# Mental health advocacy for black and minority ethnic users and carers

Over the past two years, a research and development team has been exploring the needs for advocacy services of black and minority ethnic mental health users in the Trent and Yorkshire areas of the NHS. Overall, the team found that services were very underdeveloped and the needs of these users were overlooked. The study found:

- Where mainstream advocacy services existed, they were inaccessible and often inappropriate to the specific needs of black service users and carers.

- Users and carers were dissatisfied with mainstream mental health services, arguing that these organisations misrepresent, misunderstand and seek to control their experiences and methods of expression.

- Within the study areas, black-led advocacy projects, user forums and user-led self-help groups were significantly less well-developed than mainstream user initiatives.

- Some black service users and project workers, especially those providing services for South Asian communities, believed that interpretation is a necessary component of advocacy. Others agreed that interpretation and advocacy share the aim of improving communication, but saw them as distinct services.

- Many black service users and their carers did not understand the meaning of the word 'advocacy' or how it could help them. This lack of awareness often contributed to their low uptake of services.

- Both black and white advocates felt that service users often suffered in isolation in the community, not knowing that advocacy services existed.

- Although mainstream advocacy project workers interviewed suggested they were developing posts to improve their relationship with minority groups, none were currently engaging fully with black users and their communities.

- Black and minority ethnic service users and their carers felt most empowered when they had an advocate reflecting their culture, gender and ethnicity.

## The research context

*Shaan*, a group interested in race and mental health in Yorkshire and the East Midlands and supported by Trent and Yorkshire Mind, became a network to create opportunities for black people and those from minority ethnic communities to meet and take forward mental health issues.

This action-research project emerged from the thinking of this group. Little evidence existed on how well advocacy in mental health met the needs of black and minority ethnic communities. This, together with existing evidence of inappropriate treatment and unequal access to mental heath services for minority communities, provided a rationale for the project's work.

The initial mapping exercise identified the following gaps in advocacy provision:

- There was a lack of literature highlighting the specific experiences of minority service users and how advocacy can support them.
- Only two black-led projects within the Trent and Yorkshire areas were focusing on advocacy provision.
- No information on advocacy within mainstream services was translated into formats appropriate for service users and carers from minority communities.
- Only one independent black survivor group was identified.
- There was a lack of bilingual advocates within mainstream advocacy projects; this contributed to services being inaccessible to black and minority ethnic service users and carers.

## Tensions

Mainstream literature on advocacy provision includes little about the needs of minority communities and does not promote ways of empowering black service users. Users and carers were dissatisfied with mainstream mental health services, arguing that these organisations misrepresent, misunderstand and seek to control their experiences and methods of expression.

> "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)

The experience of black advocates operating within what they perceived as a hostile environment often left them feeling worn out and frustrated.

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

Black service users and carers in contact with statutory services felt unvalued and misunderstood, and usually chose to withdraw from active participation.  Those remaining engaged with mainstream services often felt they found themselves amidst a patronising environment shaped by stereotypical attitudes.

> "The reality is I see myself 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 often question if it's my culture, gender, and or age that gets a negative reaction." (Black service user)

## Advocacy and interpretation

Mental health and advocacy projects, both black and mainstream, have argued for a clear distinction between advocacy and interpretation services but major disagreements remain.  This research found that some black service users and black projects, especially those providing services for South Asian communities, believed that interpretation is a necessary component of advocacy.   Other advocates agreed that interpretation and advocacy share the aim of improving communication, but saw them as distinct services.  However, providers can only make distinctions on the effectiveness of and the most appropriate links between advocacy and interpretation services, when the experiences and views of African, Caribbean, South Asian and other service users and carers whose first language is not English are considered.

## The concept of 'advocacy'

Black service users, carers and advocates raised similar concerns in questioning the usefulness and relevance of the word 'advocacy'. They argued that it is too technical and alienating for people speaking 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 [advocacy] into Asian languages. We start from where the user is at …  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)

One advocate, working with an Asian women's project, explained what advocacy meant in practice:

> "[It] 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. … 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)

## Self-help and empowerment

The research highlighted a number of tensions in the relationship between mainstream and minority services:

- Whilst mainstream workers regarded advocacy as a distinct service, black project workers saw most of their work as advocacy.
- The urgent need for adequate services for minority communities, combined with extremely limited

funding, means services meeting basic needs such as housing are likely to be prioritised over advocacy services.

- Low expectations amongst excluded and disempowered communities create a climate where advocacy is not considered as useful or realistic.
- Much advocacy in minority communities is informal and voluntary, being viewed as part of being a good community member or as an expression of faith and its values of helping.
- Black advocates felt that their objective of black empowerment intrinsically and inevitably involved challenging mainstream practice.

Although mainstream advocacy project workers interviewed suggested they were developing posts to improve their relationship with minority groups, none were currently engaging fully with black users and their communities. For example, in the organisations interviewed:

- there were no black or bilingual advocates;
- very few black service users were accessing the service;
- relationships with black voluntary mental health projects were weak or non-existent;
- there was little awareness of the distinctive needs of black service users;
- no information was provided in languages spoken by minority communities.

Both black and white advocates felt that service users often suffered in isolation in the community, not knowing that advocacy services existed. Reasons for this included:

- information is not given to black service users by mainstream agencies;
- the stigma of mental illness;
- mistrust of both voluntary and statutory agencies;
- language barriers;
- culturally inappropriate advocacy definitions;
- precariously funded and pressurised black projects, having little time for community development.

## Good practice in advocacy

Black and minority service users and carers identified the following elements of good practice:

- 'Black and minority advocacy' needs to challenge the double discrimination of racism and mental illness experienced by black people.
- Advocacy should promote the integration of complementary ways of healing, and facilitate access to culturally appropriate services.
- Advocacy should empower black service users and their carers to identify their own needs and culturally appropriate ways to meet them.
- Black service users wanted independent accessible black-led advocacy services.
- Advocates should reflect users' cultural background, language and gender.
- Advocacy should promote a greater holistic

appreciation of five themes - identity, faith, anti-racism, gender and spirituality - as key components for better mental health.

Additionally, advocates themselves should:

- be able to talk to users' in their chosen language;
- listen and understand their issues and experience;
- have the authority to challenge professionals;
- be someone users can identify with, i.e. through culture, identity and gender;
- be able to offer consistent long-term support;
- be trustworthy;
- provide accurate information relevant to individual needs; and
- be accessible at a community level.

Contrary to the ideals of self-advocacy, black and ethnic minority service users and carers prefer to have paid professional advocates, reflecting their ethnicity and gender and representing their views and experiences:

> "We want black workers to be a voice for us."

> "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' … it is very difficult to get white people to understand my cultural needs."

> "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."

## Advocacy in action

Based on the views of service users and carers, the project developed 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 self 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.

Importantly, service users, carers and advocates identified that advocacy must include the fundamental aspects of a shared cultural identity. They felt that advocacy services and notions of empowerment could not successfully empower minority groups without integrating culture, faith, anti-racism, spirituality and gender.

Furthermore they felt advocacy should go beyond individual empowerment and must influence 'the system'. Black advocates and mental health projects generally seek to empower service users by offering advice, information, representation, translation/

interpretation, befriending, with both specific support for particular groups and holistic support for all users and carers, and in a context of confidentiality. This promotes social inclusion by raising awareness and challenging mainstream policy and practice.

Although much black advocacy work involved reacting to crises, advocates illustrated what pro-active and culturally appropriate work meant in practice:

- contacting small self-help groups within community networks;
- working within GPs' surgeries;
- use of community radio;
- promoting services through word of mouth;
- open days held within the community;
- home visits;
- support groups for service users and carers to express distress, to identify difficulties in accessing services, or for specific groups such as women or older people;
- befriending groups for peer support;
- partnerships with generic black mental health projects.

## Conclusion

The project identified two distinct strands of advocacy. The first, common to mainstream advocacy, is about supporting the individual. The second, whilst having some features in common with mental heath empowerment, is termed 'Community Advocacy'. This approach can create culturally appropriate structures, enabling communities to identify and take control of the development of new services.

The researchers conclude that, without culturally appropriate models, advocacy and mental health services will be unable to meet the needs of African, Caribbean and South Asian communities. Integrated services, which aim to provide a service to the whole of the local community - white, black and minority ethnic people alike - still continue to alienate many people of different nationalities.

The issue arising from the research was the importance to users of being able to choose which type of service best suits their needs. However, black-led advocacy projects are sparse, and choice is not always a viable option. Mental health advocacy best meets the needs of black service users and their carers if it acknowledges their specific experiences of disadvantage, often resulting from very different causes than for white users. The team recommends a proactive community development approach – building on existing black mental health projects - for the continued development of mental health advocacy, to facilitate the empowerment of individuals and communities who are often excluded from power and decision-making processes.
The researchers suggest the following steps for mainstream advocacy networks and local advocacy providers to promote culturally sensitive services:

- make explicit commitments to sharing resources, expertise and access to decision-making with black projects, service users and carers;
- encourage black service users and their carers to define their own needs and act upon these definitions;
- 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;
- patient and user led forums should represent minority membership; this may require local capacity building in voluntary and community organisations to enable a meaningful two-way process of engagement.

## About the project

The action-research team, supported by Trent and Yorkshire MIND, and by researchers from the Universities of Hull and Leicester, set out to produce best practice recommendations in black and minority ethnic mental health advocacy. Twenty-seven projects were mapped and 12 projects were interviewed in depth; 5 of these projects were mainstream generic advocacy projects, 7 projects were within the black voluntary sector. Service users, carers and advocates were consulted in a variety of ways, including focus group discussions, workshops, one-to-one and telephone interviews.