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African-Caribbean	interactions with	mental health	services:	experiences
and expectations	of exclusion as (re	e)productive of	health in	equalities

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# **Abstract**

In the context of current concerns about health inequalities among minority ethnic groups in the UK, this paper addresses perceptions of mental health services among members of an African-Caribbean community in a South England town. Efforts to reduce health inequalities must take account of the views of local community members on the sources of those inequalities and on local health services. The statistical existence of inequalities in diagnosis and treatment of African-Caribbeans in the UK is well-established, supported by sociological explanations of these inequalities which centre on social exclusion in a variety of forms: institutional, cultural and socio-economic. However, detailed studies of the perspectives of local communities on mental health issues and services have received less attention. In this case study of community perceptions of mental health services, we find that social exclusion comprises an explanatory framework which is repeatedly invoked by community members in describing their interaction with mental health services. Interviewees assert that experience and expectation of racist mis-treatment by mental health services are key factors discouraging early accessing of mental health services, and thereby perpetuating mental health inequalities. We conclude that participation and partnership are vital means by which to generate both the objective and subjective inclusion that are requirements for an accessible and appropriate health service.

Keywords: African-Caribbean; health services; social exclusion; health inequalities

# Introduction

The relationship between health inequalities and social exclusion is the conceptual ground of this paper. Since the publication of the Black Report in 1979 (Townsend & Davidson, 1982), health inequalities have been a key concern of UK health researchers. The existence of health inequalities among the various ethnic groups in the UK is well established (Smaje & Le Grand, 1997), with a range of physical and mental health outcomes appearing to vary according to ethnicity (NHS Executive Mental Health Task Force, 1992; Wilson, 1993; Nazroo, 1998). However, the precise mechanisms through which such inequalities are produced remain ill-understood. The specific health inequality which we address in this paper is the relatively poor mental health experienced by African-Caribbean communities in the UK (Department of Health, 1999).

Under-utilisation of support services appears to be an important contributor to the poor mental health outcomes seen in African-Caribbean communities (Bhui, Christie & Bhugra, 1998). While a great variety of factors work to produce health inequalities, this paper focuses on the role of the interaction between local community and health service. The policy environment of the health services aims to eliminate any role that the health services may have in generating or perpetuating health inequalities. Equal opportunities legislation makes explicit inequality in treatment by practitioners a malpractice. Government policy strongly promotes partnerships with grassroots members of disadvantaged communities in order to ensure appropriateness and accessibility of services, and to foster a sense of public accountability (Social Exclusion Unit, 2000). Addressing patients as consumers, the rise of mental health user groups, and the deinstitutionalisation of the mental health service have created space for the active involvement of interested groups in their health promotion and treatment services. Thus, our research takes place in the context of national policy efforts to achieve greater inclusion of marginalised groups in design and delivery of health services.

We argue that it is in micro-level interactions between community members and health services that exclusion or inclusion in services is experienced, and that, therefore, an understanding of local perspectives on health services provides a key contribution to understanding the relationship between social exclusion and health inequalities. We start this paper by outlining three bodies of literature bearing on our question of interest. We first

detail the mental health inequalities faced by African-Caribbean communities in the UK, as identified in epidemiological work. We then examine sociological reasons for these inequalities, calling for greater attention to the micro-social community interactions through which exclusion is produced. The third section describes lessons learned from a number of detailed case studies of mental health service provision among ethnic minority communities. Our own empirical research takes the form of such a case study, and aims to contribute to understanding ethnic mental health inequalities from the local community's point of view.

# Epidemiological research on mental health inequalities faced by African-Caribbean communities

As with any minority community, African-Caribbean populations are heterogeneous, drawing on a variety of island, socio-economic and religious identities (Campbell & Mclean, forthcoming). Nonetheless, epidemiological analyses, mostly based on hospital admissions of clients with schizophrenia diagnosis, have repeatedly found a disproportionate representation of African-Caribbean clients among patients diagnosed as schizophrenic and detained under the 1983 Mental Health Act (Littlewood, 1986; Dunn & Fahy, 1990; Boast & Chesterman, 1995; Singh, Croudace, Beck & Harrison, 1998; Davies, Thornicroft, Leese, Higginbotham & Phelan, 1996). Disproportionate diagnosis of schizophrenia amongst black and other ethnic minority communities has also been a feature of studies in the US (Flaskerud & Hu, 1992; Snowden & Cheung, 1990). The degree of over-representation of African-Caribbean people as clients of mental health services reported varies from study to study, but it is clear that members of the African-Caribbean population have been identified as far more likely (as much as three to twelve times more likely) to be diagnosed with schizophrenia than their white English counterparts (Littlewood & Lipsedge, 1981; McGovern & Cope, 1987). This divergence may be even more marked for those children born in the UK of first generation migrants than for their parents (Harrison, Barrow & Creed, 1988; McGovern & Cope, 1991). African-Caribbean people also suffer higher rates of involuntary detainment in secure psychiatric settings and greater police involvement in this sectioning process (see Littlewood, 1986). Minority ethnic communities such as African-Caribbeans are far less likely to be offered 'talking therapies' such as counselling, more often offered chemotherapy, and tend to be prescribed higher drug dosages than their white counterparts (Callan & Littlewood, 1998).

Pervasive cultural stereotypes permeate the way in which African-Caribbean patients are more likely to be viewed as dangerous, threatening and irrational than their white counterparts (Johnson & Sangster, 1995).

Low utilisation of support services (Bhui, Christie & Bhugra, 1998) and less desirable or effective routes taken through psychiatric services (Moodley & Perkins, 1991; Commander, Cochrane, Sashidharan, Akilu & Wildsmith, 1999) are features of minority ethnic usage of mental health services. Failure to access support services at an early stage is linked to worsening mental health outcomes and greater likelihood of involuntary admission.

Insufficient accessing of services may increase with repeated contact with mental health services over time suggesting that negative experiences of health services by ethnic minorities may contribute to their under-utilisation of services (Burnett, Mallett, Bhugra, Hutchinson, Der & Leff, 1999; Cole, Leavey, King, Johnson, Sabine & Hoar, 1995). Indeed, research that asked mental health service clients about their satisfaction with services has found significantly lower satisfaction scores among black users than among white British users (Bhui, Christie & Bhugra, 1995; Parkman, Davies, Leese, Phelan & Thornicroft,s 1997). Such research suggests that problems with the health service, or at least problems in the interaction between the health service and African-Caribbean users, contribute to the relatively poor mental health outcomes of the African-Caribbean population.

# Sociological mechanisms of mental health inequality: social exclusion

Explanations offered for the mental health inequalities experienced by African-Caribbean communities generally derive from the cumulative effects of racist social exclusion of African-Caribbeans in UK society. Within this broad category of social exclusion, three specific forms of exclusion can be identified: cultural exclusion, institutional exclusion and socio-economic exclusion. In this section, we outline the literature on each of these forms of exclusion, proposing a need to examine in micro-social detail the interactions through which exclusion is experienced.

#### Cultural exclusion

The dimension of 'culture' is invoked in a range of ways in relation to poor African-Caribbean mental health. The most useful use of cultural explanations, in our view, concerns a divergence in cultural background between African-Caribbean communities and their predominantly white-run and white-oriented health services. This may lead to misunderstandings on both sides, and resultant resentment or suspicion by the individuals who feel they have been misinterpreted.

At the most fundamental level, the applicability of Western psychiatry to people of non-Western cultural origin has been been a topic of extensive debate (Sashidharan & Commander, 1993; Johnson, 1994). Critics assert that existing conceptualisations of mental health and illness are peculiarly Western constructs, and that mental health and illness are differently experienced and defined by different cultural groups. In practice, this critique is evident in reported failures by mental health practitioners to accurately recognise the problems of minority ethnic clients (Odell, Surtees, Wainwright, Commander & Sashidharan 1997).

At the level of inter-cultural communication between clients and service providers, it has been suggested that African-Caribbean service users are vulnerable to misinterpretation by mainstream services, due to divergent usage of language and gestures. In the absence of language support, usage of patois or Creole dialects may result in misunderstandings, and low levels of referral of African-Caribbean clients to psychotherapy may be due to a perceived lack of linguistic ability. Perceptions of aggressivity may result from misinterpretation of normal modes of behaviour common in African-Caribbean communities, which often seem overly 'loud' or extrovert to outsiders. Misinterpretation of the symptoms with which African-Caribbean people present may result in inaccurate diagnosis and feed into the high rates of schizophrenia diagnosis (Littlewood, 1992). Thus, cultural incompetence on the part of health service staff is proposed as one factor contributing to the mental health inequalities identified in the previous section (Johnson & Sangster, 1995). Responses by African-Caribbean communities to such reported and experienced misunderstandings may further undermine the likelihood of early and effective use of services. African-Caribbean people may resist the experience of ethnocentric stereotyping and culturally inappropriate communication by refusing to access health services (Campling, 1989).

#### Institutional exclusion

Authors discussing the role of institutional exclusion in African-Caribbean mental health inequalities have portrayed institutions as forms of social control, embodying cultural stereotypes, and unable to accommodate specific needs of minorities. Critical conceptions of UK mental health services have conceived of the institution as acting as a form of social control principally mobilised by four sets of agents: the police, prison officials, social workers and family members (Mercer, 1984). Mediating the relationship between these agents and the institutions are persistent and pernicious cultural stereotypes of 'black criminality' and a pathological analysis of black culture and black family life. Stereotypes of African-Caribbean people as being more dangerous and potentially violent than their white counterparts are said to lead to the higher drug dosages, greater usage of restraint and greater incidence of involuntary admission to acute services that is experienced by African-Caribbean clients (Commander et al, 1999; Lewis, Croft-Jeffreys & David, 1990; Callan & Littlewood, 1998). Furthermore, if ethnic minorities do under-utilise mental health services there may be a tendency that they come to the attention of mental health services only in times of crisis (Ineichen, Harrison & Morgan 1984), thus reinforcing the stereotype that African-Caribbean people have more severe mental health problems. The damaging effects of institutional racism across all societal institutions are well-recognised by the public as well as by the academic community.

Institutions are ill-equipped to cope with the unique characteristics presented by minorities. Standardised procedures and services may not fit the requirements of a unique local community, whose ethnic, religious or socio-economic composition presents specific needs. The mainstream frameworks and assumptions that are at work in the design of services may result in services unsuitable or inaccessible to minority ethnic potential users. Thus, African-Caribbean communities may feel marginalised by mainstream services and call for special, ethnically-specific provision, while institutional staff tend to suggest that minor alterations to the mainstream services will be sufficient to make them appropriate and accessible to minority ethnic users (Roach 1992). Large institutions can have difficulty making radical change or accommodating minority demands.

#### Socio-economic exclusion

The key issue at stake with regard to socio-economic exclusion concerns the well-established relationship between lower socio-economic status and poorer mental health (Gary 1988). The disproportionate location of African-Caribbean people in lower income groups, lower SES groups, and in poorer residential areas (Modood et al 1997) must play a key role in conceptualisations of the relatively poor mental health experienced by African-Caribbean community members. However, the causal direction of the relation between social deprivation and psychiatric morbidity is disputed, and difficult to establish (Harrison, Barrow & Creed 1995). Nonetheless, recent micro-scale longitudinal studies have provided support for the environmental stress hypotheses, suggesting that the quality of the local physical and social environment has a determining impact on the mental health outcomes of local residents (Dalgard & Tambs 1997). Of direct relevance to our interest in the usage of health services is the finding that those groupings (such as African-Caribbean communities) who are socially and economically marginalised are least likely to access statutory services of any kind (Lynch et al 1997).

# Social exclusion in health service-community interactions

UK work on ethnic minority mental health has predominantly taken the form of identifying the statistical inequalities that exist, as described in the first section above, or of theoretically constructing a conceptual framework with which to explain or interpret the statistical inequalities (Mercer 1984). While each of these is essential to understanding mental health inequalities, a third approach, that of detailed community case studies, has received less attention, although it has much to offer. Local perceptions of mental health promotion and treatment demand careful attention in any attempt to explain or reduce health inequalities, because it is in the micro-level interactions between individuals and health services that policy meets practice, exclusion is faced, and statistical inequalities are generated and experienced. The next section overviews the small body of literature that has taken such a perspective in the UK.

# Community case studies

This paper is specifically located within a body of research that has taken a micro-contextual, qualitative approach to examining African-Caribbean and ethnic mental health issues. Such work has taken the form of detailed case-studies which shed light on the interactional dynamics within communities shaping the relation between the community and the health service. Our particular interest is in the perspectives and experiences of African-Caribbean community members on their local services. We propose that consideration of these local perspectives extends our understanding of the mechanisms underlying health inequalities, and most particularly, the low levels of accessing services that contributes to those inequalities.

Currently, there are only a few studies available that take such a micro-contextual, qualitative perspective on minority ethnic community mental health issues. While projects that pay attention to local perspectives, such as the Frantz Fanon Centre for Mental Health in Birmingham and the Nafsiyat project in London are recognised in their field as providing particularly suitable and popular mental health care to ethnic minorities, published research taking such an approach is harder to locate. The local case studies that are being carried out are often inaccessible to the academic/ researcher audience as they are often commissioned to provide local practical recommendations by local authorities, and remain in the 'grey' unpublished literature (e.g. Johnson & Sangster, 1995). Such research is rarely available or co-ordinated on a national basis (for valuable exceptions, see Mental Health Foundation (1995) for a review of issues relating to mental health among black and ethnic minority populations, and a forthcoming Sainsbury Centre review - 'Breaking the Circles of Fear' - on African-Caribbean people and mental health services, scheduled for publication in 2002).

We have identified three case studies of mental health issues among UK African-Caribbean communities, which have provided particularly interesting findings with respect to our interest in local interactions between communities and their health services. We briefly describe these case studies here, highlighting the points of particular relevance to our research. The first case study (Roach, 1992) addressed minority ethnic people's usage of and views on community mental health services. Social exclusion played a key role in this case, as local GPs perceived that many of their patients' problems arose out of social problems,

and that, although five mental health services were provided for the community, these services were not fulfilling the needs of their minority ethnic patients. Negative experiences and perceptions of the services, focusing on perceived inequitable treatment and racism, as well as anger at the lack of representation of minority ethnic groups on health service staff were offered as reasons for low accessing of the mental health services. Satisfaction with the mental health services was low among minority ethnic community members. Pro-active programs to combat the deleterious effects of racism and discrimination were recommended.

Regarding the relationship between health institutions and community, a large discrepancy was found between the extent of change perceived as necessary by service providers and by the local community. While service providers perceived that the existing framework and channels of communication could adequately serve ethnic minority groups, members of those groups asserted a need for special, ethnically-specific provision. They lacked confidence that the white-dominated, mainstream services could ever appropriately serve the African-Caribbean community. Thus, they called for same-ethnicity staff, perceived to be the only way that potential mental health service users could make themselves properly understood to staff. The themes of interest to us in this case study are firstly, the use of a social exclusion framework among community members as explanatory of mental health inequalities, and secondly, the problem of divergent perceptions of the change necessary between service providers and community members.

The second case study details the operation of the Sanctuary project in Brixton, London, which provides two community-based crisis support services for African-Caribbean men and women as an alternative to hospital-based care (Jennings, 1996). This study emphasises that the concept of partnership between black voluntary sector agencies, users, carers and community members was of fundamental importance to the operation of the service. To implement this sense of partnership, from the outset, power, trust and respect had to be generated and distributed among very different members of the project stakeholders. Awareness of social inequalities, power relations and African-Caribbean cultural identity were explicitly placed at the heart of the project, and allowed the implementation of innovative care and promotion strategies. The positive reception of the project by the African-Caribbean community was attributed to the awareness of and challenging of social exclusion by the project.

While Jennings' study appears to present a partially successful negotiation of the social inequalities amongst stakeholders in the context of partnerships, our previous research has illustrated that implementation of such participation presents many challenges (Campbell & Mclean, forthcoming). The third case study which we describe illustrates a problem that arose in such partnership, in the relationship between institutional and local project perspectives on mental health issues (Watters, 1996). This study evaluates a partnership between an inner-city African-Caribbean mental health project and the local mental health service institutions. Different perspectives on mental illness and its appropriate treatment held by the two mental health service groups led to a conflictual and antagonistic relationship, and limited the success of the partnership. In particular, the 'radical' approach to treatment and promotion among African-Caribbean clients adopted by the project was met with resistance by institutional personnel, particularly among those whose clients' diagnoses or treatments were questioned upon referral to the project. Again, in this study, differing perceptions held by institutional staff and local community workers and community members are identified as an important source of friction and as preventing effective mental health treatment and promotion.

# Study aims

The literature reviewed above has effectively identified the mental health inequalities faced by African-Caribbean communities, and suggested reasons for these inequalities centring on social exclusion. We have suggested that, particularly in a context where policy recommends greater community involvement in services, the perspectives and explanatory frameworks held by local community members will form an important part of our conceptualisation of the operation of social exclusion in producing health inequalities. The three case studies reviewed have sought to describe the local interactional context of mental health issues and services in order to provide explanations and recommendations at the level of local perspectives. Following such a model, our case study aims to detail the local perspectives on interactions between the community and health services, through which inequalities are experienced. It is in local interactions that policy meets practice. We seek to contribute a detailed understanding of the local meanings, frames of reference and explanations which are

involved in African-Caribbean interactions with health services. We seek to understand local perspectives on mental health services in order that such services may be improved to better appeal to local potential users.

# Methodology

This qualitative research was commissioned by the local Health Action Zone<sup>1</sup> of a South East England town, in the interest of improving local mental health service provision for the African-Caribbean community, and on the basis of the authors' previous research into factors promoting or hindering the participation of African-Caribbean people in local community networks and meetings (Campbell & Mclean, forthcoming). The study aimed to elicit African-Caribbean perspectives on mental health treatment and promotion in this town, and was conducted over a three month period during Spring 2001.

The empirical research takes the form of a qualitative case study of the interaction between the African-Caribbean community and health services in one particular town. Within any ethnic community, social axes such as gender, age-group or religious or cultural identity will, of course, be associated with different experiences of ethnicity and mental illness, and different patterns of usage of services. Our sample was not large enough to support systematic comparison of the varying experiences of different social groupings within the community, but differences of opinion between statutory employees and other community members emerged and are discussed. We do not wish to claim that this case study is representative of the UK African-Caribbean population or of health services generally. Instead, we seek, firstly, to demonstrate the value of considering local community members' perspectives on health services, and secondly, to point to a number of issues that may merit attention when considering the interaction between community and health service in other geographical or socio-cultural contexts.

<sup>&</sup>lt;sup>1</sup> 'Health Action Zones' are set up in the UK to address the particular health problems faced by communities. Collaborations between local NHS organisations, local government, voluntary groups and the private sector are established, with the aim of achieving more effective and flexible use of local resources.

# Interviews and focus groups

The first author conducted audio-taped, semi-structured interviews and focus groups with a purposive sample of thirty individuals from, or working with, the African-Caribbean community in the town. Focus groups (two) were conducted with mental health services users, in line with suggestions that this group would feel more comfortable in a peer setting. All other informants were interviewed individually. Interviews and focus groups lasted from an hour to an hour and a half, and the eight interviewees who were not employed in paid work relating to the African-Caribbean community in the town were paid £10 consultancy fee. Interview and focus group topic guides sought informants' views in three main areas: (i) promotion of mental health; (ii) treatment of mental illness; and (iii) participation of African-Caribbean community members and voluntary groups in consultative fora relating to mental health issues. This paper reports on findings on the first two topics. Interviews were audio-recorded, transcribed, and analysed by a grid coding method.

# Sample

As Bhui, Christie & Bhugra (1995) recommend for research on African-Caribbeans and mental health services, our sample covers a range of different stakeholders in the African-Caribbean community in our town of interest. Members of voluntary groups and service providers were interviewed in order to glean expert opinions on services from a variety of professional perspectives. Lay African-Caribbean community members provide the non-expert perspective of the target community. While the service providers implement policy in terms of concrete interventions, it is the local people who decide when, and how, to engage such services. Thus, we chose to interview both professionals and non-professionals across a number of stakeholder sectors as follows:

- 1. African-Caribbean Statutory organisation members
- 2. African-Caribbean Voluntary agency members
- 3. Employment Officers
- 4. Police Officers

- 5. General Practitioners
- 6. Mental health service staff
- 7. African-Caribbean carers of African-Caribbean clients of the mental health service
- 8. African-Caribbean users of local mental health services
- 9. Lay African-Caribbean community members

The participants were located in four over-arching categories for analytic purposes: members of statutory organisations (including council, police and primary/secondary care workers); members of voluntary organisations; mental health users and carers; and lay African-Caribbean community members. In total, thirty individuals were interviewed, evenly divided among the four categories.

# Results: Social exclusion in everyday experience

This section presents our findings on African-Caribbean community stakeholders' perceptions of their local mental health promotion and treatment services. In this community there are basically two forms of service being provided. The first is the mainstream NHS mental health service, and the second is an ethnically-specific mental health support service, which includes an explicit focus on issues of cultural identity and civil rights, as well as providing a comfortable environment for meeting social workers and other mental health service users. While we sought both positive and negative comments on the services, negative comments far outnumbered and outweighed positive ones, in regard to the mainstream services, while the ethnically-specific service was highly praised. Although we did not explicitly frame our topic guide in terms of social exclusion, it emerged that a fundamental starting point for virtually all interviewees was the social context to mental health problems faced by the African-Caribbean community. Literally hundreds of anecdotes and arguments asserted the importance of the experience of racist social exclusion faced by black people, as a voluntary worker outlines:

You see, slavery is what has brought on our problems. It's how we've been brought up by appearance. It's conditioning from slavery. These things bring on mental health [problems]. Even though you've got all the love, you haven't really been directed right as a young man, as a

To counter this pervasive, general experience of racist social exclusion, interviewees emphasised the importance of generating 'cultural awareness' and positively-valued black identity as part of an effective mental health service. Ethnicity, as well as serving as a basis for exclusion, through racism, was also seen as an important resource upon which to base inclusion. Exclusion and inclusion along the axis of ethnicity comprise the central themes of interviewees' accounts of the mental health service. In the following sections, we present our findings in terms of the three forms of social exclusion identified above: cultural, institutional and socio-economic, demonstrating the everyday experience of exclusion reported in African-Caribbean community members' interactions with health services.

#### 1. Cultural exclusion

Exclusion and mis-treatment due to cultural difference were frequently reported.

Interviewees emphasised that African-Caribbean people must be understood to belong to a cultural community with different characteristics to the mainstream and that issues of cultural identity should be central to mental health services.

## Misinterpretation of African-Caribbean modes of self- expression

A lack of understanding of African-Caribbean culture on the part of health service staff was perceived by interviewees to lead to misinterpretation of 'normal' behaviour as 'deviant'. Thus, turns of phrase, customs and modes of self-expression particular to African-Caribbean community members were reportedly misinterpreted by health practitioners as signs of pathology. In particular, vernacular use of language, and a 'loud' mode of social interaction were cited as examples where normal behaviour was misinterpreted by (white) mental health staff.

We express ourselves a bit different, you know, because we're not white and we talk differently, so

<sup>2</sup> Documentation of interview details is as follows: Interviewee number; page number; sector: (user/ voluntary/

we might express ourselves differently and they feel that we are paranoid schizophrenia (12; p7-8, user).

People will say quite frequently, I'm gonna kill you, you know. They don't literally mean "kill", but a white person or a person who has been trained here or who don't understand the cultural background and the way language is used in the Caribbean as well, they won't have a clue. They won't have a clue. And so it goes on. (4; p3, statutory).

Moreover, the fact that African-Caribbeans use the English language is perceived to mask their cultural difference. A voluntary worker mentioned that, while the need of other ethnic groups for interpreters or language support was recognised, an African-Caribbean vernacular is not perceived to require special interpretation.

Secondly, a 'loud' or extrovert mode of social interactions among African-Caribbeans, using exaggerated hand gestures, colourful phrases of speech (as above) and raised tones of voice were reportedly threatening to someone unfamiliar with African-Caribbean culture, and thereby misinterpreted.

Especially the African Caribbean males on the ward, they do feel the vibes. They feel that people are shrinking away from them if they're trying to express themselves. What they perceive as expressing themselves, others perceive as sort of anger and almost threatened violence (14; p9, statutory).

Such experience of mis-interpretation reportedly reduced African-Caribbean community members' confidence in the mental health services, deterring them from approaching the services to seek support or treatment. Attempts by African-Caribbean clients to join mainstream services had also met with misinterpretation discouraging their further attendance at those services.

I know that I've had a client, an African Caribbean client, who was interested in getting involved in some sort of day services...He started going there but they didn't understand him and I think it was because of his culture. They felt quite intimidated by him. He was harmless. Yes, he was loud, but so am I. [Laughter] I think they felt intimidated...But he settled in really well with [name of African-Caribbean-specific service] (14; p5, statutory).

statutory/lay).

Q: Have you been to the other centres, like [African-Caribbean-specific service], but not for black people, but for everyone? M: I've passed through. A: [Names local mainstream voluntary service]. Because you know it's not for you, just by the atmosphere you know its not for you (12; p10, user).

In this context of such misinterpretation and lack of acceptance, interviewees called for the introduction of ethnically-specific and culturally appropriate support services.

# Demand for a cultural approach to mental health services

Interviewees repeatedly emphasised the centrality of ethnicity - as a *cultural* phenomenon - in the experience of mental health and mental health services. As described above, there was a perceived failure on the part of mental health staff to understand the African-Caribbean community as a cultural entity, resulting in mis-diagnosis and inappropriate treatment. Interviewees reported that the only difference acknowledged by service providers appeared to be skin colour, and that otherwise the needs of African-Caribbean community members were viewed interchangeably with those of the white population.

There's a reluctance to recognise that the African Caribbean community has culture, is a community of culture rather than a community of race, and there's a reluctance to see that cultural community as being potentially supportive, of holding within at the seams. (18; p4, statutory).

Such observations on the failure of mainstream services to recognise the cultural uniqueness of the African-Caribbean community led to proposals of two avenues for change. Voluntary sector workers and users of mental health services doubted the ability of mainstream services to adequately accommodate African-Caribbeans, or to gain their trust and in the main they recommended ethnic matching of staff and clients. On the other hand, statutory workers tended to state that, while change was needed, cultural competence training would be adequate to address the needs of African-Caribbean clients. They were concerned that emphasising ethnic distinctiveness would be divisive in a multi-ethnic community, and that integration was preferable. While the perception that culture must be more effectively addressed was expressed across all sectors, divergence between statutory and community, in terms of the extent of change needed is in evidence.

# African-Caribbean community resources for inclusion

There was a strong sentiment that informal support networks within the African-Caribbean community, such as church groups, were a strength that could be built upon as stress-buffering support systems, means of encouraging appropriate accessing of services, and advocacy and befriending services. Informants criticised the local borough council for failing to make use of existing strengths in terms of informal networks, church groups, African-Caribbean media and radio stations. Such facilities comprise culturally accepted and well-established local resources which could serve as channels through which information related to mental health prevention and services could be disseminated, as well as providing informal referral services. Interviewees emphasised the importance of recognising locally-specific and African-Caribbean-specific community strengths as a means of improving mental health service outreach.

## Culturally appropriate model of good practice

Virtually all participants pointed to the one dedicated African-Caribbean mental health service in the area at the time of study as a model of good practice. We have identified four particularly valued qualities of the service provided as commented upon by informants.

Firstly, it was felt that the service recognised people as individuals, paying personal attention to individual needs and interests in contrast to a perceived depersonalisation of users by mental health institutions. Secondly, the service includes discussion of issues of exclusion and cultural identity important to African-Caribbean clients, locating their experience in a wider societal context. Thirdly, the service is committed to informing clients about mental health issues and services so that they become knowledgeable users of the mental health system. Finally, it was seen as a service that truly reflected the needs of its community by having organic roots in the local African-Caribbean community. Mental health workers' familiarity with a local frame of reference was seen as highly important to the service's success.

#### 2. Institutional exclusion

# Centrality of whiteness in institutions

Informants repeatedly spoke of institutional stereotyping of black mental health service users, as 'mad, bad and dangerous', more prone to mental ill-health and less controllable. These stereotypes were perceived to influence diagnosis, type of treatment offered, quantity of drugs prescribed and quality and quantity of after care and support offered. The very framework of the mental health service itself and the medical training of service staff was seen by many participants as Eurocentric in nature, where white European culture is the norm, and knowledge of factors relating to other ethnicities neglected. Informants asserted that challenging cultural assumptions should be a fundamental part of staff training.

The actual staff that manage these services and so on have to be culturally aware and not have their hang-ups. A lot of them come in with their baggage and they're not leaving it at the door. They practise it every day. They see – if there's a mental health patient who is big, a big black man, six foot two, somehow they are afraid of him more than a six foot, seven foot, white man. (20; p9, statutory).

Racism was clearly perceived to structure the treatment of African-Caribbean community members, and this perception strongly discouraged people from approaching mental health services, due to anticipation of racist stereotyping and treatment.

Probably because I'm black they think I'm mad (11; p16, ex-user)

people are either radically dissatisfied with it because they're being treated aggressively; or they are seeking as far as possible to deny any opportunity to experience those services, .... because you don't really want them to get their hands on you, do you? (18; p5, statutory)

One of the ways in which African-Caribbean users were reportedly discriminated against was in the form of treatment offered. Black users were reported to be only offered drug treatments and excluded from non-drug therapies.

they don't believe – they really don't believe that black people can be treated, that black people can be given therapy, that you can talk to black people. (4; p.7, stat)

The centrality of perceptions of institutional racism in African-Caribbean community members' interactions with mental health services needs to be accorded greater concern within the statutory institutions. The following quote suggests that statutory service providers are aware of such perceptions, but do not take them as seriously as do African-Caribbean community members.

We have got one or two – well, we have one particular West Indian gentleman and he's very good. If I say to him, now, we can't do this because of this, he will then immediately come out with it's a black thing, which is absolutely ludicrous because we're not doing the thing because we're not doing the thing. It's got nothing to do with black or white, but he will use that. (13; p13, statutory)

For African-Caribbean community members, the relationship between community and institutions is fundamentally structured by racism. Explicit efforts to address this deep-seated experience and perception will have to both remove racism from the services, and ensure that the community perceives this removal.

Scepticism of council's commitment to inclusive and culturally-appropriate change

One of the factors apparently reducing the likelihood of timely accessing of services by African-Caribbean community members was a lack of identification of low level symptoms of anxiety or stress as reason enough to approach mental health services. Furthermore, awareness of the existence of support services was low. Informants suggested that current high levels of involuntary admissions might be reduced by increasing awareness of and willingness to access such services.

African-Caribbeans are not recognising the more low level symptoms of stress and anxiety as mental ill-health in themselves....Some people don't believe that you could be stressed and don't believe that... as a mental illness....[so] you're not going to go forward for access or ask for nothing. You know, people won't necessarily say, I feel depressed, I'm depressed [African-Caribbean] people won't say that (7; p22, statutory).

Thus, a need for promotion campaigns to increase awareness around mental health issues and services was emphasised. However, many informants were doubtful that the political will to

carry out such campaigns exists.

[We need] some kind of campaign and communication mechanism to upgrade the thinking and the perceptions around mental illnesses and mental wellness is crucially important Q: yeah? A: But it is not being carried out or driven forward by providers who feel maybe if they can keep schtum [silent], you know, it will go away... (7; p24, statutory).

Again the African-Caribbean community reports a sense of exclusion in terms of services offered and willingness on the part of the council to address such exclusion. Informants also suggested that the very highly-regarded, African-Caribbean-specific service in the community did not have the enthusiastic support of the council. Here, exclusion from institutional support is perceived to constrain the services available to the African-Caribbean community.

I don't think that they see it as an incorporated part of their service. They see it out there and it's as if they're looking to see if it will fail. So they don't support it properly and make sure that it does work. (20; p8, statutory).

# Positive changes to institutional culture of acute and primary services

Notwithstanding the range of criticisms of the excluding nature of mental health services, informants also welcomed recent changes towards greater accountability and cultural sensitivity, which they saw as first steps in a process of necessary change towards greater inclusion. The positive changes reported in acute settings revolve around changes to institutional culture. A shift to increasing client involvement in decision-making was appreciated, as was a commitment to equality of treatment of ethnic minority groups. This cultural shift demands transparency in service delivery and entails appreciation and development of client expertise, contrasting with the managerial 'patron' model previously dominant.

You know, you have patients going to the doctor now and explaining fully what's going on. The doctors don't even have to ask leading questions anymore. People understand what is happening to them. What they need is for a proper diagnosis to be made and for medication to be prescribed. (20; p3, statutory).

The introduction of Caribbean food to the menu of a local hospital (including the psychiatric wing) was cited as a development in cultural competence and a tacit recognition of the distinctiveness of the African-Caribbean community in cultural terms.

I like James's [pseudonym, chair of local African-Caribbean community development voluntary organisation] idea because James is sorting out that they should cook Caribbean food in the hospitals and serve them to the patients.... If they had more people like James that got together and sorted out these things, then the black people wouldn't have that problem (15; p.5, user)

Moreover, a reduction in institutional racism was perceived to have occurred in recent years. In contrast to the explicitly racist attitudes that previously structured black people's encounters with the mental health system, participants welcomed recent improvements that provided protection against overt or explicit racism.

I think when we had a change in 1997, I mean, I don't know if people will stand up and be counted, but I know that most of the staff were asked to leave because they couldn't work in the way and service a multiracial community in the way that the new Social Services department wanted them to. Q: I see. A. They were out and out racists and they weren't afraid of expressing those views, and Social Services management are aware of it, but they took action and most of them were either paid off or they took early retirement, whatever. So, now you have a different team there. So, black workers went in for the first time there (4; p8, statutory).

This improvement was frequently located within the sense of wider social change, instigated both by government and by the shockwaves and legacy of the MacPherson enquiry<sup>3</sup> which was felt to have forced issues relating to 'race' and ethnicity back onto the forefront of the social agenda in the UK.

#### Need for increased communication between statutory and community

The divergence between statutory and voluntary/ community sector in their appraisal of the extent of change necessary was striking. While the African-Caribbean community perceived the health service to be culturally insensitive, inaccessible and discriminatory, the statutory

<sup>&</sup>lt;sup>3</sup> The high profile MacPherson enquiry investigated police incompetence in a case of a racist murder of an African-Caribbean youth, concluding that institutional racism was at the root of the incompetence. The enquiry, which received the sustained attention of the UK media and UK public, stimulated widespread discussion of institutional racism.

sector did not perceive there to be a problem to such an extent. It appeared that there was a need for the statutory sector to become aware of the nature of its negative profile in the community, and the damaging sense of discrimination that people experience in trying to access appropriate care. Participants felt that communication should be facilitated through involving community members in designing plans for change in a more inclusive manner than had so far been adopted and called for increased dissemination of information about planned and achieved changes throughout the community, through culturally-relevant communication channels.

#### Socio-economic exclusion

#### Exclusion at work

The experience of racist social exclusion in employment was described with bitterness and frustration by a number of participants, who emphasised the destructive effects of unemployment and racism at the workplace on African-Caribbean people's mental wellbeing. It was widely felt that African-Caribbean people were less likely to get work, and had less employment-related opportunities and choices available to them in comparison to the white-British community. As well as having damaging psychological effects on self-image and sense of empowerment, such discrimination was perceived to be directly implicated in the African-Caribbean community's relative economic disadvantage. This economic disadvantage was also seen as integrally related to the African-Caribbean community's poorer mental health outcomes and reduced likelihood of accessing services.

You know what's really killing us? We're economically shagged. You can't go nowhere, you can't get nowhere. That's what it is. All these things will just keep escalating. It can't change. We cannot get no better, and that's what's happening. Any area where you see there is high levels of unemployment, you're going to find high levels of mental health problems. It's because these people are suffering major frustration. They can't go nowhere, they can't see nothing. They can't see the wood for the trees because there is no way for them to get out of their situation. You know, every day is a hopeless thing. They can't get the work, and then, when they do get the work, they're still going to end up with that racist thing because the employers are going to be stereotyping them. It's a vicious circle, my friend. I've been working in it for just over a year, I've been involved in mental health, and I can't believe how bad it is. (3; p6,

voluntary).

Informants asserted a vital need for anti-racist workplace interventions, as well as stress reduction programmes.

# Economic exclusion from non-drug therapies

Access to non-drug therapies was seen to be denied to the majority of local African-Caribbean people, due to the financial cost. Participants felt that there was a demand for non-drug therapies such as talking and music therapies, but that, in general, financial cost prevented African-Caribbean people from being able to access such therapies privately.

But access to those is dependent on money. You know, you can't access alternative therapies unless you've got the finances, and then you've got to remember that the sort of economic circumstances of a lot of African Caribbean communities is disadvantaged. So, knowledge of the alternatives might be there, but access to them isn't. (6; p13, statutory).

# **Discussion**

We have presented above, the views of local African-Caribbean community members on their mental health services. We have proposed that social exclusion is an important explanatory framework involved in community members' perceptions and descriptions of their interactions with mental health services. A number of themes discussed in our introduction were confirmed in our particular community of interest. Cultural and institutional exclusion were reported to characterise the African-Caribbean community's experience of mental health services, and reputedly discouraged African-Caribbean people from approaching such services. Similarly, the high levels of socio-economic disadvantage among African-Caribbeans were felt to increase the likelihood of poor mental health and to decrease the likelihood of accessing services. Echoing Roach's (1992) findings, we also found a divergence between institutional views and local community views on the extent of change necessary, with institutional views emphasising change within the existing system, such as cultural competence training, and community views recommending radical change, through the establishment of ethnically-specific services with ethnically-matched staff.

Interviewees also confirmed the importance, as emphasised by Jennings (1996), of cultural awareness and challenging power and status inequalities.

While our data have served to confirm such observations that already exist in the literature, we suggest that our key contribution is to show that a framework of social exclusion structures community members' perceptions of their local mental health services. Thus, social exclusion is not only a sociological fact, but is also an everyday experience, keenly felt and talked about by community members. Social exclusion is subjectively experienced as well as statistically established. It is used as a framework to understand interactions between the African-Caribbean community and the health service by local African-Caribbean community members as much as by academics and policy makers. Certainly, from the perspective of our interviewees, addressing cultural, institutional and socio-economic exclusion is the fundamental form of intervention needed to reduce the mental health inequalities faced by this African-Caribbean community.

With regard to factors contributing to the mental health inequalities faced by UK African-Caribbeans in general, our findings strongly confirm the suggestion by Campling (1989) that perceptions of discriminatory treatment by health services deter African-Caribbeans from accessing such services. It was commonly agreed by our interviewees that institutional attitudes within mental health services generally discriminate against African-Caribbean people, and that experience or expectation of mis-diagnosis, mis-interpretation, and over-prescription of drug treatments discourage African-Caribbean community members from accessing services at an early stage. At the same time, interviewees also expressed appreciation of what they saw as the beginnings of institutional change to greater user-friendliness and accessibility to minority ethnic groups. If the perceived racism of services is discouraging African-Caribbean people from accessing the services, then, as much as it is necessary to eliminate all forms of institutional racism, it will also be necessary to address local perceptions of services. As clearly expressed by one of our interviewees:

It could be a good service. It could be a brilliant service. Perception is key. If I perceive, if the community perceives that the facility is not really sensitive to me or geared to my needs, no matter how good it is, I ain't gonna access ... I ain't gonna spread the word (7; p21, statutory).

Finally, we would like to propose that the recent policy commitments to greater participation

by local communities as a means of addressing health inequalities (Department of Health 1999a; 1999b; Social Exclusion Unit 2000) are highly suitable and relevant to the situation of the community within which this case study is based. To counter the reported experiences of exclusion, the active inclusion of local community members in design and delivery of services is an obvious step. Grassroots participation, and partnerships between voluntary and statutory bodies have the potential both to ensure cultural appropriateness and accessibility of services, and to generate the subjective sense of inclusion that is almost non-existent according to our interviewees' accounts. This context of exclusion presents its own barriers to the initiation of participation and partnership in this community, a topic which will form the focus of a companion paper to this one. However, genuine participation and partnership must be key steps to generating both the objective and the subjective social inclusion that are essential to appropriate and accessible mental health services.

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