle that underpins service delivery and informs the organisation's particular approach or ways of working with Black service users.

❖ Interagency relationships

The nature and extent of links with statutory and/or voluntary, private sector organisations and other external partnerships.

❖ Position in community

The relationship with the wider local community or neighbourhood in which the organisation is sited or serves, as well as community-based groups and social networks and how the service is viewed by the local community.

❖ Structural arrangements, e.g. funding, assets

Sources of funding and the way in which the project/organisation is managed.

❖ Staff competence, skills and experience

This refers to the professional backgrounds, cultural awareness and understanding, personal qualities of and support structures for staff.

❖ Programmes/activities

These should be relevant, structured and appropriate and in keeping with the aims of the particular service.

Position in the community

Service users and families perceived services that were community based, 'owned' by the community and accountable to the community very positively. There was, however, a view that suggested that services that are not based in the community also have a role because they offer a sense of anonymity. It was argued that this could help to minimise the stigma attached to using mental health services.

Structural arrangements

Funding has often been raised as an issue in the voluntary sector, particularly its frequent short-term nature and the stringent requirements for funding applications. Financial matters are a constant source of insecurity for the voluntary sector. This includes fund raising and accessing statutory funding such as making applications for mental health grant and lottery funding. Another issue is the financial reporting generated from the contractual requirements of purchasers. The conflation of the functions of service provision and financial matters tend to be the responsibility of individuals who may not have financial expertise. It is an added burden on organisations, onerous for the individuals concerned, and has a negative impact on service delivery.

The inability to secure a reliable source of funding threatens the viability of organisations, making them inherently unstable and limits the possibility of forward planning. This in turn leads to them being viewed by statutory services as being ephemeral or dominated by short-termism. It is a vicious circle. If the future of the organisations is uncertain, statutory services are not going to invest the time and resources, build significant partnerships or have good interagency relations. In any case, the expectation to develop links tends to be focused on the voluntary sector. It is exceedingly difficult for the organisations to plan and provide services or attract staff if there is the constant threat of closure or if senior staff are engaged in dealing with financial crises.

The statutory sector can equally be affected by problems of resource allocation. As a result of Trust re-configuration a serious problem has arisen on ES3 Ward (South London and Maudsley NHS Trust) with over-occupancy of ward beds. Bed occupancy is approaching 200%. It is not unusual for ES3 patients to have to give up their beds and be moved to other units within the Trust catchment area while still under the care of the ward. This causes severe stress to the patients who are being moved to different wards and hospitals. It is also stressful and demoralising for staff as they feel immense pressure from the Bed Manager continuously to take new patients for whom they do not have beds, and to send away patients with whom they have worked hard to build up therapeutic relationships. At the time of the visit staff were beginning to go off sick, which in turn, placed additional stress on those staff who were at work. In instances where funding was secure, it meant that services were able to develop organisationally.

A striking feature of organisations that were successful in engaging Black people was their 'loose' structural arrangements. Tasks and duties were often not assigned according to an individual's professional

or organisational role, but more on the basis of their level of competence. These services were therefore able to provide a flexible and responsive service.

Staff competence, skills and experience

A common feature was that most staff in the site visit programme shared the cultural traditions of their client group. However, this was not seen as the most important requirement to work in these organisations. Key qualities were that staff understood and appreciated the structural position of Black people, a commitment to the service philosophy, an understanding or experience of mental illness and an ability to build and maintain positive working relationships with service users. As mentioned above, tasks were often assigned according to competence. Staff who had experience of working in both statutory and voluntary sectors were viewed as a positive asset to the organisation.

Many successful organisations had in common an enthusiastic leader, who had been able to inspire the community, attract funding, recruit committed staff and carry the vision. Leaders are required to add value to our proposed seven dimensions. But we also noticed that many of these leaders began to struggle when organisations began to grow. They became responsible for staff issues, the constant identification of new funding, paperwork and other aspects of management. Typically such charismatic leaders were neither trained nor experienced in leadership and management, but were blamed by the external world for failing organisations.

We believe that these leaders should be identified, fostered and supported, since they have the potential to create the change we are hoping to stimulate. Some of them have the potential to take on responsibilities beyond small voluntary sector agencies, but they require concrete support.

Such support could take the shape of mentoring schemes or leadership courses and activities run by role models. The statutory sector needs to be willing to back up such development with support for the voluntary sector services. Integration and inclusion should not be at client level only, but be modelled by practitioners, managers and leaders.

Programme/activities

All activities offered were in line with the stated service philosophy, but more importantly, were based on mutually agreed service user need.

These activities were aimed at building self-esteem, independence, providing choice and increasing participation. Some activities included:

- ❖ discussion groups and educational opportunities focused on Black identity;
- ❖ community-based training and employment schemes such as computer literacy;
- ❖ resource banks;
- ❖ community outreach services;
- ❖ counselling services, and
- ❖ befriending and social support.

For the lists of all the sites visited in the review and a description of

three of the sites by way of illustration, see Appendix 6. Some suggested success criteria are set out in Box 3.

Summary The seven dimensions we have identified above are considered as essential components for any organisation wishing to deliver an effective and appropriate service to African and Caribbean communities. The settings may differ but organisations both in the statutory or voluntary sector should embody and make explicit all of these characteristics. ■

Box 3 Success criteria for Black mental health services

- ❖ **Culturally appropriate environments and services**
- ❖ **Agenda is client based, addresses cultural needs and supports carers and families**
- ❖ **Strong partnerships between statutory, voluntary, private, and community organisations**
- ❖ **Placements for staff from statutory services in community-based services**
- ❖ **Services developed and rooted in local community, staff involved in wider community work**
- ❖ **Continuity of service, e.g. stable staffing patterns, maintaining contact with users post discharge (from acute services) via informal drop-in**
- ❖ **Practical help for voluntary organisations in making applications to funders is available**
- ❖ **Non-hierarchical team approach, emphasising shared decision-making, team learning and leadership**
- ❖ **Strong links with the local service user groups as well as close ties to community-based groups**
- ❖ **Personal and professional staff development using an experiential learning approach**
- ❖ **Nature of staff-user relationships: emphasises the importance of ‘treating patients as people’.**





Talking about ‘race’ and culture

“The representation of difference must not be read as the reflection of pre-given ethnic or cultural traits set in the fixed tablet of tradition”

THE CENTRALITY OF issues of ‘race’ and ‘culture’ for mental health services should not be underestimated, but nor should they be used to reinforce stereotypical views about Black and minority ethnic communities. Here we came up against the complexity of the term ‘culture’ and the various ways in which diverse groups of people use the term at different times. Sometimes the term ‘culture’ is used in a similar way to ‘race’ i.e. immutable and fixed physical attributes and/or behaviours. At other times the term seems to denote a set of shared beliefs or a system of kinship. This is deeply problematic in the context of mental health work where it is the individual’s culture that needs to be understood rather than extrapolated from given generalities. As the cultural critic Homi Bhabha (1994) put it:

“The representation of difference must not be read as the reflection of pre-given ethnic or cultural traits set in the fixed tablet of tradition.”

The implication of Bhabha’s position is that individual culture cannot be viewed as a simple extension of given national identities but must be seen as a unique instance. This is an important definition, in a context where we still encounter ‘cultural awareness’ courses which aim to define or predict the characteristics of certain ethnic groups, along with a set of standard responses by professional workers, by means of overarching generalisations.

As far as the experiences of families and carers are concerned, their response has now become a mantra: they ‘are not treated with dignity and respect, not valued, not listened to or heard’. Much more serious is the allegation that they were not treated as though they were fellow human beings. In other words they were treated as though they were sub-human. These comments are indicative of deep disenchantment with services and need to be taken on board by professionals and addressed. What service users are demanding is a positive attitude and a person-centred approach whatever the background of the staff member.

Staffing and ‘culture’

Fernando (1996) has highlighted the dilemmas for Black people working in White institutions. Similar concerns were voiced in the interviews with Black professionals. There was a common view that

Black staff were in lower paid positions, received limited support to work in hostile environments, and were not able to work from what was termed 'Black perspectives', but were obliged to adopt restrictive organisational cultures and styles of work. Black staff reported that they often felt that it was their responsibility to raise and tackle issues of 'race' and discrimination and that the responsibility for 'culturally appropriate' care was delegated to them.

Matching service users and staff from similar ethnic and 'cultural' backgrounds was valued by some respondents, but this practice was not without its own problems. One family member described her initial elation when her sister was referred to a Black professional. Unfortunately for her, this professional's approach was no different to that of the White professional and left the family with feelings of disillusionment and greater dissatisfaction. Ethnic matching also assumes that there is a shared culture between the service user and the professional, which is often not the case (Arcia *et al.*, 2002). For example, the notion of staff from 'similar cultural backgrounds' rests upon the assumption that people who originate from similar geographical regions of the world or have similar skin colours are likely to share views or understand one another on the whole complex range of elements that comprise 'culture' and 'race'. It is therefore vital that this practice is given careful consideration to avoid some of the pitfalls outlined here.

At the level of staff training and competence, staff need to adopt a more open position of questioning and learning rather than taking refuge in the false security of predictive information. They also need to recognise similarities rather than concentrate on differences. White staff need the confidence to be able to work with communities that are different to their own and to ask questions, where appropriate, and to learn how to work successfully with individuals. Ethnic matching of staff should not be seen as the principal means of solving problems of services delivery to Black service users. Cultural diversity in staff was perceived optimistically because it was seen to provide positive messages to Black people. Moreover, it provides learning opportunities for staff to share knowledge and to model good practice. However, it is not a panacea for improved service delivery.

Understanding culture

Culture is an important but much misunderstood and complex entity, particularly when it conflates other already misunderstood concepts like race, ethnicity and behaviour. One of the difficulties is that the entire debate around Black communities' relationship with mental health services tends to be articulated as an issue of 'culture' or 'cultural' complexity. Culture is invoked as the one major explanatory factor for the experiences of Black people within services. Hence the clamour for 'cultural awareness' and 'culturally appropriate services'. There are real cultural differences between the Black and White communities, but there are also understated similarities and elements of shared culture. However, it must be remembered that the Black community is also a Black 'British' community whose differences are often overstated. We are

not advocating a 'colour blind' approach, however 'cultural' approaches have a tendency to homogenise communities and stereotype individuals, and used inappropriately can hinder an approach that is sensitive to an individual client's needs.

There were specific instances where service users were genuinely saying that their way of life or their customs were misinterpreted or not respected. Likewise there were cases where professionals seemed to be confounded by these differences. Yet these scenarios do not amount to a justification for cultural awareness courses that 'reduce' culture to a set of predictive generalisations. Neither do they justify the reliance of mainstream services upon specialist agencies as the sole engines of 'cultural' change. Rather we believe that cultural generalisations cannot be made without invoking stereotypes, hence the difficulty of operationalising culture at the level of staff training or service delivery. The only way to correct such cultural misinterpretations is on a case-by-case basis through questioning and learning and above all, through the formation of a therapeutic relationship between the professional and the service user.

It seems to us that subtle shifts in the meaning of culture were operating when professionals, service users and carers variously used the term. In the former case, it often seemed to be a shorthand for saying 'they don't respect me as an individual' rather than a reference to 'culture' in the strict anthropological sense. In the latter case, professionals invoked 'culture' in relation to a set of human differences in a somewhat fixed and immutable sense, similar to biological differences and traits.

These conflicting definitions demand caution especially in relation to the issues of 'cultural awareness' training and 'culturally appropriate' services. We are not convinced that service user demands for respect for their culture amounts to a plea for ethnic matching of staff to clients, or for separate services with an obvious cultural flavouring. Rather, it appears that most service users approach the NHS expecting it to provide them with an appropriate and dignified service. Only after this fails do people demand ethnic matching and specialist services. In a study carried out by Robertson *et al.* (1999) it was found that most of the Black service users interviewed did not want an ethnically specific service but one from which all users could access and derive benefits. Initially, however, people are asking to be treated with respect and dignity – which does not equal a demand for professionals to have total cultural knowledge about Black clients. What service users valued was the ability of staff to engage with them and to see the world from their perspective and this was not dependent upon ethnic matching (Secker & Harding, 2002).

Voluntary services provided by the Black community are often heavily predicated upon culture as the main feature of difference in comparison to statutory services, yet even here we would suggest that the particular meaning of culture needs to be carefully understood. The form of their alternative services may not appear to be markedly

different from other services in the sense of, say, day care services where people would attend for recreation, meals and social contact. However, it is the content of the service which differed markedly from traditional services and from which statutory services can draw important lessons. It was the ability to tap into and reflect personal experiences and histories that marked the major differences between statutory and voluntary services. What they do best is provide a safe environment, which is non-stigmatising and affirming. However, specialist voluntary services, whilst a useful local corrective, should not be seen as the means for achieving transformation of mainstream services to enable them to adapt to local diversity. That ultimately is the challenge for mainstream services, probably increasing their respect for the voluntary sector in the process. ■





The challenge

THE CHALLENGE TO meet the mental health needs of Black people is undiminished. The systems and structures that have been introduced over the last few decades seem to have had little impact on the outcomes for Black people. Why is this so? The problem can be located at various strata or layers: structural, institutional and the community.

Structural There is a vast body of evidence to illustrate that Black people are particularly disadvantaged in society. This review has shown that mental health services mirror the social relations of Black people with other institutions such as for example, the police and schools, etc. Political, economic and social agendas for this community are set outside of the community and attempts at consultation and partnerships could easily be dismissed as merely ‘paying lip service’ to these ideals. In essence, the political, ideological and economic power to achieve change is not located in these communities (Diamond, 2001). Nor is the social capital in these communities sufficiently valued, supported and enhanced.

Institutional At this level there are a number of factors at play. These are: the way in which priorities for service delivery are set, professional cultures and training, and lack of visible leadership.

Service delivery The priorities for service delivery to Black communities are defined by professional and political leadership with little or no consultation with these communities. Where there are pockets of good practice these are often not visible nor supported by mainstream organisations and funding bodies. Moreover, it is clear that efforts at more inclusive and responsive services are mainly located at the margins and seldom influence the way in which mainstream services are configured or delivered. As long as Black people are not engaged in defining the service agenda or at least are able to influence this process, they cannot be expected to trust mainstream services and engage with them.

Professional cultures and training We have observed what could be termed ‘professional paralysis’ around issues of race, culture and ethnicity. What are some of the reasons? Mental health professionals join an institutional framework that is presumably aimed at providing care to one of the most vulnerable groups in society – yet the paradox is that ‘this system’ also has a legitimate role to restrict and contain people against their will when

they are perceived to be a risk to themselves or others. Even though professionals do not act in a deliberate way to oppress and marginalise Black people, they inevitably represent a system that gives them the power to carry out these restricting and controlling duties. These controlling methods of work unfortunately reflect how Black people experience the world generally.

It is also natural to assume that professionals who work in a system will identify with it and will have an investment in the continued existence of that system, whatever their own cultural or ethnic origin. This means that Black people will perceive professionals as representing an oppressive system and this will influence how they respond to interventions from them. The challenge is how to change the perception that mental health care is about control of deviation, and instead convince that the aim is to provide humane and individualised care. Evidence from this review also clearly demonstrated how professionals become demoralised in a system that does not enable them to provide a service that is focused on service user need rather than institutional demands.

Another area of concern is professional training. It does not seem to prepare individuals adequately to provide a model of care that is valued and respected by Black service users, families and carers. Moreover, there is a lack of adequate support and supervision to enhance professional development and conventional training programmes do not seem to provide skills and knowledge to influence outcomes for Black people.

Professionals are expected to work in environments where it is not safe to talk openly about their concerns regarding issues of race and culture. There is a fear that raising these issues can lead to individuals being categorised as racist, the big taboo of the public sector. This silence in the hope that race will disappear makes it difficult to challenge stereotypes and some of the myths about Black people, and does not help to build a model of care that includes anti-racist practice.

The structural location of key staff and the professional responsibility attached to their positions means that success or failure is individualised. Collective responsibility for failure is absent. One psychiatrist summed this up:

“The buck stops with me ... I remember a case that appeared in the media, I immediately consulted my case notes to see whether this was someone known to me and what actions I took ... ” (Psychiatrist).

Defensiveness of this nature is understandable, but personalising failure in this manner must certainly lead to a sense of dis-empowerment that can impede change. Matters are made worse due to the fact that there is a climate of risk management rather than positive risk taking based on accurate assessments. This climate is fed by stereotypes about dangerousness and violence which are not allowed to be discussed, leading to yet more fear and risk management. This is another

contributor feeding into the *Circles of Fear*. It has been suggested that we need to confront the dangerous and violent stereotypes directly, so that we can bring the perceived risk in line with any real risk that may exist (Link, *et al.*, 1999).

The inappropriate use of non-mental health professionals such as the police is not helpful either. Given the fragile relations between the police and Black communities, the fact that they are expected to convey individuals to hospital can only further damage this relationship. One can make an informed guess about the impact on Black people of pictures showing a large number of policemen knocking down the door of a frightened Black man, and the damage done to the relationship with the police. Moreover, police are also called on by NHS staff to deal with incidents on acute wards. It became evident during this review how much the police resented having to take on such roles, and it has strong implications for the view that police hold of mental health professionals.

This review observed a definite lack of visible and effective leadership to advocate for the needs of Black people at all levels and sectors of service provision. Black people are employed in the more junior ranks of services and have little or no power to effect change. Effective leadership is one of the litmus tests for quality mental health services. Leadership helps to provide drive, maintain direction and create climates in which people can think and behave differently. This area needs urgent attention to ensure that the burden of care for Black people does not remain at the margins. We need champions who can advocate for these communities, and these champions need development and support.

Community

We have to acknowledge that there are factors in Black communities that have an impact on how mental illness and health is perceived and understood. This is not to suggest that we apportion blame to these communities, instead we are hoping to open the debate by naming some of the problems, issues and concerns.

Black communities are not free from the general stigma and fears attached to mental illness. The impact of stigma and fear in combination with their distrust of services means that they seek professional help at a very late stage. It is therefore likely that they come to the attention of services with more serious levels of distress. These attitudes to mental illness also mean that Black communities reinforce the social exclusion that Black people with mental health problems experience. Evidence from this review has shown that families seem to have high levels of involvement in the earlier stages of ‘the illness’, but over time they become more detached from their relatives. This is of course not helped by the lack of professional support for family and carer involvement. As one professional commented,

“...of the Black clients I have, almost without exception the families are a lot more involved and there are a lot of instances of bad practices in terms of families [not] being supported and not being kept informed.

And so I think, there can end up being a lot of inter-family conflict as a result of that, but it's a lot to do with the fact that they're not getting enough support. So I think there's an issue there, supporting the families when families are involved like that, which is quite often the case with African Caribbean clients" (Professional).

Religion and spirituality play an important role in the lives of some Black people, but our evidence has shown that this influence is not entirely unproblematic. The church can play a mediating and supporting role in managing mental health problems. However, it can mask distress by casting it as demonic behaviour that needs to be exorcised. Such approaches may prevent early and appropriate professional intervention.

It seems that Black communities do not have a language or frameworks for talking about distress in ways that are helpful. This has to be understood in the context that talking about vulnerability is perhaps a luxury that one cannot afford when you are cast as 'Other', different, and inferior, particularly when one is fighting for self-determination and survival. This review has found that the language that Black people use to talk about distress is invoked from folk models. This is often the source of conflict between service users and professionals. It was also clear that professionals did not have the skills to address these differences.

Identity is an important component of self-esteem and positive mental health. For Black people it can serve to externalise stress, and can provide a sense of meaning, history and group affiliation (Dana, 2002). Racism however, erodes positive identity and can lead to much poorer mental health. If this is not addressed in mental health interventions, it is likely to have an adverse effect on the outcome of treatment.

Pointers for solutions

It is clear that a different focus to service delivery is required for this community. Black communities need a clear message that their needs are being taken seriously. As a starting point the Black community should have the power to define the local agenda for service delivery and the structures that already exist should be utilised to build bridges between mainstream mental health services and these communities. Where those structures are not robust enough, they should be supported and their capacity enhanced to do this.

Training for professionals should move away from only a medical approach to one where a whole-person, whole-system understanding of people's problems underlies the training of all professionals and where the promotion of this is the responsibility of everyone (Johnson, 2000). Traditional models of professional development have not been helpful; therefore a more experiential and practice-based approach should be adopted. The values and perspectives of service users, families and carers have to be central to training and continuing professional development.

Capacity building at all levels will be necessary to overcome the

barriers outlined in this report. Mainstream health and social care should be supported to build their capacity to make accurate assessments of the mental health needs of Black people and commission a diverse range of suitable services. Leadership, particularly leadership skills of Black staff, should be developed. Services should adopt a culture that says ‘it is okay to talk about race’.

To enhance the ability of Black communities to meet mental health needs, the infrastructure and leadership in these communities need to be developed as a priority. Black service user, family and carer groups should be given support to gain strength, advocacy services to and for Black communities should be developed, and more sustained financial and practical support should be available for Black voluntary sector organisations. A mental health promotion programme is needed to build mental health literacy in Black communities. A strong message should be given that it is ‘okay’ to talk about mental illness and better to do something about it as soon as there are concerns about it.

A starting point in seeking solutions may be to heed to the request of a service user who stated that:

“Why is it all getting so complicated? As a Black user all I want is access to meaningful services; access when I say I need access; to be listened to with respect and accepted; to be informed about what is going on and to be enabled to hold on to my life. Simple!”

“Why is it all getting so complicated? As a Black user all I want is access to meaningful services; access when I say I need access; to be listened to with respect and accepted; to be informed about what is going on and to be enabled to hold on to my life. Simple!” (Service User).

In conclusion, we need a programme of action that gives the following messages:

- ❖ The needs of Black people are being taken seriously,
- ❖ Black communities should have a key role in setting the service agenda,
- ❖ Strong leadership is needed to achieve change,
- ❖ It is okay to talk ‘race’, and
- ❖ It is okay to talk mental illness. ■





Conclusions and recommendations

WE HAVE PRESENTED a bleak picture of the way mental health services are provided to Black people. Service users, families and carers reported that they are not treated with dignity and respect, that their basic needs are not met, and that they fear the consequences of engagement with mental health services. But why does this continue to happen?

This review concluded that Black people do not believe that mainstream mental health services can offer positive help, so they delay in seeking help. There seems to be a lack of political will at all levels to address the concerns of these communities in ways that are acceptable and credible. Services have been unable to demonstrate that they are making progress in relating to people as distinct individuals and in achieving an understanding of the pervasive effects of racism and discrimination in the lives of service users. The approaches that have been used in services, e.g., treating everyone as the same, applying stereotypical views of Black people, or using individualistic methods that do not take account of the historical and socio-cultural context of people, are unhelpful or even counter-productive.

A fundamental problem is that as a result of the circles of fear, Black people with potential mental health problems are not engaging with services at an early point in the cycle when they could receive less coercive and more appropriate services. Instead they tend only to come to services in crisis when they face a range of risks including over- and mis-diagnosis, police intervention and use of the Mental Health Act. In order to break this cycle, it is necessary to address the issue both from the perspective of services – by making primary care and other services more welcoming, accessible and relevant – and from the perspective of the Black community – by increasing understanding and knowledge and reducing the stigma associated with mental illness.

Psychiatric wards were the places most Black people feared, some even fearing death. Like other studies, the review found that the care on the wards is failing Black people. They often receive care that is custodial, not addressing their needs. Images and experiences of wards are so negative, with such destructive consequences for both patients and staff, that tinkering at the edges will not do. A comprehensive change in the role of hospitals within the overall system of care

including the development of acceptable alternatives is necessary, accompanied by a wholesale review of structures and processes.

The review found that staff who work in areas with significant populations of Black people do not have opportunities to talk about their needs and concerns in working effectively with this client group. This obviously has implications for staff in developing the skills, competence, knowledge and understanding required to provide services that are relevant, appropriate and desirable to Black people. Staff should be provided with opportunities in their places of work to:

- ❖ talk about their needs and concerns in a safe environment, and
- ❖ build and develop their appreciation, knowledge and understanding of issues of 'race' and culture.

Black people are disadvantaged in society and there was a perception that mental health services reinforce some of these disadvantages. When this view is combined with the evidence that services are failing Black people, then we can conclude that it will be difficult for these individuals to reintegrate with their networks and communities. Establishing dialogue and partnerships with community groups and building capacity in these communities can break this cycle of deprivation.

Black voluntary sector organisations are community based and reflect the cultural traditions of the communities they serve. This review found that the support and care offered by this sector is highly valued. However, we found that these services do not receive adequate funding and support from mainstream budgets. In instances where funding was available, it was short term and linked to specific projects. This obviously has implications for the continuity of these organisations and the opportunities to build capacity. This review suggests that these organisations can be valuable in bridging the schism between Black communities and mental health services. They can help to build capacity in these communities to meet its own mental health needs.

The importance of user involvement and empowerment in achieving responsive services has been noted (Rose, 2001). The user movement has been a catalyst for promoting this agenda. Black user movements and groups are emerging slowly. This review found that there was lack of infrastructure to aid and support capacity in these groups. The barriers to developing these groups should be addressed.

What then is the answer? It is clear from the research, site visits and expert advice that progress will only be made in *Breaking the Circles of Fear* if there is systematic change in the experience of service users at each point in the care pathway. Services must be able to demonstrate that they:

- ❖ are humane;
- ❖ respond to individuals as such regardless of race or culture;
- ❖ are free from prejudice and stereotypes;
- ❖ use reliable and accurate methods to assess mental health need; and
- ❖ have a range of credible and beneficial interventions.

Black communities too, face challenges in responding to those with mental health problems. There is a pressing need to tackle stigma and to disseminate greater knowledge about mental health problems. The

circles of fear must be tackled both from within communities and within the statutory sector.

The vision for change

In order to deliver solutions, a wide-ranging programme of action addressing community development, the creation of sensitive services, workforce, management, leadership, capacity building and research and development will be needed. The main aims would be to:

- ❖ ensure that Black service users are treated with respect and that their voices are heard;
- ❖ deliver early intervention and early access to services to prevent escalation of crises;
- ❖ ensure that services are accessible, welcoming, relevant and well integrated with the community;
- ❖ increase understanding and effective communication on both sides including creating a culture which allows people to discuss race and mental health issues;
- ❖ deliver greater support and funding from the statutory sector to services led by the Black community.

These aims will not be delivered by public sector orientated management solutions using existing mechanisms such as centralised standards, imposed training and performance management. Such an approach is unlikely to have credibility in the Black community or achieve ownership by mental health staff. However, NHS and Local Government need to be involved as part of the overall strategy in order to obtain the right service delivery mosaic.

A more promising approach than a statutory sector based solution might be to empower the Black community to develop 'gateway agencies' which can build bridges with statutory services whilst advocating for the Black service users. The role of such agencies – some of which could emerge from existing community organisations – would include:

- ❖ two way communication – informing statutory agencies about the Black community and providing mental health and access information to the community;
- ❖ advocacy – for individual service users and on behalf of the community;
- ❖ some aspects of direct care, as required locally;
- ❖ an educational and advisory role around mental health and the Black community;
- ❖ providing support for other Black and generic community organisations which work with Black service users;
- ❖ providing support for Black staff in whatever form is needed (e.g. discussion fora, facilitating mentoring, identifying development opportunities);
- ❖ providing advice and support on obtaining statutory funding and/or obtaining such funding.

At a practical level it is envisaged that such an agency might be involved in anything from accompanying a young Black man on his first psychiatric appointment to advising the health authority/primary care trust (PCT) on commissioning services. But the precise range of roles

would need to be determined locally.

This core vision needs to be accompanied by a raft of related action to intervene in the cycle at a number of points from the community to high secure accommodation and from interventions such as health promotion through to medication.

The Recommendations

Our recommendations reflect this core vision and attempt to articulate a way of putting it into practice. Recommendations cover the following core elements of the strategy:

- ❖ establishing the gateway function
- ❖ supporting the community
- ❖ improving access
- ❖ developing sensitive services
- ❖ workforce development
- ❖ capacity building.

The gateway function

RECOMMENDATION 1

Gateway organisations should be commissioned to develop bridge-building programmes to support the reintegration of Black service users.

Lead: Primary Care Trusts (PCTs), Strategic Health Authorities (SHAs)

These programmes should involve two main facets:

- ❖ development of local opportunities for activity including employment, voluntary work, access to faith communities, access to leisure and sporting opportunities etc;
- ❖ individually oriented bridge building working with individuals to open up specific and desired opportunities.

This type of work will need to be led by staff within gateway agencies who can establish credibility with local Black and generic organisations as well as with service users and carers.

RECOMMENDATION 2

A national resource centre must be established to support the development of gateway organisations.

Lead: Department of Health (DoH)

A national strategy is needed to help support the establishment of gateway organisations. This needs to consist of a range of actions of which a national resource centre would be key. It is not envisaged that such a centre should necessarily be:

- ❖ expensive
- ❖ freestanding or
- ❖ a major provider of services in its own right.

The vision is that a small credible unit would be established which could link existing and emerging Black gateway organisations with the expertise they require including organisational development, training, knowledge and information. It should be able to access or develop specific expertise in key issues such as funding streams as well as to establish effective support networks across Black organisations and beyond. Its approach would be to offer positive developmental support, building on strengths rather than a patronising and outmoded model of capacity building. It should aim therefore to 'work itself out of a job'. It could be located in an existing organisation or at least receive infrastructure support from one. It must be centrally funded for the medium term. It should be accountable to a Board which must include a majority of representatives from the customers i.e. Black gateway organisations and the Black

community. One of the early tasks of the centre should be to disseminate good practice to support the following package of recommendations.

In order to back up the creation of such an agency the Department of Health and the National Institute for Mental Health would need to:

- ❖ give their explicit backing to the strategy;
- ❖ fund the national resource centre;
- ❖ set up a dissemination and communications programme which consistently supports the strategy in the medium term.

Supporting the community

RECOMMENDATION 3

The National Institute for Mental Health (NIMHE) should create and fund a national programme of mental health promotion aimed at and owned by the Black community.

Lead: NIMHE

The aims of such a programme should be to raise awareness of mental health issues and services in the Black community and to demystify mental illness and to encourage people to seek help. It must be designed in conjunction with the Black community and Black organisations so that the content, language, tone and delivery mechanisms meet the needs of the community. There is a need for a range of responses and products including:

- ❖ materials, including written and multimedia information, specifically designed for the community;
- ❖ work with opinion formers and key agencies with the community including religious leaders, youth facilities, educational settings, businesses etc;
- ❖ opportunities for mental health services to start a dialogue with the community outside the context of their day to day work.

Characteristics of the programme must include:

- ❖ community involvement and ownership;
- ❖ adequate and sustained funding;
- ❖ use of relevant settings and vehicles (e.g. churches, clubs, the Black press);
- ❖ relating the programme to wider health promotion initiatives;
- ❖ establishment of local service information;
- ❖ a range of communications mechanisms;
- ❖ evaluation.

The programme should have, as one focus, families and carers who play an important role in the help-seeking process, but often face a number of difficulties in gaining access to appropriate services. They do not have access to information about mental health services. Nor are they included in care planning and intervention. An important source of support therefore goes untapped.

Improving access

RECOMMENDATION 4

All health and social care communities with significant populations of Black people should identify practical steps to encourage early access in non-stigmatising or generic community settings as part of NSF implementation programmes.

Lead: Local Implementation Team (LIT) leads, PCTs, Trusts, Social Services Departments (SSDs)

It is clear that Black people will only reluctantly access specialist mental health services, usually as a last resort. It is necessary to take mental health care to communities rather than wait until late on in a crisis for people to access care. Statutory services therefore need to outreach to community settings in order to reach people earlier, before problems reach crisis point. Careful thought needs to be given to the way in which such services are badged. There is a variety of ways in

which services can be reconfigured to meet this need:

- ❖ by using primary care settings either by skilling up primary care staff or by outplacing specialist staff within primary care, or both;
- ❖ by operating from generic settings such as youth centres, schools, leisure facilities, businesses and churches;
- ❖ by working through Black community organisations and centres.

As part of NSF implementation LITs in the relevant areas should consider the promising settings and avenues for working locally and should develop one or more concrete proposals for developing or relocating services in generic settings.

RECOMMENDATION 5
Advocacy for service users and support for carers needs to be available early in the cycle.

Lead: Gateway organisations, Mental Health Trusts, PCTs

Advocacy must be offered at the earliest possible opportunity throughout contact with specialist services. Advocacy could be provided by gateway or other agencies. Where advocacy services already exist, Trusts should ensure that plans, funding and communication mechanisms are in place to deliver this goal. Where they do not exist, Trusts should make contact with local organisations and develop joint plans for creating services. Advocacy services must be quality assured. Advocates should help to ensure that issues of language are addressed especially during the assessment process.

Some good quality advocacy services are available. However, in order to facilitate early access and early interventions within less threatening and damaging settings it would be helpful if advocacy and support were available early in the cycle, before problems arise, to facilitate communications, reduce anxiety on both sides and to ensure that appropriate solutions are offered. This support needs to be available to carers as well as users (and from a different person) if wanted. In order that such advocacy is available the following action is required:

- ❖ advocacy services need to be commissioned or funded: they can be provided by 'gateway' agencies as a key part of their role;
- ❖ advocates must have clear briefs and be trained and supported regardless of whether they are volunteers or trained staff;
- ❖ the service needs to be publicised to specialist staff, generic staff and the community;
- ❖ it needs to be monitored and the quality evaluated.

RECOMMENDATION 6
Each health and social care community must ensure equal access to appropriate counselling and psychotherapy services.

Lead: SHAs, LITs, PCTs, Trusts

It is not acceptable that Black people have poorer access to counselling and psychotherapy services and each health and social care community should tackle this as a priority. The lack of access of Black people to a range of appropriate treatment options is dependent upon three factors. First, psychological therapies are unlikely to be offered to Black people in a situation in which the only diagnosis available to clinicians is schizophrenia or some other psychosis. This is because conventional psychiatric wisdom does not hold that the psychoses are treatable through psychotherapy. Second, even where a

non-psychotic diagnosis has been formulated, most Black service users are unlikely to be offered ‘talking therapies’ because of the prevalence of stereotypes which cast them as ‘unsuitable’ or ‘lacking in insight’. Third, on some of the rare occasions when Black people have been offered treatments such as family therapy they have not taken it up because of their own anxieties about revealing private information to mental health services.

PCTs should take the lead in ensuring that counselling services are available, particularly in practices with large Black communities, which are focused and relevant to the local community. This may involve providing greater financial and other support to Black counselling services. Trusts should use clinical governance mechanisms to ensure equal access to psychotherapy, psychological and other non-pharmaceutical interventions within their services.

Creating sensitive services

RECOMMENDATION 7

Carers and advocates must be involved in care planning.

Lead: Mental Health Trusts

Carers and advocates must be identified, invited to care planning meetings as far as possible in advance, and given copies of all paperwork unless the service user disagrees. Mechanisms must be put in place to ensure that this becomes routine practice and clinical governance and local performance management mechanisms should be used to ensure that it does. Families and carers should have access to training on mental illness to increase their knowledge and understanding about symptoms and ways of dealing with it.

RECOMMENDATION 8

Acute inpatient care for Black people must be systematically reviewed.

Lead: Mental Health Trusts, PCTs

Each provider delivering inpatient care to the Black community should urgently review the quality and suitability of that care. A local Black organisation should be invited to audit care and make recommendations on desirable alternatives, and how the environment and content of care could be made more welcoming, therapeutic and relevant. This report should be presented to the Trust board and commissioners and timescales agreed for action.

Workforce development

RECOMMENDATION 9

Training programmes in mental health should be developed and implemented for the relevant generic workers. Specifically, Black primary care staff are a key resource in bridge building. They need to be appropriately trained, supported and developed.

Lead: PCTs, Local Authorities, Police Authorities, Benefits Agency, Prisons, Probation Service

All generic health and wider public sector workers who have frequent contact with Black – and other – people suffering from mental health problems require some basic training in mental health problems. Recent experience shows that this needs to be experiential. In addition to some basic information about mental health such workers require exposure to service users and the ability to have open discussion with users and professionals about the issues arising. The staff most likely to benefit from such training appear to be:

- ❖ primary care staff including receptionists, practice nurses and GPs;
- ❖ police officers;
- ❖ social workers and housing officers;
- ❖ benefits agency staff;

- ❖ prison officers;
- ❖ probation officers.

Training programmes need to be short, focused and built around the needs of each staff group. They can build on existing knowledge and experience – for example there are already successful training events and programmes around mental health for police officers. Training programmes, and the subsequent and regular dissemination of information need to cover community resources.

Black primary care staff are likely to be the most accessible health care practitioners for the Black community, but they are under-utilised in terms of bridge building. While not all such staff may see such a role as appropriate there may be many individuals who could play a greater role if trained, supported and developed to do so. PCTs with significant Black populations should ensure that those individuals who are willing to help in this way are enabled to do so by:

- ❖ explicitly recognising this as a valued role and encouraging GPs and practice managers to support this activity;
- ❖ ensuring Black primary care staff are trained and given relevant information about mental health issues and community resources;
- ❖ asking some individuals who are interested to act as contact points with community organisations with which they may have existing links and to set up events or information sharing with them;
- ❖ ensuring personal development opportunities are available so that able and willing individuals can take lead roles in making their practices friendly, relevant and welcoming to the Black communities and particularly to those with mental health problems;
- ❖ linking such individuals with ‘gateway organisations’ some of which may wish to establish primary care linkworker roles.

RECOMMENDATION 10

Staff development programmes must be implemented to support the overall strategy. The national resource centre should act as a central point for information about training and development programmes for NHS and gateway agency staff.

Lead: PCTs, Trusts, SSDs, National Resource Centre, Gateway organisations

Current staff development programmes and training programmes around working with ethnic minority communities should be reviewed and experiential programmes developed which expose staff to debate and discussion with the Black community, service users and gateway organisations. Issues addressed must include language, assessment, carer and community involvement, non-medical models of mental health problems and conflict resolution. Some of the training may usefully be commissioned from gateway organisations. All professional training bodies should ensure that their curricula reflect content that will adequately prepare professionals for practice in a multi-ethnic, multi-cultural society. We do not advocate a national curriculum, since this can never address the diversity of communities, but we do believe in a set of general principles that allows local adaptation.

The National Resource Centre should employ an officer skilled in workforce development to pull together information on these opportunities. He or she should also identify gaps in the market which might be filled by a range of training providers. The Sainsbury Centre

for Mental Health is willing to provide expert support on the ‘technical’ education and training issues.

RECOMMENDATION 11

The leadership centre, which is part of the Department of Health’s Modernisation Agency, should develop leadership programmes for Black staff in all relevant sectors, working with Black organisations and national partners.

Lead: Modernisation Agency

This should build on existing good practice in developing Black staff, and should extend where possible to training for service users, carers and staff of gateway organisations.

Capacity building

RECOMMENDATION 12

Government should create opportunities for national and local funding via mechanisms such as Section 64 and neighbourhood renewal grants to Black organisations.

Lead: DoH

DoH should identify the most relevant grant making mechanisms across government for Black organisations working within this arena, and create opportunities for access by such organisations, or encourage other relevant agencies to foster such opportunities. Targets should be set to ensure the fair and equitable distribution of funds to Black organisations. The targets should be embedded within mainstream performance management and quality control mechanisms and an annual report on progress should be published.

RECOMMENDATION 13

The development of a national voice for the Black user movement should be facilitated.

Lead: The Sainsbury Centre for Mental Health (SCMH)

SCMH is facilitating discussion within the Black user movement about developing a national voice and forum so that it can become more influential. This process must be owned by the movement with SCMH in a supporting role only.

Other recommendations

RECOMMENDATION 14

The Department of Health should set relevant performance targets.

Lead: DoH

These should cover issues such as the availability of representative advocates, representation at care planning meetings, development of gateway organisations etc. They must be public and part of mainstream performance management.

RECOMMENDATION 15

The National Institute for Mental Health should develop a research strategy to evaluate and underpin the development of service solutions and community involvement.

Lead: NIMHE

At the beginning of this review, the Black community expressed scepticism about further research, which has often appeared to them as being of greater benefit to the academic community than to them. We agree that future research should be able to demonstrate direct relevance to its ‘subjects’. The research strategy should aim to shift the balance away from work on epidemiology and ‘causation’ towards solutions. ■





Appendix I Methodology

THIS REVIEW ADOPTED a co-operative enquiry approach to explore a range of perspectives on the impediments to change and developing solutions. This is based on the premise that users' knowledge and understanding about their own situation are essential components within the field of mental health (see Ramon, 2000). The project was conducted from a perspective that stresses the lived experiences of Black people. People with experience of using mental health services were recruited to carry out some of the interviews to strengthen the participatory nature of the project. This practice is in line with recommendations by Patel (1999) that researchers should consult members of the communities to be studied throughout the research process. This ensures that the concepts and methods that are adopted are culturally valid and sensitive to the population concerned. Participatory methods can also help to ensure credibility in the community. It has also been suggested that participatory methods can maximise community and lay involvement (Macaulay, *et al.*, 1999).

A combination of data collection methods and sources were used to corroborate each other, for example, data generated from the call for evidence informed the topics for exploration in focus groups, etc.

Group interviews are a proven method to collect qualitative data on sensitive topics from a range of people. Focus groups are used to:

- 1) capitalise on communication between research respondents
- 2) collect data from people simultaneously
- 3) explore people's knowledge and experiences in relation to services (Kitzinger, 1995).

We planned to conduct (at minimum) one focus group interview with users, one with carers and three with professionals at each site.

Sampling

The review used a theoretical sampling approach to seek out-groups, settings and individuals where 'the circles of fear' are likely to be evident (Silverman, 2000). We constructed a sample that was meaningful theoretically because it built on certain characteristics or criteria to help test the hypothesis about the 'circles of fear'. Key informants in each locality were used to direct us to gatekeepers who in turn directed us to research respondents.

- Data collection** A semi-structured interview format was used to explore respondents' experiences of mental health services. A topic guide based on the themes that emerged from the call for evidence was used to guide the interview. The interviews lasted three to four hours to allow time for briefing and de-briefing of the respondents and the interviewers.
- Data analysis** A computer-assisted programme (winMAX) for text analysis was used to code and retrieve data from the interviews. The data analysis process involved transcription of text, interpretation of text, comparison of cases, devising a system of thematic categories and an analysis of the relationship between the categories and codes. ■



Appendix 2

Terms of Reference: Steering Group

THE STEERING GROUP for the Review had the following terms of reference:

- ❖ To advise on the values, content, and work programme of the project and to determine what evidence and information is required to support it.
- ❖ To consider the implications of the key issues arising from the research, the call for evidence and the focus groups.
- ❖ To comment on the draft report and advise on the related dissemination and implementation strategy.



Appendix 3 Membership of the Steering Group

Dr Shirley Tate (Chair)	Chair, West Yorkshire Metropolitan Ambulance Service NHS Trust
Professor John Cox	President, Royal College of Psychiatrists
Errol Francis	Director, Frantz Fanon Centre, North Birmingham NHS Trust
Bruce Frenchum	Metropolitan Police, Community Safety & Partnership Portfolio (CO20)
Paul Grey	Grey Services
David Hillier	Prison Health Policy Unit and Task Force, NHS Executive
Sandra Howard	Head of Mental Health, Adult & Community Services, London Borough of Hackney
Chinyere Inyama	Inyama & Co Solicitors
Dr Frank Keating	Tizard Centre, University of Kent at Canterbury
Kevin Mantle	Health Services Directorate, Mental Health Branch, NHS Executive
Dr Andrew McCulloch	Director of Policy, The Sainsbury Centre for Mental Health
Dr Parimala Moodley	Sub-Dean, Royal College of Psychiatrists
Rameri Moukam	Consultant
Dr Matt Muijen	Chief Executive, The Sainsbury Centre for Mental Health
Millie Reid	Development Co-ordinator, Greater London Action on Disability
Dr Mark Ricketts	General Practitioner, The Nightingale Practice
David Robertson	Project Co-ordinator, The Sainsbury Centre for Mental Health
Rana Sheikh	Diversity Policy Developer, National Probation Directorate
Ann Tucker	Carer



Appendix 4

Terms of Reference: Advisory Panel

THE TERMS OF reference for the Advisory Panel were as follows:

- ❖ To advise on the values, content, and methodology of the project and to determine what evidence and information is required to support it within the broad framework set by the steering group.
- ❖ To provide expert advice and support on key aspects of the project and undertake specific areas of detailed work as defined by the steering group.
- ❖ To comment on the draft report and advise on the related dissemination and implementation strategy.



Appendix 5

Membership of the Advisory Panel

Dr Andrew McCulloch (Chair)	Director of Policy, The Sainsbury Centre for Mental Health
Dr Richard Ford	Director of Mental Health Services Research, The Sainsbury Centre for Mental Health
Errol Francis	Director, Frantz Fanon Centre, North Birmingham NHS Trust
Paul Grey	Grey Services
Charles Jordan	Chief Executive, Servol Community Trust
Dr Frank Keating	Tizard Centre, University of Kent at Canterbury
Dr Rosemarie Mallett	Social Psychiatry Section, Institute of Psychiatry
Millie Reid	Development Co-ordinator, Greater London Action on Disability
David Robertson	Project Co-ordinator, The Sainsbury Centre for Mental Health
Dr Jenny Secker	Research Director, Institute of Applied Health and Social Policy
Dr Jane Sturges	Open University Business School
Oneal Thomas	Locality Manager, Haringey Healthcare NHS Trust
Melba Wilson	Policy Director, Mind



Appendix 6

Services visited for the review

African Caribbean Community Initiative	217 Waterloo Terrace, Newhampton Road East, Whitemore Reans, Wolverhampton
African & Caribbean Mental Health Services (Manchester)	Zion Community Health & Resources Centre, 339 Streatford Road, Hulme, Manchester
Bedford Health Promotion Agency	Gilbert Hitchcock House, 21 Kimbolton Road, Bedford
Bradford Home Treatment Service	Level 3, Horton Park Centre, 99 Horton Park Avenue, Bradford
Claudia Jones Organisation	103 Stoke Newington Road, London
ES3 Ward	The South London and Maudsley NHS Trust, Maudsley Hospital, Denmark Hill, London
First Step Trust	1-3 Brixton Hill Place, Brixton Hill, London
Frantz Fanon Centre for Mental Health	12-13 Greenfield Crescent, Edgbaston, Birmingham
Lambo Day Centre	48 Despard Road, Archway, London
Peckham Befrienders	Voluntary Service Office, Douglas Bennett House, Occupational Therapy Department, Maudsley Hospital, Denmark Hill, London
ISIS	183-185 Rushey Green, Catford, London

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- Sites** Three of the eleven sites visited are described below by way of illustration:
- ❖ African Caribbean Community Initiative (ACCI)
 - ❖ Peckham Befrienders
 - ❖ ES3 Ward – South London and Maudsley (SLAM) NHS Trust

ACCI	ACCI is a voluntary sector-led initiative in Wolverhampton that provides culturally appropriate support and a range of services for Black people experiencing mental health problems. It is an NHS Beacon site.
Physical environment	The core service provision at ACCI is a resource centre, day centre, outreach support and housing support/accommodation. The day centre is welcoming and decorated in a culturally appropriate manner, e.g., colours of Africa, and African artefacts such as masks.
Service philosophy	<p>ACCI provides a genuine and effective culturally sensitive and appropriate service to people from the African and Caribbean communities with mental health problems. Services are based on a Black/African cultural perspective that emphasises self-esteem, inclusiveness and mutual respect. Mental illness is seen as representing one aspect of people’s lives and not the totality. This is underlined by their motto: ‘there is life after mental illness’. This belief is embedded in the organisational culture and in the commitment that the community should maintain ownership of the service. People who use the services are called members of the organisation.</p> <p>ACCI was set up as a response to the disproportionate numbers of young African Caribbean men in mental health services or experiencing mental distress. They maintain contact with and support people when they have breakdowns and are in hospital and provide transport from the hospital to their day care services.</p>
Interagency relationships	ACCI has a good relationship with housing, acute/hospital and other statutory services, including GPs and other health professionals. They also have good relationships with further education colleges. They carry out representation at care plan reviews and tribunals. ACCI staff will also monitor clients’/members’ medication. They accept self-referrals and referrals from mental health agencies. They have worked hard to develop an equal partnership with local health and social services.
Position in community	ACCI was set up as a result of the Black community’s concerns about the over-representation of African Caribbean people in mental health services and the inappropriateness of services. ACCI grew out of and is firmly located within the local Black community. It is an example of the local community identifying and defining its own mental health needs and developing practical and acceptable solutions. The service is open on Christmas day – staff and members bring their families. The involvement of the community brings about much greater ownership of the service. It provides ‘a safe place’ where members can talk about racism and racial abuse.
Structural arrangements, e.g. funding, assets	Funding comes from a variety of sources such as the National Lottery, Mainline, the Department of Health and the Health Action Zone and

grants from the local authority. ACCI were able to raise funds for a trip to Africa as part of a personal development programme, highly valued by members and staff. It was part of the first wave of Beacon sites and received money for this. As a consequence funding became more secure and the service more valued by the mainstream. In addition, ownership by the community ensures stability. The organisation has a Management Committee comprising of members (service users), carers and professionals from a broad spectrum of experience, all from African or Caribbean backgrounds.

Staff competence, skills and experience

The manager of the project sets the tone, is highly committed to the project and is ably supported by centre staff, volunteers and members/clients. The manager has experience of working in the statutory sector. She therefore has an understanding of how the whole mental health service system works. The project manager and the management committee are responsible for safeguarding the overall vision of the organisation and ensuring effective governance. Staff are personally committed to the work that they do and will do whatever is needed.

Staff are supportive, caring and compassionate. They provide practical help and advice in an empowering and pro-active way. They are flexible and understanding, patient and accepting of Black people's belief systems. They endeavour to encourage and motivate people disempowered by the mental health services. Lastly, all associated with the service, be they staff, member or volunteers treat each other with respect.

Staff come from a range of professional backgrounds and include qualified community psychiatric nurses and social workers. There are also voluntary workers who have a variety of skills and receive training from the ACCI's volunteer co-ordinator.

Programmes/activities

A range of services are provided including:

- ❖ Assertive outreach
- ❖ Carers' group
- ❖ Volunteer befriending services
- ❖ Housing services
- ❖ Resource centre
- ❖ Outreach to schools
- ❖ Education and training
- ❖ Counselling (using what they describe as an African-centred approach).

Transportation facilities are also available: there is a minibus for the use of members who are in hospital or may live independently or may have travelling or mobility problems.

Peckham Befrienders

Peckham Befrienders is an ethnically specific service within the statutory sector. This is a befriending scheme that aims to assist people to become more integrated within their community through a drop-in service for Black people of African and Caribbean origin aged 21-65 years and over. The drop-in accepts referrals from the Maudsley

Hospital, social services and supported housing. It is funded by and is a part of the South London and Maudsley NHS Trust.

Service philosophy

Peckham Befrienders was founded on the principle that Black African and Caribbean people with mental health problems experience greater levels of social exclusion, isolation and stigma, and uses social interventions to address these problems. The project aims to combat these by befriending African and Caribbean people. The befrienders are unpaid volunteers, drawn from the public, and they aim to develop a close and trusting relationship with clients. The belief is that Black service users need friends in their community with whom they can have an informal relationship based on mutual interests, equality and respect. This should reduce the social isolation and loneliness experienced by Black African/Caribbean people who suffer from mental illness. It is also a method of integrating clients into wider society, and increasing people's self-esteem, thereby enabling them to take control of their lives.

This includes games, socialisation, a crèche, and embroidery. The service also offers clients a range of activities, such as:

- ❖ addressing self-worth
- ❖ social support
- ❖ befriending
- ❖ addressing cultural needs and education
- ❖ help with employment, through links with job centres and PECAN (a local employment service which runs training)
- ❖ Somali volunteers are available to engage with clients from that community.

Staff and volunteers try to enable clients to make choices for themselves.

ES3 Ward – SLAM NHS Trust

Eileen Skellern 3 Ward (ES3) is an acute inpatient psychiatric ward (25 beds) in the South London and Maudsley NHS Mental Health Trust, providing services for adult men and women aged 16-65 years living within North East Lambeth. Patients come to the ward either on an informal, self-referral basis or under a section of the Mental Health Act (about 60%).

Physical environment

ES3 is a typical acute inpatient ward. The ward was clean, but very drab and the imminent refurbishment that is planned will be welcomed. There is an open TV sitting room area overlooked by a nursing office. There were a few smaller rooms alongside the sitting room area, as well as a corridor leading to bedrooms. There were no places for private conversations but there are separate sex facilities.

Concerning disability, there are no particular obstacles for wheelchair-bound people. However special provision may be required for people who have other disabilities such as visual or hearing impairments.

Service philosophy	As described by the ward manager this involves ‘treating patients as people’ and is based on what the ward manager describes as a Caribbean approach to inpatient psychiatric care. It is more personal than the British (European) style of psychiatric care. The essential feature is a less pronounced demarcation between staff and patients; for example, at the hospital in Trinidad where she had worked in the past, staff and patients prepared and ate meals together. It is more inclusive and nurturing and discourages the ‘them and us’ mentality that tends to occur on inpatient psychiatric services. The ward manager draws on this model. This together with a less hierarchical ward structure, an emphasis on team working and joint/shared decision making, makes relationship building easier. The ward manager said that she tries to bring ‘a spirit of caring and of providing genuine relationships to the ward’.
Interagency relationships	The ward has good relations with external agencies that are involved with service users, e.g., statutory services such as CMHTs, GPs and also relevant voluntary organisations. It has good relationships with the local service user group SIMBA, which is hospital-based.
Position in community	ES3 ward has been extremely successful in several ways. The ward has developed a caring atmosphere, which encourages linking with discharged patients who also use the ward as an informal drop-in service. Within the hospital community there is some recognition and support from other medical and nursing staff but they are still vulnerable to funding arrangements.
Structural arrangements e.g. funding, assets	<p>The ward is part of the NHS Mental Health Trust, so there is no specific management committee for the ward and the funding is from the Trust budget. ES3 is one of three wards within the Maudsley Hospital that forms the ‘Eileen Skellern’ inpatient unit.</p> <p>There are two consultants in charge of the ward. The two consultants manage two ‘sub-medical’ teams, which total twelve ES3 ward staff. The ward manager stated that when she first came to the ward five years ago the budget was overspent. In addition, mainly temporary agency staff ran the ward and medication was used punitively. All this has changed.</p>
Staff competence, skills and experience	The ward manager has extensive experience of working in mental health services both in England and the Caribbean (Trinidad). She states that she brings her experience of working in the Caribbean (1979-1990) to the job. There is an emphasis on personal and professional staff development and all staff go through an extensive induction and training programme in this model of working. The staff really care and are very supportive of the patients and each other. Patients are made to feel welcome and are welcome to come back to the ward, which many of them do, once discharged. It is used as a combination of informal drop-in and what one ex-patient described as ‘halfway between hospital and home’.

The ward has trained psychiatric staff and nursing assistants. The ward manager has also worked in a Psychiatric Assertive Community Treatment (PACT) team and feels that she has an understanding of the need for inpatient wards to have strong links to community groups. As a result of this, she has established strong links with local user group, SIMBA, as well as close ties with statutory community-based groups.

Programmes/activities

There are a number of activities on the wards:

- ❖ Group activities: often when group activities have been planned, various crises have redirected staff away and caused groups to be cancelled or disrupted.
- ❖ One-to-one quality time with users, particularly around accompanying users to places outside of the hospital. This varies, again due to staffing levels.
- ❖ Staff duty allocations: in the past they have tried to allocate different functions or services to specific staff. This has not always worked as planned. ■



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