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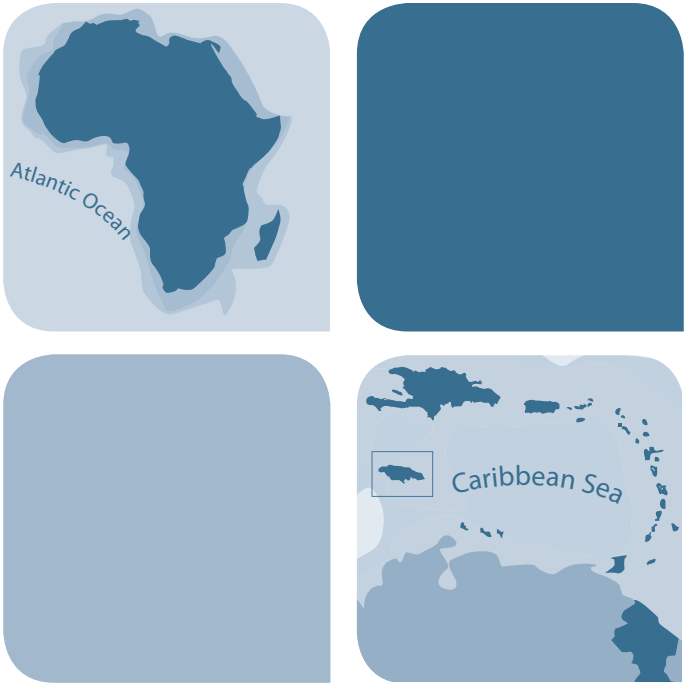
Developing mental health advocacy with African and Caribbean men: summary



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The knowledge review had two elements:

- A research review, to establish what was already known about the provision of mental health advocacy with African and Caribbean men from research reports and service descriptions.
- A practice survey, to establish what is currently being provided and what is needed. This involved an e-mail and telephone survey of organisations that might be providing mental health advocacy with African and Caribbean men, focus groups with African and Caribbean men and case studies in two different localities.

The review was undertaken by a project team that included service users, people from African and Caribbean communities, advocacy services and research staff from the University of Central Lancashire (UCLAN).

Research into advocacy for African and Caribbean men

The research review indicated a significant gap in high quality evidence of both effectiveness and process evaluation of mental health advocacy for African and Caribbean men. The review therefore drew heavily on service descriptions or accounts of specific initiatives.

Need for advocacy

There is a substantial body of evidence pointing to a negative relationship between mental health services and African and Caribbean men, who are under-represented as users of enabling services and over-represented in the population of patients who are admitted to, compulsorily detained in, and treated by mental health services. The consequences of this are poor engagement with mainstream services, restricted choices and high levels of dissatisfaction with mainstream care. The review identified the potential of advocacy to address these issues and to secure access to the most appropriate forms of support.

Provision of advocacy

Serious gaps in advocacy provision for BME communities were highlighted by studies focusing on mental health advocacy. It is apparent from both service descriptions and

studies of African and Caribbean mental health services that advocacy is provided as part of a wider role. This interdependence with other aspects of provision is viewed as promoting greater opportunities for recovery and well-being. These services have typically developed in response to community needs because of concerns about the inaccessibility and inappropriateness of mainstream mental health services for African and Caribbean and/or BME communities. However, the approach to advocacy of these organisations appears to be qualitatively different and consistent with notions of recovery and social inclusion. The lack of sustainable funding and a preference for a different conception of professional advocacy places such services in jeopardy.

All studies drew attention to the importance of cultural sensitivity and shared heritage had a stronger emphasis in studies focused on BME communities. The service descriptions of mental health advocacy services referred to cultural sensitivity but rarely elaborated what this means. However, African and Caribbean and BME services articulated this and made a strong argument for the provision of mental health advocacy by independent community organisations that understand this and the disadvantage faced by African and Caribbean men.

Impact of advocacy

There was limited information about the impact of advocacy but its potential in terms of securing basic rights, creating choices, facilitating involvement in decision making and improving access to complementary way of healing and practical support were highlighted.

Features of good practice in the provision of advocacy with African and Caribbean men

These included:

- advocacy that addresses the double discrimination of racism and mental illness
- the provision of a safe and secure relationship within which the feelings of isolation and consequences of stigma associated with mental illness and racism can be addressed
- the ability to respond to the linguistic and cultural needs of African and Caribbean men, underpinned by an approach that emphasises promotion of health, reintegration of the self, spirituality, self-knowledge and connection to the community
- choice, especially in terms of gender, and demonstrable ethnic sensitivity
- a proactive approach to personal advocacy through community-based action and engagement

- balancing accessibility and informality with professionalism to ensure that advocacy services are delivered to high standards
- a well-trained, well-equipped and well-supported workforce
- partnership working and facilitated networking across organisations to encourage cross-referrals, exchange of information, best practice and mutual understanding
- adequate long-term core funding.

Practice survey 1: email and telephone survey

This survey aimed to establish the range of mental health advocacy that can be accessed by African and Caribbean men. It involved the development of a database of nearly 400 projects, an email survey and a telephone survey of a sample of 52 organisations.

Current provision

Three broad organisational forms were identified:

- African and Caribbean-focused organisations: geared to meet the needs of African and Caribbean communities
- BME-focused organisations: designed to meet the needs of diverse BME communities
- advocacy-focused organisations: stand-alone services oriented to casework advocacy usually referred to as independent professional advocacy.

The survey confirmed that mental health advocacy for African and Caribbean men is most often provided as part of African and Caribbean or BME mental health services, providing a range of other services. They are rooted in the community and therefore understand the importance of Black history, of religious and spiritual beliefs, and of the social problems, in particular racism, faced by African and Caribbean people. Black advocates often voiced their objective as Black empowerment, which intrinsically and inevitably involves challenging mainstream practice.

Mainstream mental health advocacy services start from a different position and emphasise the importance of independent advocacy, often as a distinct service, provided by trained staff. Often this advocacy is short-term and focused on trying to change the relationship between mental health services and a particular service user to ensure they have the sort of help provided in a way that they want. These organisations often do not proactively seek clients, thus disadvantaging African and Caribbean men and members of other BME communities who may find them difficult to access.

While the ideal for advocacy is to achieve empowerment of the individual, in practice, substantial advocacy activity was led by the advocate and approximates to a representational form of advocacy. The location of advocacy

therefore becomes important in terms of the extent to which it will facilitate access to other activities that enable personal development and empowerment and are designed to tackle the underlying causes of disadvantage.

Capacity to deliver the range of advocacy is a key issue. The culturally sensitive provision, African and Caribbean or BME-focused, usually had one or two members of staff to deliver advocacy or it was part of a wider role. This raises questions about the capacity of these organisations to deliver the range of advocacy required. The advocacy-focused organisations were generally relatively well staffed, advocacy was their sole business, but, with notable exceptions did not have the capacity to deliver culturally sensitive advocacy.

Access to mental health advocacy by African and Caribbean men

Many organisations did not formally monitor the ethnicity or gender of their clients and therefore data on uptake of advocacy by African and Caribbean men was limited. Where mental health advocacy is provided by an African and Caribbean-focused organisation, more or less all of its client group will be African and Caribbean. Advocacy-focused and BME organisations have varying proportions of clientele drawn from African and Caribbean communities, reflecting in part the local demography or local provision.

It would appear that African and Caribbean men make relatively reasonable use of broader BME organisations. The use of generic advocacy and mental health advocacy services by African and Caribbean men, however, tends to be low, but there are substantial variations in usage across these services, in part reflecting demographic variations, with a proportion of inner-city services reporting higher usage. There was scant evidence that mainstream mental heath services are actively facilitating access to advocacy for African and Caribbean service users.

Advocacy outcomes

There was consensus that advocacy could enable African and Caribbean men to get heard and have their needs met more appropriately by having a greater say and greater control, particularly in the relationship with mental health services, and therefore more capacity to determine what treatment and support they received. The outcomes advocacy could deliver often related to the personal goals of an individual but in general included:

- greater range of relationships
- increased involvement in care planning and ward rounds
- increased choices and access to a greater range of culturally appropriate care, delivered more consistently and to a higher standard
- diversion from restrictive forms of care

- negotiated changes in treatment, particularly a reduction in medication
- greater independence from mental health services
- successful resolution of complaints
- positive changes in staff attitudes
- increased acceptance and awareness of mental health issues by families and communities
- more community support activated to ensure greater access to a broad range of social opportunities.

The evidence for the impact of advocacy on any of these was weak. Information about outcomes was largely aspirational or anecdotal with organisations citing capacity as the major barrier to routine data collection. Across the different organisations empowerment and the goal of self-advocacy were identified as key outcomes. However, Black and voluntary community sector (BVCS) organisations went further and identified tackling social disadvantage, including racism, as a key outcome.

Preferred characteristics of advocacy services for African and Caribbean men

These included:

- Cultural sensitivity. For African and Caribbean organisations, this usually meant shared cultural heritage. The articulation of what this means by generic mental health advocacy

services was largely under-developed, suggesting either a lack of understanding of what this means, how to achieve it or that it is a low priority.
- Facilitating choice both of type of advocacy and advocate.
- Independence from statutory sector provision was stressed by all organisations but the African and Caribbean and BME organisations emphasised the value of interdependence with other voluntary services, facilitating access to advocacy and the potential for a holistic response to a broad range of social needs enabling men to move beyond a relationship with mental health services.
- Strategies to increase accessibility – outreach strategies, location and identity of advocacy provision, provision of advocacy alongside other activities and sensitive timing of advocacy interventions all facilitate access.
- Sustainable funding enabling long-term relationships and community-based advocacy as well as advocacy in in-patient settings and outreach to prison.

Factors that facilitate development of advocacy for African and Caribbean men

These included:

- understanding of cultural identity and context of negative experiences of mental health services

- understanding of the range of advocacy and its potential
- sustainable funding
- availability of organisations positioned and with the capacity to provide advocacy with BME groups
- effective leadership and management
- collective advocacy and service user involvement
- partnerships between organisations.

Practice survey 2: focus groups and interviews

Four focus groups and a small number of individual interviews were undertaken, involving 30 men in total.

Meaning of advocacy

The term 'advocacy' does not immediately have meaning for African and Caribbean men but is welcomed once there is an appreciation of what it is. This may have implications for access to advocacy and participants had limited experience of advocacy.

Need for advocacy

There was agreement about the need for advocacy and its role in addressing the following issues was identified:

- negative experiences of medication
- lack of involvement in decision making
- lack of access to alternative treatments, particularly talking therapies
- physical confrontations and misinterpretation of behaviour by mental health services reflecting stereotyped attitudes towards African and Caribbean men
- limited opportunities to have personal experience valued
- limited opportunities of engagement with community peers and activities
- involvement of the police and courts in admission
- greater likelihood of detention and lengthier admission periods.

Characteristics of advocates

The men identified the following:

- shared cultural heritage – the importance of roots in the community and Black identity serve to build confidence in the ability of the advocate and service to accurately listen, understand and act on the men's behalf
- choice of gender – particularly access to a male advocate
- personal characteristics – the ability to listen and form a connection and demonstrate commitment to an individual
- competence – advocates need to 'know what they are doing', understand mental health,

what services are available and the needs and context for African and Caribbean men.

Practice survey 3: case studies

Two case studies, and additional interviews with other stakeholders, were undertaken to establish a more in-depth understanding of the commissioning and provision of advocacy with African and Caribbean men. They confirmed and elaborated the findings from the other elements of the practice survey. In addition they highlighted a significant gap with regard to comprehensive and informed arrangements for commissioning advocacy.

Conclusions

While the potential of advocacy for African and Caribbean men is recognised, access is limited with scant evidence of developments in advocacy-focused organisations to engage with this client group. Overlain on this is a mistrust of established mental health services and confusion over the meaning of advocacy, which gets in the way of realising its value and potential benefits.

There is a consensus that African and Caribbean men require advocacy that is culturally sensitive, addresses their experiences of negative interactions with mental health services and facilitates recovery and social inclusion. The evidence on whether mental

health advocacy should be provided by a generic BME or an African and Caribbean organisation predominantly reflected the ethnic affiliation of respondents but also demographic considerations. The review considered the advantages and disadvantages of the three different organisational arrangements and found that in general there was a trade-off between cultural sensitivity and appropriateness and the staff resources available to deliver advocacy.

Further, the review indicated a profound difference in advocacy from that of advocacy on behalf of the majority ethnic group. For African and Caribbean men both culturally specific issues and the context of negative experiences and consequent suspicion of mental health services means that advocates will need to ensure that staff are thoroughly informed and may encounter additional resistance from services. It has also raised questions about the role of mental health services in promoting access to mental health advocacy for African and Caribbean men, and indeed for African and Caribbean women and people from other BME communities.

Delivering race equality identified the development of mental health advocacy for BME communities as a key action for primary care trusts (PCTs). This review indicates first, that a strategic approach to the development of a whole system of advocacy provision is needed. This entails understanding the diversity of needs

within African and Caribbean communities, including those of women and newly arrived communities, notably refugees and asylum seekers, as well as established communities. Transparency, clarity about decision making and the engagement of communities in this process are essential. Second, it implies reframing what advocacy means to include holistic and collective definitions of advocacy, as have developed within the BVCS. It is important that this model is not disadvantaged or dismissed in any future moves to formalise advocacy and the development of more systematic commissioning arrangements. Third, it requires investment in the capacity of the BVCS to deliver mental health advocacy alongside investment in organisations to support their development. The economic costs of providing inaccessible and inappropriate mental healthcare and the potential for recommissioning need to be explored and realised.

The approach and philosophy of BCVS organisations means that advocacy rooted within these organisations is potentially aligned with current models of recovery. This means that advocacy provided by these organisations has the potential not only to ensure the delivery of more appropriate care and achieve the goal of individual empowerment but also to contribute to tackling underlying social disadvantage and inequalities faced by African and Caribbean men.

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