



## BRIEFING 17

The Sainsbury Centre for Mental Health is a registered charity, working to improve the quality of life for people with severe mental health problems. It aims to influence national policy and encourage good practice in mental health services, through a coordinated programme of research, training and development. SCMH is affiliated to King's College London.

Copies of *Breaking the Circles of Fear* are available from SCMH at £15 plus 10% p&p. Please call T 020 7827 8352 (Publications), 134-138 Borough High Street, London SE1 1LB.

## An Executive Briefing on *Breaking the Circles of Fear*

THERE HAS BEEN widespread concern about the mental health services received by people from ethnic minorities, especially African Caribbeans, for at least 30 years. Now the issue has moved on to the Government's 'modernisation' agenda for the National Health Service with the planned publication of a national strategy to be launched in the autumn of 2002. In this context, the Sainsbury Centre for Mental Health (SCMH), with the support of a number of key organisations and individuals in the mental health field, has launched the major report *Breaking the Circles of Fear: A review of the relationship between mental health services and African and Caribbean communities* on its two-year study of mental health services received by African Caribbean people.

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.

However, the approach of the report differs from the numerous statistical studies of this problem in one key aspect. This is a qualitative study, focusing on the experiences and views of service users, carers and staff working in the various mental health sectors, and concluding with a series of far-reaching recommendations aimed at producing decisive change in the quality of mental health services received by African Caribbean people.

Additionally, SCMH has committed itself to supporting a programme of activities aimed at spearheading change through collaborative programmes of work with key agencies in the health and social care field. This Executive Briefing summarises the findings of the report.

**The audience** The 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 structure of the review** In developing a strategy to meet the specific needs of the client group the review aimed to:

- ❖ define the client group;
- ❖ describe the Black community in context;
- ❖ explore the ‘circles of fear’ which exist between the Black community and services;
- ❖ identify impediments to change;
- ❖ understand Black service users’ experience of treatment and care;
- ❖ identify positive practice;
- ❖ explore issues around race and culture;
- ❖ provide an analysis of the current situation;
- ❖ generate an agenda for change.

**Why focus on African Caribbeans and ‘fear’?** The report focuses on African Caribbeans because the statistical evidence shows that this community is massively over-represented in the most restrictive parts of mental health services, and in terms of negative



experiences and indicators, therefore it was felt that special attention was required. The subjective notion of 'fear' frames the report because there is ample evidence that this emotion permeates so much of the social context surrounding a community whose profile within political debate and social policy is disproportionate to its size within the general population. This is true whether we look at policing, education, social work or health.

It was also decided to break with the tradition of bringing together all concerns relating to ethnicity and culture under the rubric of 'Black and ethnic minorities'. It was felt that unless there was a focus on a specific community to devise dedicated strategies, a clear health care and social policy priority would be missed.

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*.

This review did not look at the epidemiology of mental health problems in the Black community, which has been the subject of a number of studies. Genetic or biological explanations for the over-representation of Black people in mental health services may appear convincing but have little evidence to support them. Instead the review focused on the interactions between Black service users, the community and services.

### **'Race': a key issue for mental health services**

There have been a number of high-profile public inquiries over the past decade, which document increasing concern at the policy and political level in relation to mental health services provided to Black and ethnic minority people. However, the impact of the Macpherson report into the death of Stephen Lawrence, and the subsequent Race Relations Amendment Act 2000, means there is now a specific requirement for public authorities to be pro-active about the quality of service provided to Black and ethnic minority people and to tackle possible areas of exclusion and discrimination.

Health services will be particularly vulnerable to criticism in relation to 'institutional racism' because the NHS has been less exposed to critical inquiry and reform than, say, the education, criminal justice and social work sectors. The report therefore challenges mental health workers to look at their practice in ways that much other research on the issue does not.

### **How the review was conducted**

The review took place in several interlinking stages, i.e., the call for evidence, regional launches, focus group interviews, site visits, follow-up focus groups, and the implementation and dissemination of the findings. It was led by a steering group representing key stakeholders chaired by Dr Shirley Tate. 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.

### Why is there poor engagement of African Caribbean service users?

The report reveals the ‘circles of fear’ that surround the poor engagement of service users. On the one hand service users fear that engaging with mental health services will ultimately cost them their lives. There is a clear association, amongst service users, between the mental health services as part of a coercive ‘system’ and the criminal justice system in terms of regulation and control.

Health workers, on the other hand, are clearly afraid to talk openly about issues concerned with race and culture that affect their practice. This in turn inhibits their willingness to take reasonable risks or to experiment. With only oblique references to the African Caribbean client group, professionals also speak about their fear of aggression from patients and about their physical size in relation to their propensity for violence.

Carers also have their fears. They worry that their loved ones may be involved in a tragic incident and also about the deleterious side-effects of psychiatric treatment. They also fear that demands for ‘respect’, or information about the person for whom they care, will have negative consequences.

*“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).*

### 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**

The pathways by which Black people come to the attention of psychiatric services often do not involve primary care or community-based alternatives to hospital.

#### **5 Acute care is perceived negatively and does not aid recovery**

Black service users liken acute inpatient services to custodial ‘sentencing’ and therefore derive few therapeutic benefits.

#### **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**

There should be greater involvement of Black service users and carers in the planning and delivery of mental health services.

**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. This does not amount to a recommendation to deliver separate services, although some distinctive and accessible services aimed at this community are essential. What the report is saying is that specific action is required based in Black communities **and** mainstream services to enable mainstream services to work more effectively with such communities.

**The Recommendations**

The review generated 15 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 NSF implementation programmes.

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



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	<b>RECOMMENDATION 6</b> Each health and social care community must ensure equal access to appropriate counselling and psychotherapy services.
Creating sensitive services	<b>RECOMMENDATION 7</b> Carers and advocates must be involved in care planning. <b>RECOMMENDATION 8</b> Acute inpatient care for Black people must be systematically reviewed.
Workforce development	<b>RECOMMENDATION 9</b> 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. <b>RECOMMENDATION 10</b> 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. <b>RECOMMENDATION 11</b> 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	<b>RECOMMENDATION 12</b> Government should create opportunities for national and local funding via mechanisms such as Section 64 and neighbourhood renewal grants to Black organisations. <b>RECOMMENDATION 13</b> The development of a national voice for the Black user movement should be facilitated.
Other recommendations	<b>RECOMMENDATION 14</b> The Department of Health should set relevant performance targets. <b>RECOMMENDATION 15</b> The National Institute for Mental Health should develop a research strategy to evaluate and underpin the development of service solutions and community involvement.
<b>The needs of Black service users</b>	In this report, there are few pleas for culturally determined services. Instead, service users and carers repeatedly ask to be treated 'with respect and dignity' and they demand better information about services with less coercion, less reliance upon medication and other physical treatments and more choice. In this they concur with the views of many other service users and carers who have commented on their experience of mental health services. They wish to be treated and respected as individuals.
<b>The problem of 'culture'</b>	In a major departure from many other reports concerned with tackling discrimination, the report questions the validity of organising services around cultural identity. The observation is made that disparities in health and social care persist despite the many cultural initiatives that have taken place. Culturally based reforms have led in some cases to poor standards and a new set of stereotypes based upon simple generalisations and assumptions about the relationship of individuals to 'their' national culture. Instead, the case is made for services to tackle inequality as an issue of 'customer care' rather than as a problem of ethnicity.
<b>Capacity building</b>	A key recommendation in the report concerns capacity building. It is recommended that ' <i>a national resource centre must be established to support the development of gateway organisations</i> '. This key recommendation is intended to increase the potential of the Black community to be both a more significant player at the provider level and, also, to enhance the

infrastructure of the community generally so that it can be more self-supportive. Furthermore it is suggested that there should be greater involvement of the Black independent sector in the provision of mental health services in contractual and collaborative arrangements with NHS Trusts and in advising on effective commissioning.

### **What is SCMH going to do?**

The Sainsbury Centre for Mental Health is committed to a programme of change based on these recommendations. The proposed work programme will be based on the areas of activity for which SCMH is already known.

#### Research and development

We believe that there is a need for a shift in the priorities of research, away from the traditional hospital-based epidemiological studies, towards both qualitative and quantitative community studies in which the hospital is not the sole sampling frame. We are particularly interested in 'intervention studies' which aim to comparatively evaluate outcomes from, say, innovative services provided by Black voluntary agencies alongside traditional statutory services. These could be carried out by a range of research organisations, not necessarily SCMH.

#### Training

The substantial investments that many health and social care organisations have made in different forms of 'cultural awareness' and related training have not produced much evidence of change in patterns of inequality. We believe there is need for a major rethink in the form and content of training in this area. We intend to develop 'learning sets' that focus on areas of practice rather than on aspects of culture. Based on the findings of this report, we wish to focus on practitioners' and service users' concerns such as the fear that affects the assessment and engagement process; building positive relationships with service users and carers; and devising care programmes that are appropriate to individual needs.

#### Capacity building

The evidence of under-investment in the Black voluntary sector and the lack of a national resource that can be a catalyst for change in various institutional contexts emerged strongly from this review. Therefore we intend to work closely with the Black voluntary sector and funding agencies, and with service users, to enhance the capacity and status of existing organisations so that they can play a more significant role in the health and social care community. ■

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