# Best practice in mental health

## Advocacy for African, Caribbean and South Asian communities

Asha Rai-Atkins
In association with Anab Ali Jama, Norman Wright, Velma Scott, Chris Perring,
Gary Craig and Savita Katbamna

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**Asha Rai-Atkins** is an independent research and training consultant. She has recently taken a post with South Derbyshire Community and Mental Health Services NHS Trust as the Patient Advice and Liaison Service (PALS) lead.

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# Contents

# Acknowledgements

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# Dedication

Moving from silence into speech is for the oppressed, the colonised, the exploited, and those who stand and struggle side by side, a gesture of defiance that heals, that makes new life, and new growth, possible. It is that act of speech, of 'talking back' that is no mere gesture of empty words, that is the expression of moving from object to subject, that is the liberated voice.

*bell hooks, 'talking back', 1987*

# Terminology

**Service user** within this report refers to people who use mental health services. The term also includes survivors of mental health services. We would like to emphasise that this term poses difficulties for black people. We found that often people resisted being further defined by terms that they believed stigmatised and alienated them from being active participants in both institutional and community life.

**Carer** is used to describe a relative, parent, friend, neighbour or sibling who provides short and/or long-term emotional and practical support for someone who is experiencing distress.

**Black** refers to people living in Britain who experience disadvantage and unequal treatment from various institutions and societal structures because of their difference in skin colour, language, religion, gender and/or cultural beliefs. We use the term **ethnic minority** alongside 'black' to encompass the similar experiences of newer settled communities. We acknowledge that the relevance of these terms to capture and describe a diverse group of people is becoming an increasingly contentious subject. But until black people decide for themselves more appropriate descriptions reflecting their cultural identity and experience of disadvantage, we are left with little alternative than to use these terms in a general sense. Clearly, this research did not cover the experiences of all black communities – it is specific to Somalian, African Caribbean, Punjabi and Pakistani service users and their carers.

**Yorkshire and the East Midlands region** We refer to this term to cover the geographical areas included within the research. Mental health advocacy projects in Leeds, Bradford, Sheffield, Leicester, Nottingham and Derby were mapped as part of the research.

# 1

# Introduction

Psychiatry and its clinicians have received severe criticism from some quarters for the systematic oppression that can strip away the basic human rights of an individual perceived or diagnosed as suffering from mental illness. Over the years many mental health activists have persistently campaigned and lobbied for an end to the degrading and involuntary mistreatment of mental health service users. International affirmative action by mental health service users and activists such as the Patients Liberation Movement has spurred the development of mental health advocacy within Britain. The aim of the advocacy movement is to empower service users to take back some control over their lives and experiences within the mental health system.

Anyone with an interest in mental health, whether as a survivor, a user or a professional, will be aware of the significant difficulties experienced by black and ethnic minority communities. Unequal access, coercive treatments, misdiagnosis and inappropriate care are cited within many reports, textbooks and research agendas as evidence of a deeper underlying problem. (Fernando, 1995; Wilson and Francis, 1997; Christie and Bhui, 1999).

The importance of 'race' and culture in mental health has received significant attention over the last decade. How effective these shifts in ideology are, and how they have increased the quality of care or changed oppressive attitudes, is still widely debated. Racism, overt or subtle, continues to prevail, rooted innately as it is in individual practices and institutional structures (Fernando, 1991).

In response to the unequal treatment of black service users within the mental health system, a collective of people in Yorkshire and the East Midlands interested in race and mental health met as a group called **Shaan**. Shaan, supported by Trent and Yorkshire Mind, became a network for creating opportunities for black and ethnic minority people to meet and take up mental health issues. The overriding aim of Shaan was to challenge racism within the mental health system. With support from Professor Gary Craig, the group developed an action research proposal to look at best practice in mental health advocacy for African, African Caribbean and South Asian communities. The relevance and importance of this proposal was acknowledged with funding awarded from the Joseph Rowntree Foundation.

This action research presented the opportunity for a diverse team of researchers to identify and assess the appropriateness of current advocacy provision specifically for African Caribbean, Pakistani, Punjabi and Somali service users and their carers across the Yorkshire and East Midlands regions.

This final report, from the action research project with guidance from black service users, carers, the advisory team and black mental health professionals, represents the meanings of advocacy, self-help and empowerment as defined by the communities selected.

The findings may challenge mainstream Eurocentric mental health advocacy sensibilities. We do this knowingly. The findings highlight that within the Yorkshire and East Midlands region mental health advocacy at present is a luxury rather than a right, especially for minority communities. This statement presents a direct challenge for mainstream advocacy activists, providers, purchasers and commissioners who have worked hard to bring advocacy services to the forefront of mental heath.

Importantly, the report highlights that black service users and their carers can assert their rights and express their pain only within a safe environment. This place of solidarity is almost always located within black mental health projects, which survive precariously within the black voluntary sector. Our findings indicate that the process of black self-help and empowerment differ significantly from European conceptualisations.

For example, western empirical approaches to life dominate British contemporary society. This is seen in, for instance, the dominance of medical models in healthcare, although there has been a recent rise in interest in complementary approaches. In contrast, many communities worldwide are guided and run on holistic and intuitive principles. This means there is a fundamental difference in 'world views' which inform how we relate to each other as human beings.

In terms of empowerment and advocacy, it means that culturally sensitive services are not simply mainstream services with cosmetic changes. Rather, we need to understand that authentic cultural sensitivity occurs when services are based on a fundamental way of being that is in keeping with the beliefs, values and experiences of minority communities.

The original proposal set out to produce best practice recommendations in mental health advocacy. The research has only partially fulfilled this expectation, primarily because mental health advocacy for diverse minority communities is not developed enough to present many conclusive examples of best practice. The journey has thus just begun. What you will find within this research is both an analysis of current service provision and recommendations for best practice that need further testing out with relevant communities. The report explores the reasons why advocacy is less accessible to black service users and carers, the barriers they experience, and the changes that need to take place within the mental health system with specific reference to advocacy.

Advocacy has the potential to secure vital redress and challenge perpetual inequality and discrimination. It will achieve that potential only if it aligns itself to the experiences, values and diversity of the people it seeks to serve. Advocacy can be an empowering intervention by promoting philosophies that accept interdependence as a key aspect of sustaining a shared cultural identity in an often hostile environment.

The report findings reflect the research process as much as its outcomes. They are derived from our experiences in the Yorkshire and East Midlands regions, and have profound relevance beyond. The report concludes that voluntary and statutory agencies must apply more commitment, resources and recognition of differing needs, in order to develop best practice to meet the needs of the whole community.

Even more fundamentally, the report advises agencies to think through the most beneficial models for advocacy services. Should they be integrated within the mainstream? Should they be separate and specific? Or should there be a choice, with both on offer?

This report has taken a significant step towards black empowerment within a mental health context by enabling black service users and carers and black advocates to express their views and highlight their priorities for culturally sensitive advocacy services according to their realities.

For this reason, we have situated the case studies written by a black mental health service survivor, a Somali mental health project and a black-led advocacy project at the heart of the report.

The report begins with a description of how we approached the investigation. Before moving on to the research findings, we give an overview about general mental health advocacy. Controversially, perhaps, we include full and authentic accounts from three of the project leaders/participants who took part in the research, in order to underline their own distinctive voices. This sets the scene for the next section, which provides detail about black empowerment and advocacy in this specific context and pays particular attention to issues of access for black service users. From our analysis, we have been able to move understandings about empowerment and disempowerment forward. The report concludes with recommendations for practice in five key areas:

1. funding;
2. black user involvement;
3. language and communication;
4. culturally appropriate advocacy;
5. culturally appropriate services.

## 2

# Mental health advocacy

## Overview

This section provides a brief overview of the development of mental health advocacy. It highlights developments within the mainstream advocacy movement, and also presents issues specific to the experience of black and ethnic minority communities within a mental health context. Information and evidence is presented that support the view that mental health advocacy is a tool that is essential for facilitating black user empowerment within mental health services. The chapter emphasises that current advocacy literature provides very little information relating to black users' experiences.

### *History*

The emergence of advocacy began in Europe and the US in the late 1960s. However, it is important to note that advocacy is not a new concept: as a form of speaking out against discrimination and inequality, it has existed throughout the world, in a variety of forms and expressions, for much longer. People from all cultures, classes and ethnic backgrounds practise advocacy with and for their children, friends, elders and relatives. Universally, advocacy can enable people to make informed choices about, and take control of, their own care and experience. It can help people access information, understand the options of care available to them and, importantly, make their views and wishes known. There is a growing literature that reviews and charts the development of mental health advocacy (see for example Brandon, 1988; UKAN, 1994; Wallcroft and Read, 1994; Atkinson, 1999).

The black civil rights movement in the 1960s inspired many other oppressed groups, both within the US and elsewhere. One result of this in the US was that former mental health service users began to come together and develop organised networks. This became known as the mental health patients' liberation movement (Chamberlin, 1987). Service users collectively identified the struggle over power, loss of control and persecution, and in response began to advocate for self-determination and basic rights (Chamberlin, 1990).

### *Development of mental health advocacy in Britain*

In Britain, advocacy can be traced back to 1620. More recently, mental health advocacy took off during the early 1980s. During the last ten years or so there has been a flurry of activity, resulting in the unprecedented growth of service user forums, patients' councils, self-help groups and national advocacy organisations. Collectively, these agencies aim to ensure active user participation in accessing appropriate support and treatment, thereby helping to identify unmet needs and promote the rights of the individual.

Patients' councils (PCs), a form of collective advocacy imported from the Netherlands, was first introduced by Nottingham Advocacy Group (NAG) at Mapperly Hospital, Nottingham, in 1986.

Parallel to these developments, advocacy activists have achieved significant recognition socially and, more recently, politically. The hard work achieved over the last decade through advocacy has forced the government to recognise that advocacy and user feedback are important ingredients for effective and responsive services. NHS Planning Guidance 1998/9 states: "Give greater voice and influence to users of NHS services and their carers in their own care, the development and definition of standards set for NHS services both locally and nationally" (NHS Executive, 1997).

Models of self-advocacy drew heavily on the ideas of Wolf Wolfensberger, writing in the 1970s, and later on those highlighted by O'Brien in the 1980s. The self-advocacy movement in Britain has been rooted primarily in locally based groups that concentrate on the realities of local situations for local people. By starting with the current realities of individuals and communities and working in a 'grassroots' or 'bottom-up' manner, self-advocacy gains a credence and authenticity lacking in solutions imposed externally, or 'top-down'.

In recent years, self-advocacy has developed into two main strands: national and local. Campaigning initiatives with a national focus include Mindlink, United Kingdom Advocacy Network (UKAN), Citizen Advocacy Information and Training (CAIT), Survivors Speak Out (SSO) and Advocacy Alliance. These coalitions address broad issues relevant to mental health service users and survivors.

Locally based advocacy groups share the same concerns as national groups. One of the main differences between national and local groups is simply the level at which they work. Both local and national groups challenge oppressive services, conditions and attitudes that are experienced as abusive and inappropriate. The aim of both is to change these types of practices and improve the experiences of those they advocate for. In addition, locally based groups provide a vital redress for many oppressed groups and people.

In summary, then, advocacy exists to express individual or collective 'voice power'. One of its ultimate aims is to enable service users themselves to voice their rights and speak up for themselves.

And herein lies our first problem. Most local and national action and campaigning groups have emerged from a predominantly white, male perspective. This gender dominance results in an imbalance of power that is maintained at the cost of other less visible groups, whose voices remain unheard. In practice, this means that the experiences of other marginalised groups are not embedded within service development or delivery.

It is important to recognise that mental health service users experience many sociopolitical barriers when speaking up within a hostile and often disempowering care system – so much so that speaking up is often not a reality for many, such as black and ethnic minority groups, children, women and disabled people. Further, there are issues that limit the ability of white advocacy groups to represent or accurately reflect the needs and experiences of linguistically diverse communities.

Patient Advisory and Liaison Service (PALS) is a new core service to be provided by all NHS and Primary Care Trusts by April 2002. PALS will be:

- trust based;
- accountable through a nominated senior manager to the trust board;
- identifiable and accessible to patients, their carers and families;
- act as a catalyst for change, by feeding back the views of patients directly to the board.

PALS will act as a facilitator in relation to the concerns of patients, their carers and families, with the power to negotiate on-the-spot resolution of issues quickly and efficiently. It will also signpost patients on to external specialist support agencies, for example, independent advocacy services.

This development raises profound issues specifically for black and Asian mental health service users. It is unclear what the PALS will look like in practice and how they will deliver a service to patients. The best practice in mental health advocacy research currently being conducted by Durham University will inform government plans, but it is unclear what this research will recommend about black and ethnic minority mental health service users. Both in policy and in practice, PALS will need to address dimensions of race, gender and cultural sensitivity if they are to respond effectively to diverse needs and experiences.

### *Advocacy in action*

The themes and aims of mental health advocacy in current literature cover a multitude of expressions that are formulated into practice. Explanations include 'pleading the cause', 'acting on behalf of' and 'supporting others' (Wertheimer, 1993). UKAN agrees with these explanations and further adds the aim "to secure services ... rights to which they [patients/service users] are entitled"

(UKAN, 1999, p B1). Atkinson (1999) expands these definitions by adding that “it [advocacy] becomes more of a necessity where legislation assumes the involvement of the users of services in their design and delivery”.

Advocacy falls into four broad categories:

- **Self-advocacy** seeks to empower service users to speak up for themselves by expressing their own needs and representing their own interests. This process can enable the service user to regain some control and power over their experience. Many advocacy projects have an explicit goal of consciousness-raising and power sharing for service users (Conlon and Lindow, 1994).
- **Peer advocacy** is a process whereby one person advocates for another who has experienced, or is experiencing, similar difficulties or discrimination. Survivors of the mental health system may be more acceptable advocates for mental health users by being able to show empathy and understanding (Atkinson, 1999).
- **Citizen advocacy** is usually a one-to-one and long-term partnership between a trained unpaid ‘citizen advocate’ and a service user (Brandon, 2001).
- **Professional or paid advocacy** involves a trained paid worker responding to an identified problem, event or change in someone’s life. The advocate’s support is time-limited (Barnes, 2000).

A recent literature review on advocacy provision conducted by Atkinson (1999, p 12) identified four key principles to underpin advocacy provision:

1. empowerment;
2. autonomy;
3. citizenship;
4. inclusion.

Barnes’ (2001) summary of advocacy identifies three main elements:

1. protecting vulnerable people;
2. giving them a stronger voice;
3. promoting their rights.

These seven principles and elements provide an important framework for advocacy services. We identified a further two during our research:

- **choice:** this relates both to type of advocacy and to the decision to advocate;
- **self-definition:** the journey towards self-definition provides a powerful opportunity for black service users to challenge externally defined and controlling stereotypes which often result in psychological attacks on their personhood and dignity. The process of self-definition will enable black service users to ‘reframe’ advocacy for themselves, thus validating black service users’ power as human beings.

In conclusion, advocacy can be construed as being based on different principles, but always with the aim of empowering services users to express their views. Advocacy as a concept of equality should promote accessibility, representation and self-definition.

Although we have seen some development of advocacy in various guises, empowerment and action for black and minority ethnic communities clearly remains in the margins of the advocacy movement. So we can conclude that, while in principle advocacy exists for all service users, in practice access to services is far from universal.

## *Tensions and debates*

Over the years, many different forms of advocacy have come to coexist and have culminated in rich and diverse forms of self- and collective expression. The challenges that now face advocacy are multi-layered; for, even though the different mainstream forms of advocacy coexist, this proliferation of advocacy is often beset by internal conflict.

One of the dilemmas facing advocacy is the problem of finding the right balance between self-definition and an organised universal framework. Should it become part of the wider system of mental healthcare managed by a statutory sector or national organisation, or remain independent? Kelly (2001) indicates that the government will incorporate into the PALS initiative recommendations from research by Durham University into best practice in mental health advocacy. Mainstream independent advocacy activists have expressed their resistance to this new initiative, for two main reasons. First, advocacy may risk becoming a homogeneous provision, which implies universality. Second, this service will not be independent and may not be able to advocate without prejudice.

Even though advocacy takes many different forms, it remains unclear how it meets the needs of minority groups in secure establishments, hospitals and community services. The research by Durham University fails to incorporate a race dimension in evaluating advocacy provision. The report highlights that black service users were less concerned with advocacy and more concerned with culturally appropriate care. One way of interpreting this is to say that advocacy risks reflecting only what white mental health service users identify as being important.

Over the last few years, supported by initiatives arising from the 1990 NHS and Community Care Act, we have seen some service developments that reinforce the value of advocacy provision. Various forms of advocacy are now taking place, and there is no one definition of advocacy. On the one hand, this is positive, as it allows individuals and projects to mould advocacy according to the individual or group it is intended to serve. On the other hand, tensions surrounding such differences between professionals and service users are beginning to show more markedly. Brandon (1988) expresses a growing concern about the danger that advocacy may become an 'aerosol word' like 'community' and 'empowerment'.

Some organisations providing mental health services refer to service users as 'consumers', a term promoted by the Thatcherite approach to welfare provision, and opposed by many. To some, this term falsely signifies that service users have the power to choose and to refuse unsuitable services. The reality for almost all users is that they have neither the choice nor the power to select appropriate services. In Britain, users of mental health services prefer to refer to themselves as 'survivors' or 'ex-patients' and increasingly as 'service users'.

Some service users contend that fixed definitions such as those mentioned above are unhelpful, as they fail to recognise individual and group diversity. Kendall and Barnes (1999), who suggest that definitions can be divisive, support this view. This issue is an important area of concern, and one that needs to be acknowledged. Our research found that it is a key issue. The use of terms such as 'service users', 'survivor' and 'ex-patient' can be perceived as exclusive or inclusive. During the research, as we spoke to black service users we found that such labels were perceived to stigmatise and label people further, rather than empower them.

The strength of advocacy to seek redress for individuals and groups of people within the mental health system is not in dispute. However, this process of equality is not yet easily accessible for marginalised and often invisible service users. As advocacy slowly begins to filter through to marginalised community groups, and as those groups have more input into the wider debate, we will increasingly see conventional understandings of advocacy being subject to many more challenges. It is impossible to define advocacy. Its processes are no more homogeneous than the experiences of mental health service users.

## A black perspective

This section builds on the good work already covered by many leading specialists in black mental health. Littlewood and Lipsedge (1993), Fernando (1995), Wilson (1995), Christie (1996) and others have extensively described the reality of black people's experiences of mental health. They have detailed and explained the experiences encountered within a hostile and foreign system of care. Importantly, they have differentiated culture from ethnicity, and developed a greater understanding of the differences and similarities experienced by and between African, African Caribbean and South Asian communities. Equally importantly, they have highlighted that the black community is not homogeneous.

Here, we use evidence from various black activists and highlight why advocacy is a valuable process that can help to challenge the current state of differential care, unequal treatment and inappropriate mainstream service provision for minority communities.

Research shows that many minority groups fear and mistrust the mental health system (Fernando, 1995; Wilson, 1993; Sashidaharan, 1988). This view is supported by frontline black mental health professionals, advocates and some voluntary support agencies. Not surprisingly, they criticise psychiatry and mainstream mental healthcare for reliance on over-medication, compulsory admission and treatment management, and involuntary incarceration of minority groups. At the same time, they point to the lack of less invasive treatments, such as psychotherapy, for black and minority people. Their combined efforts have resulted in growing demands for changes within the mental health system. Their commitment is unquestionable, and for over twenty years their collective voice has expressed their views and experiences. Their reports and accounts regularly conclude that disadvantage, discrimination and racism are endemic. They have repeatedly recommended that our mental health system, which is so punitive and degrading for black and minority ethnic people, must face the challenge of its own demons.

Current mental health systems and services frequently fail to support and understand the needs of African, African Caribbean and South Asian communities (Wilson, 1993; NHS Mental Health Task Force, 1994). Numerous social and structural barriers deter these groups from seeking treatment and support. Even if they succeed in accessing services, they face treatments that are often inappropriate to their needs. Research evidence also consistently demonstrates differences in treatments and pathways in to mental health services (Lloyd and Moodley, 1991).

Minority communities are disadvantaged in gaining access to psychiatric services (Littlewood and Lipsedge, 1989; Fernando, 1988; Rack, 1982). Black people are more likely to be admitted to psychiatric hospitals by means of compulsory detention (Wilson, 1997). The police are more likely to be involved in the admission of black and minority ethnic people. Black people are more likely to receive high doses and dangerous ‘cocktails’ of psychiatric medication. Even government reports such as *Big, black and dangerous* (Ritchie et al, 1994) have identified such abuses. These are just some of the coercive methods that are applied when black people are perceived as mentally unstable.

The flip side of this coin are the experiences of minority communities who remain outside the margins of mainstream statutory services. This area has also been extensively covered in the literature. Christie provides an important recognition that communities of Asian descent who are linguistically diverse are often perceived as having a different culture and different ways of doing things. She summarises the view of mainstream providers as seeming to be that “their culture is so private/different; they look after their own” (Christie 1995, p 5). The mainstream can use this view to excuse the failure to provide welfare services across the spectrum. Christie further goes on to say that minority groups often interpret such statements as really meaning that “we cannot be bothered to find out what they want, so we will do nothing” (p 5). The lack of bilingual staff, too few link workers and marginalised, under-resourced generic interpretation services continue to exclude many minority groups.

People from minority communities and their families have continuously asserted that they experience the mental health system as a product of white, European culture, shaped by research and ideologies that are primarily Eurocentric in belief and elitist in conceptualisation. It sustains power imbalances, which in turn support and nurture racism. In practice, these cultural norms present biases, misconceptions and stereotypes of diverse groups. Black people experience the impacts of such regimes in soul-destroying ways, both on a personal level and in hospital and community care settings.

Cultural differences are often reflected in differences in preferred ways of coping. Culturally rooted traditions or religious beliefs play an important part in facilitating mental well being. In many traditional eastern societies, mental health problems are often viewed as spiritual concerns, connected to the physical and mental psyche. “Many people of all racial and ethnic backgrounds believe that religion and spirituality favourably impact upon their lives and that well being, good health, and religious commitment or faith are integrally intertwined” (Taylor et al, 1997).

In the mid-1970s, Solomon (1976) advocated the importance of specific strategies to reduce, eliminate and reverse negative valuations by powerful groups in society. She drew our attention to black and minority ethnic communities and highlighted the fact that people from these communities have been negatively valued for so long that their powerlessness is extensive and crippling.

As we continue to address the inequalities experienced by black and minority ethnic communities, black mental health advocates are proposing strategies that can help not only to empower black service users, but also to determine culturally specific approaches which can facilitate self-definition and inclusion. Sassoon (1995) has advocated service user involvement as one way of challenging the current state of unequal provision including treatment.

There is a growing mainstream literature on advocacy provision. However, it includes little about specific needs, such as those of minority communities, and fails to capture the diversity of black and ethnic minority needs. It does not integrate what we know about black service user empowerment strategies, partly, perhaps, because of the invisibility of black service users within the mainstream movement. However, many black activists and professionals have long advocated the need for black user empowerment. This information remains untapped and ignored by the mainstream and has not received due attention in the context of mental health advocacy.

Literature, reviews and training manuals on advocacy all acknowledge that advocacy needs to take a different approach in accessing 'hard to reach groups'. Terms like 'hard to reach groups' reveal the notion that the mainstream has to be the starting point and is therefore entitled to see 'others' as 'hard to reach'. We argue that the correct starting point is that of full social inclusion and equal access. The phrase 'hard to reach' will then lose its meaning, and services will consequently be set up to be more equitable.

Atkinson (1999) identifies the needs of black and ethnic minority communities among the gaps in current provision. She highlights the fact that marginalised groups of people who experience discrimination as asylum seekers and as victims of racial harassment are in particular need of advocacy services.

Little research refers to mental health in the context of black people's own experiences. There is no real evidence to indicate where advocacy is available, how effective is it, or how it improves the experiences of minority service users. Until this happens, we are left with a narrow Eurocentric view of services. In the white mainstream, advocacy has grown up in response to service users' disempowerment. Layered on top of this, the culture of western scientific analysis and method has led to service delivery, including advocacy, being compartmentalised and defined as distinct and separate. In contrast, everything that black and ethnic minority communities and people do in a white western culture is a form of advocacy. This is because of the extreme and endemic disempowerment of these communities by white society and culture. This development leads us towards some new and important insights into definitions of advocacy.

All too often, people from minority groups are subjected simultaneously to further marginalisation and discrimination within mental health services. These structural and social practices of oppression become the mechanism within which systems of distress are perpetuated. The research team has listened to passing remarks from advocacy providers that 'true' advocacy is about choice and self-definition. Yet evidence from this research suggests that black mental health users have not been given the opportunity to define for themselves their understanding of advocacy.

Over the last decade, much has been written about mental health, race and culture, but relatively "few black service users of mental health services have ever been involved in discussions about black mental health" (black service user).

This phenomenon has arisen partly because of the degrading and negative experiences encountered by black service users. When they come into contact with statutory services, black service users have no reason to feel valued or understood, and usually choose to withdraw from active participation. Those that do engage with mainstream services often find themselves in a patronising environment, where their experiences are reflected back or dealt with by stereotypical attitudes. This process wittingly or unwittingly seeks to keep black service users passive recipients of services that continue to cater for the needs of the white majority, thus reducing them to objects on the fringes of mainstream society.

Mainstream services fail on at least two levels. At one level, not enough effort is put into providing access to services for people from minority communities. At another, discrimination and racism lead to the provision of inequitable and damaging treatments for these people, partly because of the failure of mainstream services to take account of their cultural and religious traditions.

Conversely, some mental health organisations will enlist the involvement of black service users. Equal opportunities policies are based on ideologies that allow mainstream organisations to mask their failings. The way this is done often means involving a few selected minority representatives to participate in consultations and forums. Yet this presents further problems. First, without an appropriate support system, it is very hard to express views or experiences that are markedly different from those of the majority. Furthermore, white agencies assume that the views of one black person reflect the issues of all black people, in contrast to the experience of white service users.

Culturally competent mental health services, including advocacy, should incorporate respect for, and understanding of, diversity. **Diversity** is an approach that allows the expression of different histories, beliefs, traditions and value systems. Britain sees the demographic growth of existing minority groups and newer refugee communities. Without culturally competent models, the failure of advocacy and mental health services to provide for African, African Caribbean and South Asian communities looks set to provide, at best, unsuitable and (in practice) marginal services.

The experiences of ethnic minority communities in Britain are reflected in differences of economic, social, migratory and political status, which in turn have been strongly linked to mental illness. The enigma of incarceration, misdiagnosis, over-medication and stigma will continue if black service users and the black community in general continue to be unable to present their case, and if the mainstream continues to be unable to listen and unwilling to change.

Advocacy clearly has a role in supporting, representing and challenging the multitude of inequalities experienced by mental health service users from minority communities. To achieve this, the discriminatory practices that are rooted in racism will need to be challenged. Advocacy may have an important role to play in redressing the inequalities experienced by black service users, but only if it is responsive to and reflective of the specific needs of minority communities.
Advocacy will continue to fail black people if its discipline or practice does not align itself to the values and beliefs of individuals within diverse social and cultural contexts. The aim of advocacy and of the people who provide it should be to question its own prejudices, ideology and power structures. If advocates are prepared to challenge their own idioms, then we may move closer to a service that develops into a self-reflexive process.

# 3

# The project

## Origins of the project

From 1996 onwards, a group of people interested in race and mental health met as a group called **Shaan** in Yorkshire and the East Midlands. Chris Perring, as regional director for Trent and Yorkshire Mind, and David Henry, then manager of Sheffield African Caribbean Mental Health Association, set up this network to create opportunities for black and minority ethnic people to meet and take forward mental health issues.

At bi-monthly meetings people learned from each other, and occasionally from external speakers, about many aspects of race and mental health. These included the experience of refugee children, mentoring for young adults at risk of exclusion from school, NHS policies, mental health and the criminal justice system, and psychotherapy for people with dual heritage. There was also a strong peer support element and a desire to work for improvement in the relationship between mental health systems and black and minority ethnic communities.

A major concern was the difficulty that black and minority ethnic service users faced in terms of empowerment and self-empowerment. Of the 80 or so people on the Shaan mailing list, fewer than three identified themselves as service users.

To assess this work, a small group of Shaan members (Savita Katbamna, Elaine Horne, Anab Ali Jama and Chris Perring) mapped potential projects for which the Mind regional office would seek funding. Shaan had already recognised that research on various aspects of mental health need in black and minority ethnic communities was ‘over-researched’, so they decided to focus only on projects that would bring about direct change and benefit to black and minority ethnic communities. The group produced a shortlist of seven potential projects, agreed by Mind’s management team in July 1998.

The group developed one of these – empowering black and minority ethnic service users – into an action research project, with further advice from Professor Gary Craig. An action research proposal was submitted to the Joseph Rowntree Foundation (JRF) to look at advocacy, determine service user involvement and test models of best practice, in partnership with a range of community groups.

## Aim

The aim of the project was to review existing literature and gather information from users, carers and their advocates that would enable them to develop material and training on best practice in mental health advocacy. The specific focus of the project was to investigate how advocacy services can best meet the needs of black and ethnic minority people.

## Ethos and process

The project’s processes were designed to include several elements:

- empowering black and minority ethnic service users and developing service user involvement;
- exploring advocacy in and for black and minority ethnic people by testing models of best practice;
- bringing about direct change and benefit to black and minority ethnic communities; and
- working in partnership with a range of community groups in two or more areas of the region (to take account of differing local context).

## Methods and approaches

The selection of methods used in the research was further influenced by several important demographic and social factors. For example, one of the most important features of the British minority ethnic communities is the immense diversity that exists between and within communities. Some of the most noticeable differences between and within groups are related to their history of migration and settlement patterns in Britain, their socioeconomic and educational backgrounds, and access to health and social care and formal and informal social support networks (Owen, 1993; Modood et al, 1997). While some people within the African Caribbean and South Asian communities have a long history of residence in this country, this is not so for all minority ethnic communities, including asylum seekers and refugees from Africa, eastern Europe and Middle Eastern countries who have recently settled in Britain. Introduction of strict immigration laws has restricted the rights of families to reunite with their members. This has had a negative impact on kinship and wider social support networks.

Evidence also suggests that there is a higher level of disability associated with mental health problems among older people in the black and South Asian communities (Atkin and Rollings, 1993; Patel, 1993). Consequently many people, particularly those with mental health problems, are isolated and may not be part of either formal or informal support networks. In addition, stigma attached to mental health problems, although not necessarily restricted to people in the minority ethnic groups, often prevents such people with mental health problems and their families seeking help from others. In many cases, the isolated position of many service users is compounded by language and communication barriers and the lack of familiarity with the way health and social care agencies work. The recognition of the changes in demographic and social trends, and the importance attached to the full participation of many marginalised groups and individuals, informed the methods used for this project.

## Recruitment of lead researcher and research consultants

One of the project's aims was to provide opportunities for black and minority ethnic people to empower themselves. It therefore sought to recruit workers who would benefit from training or coaching and from the experience of working on the project. These workers were able to draw on additional expertise from the Advisory Group. However, the project team and the Advisory Group both regretted having to neglect many significant communities in order to maintain a viable workload.

The small scale of the project meant that it could do justice to the specific cultural differences of only a few of the many distinct communities in Yorkshire and the East Midlands. The Advisory Group debated how best to reflect the diversity of the region, and advised that the project team focus on recruiting a lead project officer, who in turn would recruit project consultants from other communities. In this way the project team would be able to bring together a mix of experience and skills, including some specific language skills, from different communities.

A number of steps were taken to ensure that some of the main requirements of the project were fulfilled. The post of research officer was advertised in national and local newspapers, including minority language newspapers. Press coverage included interviews in local radio stations giving information about the project to encourage people with appropriate language skills, including service users, to apply for the post.

The project was strongly rooted in the model of community participation to ensure the involvement of groups and individuals in all aspects of the work. This included the process used in the recruitment and selection of the part-time research officer and research consultants. The project team had also emphasised the importance of involving service users from some of the marginalised communities, such as the Bangladeshi, Somali and Pakistani communities, where levels of fluency in English were relatively low and social deprivation high. Therefore the recruitment of a research officer with fluency in at least one such language was an essential requirement. It was also essential that such skills would be complemented by a small team of research consultants with skills in other minority languages, such as Somali, Urdu, Chinese or patois, who would be employed on a sessional basis.

The recruitment process also had to be sensitive to culture and gender issues by ensuring that the small team of research consultants included both male and female members.

### *Composition of the four-person research team*

The research team comprised:

- 3 women
  - 1 Punjabi Indian
  - 1 African Caribbean
  - 1 Somali
- 1 man
  - African Caribbean

## Mapping and collation of resources

An initial mapping exercise identified 30 mental health projects, including advocacy projects operating in Yorkshire and the East Midlands. We found little literature or information on advocacy for black people. Literature sources, in the form of training packs, evaluation methods and an extensive literature search on mainstream advocacy and mental health, were made available to the research team by core Advisory Group members.

The early months of the project's work focused on identifying and collating these resources and surveying the groups. We gleaned very little information from our postal survey. Furthermore, the literature shone little light on how effective mental health advocacy is in addressing and meeting the needs of black and ethnic minority service users and carers. Similarly, there were few indicators regarding independent black advocacy, and little evidence of self-sustaining black user-led projects.

It was also difficult to identity which black mental health projects were purely advocacy projects. We did not want to exclude projects that did not define themselves using mainstream terms of advocacy or empowerment. In consultation with the advisory group, we decided that definitions of self-help and empowerment within a mental health context would need to be broadened to include black projects that might be providing advocacy that was culturally appropriate but diverse and therefore not recognisable to the mainstream as advocacy. Consequently, some of the identified projects may not be accepted as *purely* advocacy projects. What was clear was that all of the identified black projects aimed to ensure better access to appropriate services for black service users by representing the views of black service users.

Reliance on just the postal survey for quality and clarity was not going to be sufficient for the aim of the research. Again in consultation with the Advisory Group, the research team felt that the best way to gather information would be by visiting the individual projects. This was for several reasons:

- There were ethical issues, such as wishing to show respect for the projects.
- It was desirable to develop a personal relationship with local project workers, based on trust and good will.
- Information was more likely to be gathered in person than from a paper-based questionnaire or survey.
- Early telephone calls showed that few projects had written information about their service; furthermore, these telephone calls did not elicit full information.
- Local project workers were very busy, and we judged they were more likely to talk about their project face-to-face than over the phone, or in writing.
- Project workers would be able to gain first-hand impressions of local projects by site visits.

## Fieldwork

### *Selection of projects*

Originally the research proposed selecting eight local projects for in-depth consultations and interviews. Because of the limited scope of advocacy projects and the relative invisibility of black service users, the research team decided that, in order to gain a diverse perspective, the number of projects would have to be increased.

The project team experienced severe difficulties in initiating contact with service users and carers. Consequently, fieldwork took much longer than had been originally envisaged, and a six-month extension was negotiated and confirmed by JRF. Throughout the lifetime of the project, the project team spoke to 35 service users and carers within the region, facilitated six workshops, and made presentations at two national conferences. In total, the team consulted with over 142 users, carers, advocates and professionals.

### *Difficulties in gaining access*

The main reasons why service users do not access advocacy services are rooted in the invisibility of black service users' involvement within mental health services generally, and with advocacy in particular.

It was impossible to contact service users directly. We were unable to identify any black user network or self-help group that was self-sustaining. The only way in was to gain access via negotiation with community 'gatekeepers' and voluntary organisations. Again, we faced difficulties relating to the stigma of mental health within minority communities, to research fatigue, to the immense pressure the project workers were under and to the fact that there appeared to be no black users or carers accessing advocacy services in the mainstream voluntary sector.

### *Selection criteria*

The criteria for selection of projects were:

- generic or dedicated mental health projects;
- mainstream advocacy providers;
- black-led advocacy projects;
- advocacy for carers;
- specific projects, for example women's projects;
- linguistic diversity.

### *Projects selected*

Twelve projects were selected:

- 5 were white-led, mainstream advocacy projects;
- 3 were black mental health projects with a focus on advocacy;
- 2 were specific black-led advocacy projects;
- 1 was a black-led carers' project;
- 1 was a black survivor group.

## Individual interviews with service users and carers

The research team also undertook individual face-to-face interviews with both service users and carers, who were each paid £50 for their expertise and participation. All the interviews were carried out in the chosen language of services users and carers. Interviews were taped, except where service users felt uncomfortable with research instruments such as tape recorders: here, we wrote down the information.

We ran two focus groups to facilitate contact and discussion between the research team, users and carers. These took place in Rampton High Security Hospital and the Leicester Mental Health Shop. Such groups have several advantages as a data collection technique for research in the area of minority ethnic users – they give the opportunity to speak freely about any negative experiences encountered; they do not discriminate against people who cannot read or write; and they can encourage participation from people reluctant to be interviewed on their own (Kitzinger, 1995).

## Sharing information

Our consultative process throughout the research typically consisted of project reviews, team meetings, support meetings and Advisory Group meetings. Conferences, forums and workshops provided opportunities for the research team to share information, raise awareness of the research, present preliminary findings and gather information and experiences from service users and advocates. The consultative process became an important process and served as a reflexive strand to the research team. Overall, the research team spoke to over 250 people locally and nationally.

The team facilitated workshops, discussion and consultative forums, both regionally and nationally, with the following projects:

- Leicester Mental Health Shop
- London Advocacy Network
- UKAN
- Nottingham Advocacy Group
- Sheffield Law Centre
- Mind regional forum
- Mind national conference
- National Schizophrenic Fellowship

The research team also produced a newsletter featuring the research proposal and the intended outcomes. Two articles were written for *Diverse Minds* and *Mindlink*, both with the aim of sharing information about the research.

The research team received significant inquiries into the research and its findings, particularly from black projects and black advocates across the country. This aspect of our consultation process indicated strongly that there were no links or infrastructure that facilitated the support, advice and development of black advocacy services and advocates, locally or nationally.

## Research team reflections – the *real deal*

The experiences and feelings of the research team regarding the action research project are as diverse as the research team itself. Our overall feelings are of optimism and a sheer commitment to seeing the recommendations of the final report put into practice. As the lead researcher, I can clearly remember the day I received the phone call of the job offer. It was truly an affirmation of faith and opportunity.

First, I would like to acknowledge that, had I remained a lone black researcher, I am not sure if I would have survived the tide. I have survived it, largely because of the research consultants. The intensity and sheer magnitude of the research agenda and the issues encountered by the research team often felt like a roller-coaster ride.

Second, we cannot therefore underestimate the power and strength of a collective team, all diverse but with a shared experience and one aim. The research team provided a vital opportunity for mutual peer support, reflection and discussion.

The action research project aimed to empower minority service users and black projects, yet there were occasions when we as a research team felt disempowered. Some of the difficulties we experienced were not dissimilar from the difficulties experienced by black service users and projects. We often found ourselves experiencing a ‘parallel process’.

At times it was difficult to gain the appropriate level of support required to match the sensitivity and uniqueness of the research agenda. As researchers, we were employed for our abilities to relate to the communities involved in the research, our knowledge of mental health, our understanding and experience of social exclusion. However, at times there were situations that perpetuated our experience of discrimination and disempowerment.

When the research began, the project was located at the Trent and Yorkshire regional Mind office. The lead researcher was managed by the then regional director who, with all due respect, proved to be very sensitive and aware of the issues of being a lone black worker in a mainly white environment. This director took steps to facilitate a team environment that was sensitive, supportive and respectful; even so, it proved to be unsuccessful in the long term.

As black researchers, it was our collective experience that working in partnership often meant trying to fit into the dominant culture, which for us proved impossible, for two significant reasons. First, the research team felt that the regional office, and the organisation as a whole, was an unhealthy environment for us as black people. We experienced a general lack of cultural awareness which resulted in a member of the research team experiencing racial abuse by a white member of staff. As black researchers we experienced some of the organisation’s internal politics as hostile and alienating.

Second, at the most critical point, that is, halfway through the research, National Mind began to close its regional offices. The project had started as a collaborative piece of work between JRF and National Mind; and when Mind’s internal restructuring entailed its closing of its regional Sheffield office, where the project was based, this had a severe effect on the stability and infrastructure of the project. The project found itself ‘homeless’, having lost not just the roof over its head but also the management support and infrastructure of the financial, administration and personnel departments.

The research team, supported by the Advisory Group, recognised that the significance and impact of the research agenda should not be compromised. Efforts were made by the research funders and proposers to highlight the impact of these unforeseen circumstances. At this crucial stage the research team felt an overwhelming sense of ethical responsibility and a sense of commitment to mental health advocacy for black people.  With few options available, the lead researcher re-housed the project at home, completing the project from there.

On reflection, lessons are to be learnt from this experience, some of which are mirrored in the experiences of the research participants. Professional titles for black people do not exempt them from the unequal treatment experienced by black people in society generally. The research team is left with the opinion that even organisations with the best of intentions of addressing inequalities often perpetuate and enforce their powerful structures, which nevertheless discriminate and oppress those less powerful.

# 4

# Case studies: hidden voices

## Case study 1: The Mental Health Shop, Leicester

Jacqui Sealey
Advocacy/project worker
March 2001

### *Origins*

In the early 1980s, a small group of concerned African Caribbean, Asian and white individuals started to meet to look at the issues affecting black people experiencing mental health problems. By 1985, this group – the Leicester Black Mental Health Group (LBMHG) – composed of people working in psychiatric hospitals, social services, education and community organisations (both mental health and general), was meeting regularly to campaign and publicise the racism and discrimination experienced by black people in contact with mainstream mental health services. Of particular concern was the double discrimination of racism and mental ill health. (The lack of credibility that service users encounter, whereby many concerns are put down to symptoms of their mental health condition, for example racism by staff and other service users on psychiatric wards, remains an enduring problem.)

Work included meeting with professionals within the health and social services, to raise awareness of the need for radical changes and of an expansion of services to meet the needs of black service users and their families and friends caring for them.

The LBMHG felt that there was a need to conduct action research into the experiences of African Caribbean and Asian people in Leicester, to see if local experiences matched those found in surveys in other cities in the UK. The research, published in 1989, concentrated on personal views and experiences of those using services rather than on statistics, as had many other surveys. Following on from the research findings, the LBMHG felt that a funded project was needed to provide direct advocacy, mainly to African Caribbean and Asian mental health service users and carers, by African Caribbean and Asian staff.

The innovative project, which became the Mental Health Shop, targeted black people (aged 18 and over) living in the Highfields area, which has a high black population (but it did not exclude white people). Funding for four years was obtained in 1989 from the old Leicester City Council Inner Area Programme Scheme. Early requests for advocacy from people resident outside the initial catchment area meant a swift extension of services to the whole county. Since then, staffing has expanded from two to five full-time workers. Our current management committee is comprised of African Caribbean and Asian members, including service users.

### *Aims*

The main aim of the Mental Health Shop is to empower black service users (and carers) to identify their needs and find ways to meet them, thus enabling the users to gain or regain control and/or change those parts of their lives affected by or affecting their mental health.

## Advocacy

In the 1980s, advocacy for mental health service users (both hospital inpatients and those living in the community) evolved as an effective method of enabling people to assert their rights. This has involved challenging diagnoses as well as focusing on medication issues, sectioning and the lack of appropriate services. Mental health advocacy had been recognised as a valuable process in the Netherlands, and has begun to be similarly viewed in the UK by mental health organisations (including Mind) and groups of service users. (Local Mind members were involved in the early stages of the Shop.)

Self-advocacy is the ideal, but for people who need an advocate, whether a peer, a citizen or a paid advocate, it is still important to aim to empower people. For example, if a client needs a lot of support to sort out difficulties, we inform them about systems and resolution options, so that, even if we are doing the work, it is still based on their informed choices.

In 1996-97 voluntary sector mental health groups, together with Leicestershire County Council (who had sole control of social services before local government reorganisation in 1997) and the health authority, between them agreed a definition of advocacy. This is adhered to by the six projects (two mental health, two generic, one for carers and one for older people) currently funded to provide advocacy:

> “Advocacy is a process of empowering people. It enables them to express their views and needs, thereby achieving their rights and entitlements. It also assists people in securing relevant information and knowledge, enabling them to make informed choices.”

This position has shifted as far as the statutory sector is concerned, and this will be discussed later.

As far as the Mental Health Shop is concerned, as well as mental health review tribunals, hospital management panels, care plan approaches, community care reviews, complaints, and so on, advocacy also entails helping clients to resolve problems regarding Housing Benefit/debt, child care, legal matters, physical health, education, vocation or recreation, if these areas are affected by or affect their mental health.

## Client group

The four advocacy workers deal mainly with African, African Caribbean and Asian people living in the city of Leicester and the county of Leicestershire. Three advocates are city-based and one is county-based. Clients must be 18 or over, though occasionally we work with under-18s, usually because there is no other appropriate service available. There is no upper age limit. One city advocate works with the local black Prisoner Support Project, with black prisoners and people on remand who have mental health problems. The county worker works only with black people. The city workers do on occasion have white clients, including carers of black partners or children, those experiencing mental ill health and those living in smaller village areas where they prefer to seek help from the Shop because of concerns about confidentiality if they used their local services.

Two of the advocates speak Punjabi, Urdu and Hindi. One of the advocates and the administrator speak patois. If clients speak other languages we pay for interpreters from social services, though we recognise that this is not as good as communicating directly with the client. The client group served is composed of people who have been identified by research as suffering from discrimination and having received poor, inappropriate or no services from mental health services.

Contact with other ethnic minority groups, including refugees, is limited, although we try to help if approached. If we are sent information that is printed in languages that we rarely use, we forward it on to the particular communities, for example Chinese, Polish, Bengali and Somali. The complex and extensive mental health needs of refugee/asylum seeker communities have not yet been addressed by statutory providers. As members of the local black Carers’ Workers’ Network, we have taken part in two Carers’ Fun Days, where participants included people from the Chinese, Polish and Irish communities as well as black communities.

## Project pros and cons

The following list is not comprehensive.

### Positives

- We can concentrate primarily on black mental health issues, which provides a clear focus for our clients and for our work of raising awareness.
- We can make referrals easier from whatever source, because people recognise what we do.
- Our remit under the umbrella of black mental health means that our clients can have many needs met by us – we work holistically to provide as culturally an appropriate service as possible.

### Negatives

- There is a high demand for individual advocacy, which can be very intensive and extensive, in terms of both issues addressed and time taken.
- There is also a high demand for information from individuals and agencies locally and nationally.
- We are regularly asked to take part in statutory sector planning for conferences, and so on. It is difficult sometimes not to feel that our involvement is token, and we certainly are aware that we cannot represent every black community.
- Agencies sometimes refer their clients to us rather than try to assist them themselves. This includes clients whose needs are difficult to meet.

(I realise that some of the positives have doubled up as negatives.)

## Relationships with mainstream and other black projects

### Black groups

With other black mental health groups (which include two Asian voluntary groups, three social services day centres for older people – two for Asian, one for African Caribbean – and a mental health worker within an African Caribbean housing project), we have good relationships because of our mutual concerns and sometimes mutual clients. We share our minibus with two Asian projects.

With non-mental health black groups, relationships vary. Many are interested in mental health and request information, training, joint initiatives, referral of clients. Their interest has increased over the years – in the early days there was a lot of ignorance about mental health. We sometimes use the premises of these black projects for meetings.

### Voluntary sector

Generally, we get on well with these groups. There is a Voluntary Sector Mental Health Forum, comprised of city- and county-based agencies, in which we work together, elect representatives to statutory forums and exchange information and advice. Some groups are more aware of black mental health issues than others.

Contact with non-mental health community and voluntary groups varies. These days we all face similar pressures concerning funding and monitoring, and to some extent this has led to more camaraderie – partially replacing what used to be a more competitive situation (in terms of groups applying to the same sources for funding).

### Statutory sector

Prior to local government reorganisation in 1997, when Leicester City, Leicestershire County and Rutland became separate entities, we enjoyed good consistent support from the County Council social services, who used to fund most of our organisation. Since the city has taken over most of the funding, there has been more pressure to justify our work and make more changes to our services agreement, aimed at restricting our service by prioritising social services and selecting only those clients who meet their criteria. Over the last two years there has also been more scrutiny of advocacy generally, with emphasis on the cost of a project and value for money, and suggestions of a ‘One Stop Shop’ (see below), with which none of the six advocacy groups agrees.

The health authority has had to address advocacy because of government directives under the National Service Framework and the proposed Mental Health Act Reform, to which attitudes have been similar to those described earlier.

This has often been demoralising and felt to signal a return to the situation before the Shop and other projects were set up. However, the Shop is regularly consulted on new initiatives and invited to participate in some aspects of statutory planning.

### *Future issues*

- There needs to be much more user involvement in planning and commissioning. In the county, money has been made available for a specialist consultant to work with the People's Forum, a user group which has been involved in proposals for an out-of-hours service as well as other planned services. Leicester City is currently exploring ways to increase user involvement, especially by black and other ethnic minority service users. It is considering funding a consultant to map the gaps in services for black people. Similar exercises have been carried out in the past.
- Voluntary groups need to engage more meaningfully in all stages of planning.
- Statutory agencies need to be more accepting of what service users and carers want, rather than imposing their own, often narrow, definitions of advocacy on them and on the organisations providing services.
- There is always a need for more resources by black groups and advocacy groups. Additional resources would enable more mental health awareness training within black and other marginalised communities.
- The Shop needs funding for bigger premises and then for more staff. We have been on a stand-still budget for the last three years and expect this to continue. A few years ago our main funder considered cutting our budget (as well as those of other black mental health groups and advocacy projects). Being a unique project has stood us in good stead, but we cannot assume that this will protect us from funding cuts in the future.
- As previously mentioned, some social services and health authority managers have suggested a 'One Stop Shop', either for mental health advocacy or for advocacy as a whole. This ignores the fact that advocacy projects have come into being based on different communities'/client groups' needs, and seem to be driven more by cost considerations than by improvements in service.
- It is difficult sometimes not to feel pessimistic and worn out by the constant escalating pressures. However, I believe that advocacy remains one of the best ways for mental health service users, especially black people, to assert their rights and to try to improve the services they receive.

## Case study 2: Buddies

Carol Jenkin
Founder and coordinator of Buddies
and black advocate
August 2001

*[The term 'black' in this case study refers to African, African Caribbean and shared heritage communities.]*

I was asked to write about my experience as a sufferer, a black mental health consultant and a person who has set up a user-led black mental health support scheme.

Over 20 years ago I went through a long period of mental health problems, including three years of severe mental depression and a further six years trying to get myself back on track. I then went on to build my self-esteem through self-development, education and involvement in (conflict-free) organisations that were relevant to my own needs.

Having succeeded in doing this, I wanted to share the achievement with others who were going through the same anguish. So seven years ago I decided to set up a group in Bradford called **Buddies**, to support anyone who felt they were suffering with any mental health problem. It was to be an informal service, and what I planned to offer was based on what I myself would have wanted or found beneficial in my own time of crisis.

The idea for Buddies originated in early 1993, when I was on student placement with Mind in Bradford. While on placement, I discovered that the few black clients that Mind had were not happy with the organisation or with the atmosphere of its drop-in centre. They gravitated towards me simply because I was of the same racial background; also, having myself suffered a period of mental illness, I was sympathetic to the thoughts and feelings of the people I was observing.

The report that I produced of my observations while in Mind seemed to have been received by Mind as criticism, rather than feedback and advice on how to generate a more ethnically sensitive service. At the time I was concentrating my efforts on my college work and felt unable to do anything about the situation I had uncovered. Perhaps naively, I thought that, having pointed out the gaps in their service, Mind might attempt to fill them.

One year later I again entered the mental health field via the Black Mental Health Forum, which was then being led and dominated by Bradford's black professionals. This is where I encountered my first obstacles. The black professionals dominated the other individuals within this field and were reluctant to listen to users' views. At one of these meetings, I was shouted down and told to shut up when trying to advise on how users could attend a conference that was being planned.

After threatening not to come to this forum again, I was given some positive encouragement, by a worker who was attached to the forum, to start the proposed group. This worker was linked to the Bradford Council for Voluntary Services.

Such help came with a price, however. The group at first had to rely on this worker's organisation's telephone to pick up its messages. We learned very quickly that she was not passing the messages on to us, but instead was directing clients to other groups that she was in the process of setting up. She also told us, when we asked her about screening the phone calls, that she was asking the callers to come in and see her; then she would either refer them to another organisation or (rarely) leave a message for our group. When confronted about this issue, she stated that she needed to do this to ensure that they were the right people for our group. I had to tell her that anyone phoning the group was right for the group and that she had not been asked to do this vetting: she did not have the right or the experience to vet people on our behalf.

By this time we had received a small grant, and so decided to purchase a mobile phone. This meant that we had to spend part of the small pot of money received to change the printed publicity, as we quickly decided to restrict this worker's role in order to limit the damage being caused to the often vulnerable people who were seeking our help: instead of being interviewed once, they were being asked to describe their situation to several people, causing them further anguish. Soon afterwards this worker became very distant from our group, and ceased to do anything more for us. We then learned that, unfortunately, funding applications had to go through her as she acted as adviser to the funding. This domination of the professional's view over the users is still being seen today.

Another barrier the group faced was that it was focusing on helping *anyone* with a mental health problem. Unfortunately, funding was targeted at people with severe and enduring mental health problems, and not on the prevention of mental ill health.

However, by now the group was beginning to get good at dodging the numerous obstacles and barriers being placed in its way by the mental health services, such as:

- promises of statutory staff to support the group that was not forthcoming;
- promises of funding that was not forthcoming;
- lack of referrals from the statutory agencies;
- ongoing rejection of funding bids;
- failure to be invited to consultation meetings into which Buddies could feed black user perspectives.

A lot of people who come into contact with Buddies have been unaware of our services. Even though statutory staff members are aware of the group, they do not seem to be informing service users of this specific black support scheme. When people do succeed in making contact with us, they find cultural solace and derive benefits from attending monthly sessions.

A tactic that Buddies has had to adopt is to work outside its home ground in order to keep itself in the limelight. If it had to rely on Bradford for its existence, it would not be here today. Through networking and promotion at national conferences, workshops and through membership on committees, Buddies has become a national organisation in order to stay afloat and gain recognition more locally.

As a practising black advocate, I find that the term ‘advocacy’ and the title ‘advocates’ are hard concepts for black people to understand. I often spend a lot of time explaining what the former is and what I, as the latter, do. When I think I have explained my role and responsibilities, I am asked to explain it all again. I then revert to saying, “I am here to support you”. I believe less complicated titles/roles should be used, such as ‘befriending’ and ‘support schemes’. Such complicated, professional terminologies cause further mental anguish to people who can do without any further complications and mental distress in their lives.

Modern day advocacy is too professional, too westernised, too legal and too non-flexible. It fails to adapt to individuals from differing cultures. Instead, it is left to the users to fit around the model. This adds further alienation and obstacles to people who are in urgent need of help. The best part about the Buddies project is that there are no time constraints on getting to know the individual concerned. Most of my role as a black advocate involves getting to know people; I can spend between one month to one year getting to know someone, gaining their trust, without having to begin to advocate on their behalf. Further projects for black people need to be equally flexible: they need to be given both the funding and the time to become well established (to gain the trust from black service users).

Black service users and black communities are often the victims of short-term, fly-by-night organisations who are there one minute and gone the next. The blame for this is often laid at the funders’ doors. I believe that no one is aware of the continual damage inflicted on the service users of such projects, who put their valued time, efforts and soul into them, to see their work closed down and then to have to start again – if they have any more commitment to give – leaving those they were helping further damaged, isolated and emotionally scarred.

When I first set up Buddies, I stated that, regardless of funding and staffing, Buddies would continue to be there in years to come for those who need it (users, carers and community). This has not always been easy. Black organisations in other cities are unable to come to the rescue of groups such as Buddies: they are funded to work only within their funded areas. But even if such organisations *were* allowed/funded to assist outside their borders, I wonder if they would. Do such organisations have the commitment or will to help users and user-led projects? After all, if user-led projects and individual users prosper, the roles of professionals would become obsolete and their jobs would be on the line!

Future models of advocacy need to get involved with people who have first-hand knowledge of the systems they are challenging. Without these first-hand accounts and experiences, the system will remain unchallenged and resistant to change. Organisations providing mental health services need to look hard at whom they are providing the services for and who should be getting the benefits from them – is it for the users, for the community or for the professionals who are supposed to be providing the service? Each of these sectors has its own agenda, its own views that conflict with others’ perspectives.

I do not believe that black users play an active role in the service models currently being provided. A majority of the black projects have been set up by professionals or by community pressures.

Black users in general tend to withdraw from their oppressors rather than confront them. A few black individuals do challenge the system, but most fear the system’s reprisals when they complain, criticise or challenge working practices. Within the black community it is not the done thing to advertise your personal problems or difficulties to anyone: best to keep your business to yourself. There is a view in the black community (generally among the older generation) that the professional knows best and should be trusted implicitly, that it is not their place to question the professional’s authority. Many of the older people still feel as though they are guests of the country rather than committed taxpaying citizens. On the other side of this coin are those of us who were born in the UK and regard ourselves as ‘British’, and as such feel that we should be treated with respect and equality with our ‘white’ brothers and sisters. There is within the black population as a whole an underlying anger at the system’s blatant disregard of their needs, treatment and cultural understanding.

### *Things must change*

There are a large number of black users (and individuals from other ethnic backgrounds) who are quite willing and able to give their views on the services they are using, but are not being given the encouragement or the opportunity to do so. There is a role here for national organisations to provide regional meetings and forums for these isolated service user activists, to enable them to gain some support from others who are trying to do the same work – forums should be set up specifically for black and ethnic minority workers. Black and minority ethnic users' views are being distorted by the second-hand perspectives fostered on them as facts by professionals.

It is time for the black professionals to start giving support to the growing black user movement, to give them the encouragement needed to challenge the large, old, western, psychiatric models that are so ingrained with sexism, racism, ageism and all the -isms going. These voices are needed to break the negativity that is being projected on to the black mental health field and the sufferer. There is also a need for people who have come through the system to act as positive role models to give others hope. There is a need for people to feel in control of their destinies.

All these attempts to speak on the behalf of the service user only go to stigmatise the users further; to press upon them the view that they cannot speak up for themselves, and are completely reliant on the system's professionals, that they are helpless, incapable victims, which they are not. It is about time someone put a foot in the system's revolving door and stopped this not so merry-go-round of users who cannot escape the system's stranglehold.

The reason I am trusted and valued by service users is because I am a survivor. They also find comfort in my belief that people who suffer with a mental health problem *can* move on, can have a life after a mental illness and make something of their lives. This I believe is not intrinsic in the mental health system in the UK, where dependency and deterioration are built into the whole system (magnified if you are black).

There is a definite need for black role models to give some light to what is deemed as a negative situation. I hope that this report has shed some light on a difficult and complicated subject.

## Case study 3:
## Somali mental health in Sheffield

Somali Women's Welfare group
April 2001

There has been a Somali community in the UK since the end of 19th century, when the British Somaliland protectorate was established in eastern Africa. As the protectorate was on the route to India, it was easy to recruit able Somali seamen, some of whom ended up in home ports like London, Liverpool, Cardiff and, later, inland in the factories in Sheffield. Most were expatriate workers who intended to go back and retire to eastern Africa once they had made their fortune. But all this changed in the aftermath of the war in Somalia, when many more of their country-people had to flee.

Somalis are nomadic pastoralist Muslims who live in strong, bonded, extended families. They are migratory by nature, but as expatriates they keep their culture and identity strong and separate. Most relationships are within their own communities, and socioeconomic and religious cultural boundaries help keep them apart, even in the 'melting pot' of multi-cultural Britain.

Back in East Africa, Somalis suffered less from mental illness, especially depression, which is one of the main causes of ill health in the UK Somali communities. However, because of their experiences of the war in Somalia, the majority of the community members who arrived in the UK in the late 1980s and early 1990s were highly traumatised. This was worsened by the shock of living conditions in the UK: the new arrivals tended to end up in the inner-city areas of the country, where their situation was made worse by poverty, unemployment and social exclusion. Another serious problem was the cultural shock of life in the West, which was greatly different from the way they used to live in Somalia. In the Somali communities in the UK there are a large number of fragmented families, including single mothers with children, for whom it proved very difficult to cope without the traditional support mechanisms, thus increasing the risk of depression and loss of motivation.

The Somali Mental Health Project was created as a result of the experience of the Somali community in Sheffield. The project aims to function as a bridge from the community to existing mental health services and to support members through each stage of the system.

The Somali community faces many problems and barriers. Language is one of them. Not only is English as a foreign language a difficulty for most users, but a clear understanding of terminology, descriptions and symptoms is also vitally important, and difficult to grasp. For example, Somalis do not 'hear voices': they 'talk to themselves'. So an interpreter or carer may tell the doctor that the patient does not hear voices, when in fact they do.

Cultural perceptions and beliefs also have a role in health and especially in mental health provision. Serious problems had to be overcome in regard to the taboos and stigma surrounding mental illness. Somali mistrust and fear of the system had to be resolved. Issues concerning medication, sectioning and hospitalisation were among the more serious hurdles. The use of medicines that significantly alter people's personalities are especially feared.

The project starts its work at the initial referral and continues it through assessment, hospitalisation or sectioning/medication, and counselling; it also works through discharges from GPs, consultants, community mental heath teams, community psychiatric nurses, social workers and other related statutory and voluntary workers. The project now has about 70 cases being supported at different levels in hospitals, in secure units and at home.

One of the main problems is Khat[1] as a cause of mental illness, especially among the male population of the UK Somali community. This causes, among other things, a high incidence of drug-induced psychosis, mostly among young men. Khat culture in the UK also leads to general ill health, malnutrition, social malfunction, economic ruin and family problems.

The city-wide Somali Mental Health Project trains community members as volunteers in basic counselling, advocacy and support. The project employs a mental health worker, a development worker, administrative staff and four support workers. The Somali Women's Welfare Group works closely with the Somali Mental Health Project.

Barriers to better services include language, culture, social exclusion and the lack of appropriate information. Another problem is stereotyping according to insufficient knowledge and understanding on the part of mainstream service providers.

Advocacy is one of the project's strong points. This covers many aspects, including explaining the Mental Health Act and welfare rights, looking into housing and living conditions, and providing for home care and support for families and carers – in effect, reading the small print for them.

Advocacy also seeks to establish the right of the community to appropriate and culturally sensitive services in health, medicine and the social services. It is a tool for empowerment through raising awareness, both for community members and service providers. Other examples include dealing with the opposition to mixed wards and the resulting clash of cultures, with doctor and staff gender needs (women wishing to be treated by female staff, and so on), with food and dietary requirements, arranging for mosque and community centre visits and, importantly, having considerations for the opinions of the immediate family members who care for their relatives.

Advocacy is one of the means used to influence policy and maximise service delivery and uptake. It is also important in supporting and highlighting women's issues and multiple needs, because many Somali women are suffering from depression as lone parents with large families.

One example is the project's support for traditional healing methods. Somalis believe in spiritual disorders, and demons play important roles in mental ill health. These can be addressed through the use of the Quran to exorcise and banish demons. But more interesting is the role of the holy book in traditional counselling: verses are recited to the mental health service user, to help them relax and 'cool' (calm) them, while giving them the inner strength to face their illness

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[1] Khat is a green-leafed shrub that has been chewed for centuries by people who live in the Horn of Africa and Arabian Peninsula. It has recently emerged in the UK, particularly among emigrants and refugees from countries such as Somalia, Ethiopia and the Yemen. Khat is a stimulant drug with similar effects to amphetamine. Chewing it can make people feel more alert and relaxed. Regular long-term use can lead to insomnia and can also suppress the appetite.

through prayers and seeking divine intervention and rescue.

A case study involved a mental health service user who was suffering from paranoid delusions and had psychotic symptoms. His family insisted on traditional religious counselling, but the doctors were at first reluctant to accept this as a viable option. We advocated that this was a method that could help both the mental health service user and his family deal with the illness in ways they related to and had faith in. He was taken to a sheikh in Leeds where he had the Quran recitations 'put on him'. A few weeks later he was well enough to be discharged. Counter-claims were made between the family and the doctors as to whether it was conventional medication or the sheikh's intervention that got the man well. In any case, he is now recovered and leading a normal life. Such cases strengthen the communities' faith in a holistic approach to the treatment of the whole person, not 'just their heads'. Islam believes that a person's spiritual needs are as important as all others.

The average Somali does not have an easy time accessing mental health services. Because of the lack of information about mental illness and related symptoms and about available services, the project usually comes into service on a post-crisis basis. It is also difficult for GPs to make a correct diagnosis because of language and cultural barriers. And of course, there is the fear and mistrust involved in the prescribed treatment and medication.

The project takes each individual case from the initial referral from family, friends, doctors or even the police, through the assessment process and diagnosis in collaboration with the consultant psychiatrist, social workers, GP and other mental health team members. The prime role of the advocate is to interpret and understand as clearly as possible the culturally different ways in which symptoms are described. Each individual's needs and support requirements are tailored to their situation and condition. The user comes first, and their voices are heard and concerns considered.

Achievements include:

- community-based access points;
- access and reliable service on demand;
- discreet understanding and confidential setting;
- interpretation, information and demystification of issues;
- continuous support, both in hospital and within the community;
- better identification and understanding of needs;
- help for providers to better understand and help the community;
- better coordination and streamlining between different service providers.

The project is widely recognised as an effective advocacy and support unit by the local Somali community and healthcare providers. As a worker from a local hospital put it, "We couldn't begin to work with Somali patients without the input of the project".

The reliance of the Somali community on the project as a reliable contact and as service on demand has made a significant difference in the community and continues to do so. Today there are no people with mental ill health unaccounted for, including those who resist or reject help. Even better, there are no Somali community members sleeping rough on the streets of Sheffield, as there are in other cities in the UK and used to be here before the project was set up.

# 5

# Themes arising from the research

The previous section presented the powerful voices of both mental health survivors and advocates. Their stories are evidence of the experiences and difficulties encountered. Importantly, the authors give conclusive examples of why they are the experts at defining their own realities. Their expressions form the basis of this chapter, which continues to present evidence directly from the research.

User involvement within the mental health service is now enshrined in government policy and the NHS Plan 2000. Both the 1990 Community Care Act and the NHS Executive's Patient Partnership Strategy promote user consultation. The guidelines recommend that users should be consulted in their own treatment, as well as in overall service development. There have been some developments within the mainstream; for example, consultations with, and the views of, service users have been gained through partnerships involving advocacy groups and patients' councils. However, these liaisons take place predominantly with white service users. This report demonstrates that black service users and their carers have virtually no participation or influence, either within these partnerships or in the wider debates around advocacy.

The original research proposal highlighted the fact that there was insufficient evidence of how effective mental health advocacy is for minority communities. The gaps in current provision became apparent very early on in the project. This was demonstrated by:

- a lack of literature highlighting the specific issues relating to the experience of minority service users and explaining how advocacy can support them;
- the existence of only two black-led projects that were specifically focused on advocacy provision;
- the absence of information on advocacy within mainstream services that was translated into community languages other than English;
- the absence of independent black survivor groups[2].

The research undertook a regional mapping exercise covering the Yorkshire and East Midlands region. Thirty mental health projects indicated that they were providing mental health services with some advocacy services to minority communities. Many of the mapped projects were addressing the needs of minority communities. However, there was little clarity on what was defined as general support and what as advocacy. This lack of clarity is not unique to black projects and is a reflection of general confusion around what advocacy looks like in practice.

As a result of the initial mapping exercise, we found that only 12 projects across the region were using the term 'advocacy' in their literature and were also providing a service specifically for African, African Caribbean and/or South Asian communities. Although many of the projects did not use the term 'advocacy', however, most of them were providing mental health services that were primarily supportive, informative and specific to the needs of minority communities.

We decided that our criteria should be to select projects that described themselves as providing 'advocacy'. However, we must stress that this may have excluded many other groups that did not identify themselves as advocacy projects, but may nevertheless have been providing advocacy without defining it as such. The restrictions of time and resources on the research project allowed the research team to focus only on the original scope of the research (see Chapter 3 on methodology).

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[2] Our research identified only one black survivor group within the Yorkshire and East Midlands regions.

- There were therefore 12 projects in which we undertook in-depth semi-structured interviews. Four of these projects were providing black mental health services with some emphasis on advocacy. These projects were valuable examples of good practice as they were meeting the specific needs of marginalised groups, that is:
  - Somali community
  - Asian women
  - Carers
  - African Caribbean community
- The fifth project was dedicated to the provision of advocacy for black communities, the sixth incorporated both advocacy and interpretation, the seventh was a black survivor group, and the remaining five were mainstream white projects.

We interviewed service users and carers who described their cultural background as African Caribbean, Somalian, Pakistani and Punjabi. Black and white advocates were also interviewed in a variety of ways. Our approach included a number of qualitative methods, such as discussion groups, workshops and individual interviews, both by telephone and through support groups.

The interviews were designed to gain a better understanding of the following issues as seen through the perspectives of users, advocates and carers:

- Delicate roots
  - Lack of black-led advocacy
- 'Resist to exist'
  - Problems of access
  - Lack of bilingual advocates
  - Lack of awareness
- Good practice in advocacy
  - Meaning of 'advocacy' to black communities
  - Advocacy in action
  - Advocates who reflect cultural background, language and gender
  - Power to influence culturally appropriate services
  - Challenging racism
  - Black-led empowerment
  - Black-led advocacy

The findings now discussed reflect the above list, which informs the broader structure of the report.

## Delicate roots

### *Lack of black-led advocacy*

As discussed in the introductory section in Chapter 2, the advocacy movement emerged as a grassroots service user initiative. As advocacy gained momentum, both service users and mental health professionals began to accept its values and aims. Advocacy services are delivered in three main ways: via support groups initiated by mental health survivors, through mainstream voluntary sector mental health projects and, recently, from some statutory organisations that have incorporated these into their service framework.

During the process of inquiry through the mapping exercise, and as a result of interviews, we made a significant discovery. The mapping exercise highlighted that there were very few black-led advocacy initiatives. At that time it was difficult to understand why. However, once we engaged in in-depth interviews with both generic black mental health and specific advocacy projects, we were able to identify several key issues.

The first relates to conventional definitions of advocacy. While mainstream service definitions would place advocacy as a distinct service, black projects saw *most* of their work as advocacy. Second, the urgent need for decent services for minority communities combined with extremely limited funding meant that more fundamental services (housing, information and support) were likely to be prioritised over an advocacy service. Third, we suspect that low expectations among excluded and disempowered communities and individuals may create a climate where advocacy is not considered a useful or realistic goal. Finally, much advocacy in minority communities is informal and voluntary; it is regarded as part and parcel of being a good community member, or as an expression of faith and its values in helping.

Black advocates and mental health support workers provided substantial information as to why black advocacy was less developed. The issues they identified are the very same ones coming out of black-led research across the country. The black voluntary sector lacks the appropriate infrastructure to support and sustain its development. This basic fact has impacted significantly on the development of black-led advocacy services.

Over the last few years, there has been a greater acknowledgement of racial disadvantage, and more attention has been focused on both ‘service provision’ and ‘service delivery’ in training and education. However, this rhetoric is not being converted into action. Above all, are such interventions filtering through into the black voluntary sector to benefit at the grassroots level, through community development?

The development of the black voluntary sector has not been broadly contested by the mainstream white voluntary sector, but nor has it been actively supported. Over the last 20 years we have seen the rise and fall of many black-led projects on both a national and a local level. (To gain a more in-depth awareness of the shortcomings of both statutory and voluntary organisations, see the studies by Connelly, 1990; Harding, 1995; Bhui and Olajide, 1999; Chauhan, 2001.)

Black projects are providing generic mental health services and, more recently, advocacy services. Despite this, such projects and the people who provide such services remain on the periphery of key decision-making processes. One result of this lack of consultation is that projects have to provide new services within an existing financial budget. “Whereas mainstream voluntary organisations have attracted major sources of funding, and have some impact on shaping government policy, they have not delivered well to black communities” (Zahno, 1997, p 7).

The expansion of black mental health projects is crucial to ensuring culturally appropriate services. Of the 12 projects interviewed, eight were black mental health projects; five of which were generic mental health projects offering a range of services, including welfare, housing, employment, social activities, cultural space and general healthcare services.

Out of these eight projects, only one had a specific focus on advocacy, while the others integrated advocacy and interpretation under the one service. The research team could identify only one independent black survivor group.

To understand why advocacy is less well developed for minority communities, an analysis is required which puts the ideological, political and social difficulties experienced by mental health projects within the context of the voluntary sector. In general terms, the voluntary sector is an important player in providing social care services: it provides information, culturally appropriate services and mutual support systems that advocate equality of access.

Discrimination on the grounds of race has underpinned the historical and philosophical origins of the black voluntary sector, which draws its strength from community connections. These roots of self-empowerment and self-definition have been the fundamental tenets of collective survival. The achievements thereby gained have culminated in a diverse and culturally sensitive support network.

The British voluntary sector includes campaigning and political parties and movements, church or chapel groups, sports groups, service provision, credit or financial partnerships, employment opportunities and much more. Two contrasting strands in the history of this sector are a paternalistic approach of ‘helping those less fortunate than we are’, and a contrasting theme of self-help and empowerment in the face of oppression. Both of these can neglect the diversity of our society and presume to speak on behalf of others.

The reasons why advocacy is less developed for minority communities include a lack of resources, an imbalance of power and a lack of understanding of the realities experienced by workers operating in a climate of competition that often forces them to tolerate the status quo. The developments of mental health advocacy have been instigated primarily by service users and mainstream projects and, importantly, have been commissioned by mainstream funders who are, of course, predominantly white. Advocacy development has remained effectively firmly in the palms of these people. Yet many mainstream voluntary and statutory organisations concerned expect to offset their responsibility for providing for all people by assuming that black projects will take responsibility for meeting the needs of black people. Thus, black projects are left with a further double burden of (a) introducing the western concept of advocacy to communities, and (b) then providing it.

One black advocate expressed her feelings by saying:

> "Advocacy is not understood; mainly people think it is a legal term. To raise the awareness of communities we have to go to their level. Too much jargon from mainstream providers is making language oppressive." (black advocate)

In the light of unmet needs, severe hardship and social deprivation, black people have responded and have taken collective responsibility to meet and identify their own needs, culminating in the emergence of black-managed voluntary projects, primarily in response to the failings of the mainstream. The survival of the black voluntary sector in a hostile and unequal system of changing social and economic politics demonstrates its capacity to survive. However, bare survival is not an ideal recipe for sustainability.

The black voluntary sector, in spite of its comparatively short history, *could* be flourishing. This is recognised in recent government initiatives to stimulate the growth and networking of the sector, through regional developments and criteria for National Lotteries Charities Board (NLCB) funding – now known as the Community Fund. What we cannot yet know is how successful these initiatives will be in either the short or the long term. Currently the black voluntary sector finds itself in a state of perpetual vulnerability. Whereas the mainstream voluntary sector has the capacity to widen its horizons, the black voluntary sector finds itself losing out.

One advocate highlighted that,

> "We have been on a stand-still budget for the last three years and expect this to continue … resources are slim, but the need for our service is growing. This is putting a lot of pressure on us. It's a heavy burden to be expected to meet the needs of all minority groups but [with] no extra resources." (Asian advocate)

And another black advocate put it:

> "Securing the future of the project is very hard. We never know if we are going to be here next time. Getting funding is the most difficult thing we have to deal with; it always feels as if we have to justify our existence by providing examples of how we are meeting the needs of the community. I often feel as if the project has to kiss the hand that feeds us." (black advocate)

The most effective way of targeting funding for minority communities may well be to ring-fence financial support for black groups, in recognition of the fact that they are very often best placed to provide and manage services to their communities. To realise this, funders need to appreciate that mainstream and black organisations are not bidding from a level playing field.

Funders need to ensure that black groups are not set up to fail, by providing additional resources to enable them to expand their capacity and support their internal infrastructure. Funding should recognise that the lack of opportunity to manage services in some communities means that their pool of volunteers and potential trustees or group leaders may need some additional or 'catch-up' training in, say, organisational and financial management, completing increasingly complex forms for funding and monitoring, personnel matters and so on.

Funding and the contract culture facing the voluntary sector generally over the last decade has increased in bureaucratisation. The funding climate instigated by charities, central government, the NLCB and European sources has generated a frantic and competitive environment, which promotes and creates pressure to establish suitable partnerships.

This presents two significant dilemmas for black voluntary projects: independence, and self-definition. These are much harder to maintain if you have a 'big brother' watching over you or, even worse, dictating what is important and relevant to your community. The other consequence is that mainstream white projects are given a significant proportion of funding to meet the needs of all community groups. This is inevitably at the cost of black projects. Francis and Jonathan (1999) provide examples from black professionals who cite that white service providers are frequently seen as a 'safer option' to provide services for black groups, despite their continued failing. How this funding culture affects black mental health projects is a critical consideration, especially when new initiatives such as mental health advocacy are commissioned.

One advocate expressed her frustrations by saying that,

> "Black service users and black projects are often the victims of short-term, fly-by-night organisations, who are there one minute and gone the next … no one sees the damage this does." (black advocate)

Many projects raised funding as the most crucial factor in ensuring creative and responsive service provision for minority communities. One advocate expressed her frustration by saying that, while the demands as a black service provider had grown, with advocacy being offered in a holistic way, meeting a range of needs, no additional funding was secured. She said:

> "We have to dip into reserve funds. The pressure to raise money is huge and very time consuming. Our funding has not changed since inception." (black advocate)

The black advocates we spoke to identified funding as the main issue that prevents the development of new services. Again and again this fact kept reappearing. Advocates questioned the ability of under-resourced and isolated projects set apart from the mainstream to develop actively in line with the developments of the mainstream.

Alongside the evolution of the voluntary sector, British society has undergone a radical shift. 'Multi-cultural', 'multi-lingual' and 'multi-faith' are just some of the expressions used to describe the diversity of people supported by statutory and voluntary sectors. Such organisations have an ethical obligation to provide high-quality and equitable services that achieve social justice for all communities. Certainly we should expect public money to do this, including the Community Fund (formerly NLCB). However as Bashin states, inequality is perpetuated by the

> "[p]ersistent presence of covert and institutional racism in mainstream voluntary agencies which is barring the creation of non-medical, holistic and culturally aware services. A lack of respect for the expertise, structures and experiences of black voluntary organisations is also apparent." (Bhasin, 1997)

The ongoing tensions of race equality lie in the inability of this predominately white sector effectively to meet the needs of a population that is culturally diverse. Personal and professional testimonies from black people in this research, supported by existing literature, challenge the ability of the white voluntary sector to meet the needs of marginalised minority communities.

Again, one advocate highlighted that mainstream services cannot effectively meet the needs of specific groups, in this case Asian women. The project was originally a generic women's project aimed at meeting the needs of all women. However, over the years more than 85% of their service users came to be Asian women. She asserted:

> "Voluntary health and statutory services do not have the experience and knowledge of the needs of Asian women. If by chance an Asian woman does contact a mainstream project we usually find that, due to differences in culture, language and issues experienced by Asian women, they are referred to us." (Asian advocate)

What relevance does this overview have in the context of mental health advocacy?

First, it is important to note that the principles and aims of mainstream advocacy have a long history in the empowerment of the black community. The development of the black voluntary sector applied the fundamental principles of self-definition, choice, autonomy and citizenship in an often hostile and oppressive social system.

'Consultation' and 'partnerships' have emerged as the new 'buzzwords' for continued inequality. In reality, 'consultation' can often mean nothing more than a last-minute dissemination of information about impending service developments. Partnerships are often based on unequal power relationships, which often means that smaller projects are thought of at the last minute or missed altogether. The terms imply change, but this change does not address the fundamentals that black communities have identified for decades.

Second, black service users are usually left out. Their inclusion in policy formation and service creation is essential (Francis and Jonathan, 1999).

The black voluntary sector must advocate for local autonomy, for the recognition of black projects' cultural strengths and their participation, empowerment and flexibility. It is important that black self-empowerment and funders' responsibilities move forward together, so that black mental health voluntary agencies can survive and thrive in this millennium.

## 'Resist to exist'

### *Problems of access*

From the interviews, it became clear that black and ethnic minority service users access black projects in a rather unsatisfactory way. Black service users within the mental health system are referred reactively to black projects by statutory and voluntary agencies, primarily when the relationship between the statutory agency and the service user has broken down. Furthermore, once mainstream services refer black service users to black projects, there is little continued input or support from the mainstream projects. There is nothing proactive or positive about the way black service users are referred to – or, to put it another way, 'dumped' – on black projects.

Many black advocates raised this as an issue that needs to be addressed. One advocate said:

> "Agencies sometimes refer their clients to us rather than try to assist them themselves and sometimes inappropriately. This includes clients whose needs are difficult to meet."
> (black advocate)

All the mainstream white projects interviewed demonstrated a failure to engage with black users and their communities. Advocates working within mainstream projects identified two main concerns:

1. Black service users were not accessing mainstream services.
2. Mainstream services did not have appropriate resources to meet the needs of black and ethnic minority service users and carers; that is, they had no bilingual workers, limited out-of-date translated information, patchy access to interpreters and weak links with local black projects.

We interviewed five voluntary sector mental health advocacy projects across the region. All accepted that all people have the right to an advocate. Mainstream advocacy projects were very forthcoming with their recognition that they were having difficulty in making their services accessible to black and other minority groups. Most of the advocates we spoke to clearly identified the need for action to redress this gap, and many advocates felt that one way to achieve this would be to recruit a black advocate. From our interviews with white advocates, we also found that their relationships with other black mental health projects, including advocacy projects, were very weak.

As black researchers, we found it very hard to handle this apathy. It was difficult to retain a sense of objectiveness and see beyond trite goodwill intentions. The reasons given ranged from "we don't know what the needs are", "the project does not attract black workers" and "can't speak the language and interpretation services are poor" to "we get very few referrals".

In summary, a 'colour-blind' approach still seems to be the most accurate way to describe mainstream advocacy services. A **colour-blind approach** is one in which there is a failure to recognise the impact of colour. Drawn from the language of art into human relationships, it means that 'people of colour' are presumed by white people to have no specific needs. In analogy, a 'gender-blind' approach indicates that women's needs are presumed to be the same as men's. Both lead to the erroneous conclusion that there is no need to develop specific responses to meet specific needs. This leads to an insidious and damaging form of discrimination, where blame is placed on the victim for 'failing to fit in' and where the victim's needs pass unrecognised, undefined and unmet.

The key findings that we found through our contact with these five organisations included the following:

- There were no black or bilingual advocates.
- Very few black service users accessed the service.
- Relationships with mental health projects in the black voluntary sector were weak.

- Only one of the projects had links with black self-help groups; in practice, this was nothing more than a paper relationship.
- Some projects showed little awareness that the needs of black service users were any different from those of white service users.
- All of the projects asserted that specific posts to improve relationships with minority groups were being developed.
- No information was available concerning advocacy or the project in languages spoken by minority communities.

### *Lack of bilingual advocates*

We visited and interviewed five mainstream projects. In all these projects interviews took place with a white worker. We did request the participation of black workers, as we felt this would have enabled a perspective that reflected diversity and recognition of specific need. However, none of the projects could meet our request, as at the time no black advocates were employed within these projects.

The reasons for there being no black or bilingual workers fell into two main categories. First, many mainstream projects did not get past the initial hurdle of recruiting black or bilingual workers. Second, the projects that had managed to recruit black advocates did not have appropriate support systems, a fact that indicated the difficulties experienced by a lone black advocate in a predominately white organisation.

We did speak to two black advocates who at one time had been employed as part of a mainstream team, one in a senior management position. Both had experienced severe hardship when they challenged bad practice and asserted the specific needs of black service users. After some time of internal conflict, one of the advocates put in a complaint of racial discrimination, which was not upheld; the other advocate was subjected to disciplinary action. Feeling isolated, marginalised and vulnerable, both had subsequently left the service.

The experience of these two advocates shows how difficult and oppressive it can be to work in a team that is not culturally sensitive or reflective. It is not within the remit of this research project to examine why this type of hostile environment is not challenged, although it is a question that

## Statements from white advocates

"We have an affiliation of 250 groups; only six of those are from black groups. It is hoped that this number can be improved. A developmental worker is looking into this area. Given the nature of our project, if the projects are not there, then it will be difficult to get individuals to access them. We are willing to develop new groups within minority communities."

"The main groups we have difficulty in reaching are groups that are non-English-speaking, although there is the possibility of using interpreting services."

"We do not know what the needs and demands are. We did identify the need for minority workers some time ago, but funding was not made available. In the past we have translated leaflets into a minority language and did receive phone calls, but were unable to respond or communicate because [we had] no staff members who could speak the language."

"Referrals from black and minority ethnic service users are low; we struggle to make contact partly due to language barriers."

"The project gets hardly get any referrals from African Caribbean and South Asian users."

"We would like to attract minority groups to use this service and maybe help individuals to set up groups, particularly for minority communities. We do identify a gap in our service, but we're not sure whether we as a white project should direct changes or support existing initiatives. Also, we have found a resistance from African Caribbean and South Asian users and projects. Resistance to our service comes from outside, as we welcome all. The perception is that we are a white project providing for white people."

"Service does not meet needs of African Caribbean and South Asian users."

"Our project does not provide a service for particular groups; [we] do not consider the problems associated with going through the mental health system to be any different for black people."

definitely needs to be addressed. This example highlights several different issues, all different but concealed in the same guise of institutional racism. The experiences of the above advocates provide evidence of the difficulties and frustrations faced by black workers, the climate in which they occur and ultimately the negative impact these experiences have on black service users. How is it possible to empower black service users in an environment that disempowers black workers?

Our interviews explicitly demonstrated that no substantial inroads have been made in the training and awareness-raising of mainstream mental health providers. The research provides overwhelming evidence confirming that mainstream providers fail to understand or support the predicaments that many black groups experience when dealing with mental distress. This ignorance partly explains the struggle experienced by black service users to make themselves visible, while black advocates and mental health professionals continue to battle with severe difficulties in sensitising the powerful majority.

### *Lack of awareness*

This research reveals that solidarity for black service users is experienced once they are in contact with black projects. But black and ethnic minority service users often find themselves on the doorsteps of black projects only after encountering difficulties accessing mainstream services.

Many black and white advocates felt that service users entrenched within the system as well as those suffering in isolation in the community did not know that an advocacy service existed. There were many reasons for this:

- information not given to black service users by mainstream agencies;
- decision of many to suffer in silence within the community;
- the stigma of mental health;
- mistrust of both voluntary and statutory agencies;
- language barriers;
- advocacy definitions not culturally appropriate;
- black projects precariously funded; pressure of providing a multi-faceted service with no increased funding often resulting in little time for community development.

Barriers to effective communication have continuously been highlighted as evidence of inequality; again, this research found that such barriers include:

- lack of bilingual workers;
- lack of translated information;
- poor interpretation services;
- lack of understanding of culturally appropriate forms of communication (for example issues of gender, religion).

Over the years, policy, legislation and good practice have been initiated at both national and local levels to attempt to overcome these communication barriers. There is a statutory requirement for health authorities to provide appropriate methods of communication. However, this research has revealed that both specific advocacy projects and holistic mental health projects from the black voluntary sector continue to express concerns about and dissatisfaction with the quality and efficiency of interpretation services.

On the same spectrum, another major disagreement surrounds the difference between advocacy and interpretation. Many mental health and advocacy projects, both black and mainstream, have argued for a clear distinction between advocacy and interpretation services.

Conversely, this research found that some black service users and black projects, especially those providing a service for South Asian communities, believe that interpretation is a necessary component of advocacy services. Best practice models of black advocacy would incorporate bilingual advocates, and this should be complemented by interpreters who are trained in mental health and should reflect the communities with whom they work.

Advocates, who oppose the above model of advocacy and interpretation, agree that interpretation and advocacy share the aim of improving communication, but see them as distinct and separate services. They contend that interpretation is a facility that primarily serves professionals, and argue that interpretation makes communication possible but that it is not a process that allows mutual discussion.

Advocacy, however, is based on notions that recognise the unequal power relationship between user and professional. Advocacy serves the user, as it provides the legitimate opportunity for users to inform and challenge the views of service providers and professionals.

We argue that the failure to recognise the need for advocacy and interpreting services to be combined stems from the same Eurocentric view of advocacy and of services more generally that we referred to earlier. When the experiences of black, Asian, Somali and other service users and carers whose first language is not English are brought into the limelight, then we begin to have evidence for an informed decision about the most appropriate links between advocacy and interpretation.

Mental health practitioners in the UK today, like the majority population as a whole, are well known (perhaps a little stereotypically) to be generally unskilled in languages other than English, and somewhat reluctant to learn any. The seriousness of this problem arises when the linguistic skills of the professional do not match the language of the client. Mental health practitioners, interpreters and advocates must be mindful that, if cultural assumptions continue in the mainstream as a result of cultural bias, then the potential for integrated mental health advocacy and interpretation services is substantially diminished, if not blocked altogether.

Currently the main role of an interpreter is to relay professionals' questions and inform the service user of the decisions and directives made regarding the diagnosis, treatment and care of the service user. Therefore it is true to say that interpreters primarily serve the interest of mainstream professionals. This research maintains that the continued separation of advocacy and interpretation services will only perpetuate the existing power imbalances between black users and mainstream professionals.

Interpretation currently is nothing more than an empty shell, which simply makes possible basic communication on a superficial level. Interpretation services and interpreters do not have any power to redress this imbalance, but advocacy can.

## A case study

An Asian woman who spoke very little English was experiencing mental health problems and was placed by social services in a residential home. Some time later social services contacted the Asian women's project with a referral that described this woman as very difficult and demanding. During her time at the residential home she had had no contact with anyone from her own community, nor had she experienced any reinforcement of her cultural identity. She began to display signs of unhappiness. The lack of culturally appropriate provision or recognition of cultural expression left her feeling extremely frustrated, which resulted ultimately in her expressing her anxiety overtly, displaying her feelings of isolation in front of the other residents and staff. She began to resist taking her medication, raised her voice, refused to eat and prayed. The staff became increasingly concerned and perplexed by her actions. Their response to this situation was to insist that she take her medication. She continued to resist. Her resistance to their authority resulted in forceful physical restraint. The Asian woman fought back with strength, at which point the police and social services were called.

It is at this point that the Asian advocate from a local project was called upon. The advocate arrived to a scene that horrified her: she found an Asian woman being forcibly restrained by a white male police officer. Fortunately, the Asian advocate was allowed to intervene and persuade the white professionals to allow her to do her job. The advocate quickly eased the situation, primarily by making contact with the woman through their common gender, language, ethnicity and empathy. Had the advocate not been present, this Asian woman would more than likely have been sectioned.

In the short term, intervention by the advocate allowed this woman vital representation in a situation that was disempowering and degrading. In the long term, the advocate and the Asian woman were able to build a relationship on which they could collectively address her holistic needs. Most importantly, this woman now had a vital 'lifeline' to sustain and nurture her identity as an Asian woman.

## Good practice in advocacy

### *Meaning of 'advocacy' to black communities*

Advocacy has challenged inequality and injustice within mental health services since the 1980s in the UK, and for longer in the Netherlands. This has led to some progress within mental health services, and many national and local advocacy projects have continued to promote the rights and views of mental health service users, moving advocacy from the margins into the mainstream.

One of our early findings was that mental health advocacy was much less developed for minority communities. We were unsure why. Consultations indicated that some black projects were providing services that could be identified as advocacy practices, but these projects did not use the umbrella of mainstream definitions to define their service. For a better understanding, we decided to ask projects and service users what they understood by 'advocacy'. There were three reasons for doing this:

1. to provide the opportunity for black users, carers and mental health advocates to define for themselves their understanding of advocacy;
2. to address the gap in the literature by presenting views and experiences specific to minority communities;
3. to establish what models of advocacy workers are using when working with black and ethnic minority service users.

When we asked the question, hardly any service users or carers had any idea either of what advocacy was or of what it could achieve. This lack of awareness or understanding of advocacy as a concept and of its aims of empowerment may not be specific to black and ethnic minority service users. The general lack of awareness of 'advocacy' was a recurring theme. It meant that we had to explain the aims and principles of advocacy. We could not use definitions from mainstream advocacy projects such as UKAN, Mind or NAG, as we found they lacked cultural emphasis. Instead, we translated the main strands of such definitions into a format that user and carers did understand. This included using examples of inappropriate services specific to the experiences of black people, definitions of mental health within a cultural context and discussions about feeling valued and listened to. Often we conversed in the service user's and carer's first language (that is, patois, Punjabi, Urdu) allowing us to develop a sense of mutual understanding.

Once we had overcome the cultural barriers to communication, we were able to engage in serious discussion, which provided further insight into the reasons why advocacy is not readily understood or accessed. We found that language and communication played an important role. (This issue is given further consideration later.) Carers and service users questioned the meaning of 'advocacy', as many had not heard of the word before or found the concept complicated.

One black service user summed up her feelings by saying:

> "I'm not a high-flying intellectual. I think 'advocacy' has a lot of subsections to it but I'm not sure what they are. I think advocacy should be about giving someone a voice in a certain situation where they cannot speak for themselves." (black service user)

Black advocates raised similar concerns and questioned the suitability of the word 'advocacy'. Several advocates said it was a useless word – too technical, and alienating for people who speak languages other than English.

> "The word 'advocacy' is not understood by our service users, and we don't try to enforce it on them. It is difficult to translate the word into Asian languages. We start from where the user is at; this means placing emphasis upon empowering service users by ensuring that their needs are met. We do this by representing the views of our service users, as many do not want to, or because of language barriers cannot, express themselves directly." (black advocate)

Terms like 'advocacy', with roots in the primarily white service users' liberation movement, fail to acknowledge or accurately reflect the language, experiences and views of black users. In practice, this often means organisations applying a universal framework, which assumes that all service users have the same needs.

Many advocates felt that they were trying to work to an advocacy framework designed and formulated exclusively by white groups. They stressed that the development of advocacy provision within the black voluntary sector responded to the criteria identified by national and local advocacy networks. This was in spite of the fact that many of the black projects were not involved in national, regional or local initiatives that aimed to develop advocacy.

One black service user made a strong point by highlighting the following:

> "I would expect my advocate to be paid and trained for their work. I am baffled by the word 'advocacy' and not really sure what it is supposed to mean. I think in general, advocates should help service users or speak on behalf of a person if they [service users] cannot speak to the white professional. Also, a black advocate would be putting across those views to a white system, so the advocate would have to be knowledgeable of white people – who don't see black service users as having any rights and [do] not respect them as a human being." (black advocate)

Black mental health advocates that we spoke to reinforced the view that advocacy as a mechanism for equality and change should aim to achieve the same outcomes of better services, choice and cultural sensitivity. They also highlighted that the process of achieving equality may well take a variety of different approaches.

Advocacy as a process of empowerment for black and ethnic minority service users was identified as a reactive response to inequality and discrimination. Many black service users highlighted the fact that, by the time they gained access to a black advocate, they had already experienced severe discrimination, which had led to misunderstandings and referral to inappropriate services. This experience left many service users and carers feeling frustrated and unwilling to engage further with mainstream services.

Black advocates asserted that advocacy should also take on a more innovative role, and many black groups throughout the country have placed emphasis on the value of collective consciousness-raising, where black service users, survivors and carers can come together to share and examine their own experiences. This process also allows oppressed groups to contextualise their experiences according to their social and political realities. The strength of this approach lies in the fact that groups of people who share similar experiences can offer validation to themselves, to each other and in wider social networks. Advocacy should then be an ongoing process that acknowledges the systematic struggle, charts the history of survival and empowers vulnerable people as a collective.

Many of the black advocates we spoke with were under extreme pressure to respond to the inequality experienced by black and ethnic minority service users. With limited resources, they felt that they were not well resourced or supported. When they were included or consulted, black advocates often felt that their "involvement is tokenistic" (black advocate). Conversely, many specific mainstream (that is, white-dominated) advocacy groups and organisations are well connected to local and national networks, which often means that they have access to the necessary infrastructure to support and promote their service.

Service users and carers raised the following points during our discussion with them:

- The aim of advocacy, in the context of black and minority ethnic communities, means that it needs to challenge and address the double discrimination of racism and mental health experienced by black people.
- Black service users and their carers highlighted the importance of advocacy in practice, stressing that it should promote the integration of complementary ways of healing and facilitate access to culturally appropriate services by challenging mainstream white frameworks.
- It was also stressed that advocacy should empower black service users and their carers, so that they can identify their own needs and be able to develop culturally appropriate ways to meet them.
- Black service users supported the need for independent black-led advocacy services, located within community settings.
- Carers and service users alike preferred an advocate who reflected their own cultural background, language and gender.
- Many service users and their carers appealed for advocacy to promote a greater appreciation of five themes – identity, faith, racism, gender and spirituality – as key components for better mental health. These should underpin advocacy frameworks, thereby ensuring that any service that seeks to meet the needs of minority communities must adopt holistic ways of being.

## Key aspects of culturally specific advocates, identified by black and ethnic minority service users service and carers

- Someone you can talk to in your chosen language
- Someone who listens and understands your issues and experience
- Someone who has the authority to challenge professionals
- Someone you can identify with, that is, through culture, identity and gender
- Someone who can offer consistent long-term support
- Someone you feel you can trust
- Someone who can provide accurate information relevant to individual needs
- Someone whose services are accessible at a community level

### *Advocacy in action*

One black advocate working for an Asian women's project gave an in-depth explanation of her understanding of advocacy and how she provides advocacy in practice:

> "Our understanding of advocacy is getting the voice of the women across, primarily to statutory and voluntary organisations. This means … presenting their issues and their experiences within the mental health system, with the aim of getting those with influence to take notice. For us, advocacy goes beyond that. We also assist the women by attending appointments with them, explaining their medication. We find that Asian women don't feel confident in expressing their views to white professionals. They often ask the advocate to speak on their behalf." (Asian advocate)

Black advocates and mental health projects generally seek to empower black service users by providing the following services:

- advice;
- information;
- representation;
- translation/interpretation;
- befriending;
- specific support for women, carers and young people;
- holistic support covering a range of emotional, spiritual, cultural and physical needs;
- social inclusion by raising awareness;
- help in challenging mainstream policy and practice;
- confidentiality.

Implicit in this is a community development approach. This means that development begins in the communities, working with them on their own terms and towards the goals and aims that they determine. It is a 'bottom-up' process of empowerment, which recognises the need to develop confidence and skills for people, rather than a 'top-down' process of imposing education or training as defined by those outside the community, in positions of authority or power.

Black advocates working within black projects gave clear examples of culturally appropriate contact with black service users and carers. Although a large part of the work of black projects involves *reactive* responses to crises, advocates emphasise the importance of *proactive* engagement with service users and carers. This is achieved by raising the profile of the project and the community by outreach work, for example through:

- small self-help groups within community networks;
- GPs' surgeries;
- community radio;
- word of mouth;
- open days;
- home visits.

Other examples of good practice identified by this research include advocates facilitating:

- support groups in which black service users and carers can come together to share their mutual experiences of mental distress;
- space to identify the difficulties experienced in accessing appropriate support as black service users;
- support groups for carers;
- befriending groups for peer support;
- specific support groups that recognise gender, age and language diversity;
- partnerships with generic black mental health projects.

### *Advocates who reflect cultural background, language and gender*

Contrary to ideals of self-advocacy, black and ethnic minority service users and carers prefer to have a paid professional advocate who reflects their ethnicity and gender to represent their views and experiences. Most people asserted their choice by saying:

> "We want black workers to be a voice for us." (black service user)

> "I prefer to have an advocate who is of the same cultural background, because there is more chance of them seeing things from my 'shoes'. In my experience it is very difficult to get white people to understand my cultural needs, I'm not saying that there no one out there, but there [are] not many." (black service user)

> "I would be happier if I had a worker from my own background. I do not expect a white worker to support or understand the pressure I am under as a black person. I don't think they [white workers] can empathise with people from different cultures. In my experience they often misunderstand things." (black service user)

Service users also expressed their need for an advocate who reflected not only their cultural background but also their gender. This issue was mentioned primarily by female service users:

> "I am lucky I have a female worker, as my gender is also very important to me. I would not feel happy with a man representing my needs as I feel they would not understand my issues; we live in a man's world." (black service user)

These assertions are not surprising, as black service users and black people in general continue to experience intersectional discrimination, which has a significant impact on mental well being. Many black service users feel that they do not have the individual power to put themselves on the front line of challenging bad practice.

The burden remains for black users and survivors to identify and assume control over their lives and their mental health experiences. Sassoon and Lindow (1995) have suggested that, in contrast to the white survivor movement, where considerable importance is placed on user-only space without professionals, there is often a mutual understanding between black professionals and black users, and a shared sense of identity, culture and experience.

By listening to black service users, carers and advocates, we began to arrive at a culturally appropriate definition of advocacy:

- **Advocacy** is a process rooted in the foundations of individual empowerment. It recognises that interdependence is a key attribute in achieving a sense of personhood and alliance. Advocacy therefore aims to secure 'diverse solutions for diverse needs' by applying the tenets of self-definition, equality and assistance for all people, in their time of need, in ways that they choose.

### *Power to influence culturally appropriate services*

Importantly, service users, carers and advocates agreed that advocacy must include the fundamental aspects of a shared cultural identity. Advocacy services and notions of empowerment cannot successfully empower minority groups without integrating the culture, faith, racism, spirituality and gender of the groups. Furthermore, advocacy must go beyond individual empowerment and must influence 'the system'.

One way in which this can be achieved is by promoting the right of service users, carers and advocates to inform and contribute to the development of services, both generic and specific. It is essential that black service users and their advocates are visible within both black and mainstream decision-making forums. This will mean professionals giving up some of their power, so that people with diverse experiences can freely speak for themselves and affect the very structures that should be seeking to serve them.

### *Challenging racism*

Black users, carers and advocates are far from being empowered. They continue to be disempowered within mental health systems of care. One user's view mirrored the feelings of many more when she said:

> "White people feel we can't look after our own affairs." (black service user)

Within our discussion groups, users and carers collectively expressed their dissatisfaction with mainstream mental health services. They restated that these organisations misrepresent, misunderstand and ultimately seek to control their experiences and methods of expression. One black service user expressed her views by saying:

> "I have so much difficulty in getting white professionals to see me as a black person. I feel they see me as a stereotype and not as a person." (black service user)

Another black service user said:

> "The reality of myself [is] as 'normal', but a lot of people don't see me as normal. I see other people who have similar experiences as me but they are not seen as mentally ill. I have mixed feelings about what's going on in the system. I often question if it's my culture, gender, and/or age that gets a negative reaction." (black service user)

The experiences of black advocates operating within a hostile environment often left them feeling worn out and frustrated. One advocate's feelings reflects the experiences of many others interviewed when she stated that:

> "Mainstream white services feel threatened by black advocates." (black advocate)

Black advocates felt that their objective of black empowerment intrinsically and inevitably involved challenging mainstream practice. One advocate asserted that:

> "Our role involves training, health promotion and in particular raising the awareness of social and healthcare professionals." (black advocate)

Conducting the action research has explicitly informed us that on a structural level black advocates and projects have had very little influence on mental health advocacy policy. One of the barriers encountered links back into the advocacy movement, where black users have not been visible. The advocacy movement has grown and achieved significant recognition. It is only now, when advocacy is about to take centre-stage within mental heath, that the representatives of the movement and service funders are beginning to question why black people are not visible within it. Parallel to this, many black mental health projects, including specific advocacy projects, continue to bridge the gap between black service users and mainstream projects, a task that is not always easy or healthy to undertake.

### *Black-led empowerment*

'Empowerment' as a new buzzword, heavily branded by both white service users and professionals, fails to acknowledge the uniqueness of the experiences, history and expression of black people. The problem with this term, as with 'advocacy' itself for black users, advocates and carers, lies in the fact that the language is Eurocentric, jargonistic and based on the values of the mainstream. When such terms are used, they are embedded in a culture of white dominance. What is not acknowledged is the choice of an individual or a collective rightfully to define for themselves how best they can feel empowered.

A common definition of empowerment in a mental health service users' context is 'taking power back'; 'regaining control over one's life' (Sassoon, 1995). This concept of influence (or lack of it) is expanded further and has been defined by both mainstream service users and researchers as "Gaining control over one's life in influencing the organisational and societal structures in which one lives" (Segal et al, 1995). In the context of black service users, these prevailing types of definition fail to understand the realities of discrimination experienced by black mental health users. Furthermore, they assume that what applies to the dominant majority also applies to the minority. During our discussions with both black service users and advocates, it became clear that these blanket statements are not adequately representative or reflective of black empowerment. Black empowerment has a long history, both globally and nationally; yet none of this is referenced or acknowledged in British advocacy literature.

Black people have a long lineage of empowerment. Collective and direct action in our struggle against racial domination by the majority included the American Civil Rights Movement; the South African Anti-Apartheid Movement; British uprisings against racism (Birmingham, Brixton, Bradford, Nottingham, Liverpool); Southall Black Sisters; and more recently the development of the black voluntary sector. This history of black empowerment should inform contemporary black empowerment, and mainstream advocacy should acknowledge that black people can define for themselves issues of oppression and the best routes to self-determination.

Black empowerment models differ from western ideals. There are distinct differences in belief systems, which coexist within eastern cultures. The western concept of empowerment that underpins mainstream advocacy actively promotes individual or self-empowerment; yet in our exploration it became clear that this is not the aim of many black and ethnic minority service users or carers.

Treating the individual as if they were entirely autonomous is seen as a positive attribute of individual personality in the west, but this is not the case in many other cultures (Marsella and White, 1982). This individualism also neglects and denies a self-defined role of families in many non-western cultures to provide care for ill relatives (Mumford, 1994). Added to this are the barriers facing black families when trying to access care and support from disparate and uncoordinated public agencies, many of which pathologise and ignore alternative systems of kinship and healing.

Empowerment for black users must be situated within cultural, religious and spiritual beliefs. These aspects are all fundamental to the well-being of mind, body and spirit. Many black and ethnic minority service users that we spoke to challenged the view of mainstream advocacy that places such great emphasis on the self.

### *Black-led advocacy*

Many of the mainstream projects involved in this research clearly expressed their concerns about black users not actively involving or aligning themselves to their services. One reason for this may be that mainstream definitions of advocacy fail to acknowledge that taking control over one's life cannot be accomplished universally. Advocacy activists use terms such as 'self-definition' to promote user empowerment. But however empowering such terms are perceived to be, mainstream advocacy fails to encourage or accept black users' own perspectives, which would enable them to define empowerment for themselves according to their own realities. Although in principle advocacy now recognises the importance and value of black users, in practice it is no less tokenistic than most equal opportunity policies.

An integrated advocacy service – one that aims to provide a service to the whole of the local community, white, black and minority ethnic people alike – poses many difficulties and dilemmas for black service users. These are further compounded by the failure of mainstream advocacy organisations to provide a service that is culturally sensitive. White advocates frequently hold notions and stereotypical assumptions that present many obstacles for black service users. This is magnified when black users enter the advocacy arena, which is dominated by white users and professionals. This environment can make it very difficult for black users to voice their specific needs.

It is true that advocacy has evolved strongly as part of a movement that challenges inequality and oppression. However, it is not clear where power is taken from: is the empowered individual in fact taking power and resources from those with less power, rather than from the wider society? Payne (1997) highlights an important point when asserting that, in the social and political environment where resources are limited and experiences diverse, empowerment strategies may be setting one oppressed deprived group against another, rather than uniting them. This is a complex and sensitive issue, as those in power often maintain their position by setting those less powerful up in competition against each other – the 'divide and rule' syndrome.

The challenge for black people today is to reconnect our past to our current struggle. The mental health system and the experiences of black people within it have inflicted severe blows to our capacity. We have become so entrenched within an oppressive regime that independently we hold very little power. The mainstream advocacy movement fails to questions how power is distributed. The question that needs to be asked is: how much power do black people have? The experiences and views of service users and advocates that we spoke to clearly challenge the status quo.

Advocacy within mental health can best meet the needs of black service users and their carers if it acknowledges their specific experiences of disadvantage.  These experiences may appear to be the same as those of mental health users generally, but the causes are significantly different.  Advocacy has a duty to offer some vital redress, and this can be achieved by accepting that we live in an culture-blind society, where diversity is often perceived as a threat rather than an asset.

There have been long-standing debates about separate or integrated services, and both of these options bring with them difficulties. What seems clearly apparent to us as a research team is that integrated services, despite the goodwill intentions, continue to alienate many people of different nationalities. It is therefore our opinion that the important issue is one of choice. However, as the research has demonstrated, black-led advocacy projects are sparse, which means that choice is not always a viable option. Everyone should have the right to choose the type of service, specific or generic, that best suits their needs.

# 6

# Recommendations: best practice for advocacy

This report recommends a proactive community development approach for the continued development of mental health advocacy. The underlying principles of community development should inform and guide providers, professionals and mental health advocates to develop culturally appropriate advocacy services. In practice, this approach will facilitate the empowerment of individuals and communities who are often excluded from power and decision-making processes.

This can be achieved by acknowledging the value of existing black mental health projects, because existing projects are already challenging and exposing the failings of the mainstream. Thus, while they may not term themselves as ‘advocacy’ projects, they are carrying out the role of advocacy on behalf of whole communities as well as individuals.

During the process of the research, our understanding of advocacy crystallised around two distinctive strands. The first is common to mainstream advocacy and is about supporting the individual. The second, while it has some features in common with mental heath empowerment, we have termed ‘community advocacy’. Up to now, this has largely gone unrecognised.

Community advocacy will strengthen the development of skills and knowledge within the community, so that people can begin to feel more valued and respected. Moreover, a community development approach can create culturally appropriate structures which will enable communities to identify and assume control of the process by becoming involved in the development of new services.

Out of this arises the debate about integrated versus separate services and local choice of both. To an extent, we already have separate services, with those for minority communities poorly and insecurely funded. However, this is masked (a) by a reluctance of the mainstream to acknowledge that it is incapable of providing services to minority communities and (b) by its failure to allocate a rational level of resources to meet diverse needs.

The research concludes that the biggest challenge for mainstream advocacy networks and local advocacy providers is to actively promote strategies of social inclusion. This means being prepared to:

- share their resources, expertise and access to power and decision makers;
- encourage black service users and their carers to define for themselves their own needs, based on their own experiences and realities;
- listen to and understand what black service users and carers are saying; and
- transform themselves into services that genuinely meet the needs of all communities.

Failure to accept these often repeated challenges will result in black advocacy services falling foul of ethnocentric models of empowerment, which are geared towards meeting the needs of the white majority. Until advocacy services recognise the specific experiences of black communities, and reflect the diversity of multicultural British society, black communities will continue to be marginalised and will remain invisible within the movement.

This final chapter relates the findings to best practice recommendations. The recommendations outline five key issues that can facilitate a radical shift from provider-led to black user- and carer-led initiatives seeking to promote inclusion and active participation in mental health advocacy. For each issue we propose a 'minimum standard' that could be adopted in every health and social care community. The issues are:

- funding;
- black and minority ethnic service users' and carers' involvement;
- language and communication;
- culturally appropriate advocates;
- culturally appropriate advocacy services.

## Funding

Funders have an essential role to play in matching resources to needs, and ensuring that public money for mental health, including advocacy, is being allocated appropriately to service providers. Finding a balance between what services are required and how best to deliver them is not always a smooth task. However, this report clearly demonstrates that mental health advocacy for minority communities is underdeveloped, and that lack of funding and failure to recognise black projects as core providers are influential reasons why this is so, reflecting broader issues of racism in the delivery of welfare services.

Parallel to this, there is also an urgent need to fund independent advocacy services, aimed specially at the African, African Caribbean and South Asian communities. The report identified only two independent black-led advocacy projects across the Yorkshire and East Midlands region.

### *Actions required*

#### *Valuing diversity*

This research identified black projects as the frontline providers, but these projects are few and far between. A more committed and assertive outreach initiative by funders and mainstream providers must be negotiated with black projects.

#### *Funding*

The funding difficulties experienced by the black voluntary sector must be recognised. The importance of strengthening this sector should include the development of a regional network that builds on the current capacity but also consolidates and disseminates innovations, which currently exist in the black sector.

Resources for specific projects should be 'ring-fenced' by encouraging relatively well-resourced voluntary organisations to 'step back'.

#### *Minimum standard*

Statutory funding for health and social care is currently allocated on the basis of the ethnic breakdown of the local population. At least 75% of this funding should go directly to black and ethnic minority groups. For example, if the local population includes 33% of South Asian people, then 33% of statutory funding should be allocated to meet the needs of this part of the population.

These changes will represent a positive affirmation of the skills, expertise and commitment of many black projects. They will also ensure that mental health advocacy is reflective and responsive to the needs of minority communities.

## Black and minority ethnic service user and carer involvement

The research team experienced severe difficulties in accessing service users and carers directly, through either mainstream or black voluntary sector routes. The team found it very difficult to identify any existing regional infrastructures that link black mental health projects in the East Midlands and Yorkshire areas. There were a number of reasons for this:

1. At the time of the research, mainstream white advocacy projects could not identify any black service users or carers who had accessed their service.
2. There appeared to be no black advocates within the mainstream who could act as our links to mainstream projects.
3. Few black-led advocacy projects appeared to exist.
4. Black projects were extremely under-resourced, which often meant that black workers did not have the time to commit to the research.
5. The research could identify only one African Caribbean mental health advocacy self-help group.

6. There seemed to be no local black-led mental health advocacy forums specifically for black and minority ethnic service users or carers.

Service users, carers and black projects raised the following issues:

- research fatigue;
- mistrust;
- failure of consultations to have any direct benefit for users and carers;
- lack of follow-up by research teams;
- failure of recommendations to be followed up by action.

All of the above factors affected the research process. Further, and importantly, they provide evidence of why advocacy services are underdeveloped. Although there are existing mechanisms (such as patients' councils, user forums and advocacy projects) that seek to facilitate user involvement, black service users continue to remain invisible within them.

Mental health commissioners, purchasers and providers must address the issues highlighted above and recognise the need for ensuring community ownership. Without this, advocacy services will continue to develop using mainstream models that are intended to be *for* minority communities but are not *by* minority communities.

### *Actions for black service user and carer involvement*

#### *Development*

There is a need for the development of local mental health advocacy infrastructure, which links users, carers and black mental health projects together, including advocacy and interpretation services.

#### *Outreach*

There is a need for community development based initiatives, which will nurture and support organic systems of involvement. This will mean black advocates going into the community, facilitating consultations and service development in venues where users and carers feel 'safe'. It may be unrealistic to expect marginalised and vulnerable groups of people to attend large unfamiliar meetings or conferences.

#### *Peer advocacy*

There is an urgent need for collective consciousness-raising support groups for black and minority ethnic users and carers. Financial, administrative, location and training opportunities and support from black professionals are vital resources required to ensure the sustainability of these groups.

#### *Minimum standard*

Every health and social care community should consult on and fund the setting up of a locally relevant way of ensuring that black and ethnic minorities have access to local advocacy services and decision-making forums.

## Language and communication

Problems of communication account for a significant proportion of the difficulties encountered by linguistically diverse communities. A shared language is one of the most important ingredients to engender a mutually respectful relationship between a service user, their carer and their advocate.

The report highlights that access to advocacy services for linguistically diverse service users and carers are significantly reduced, primarily because of the lack of bilingual advocates within mainstream services. Interpreters and interpretation services are not well integrated into mental health advocacy services. Even when interpreters are available, the quality and experience specific to mental health systems, policies and practices are often problematic.

### *Actions required for communication and language*

#### *Bilingual advocate*

The preferred choice of black service users and carers is for a bilingual advocate. This was identified to be a positive way of helping service users and carers to feel empowered.

#### *Interpreters*

The recruitment and training of interpreters should be based within a black mental health perspective, to ensure situating the experiences of black mental health users and carers within a social, political and institutional perspective.

Stronger links between interpreters, black mental health projects and mainstream organisations are important in ensuring a mutual understanding as well as for facilitating the inclusion of interpreters who often operate beyond the margins of mental health provision.

*Minimum standard*

Every health and social care community should ensure that service users and carers have free access to advocacy in the language of their choice.

## Culturally appropriate advocates

Service users and carers expressed their preference for representation from a paid advocate reflecting the gender, culture, language and other significant aspects of their identity. At the time of the research, the only place where a service user or carer had access to culturally appropriate services, with an advocate who matched their own cultural identity, was from within the black voluntary sector.

The research found only one Asian bilingual advocate, who has since left the project. In Yorkshire and the East Midlands we found no African Caribbean advocates working within white advocacy projects. There seemed to be two main reasons for this:

1. lack of recruitment of black advocates;
2. lack of appropriate support systems for black advocates.

These two problems may well be rooted within deeper underlying problems, for example:

- lack of 'political will' from white projects;
- institutional racism;
- ignorance of the specific needs of black and minority ethnic people.

Black and minority ethnic advocates working within a white advocacy project often find themselves caught in a position of 'double/triple jeopardy'. Lone black workers are often expected to provide a service based on the values of the majority workforce. These include unrealistic expectations about being able to meet the needs of all 'ethnic' people, and often having to defend themselves from suspicious colleagues in their attempt to address the uncomfortable issues of institutional and individual racism.

The capacity of black advocacy projects remains significantly behind the mainstream in terms of funding, resources and fragmentation of services. For this sector to succeed in meeting the needs of diverse minority communities and to develop new initiatives, a radical shift must be made from short-term to long-term funding accompanied by a recognition of the expertise and specific skills of black projects.

### *Actions required*

*Recruitment*

It is vital to recruit, develop and sustain a black and/or minority ethnic advocate who can help to deliver a high-quality advocacy service that is fair, reflective of diversity and responsive to specific needs and experiences.

*Support*

If mainstream providers are committed to ensuring equal opportunities, then there is an urgent need for the following actions:

- development of a local support system(s) for black and minority ethnic advocates to link into for support, validation, and information;
- supervision that emphasises strengthening the unique skills that a black or minority ethnic worker brings to the project;
- practical support that recognises the emotional issues of providing a complex service to disempowered individuals and groups;
- the development of a regional black forum which operates independently, in order to:
    - liaise with mainstream providers to identify and disseminate good practice in black mental health including advocacy;
    - challenge bad practice, perceptions and practices;
    - support the development of new black advocacy initiatives.

*Minimum standard*

Every health and social care community should ensure that service users and carers have access to an advocate who is competent in issues of race, culture, heritage and gender. This competency must be monitored and evaluated by supervision and appraisal opportunities.

## Culturally appropriate advocacy services

From interviews with mainstream projects, the research concludes that mainstream advocacy providers are not meeting the needs of minority communities. Advocacy services operating from high-security hospitals are also failing black and minority ethnic patients. The reasons for this include the following:

- There are no black advocates.
- Advocacy provision is provided mainly via a colour-blind approach, which fails to take into consideration specific issues relevant to minority communities.
- Links with black mental health projects are weak.
- Information is not culturally or linguistically appropriate.
- Mainstream providers do not yet recognise that their environment is not culturally sensitive or appropriate for black and minority ethnic workers, users and carers. If they do recognise this fact, they fail to rectify it.

### *Actions required*

*Patient Advocacy and Liaison Services (PALS)*

The NHS Plan aims to ensure that the views and experiences of patients and their carers are heard and responded to. This commitment must recognise the importance of cultural sensitivity and awareness, especially where there is a high proportion of black and minority ethnic patients. Within these areas, advocacy must seek to:

- promote cultural identity;
- challenge racism;
- provide information that is culturally specific;
- develop equality strategies that empower minority patients to be included into patients' councils – or, alternatively, to facilitate the development of black-only patients' councils.

*Training*

There should be 'race' awareness training for mainstream mental health advocates, preferably by an independent black consultant, which focuses on:

- training that acknowledges the roots of discrimination, and the obstacles and difficulties it creates for minority communities, both within the community and social care institutions;
- the diversity of beliefs and values systems within the community, including differing notions of empowerment;
- taking practical steps for community development which enhance the advocates' and projects' ability to initiate culturally appropriate methods by increasing contact with mental health projects and black service users;
- recognition of privileged power imbalances.

*Minimum standard*

Mainstream services, including advocacy, must reach a minimum standard of cultural competence. This standard should address the five themes of identity, faith, racism, language and gender. The standard should be agreed at national level and should be a precondition for any statutory funding to the voluntary or independent sector.

## Next steps

Our conclusions echo much research in the field from the last 10 or more years. The recommendations will be no surprise to people who have long called for such changes. We see the greatest need now as being to champion practical implementation rather than to carry out yet more research. We therefore propose the following initiatives to embed the findings into practice:

- There should be seminars to test out the minimum standards with relevant communities. These standards should then be adopted nationally, as a precondition for any statutory funding for advocacy services.
- There should be a promotion of community development approaches to advocacy so that advocacy services for minority groups are located at a community level, for instance

funding pilot projects to work with existing black and minority ethnic community groups to develop individual and community advocacy led by local service users.

- A training pack providing cultural awareness for mainstream advocates should be developed and disseminated.
- A comprehensive training programme for minority people who wish to become advocates, akin to the call for a national training programme for all advocates, should be established.
- Support networks for black and minority ethnic advocates should be set up; ideally, these would be both local and regional.

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