

Black Spaces Project



The *Strategies for Living* project is a user-led programme of work based at the Mental Health Foundation and funded by the Community Fund. It aims to document and disseminate people's strategies for living with mental distress through a UK network of research and training, conferences, newsletters, and publications.

Note on Terminology and the Use of Language

The phrase 'Black Spaces' has been used in the title of this project as a way of connecting citizens – African, Asian, Chinese, and other non-white peoples and communities under one banner. The steering group for the project acknowledges that this is not ideal but to date there is no universally acceptable word that can be used to describe people who are non-white. This report therefore uses the term 'Black' when making general references but uses African, Asian or Chinese when specific references can be made.

In the descriptions of projects visited the terminology used by the staff and users to describe their services has been adopted, for example, assertive outreach work or rehabilitation centres.

Contents

Executive summary	2
Foreword	4
Preface	5
Acknowledgements	6
The birth of the Black Spaces Project	7
The harsh reality of Black people’s experience of mental health services	9
What happens at seven Black spaces?	11
1. African Caribbean Community Initiative (ACCI)	11
2. AWAAZ Manchester Limited	11
3. AWETU	12
4. Forward Project	13
5. Family Health ISIS	14
6. Newham Asian Women’s Project (NAWP)	14
7. Qalb	16
How the Black Spaces Project established itself	17
Action on the ground	18
Recommendations for future work	31
Conclusion	33
References	34
Appendices	35

Executive summary

Black African-Caribbean people in the UK are over-represented in secure psychiatric units and are twice as likely as white people to be diagnosed with a mental health problem but are less likely to access some forms of treatment and care, such as psychotherapy. Other communities and groups hardly access mental health services at all. So it is not surprising that Black people feel their needs are not met by the mainstream mental health system. As a result a number of Black voluntary organisations have tried to fill the gap. They have created culturally sensitive environments, offering alternative forms of therapy and advocating for Black people in the mainstream mental health system. The Black Spaces Project set out to discover how some of these organisations work and to disseminate learning from their experience to other Black organisations and the wider mental health care system.

The Black Spaces Project forms a key part of the Mental Health Foundation's focus on user-led research. It is part of the Strategies for Living programme that encapsulates a strong belief in learning from the experience of users as well as staff. This was a dominant feature of the site visits, which supported this programme.

However, many Black organisations do not have time to find out how other organisations operate as they are stretched to the limit, working with few resources and trying to provide a range of services.

The Black Spaces Project aimed to plug this gap by researching and documenting the experience of seven Black organisations, so that both Black and mainstream mental health services could benefit from their expertise.

A small focus group of experts in the field was set up to guide the project and a team of consultants including users was engaged to visit seven Black and Asian organisations.

Their feedback is detailed in the report in terms of brief descriptions of the projects, key themes that emerged and recommendations for good practice.

Key themes include:

- The importance of working in partnership.
- How advocacy is vital to secure Black people's rights.
- Unsuitable premises cause problems for service users and staff.
- The importance of empowering users.
- Balancing organisational expansion with retaining a focus on core activities.
- Strategies for preventing people from unnecessarily entering the statutory mental health system.
- The importance of cultural sensitivity to Black service users.
- How culture specific fear and anxiety around mental illness can impact on Black users and services.
- Organisations having to dance to the funders' tune.
- The importance of outreach work to engage positively with service users.
- Involving families and the community in care.
- Creating organisations with a sense of Black identity.

Examples from the projects illustrate how these themes impact on users and staff. The consultant team has distilled this information into a set of suggestions for best practice, learning from the experience of the projects.

These include:

- Conducting outreach work.
- Respecting clients as citizens.
- Promoting adult education classes and training.
- Providing gender specific services.
- Attaining tangible quality standards.
- Influencing the design of buildings.
- Co-ordinating volunteers and allowing service users to volunteer.
- Respecting cultural differences.
- Focusing on wider issues.
- Producing and distributing information.
- Empowering users.
- Training student mental health workers.


The report also sets out recommendations for future work by the Black mental health sector as a whole. This includes setting up a user consultancy team to help develop organisations. It also advocates closer collaboration between organisations in order to learn from each other and to influence the mainstream mental health sector.

Foreword

I am very pleased that through the leadership of Yvonne Christie, the Mental Health Foundation has been able to support this small but significant project to document some of the good practice which exists within Black led mental health services.

As someone involved in mental health services and policy in a number of ways for many years, I have always been shocked by the treatment of Black people within the mental health care system. I have personally observed many problems including patronising and paternalistic attitudes, over-representation in some parts of the system and under-representation in others, poor involvement of families, carers and communities, and possible covert racism. My experiences of observing and monitoring mental health services, and participating in the Sainsbury Centre's Review *Breaking the Circles of Fear*, have left me angry and ashamed about the treatment of Black people. However, I also believe there is real hope of providing better mental health services to Black people through a combination of more sensitive mainstream services and support for Black led services, working in partnership with the statutory sector.

I hope you find this report helpful and I commend it to you.

A handwritten signature in black ink, reading "Dr Andrew McCulloch". The signature is written in a cursive, flowing style.

Dr Andrew McCulloch
Chief Executive, The Mental Health Foundation

Preface

This report has been pulled together in celebration and recognition of the varied and important work that is delivered by the Black voluntary sector to people who have mental health and or psychological needs. For many years – these particular service providers that work for their communities have gone unrecognised – not because the delivery to Black people is unappreciated but simply because there have not been sufficient publications heralding the Black voluntary sector work in the mental health field.

Black Spaces can hopefully go some way to shifting that story – in its appreciation of the seven projects that are documented on the following pages.

I hope that this publication gives an accolade to the many people who set up these organisations for the Black community – often on a shoe string relative to the work that is delivered and often deeply appreciated by those communities who find mainstream mental health services officious, stuffy and unwilling to look deeply enough at the ‘human and practical needs’ that many Black individuals require to be met to ensure that their world changes for the better.

I really appreciated spending time with all of these projects, shadowing their work on a day-to-day basis, allowing insight into some of the good work that is being delivered. I am sure that we all know that there is still much work to be done, before we can sit back on our laurels and state that we are delivering all that people need, but this work and report is the beginning of more work to come in the field of Black mental health.

Yvonne Christie
Black Spaces Lead Consultant

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Much appreciation is also given to all the projects, including their workers and managers, who offered their thoughts, histories and time. Thanks also to the people who use the services who kindly allowed us to observe their lives.

Finally, thanks to the all the user consultants: Helen, Premila, Paul, Dominic, Hanif and Veronica for all their hard work.

This report was written by Yvonne Christie and Nicola Hill.

The birth of the Black Spaces Project

In 1995 the Mental Health Foundation held a seminar called: ‘Race and Mental Health – towards a strategy’. Participants stressed the need for dissemination of the experiences of Black voluntary sector organisations working in mental health.

The following year, the Mental Health Foundation carried out a user-led survey, directed by a group of service users of alternative and complementary treatments and therapies in mental health. The evidence from the survey, published as *Knowing our own minds*, suggested that while many people find medication to be helpful, many have also tried a range of different ways of dealing with the difficulties they face. These range from formal psychotherapy or counselling and the whole range of complementary therapies, through to hobbies and leisure activities such as walking, sport and reading. In addition, the majority of people in the survey reported that they had developed their own personal ways of coping, and two-thirds mentioned self-help strategies.

The survey was followed up by in-depth interviews with 71 people who had experience of mental health problems. This research identified common themes, ‘most helpful’ strategies and support systems, and was published as *Strategies for Living*. The overwhelming theme running through people’s ‘most helpful’ strategies and supports was the role and value of relationships. These could be with family or friends, people encountered through day centres and self-help groups or mental health professionals such as counsellors, support workers or social workers.

In 1998 the Foundation started its innovative work in supporting a series of user-led research projects. Reports on the first five projects were published in 2001. They include: *An Investigation into Drop-Ins*, *Research Project into User Groups and Empowerment* and *A User-led Research Project into Mosque: exploring the benefits that Muslim men with severe mental health problems find from attending Mosque*.

Through its research the Strategies for Living programme seeks to influence a wide audience from frontline workers and professionals to researchers, policy makers and service users. It emphasises the importance and value of ‘expertise by experience’ and of evidence gained through user-led research and initiatives.

‘We are all the primary experts on our own mental health and about what works for us . . . we can and should value the coping strategies we have developed for ourselves.’

A fundamental principle of the programme is the belief that we are all experts on our own mental health, and our expertise needs to be both valued and shared. The project is led and staffed by people with experience of mental distress.

Key elements of the programme’s current work include supporting user-led research into subjects such as self-harm, domestic abuse and coping with mental distress in a psychiatric hospital setting.

The Foundation is also supporting projects looking at examples of good practice in user-centred initiatives in adult mental health and supporting people with the label of personality disorder, as well as evaluating the use of advance statements for service users. The Black Spaces Project is a part of the Strategies for Living

programme. The aim of the project was to spend some time with a small sample of Black mental health voluntary sector organisations, in order to understand the services that they deliver and assess lessons to be learned from their experience.

The aims of the project were:

- Encouraging the documentation and the development of similar Black projects.
- Enabling mental health services to work more effectively with Black people.
- Giving an opportunity for voluntary sector projects to receive appropriate recognition.

Objectives of the Black Spaces Project

- To conduct visits to seven Black mental health voluntary sector projects identified through the Foundation's Strategies for Living research.
- To document what enables the Black voluntary sector to operate successfully and discover what is unique about it.
- To ascertain how Black staff try to deliver a Black service.
- To involve user consultants to give a different yet crucial component to the observations and visits.
- To document the visits in an appropriate fashion for sharing with other organisations who may need practical guidelines for service provision.
- To explore with the identified projects and staff, what other outcomes or products they would find useful, with a view to developing a proposal for future work in partnership with the Foundation.

The harsh reality of Black people's experience of the mental health system

– why Black spaces are important

Research shows that Black groups often have a negative experience of the mental health system. African Caribbean people are over-represented in secure psychiatric units, are twice as likely as white people to be diagnosed with a mental health problem and three to five times more likely to be diagnosed and admitted to hospital for schizophrenia. Yet this experience does not marry with the epidemiology – a recent Home Office report suggests that African Caribbeans do not have significantly higher rates of psychotic illness – including schizophrenia – than other population groups.^{1 2 3 8}

Mainstream mental health services often fail to meet the needs of Black communities because they are not sufficiently sensitive and responsive to the diversity of culture and experience.³ Research also suggests that Western approaches to mental health treatment are often found to be unsuitable and culturally inappropriate to the needs of Asian communities, who tend to view the individual in a holistic way, as a physical, emotional, mental and spiritual being.⁷

Black groups are also reluctant to engage with mainstream mental health services because of negative and sometimes traumatic experiences of medication and hospital treatment. Other factors include the perception that psychiatry is intrusive, the stigma of mental illness and the view that mental health professionals are exercising another form of discrimination and social control.^{9 13}

This reluctance can lead to a downward spiral of negative experiences. As Black people tend not to access mental health care through primary care settings, their condition worsens and they often present their needs in a public crisis when the police and compulsory procedures are involved.¹²

Once Black people do present for treatment, they are also more likely to be given a diagnosis of severe mental illness, to be held under a section of the Mental Health Act (1983)⁵ and are more likely to receive medication rather than be offered therapies such as psychotherapy.⁶

Further research shows that when people from Black groups are in the mental health system, those who have a diagnosis of severe mental illness are more likely to disengage from mainstream mental health services, leading to social exclusion and a deterioration in mental health.⁴

Various public policy initiatives have tried to tackle these problems. The 1999 *National Service Framework for Mental Health*¹⁰ emphasised the poor sensitivity of existing services to African and Caribbean people. One of the key aims of the 2002 NHS Plan was to address inequalities in health, especially for people from minority ethnic communities.¹¹

However, the Department of Health issued a report in March 2003 acknowledging that neither of these policy initiatives adequately addresses the particular needs of Black people. The report, *Inside/Outside: Improving mental health services for Black and minority ethnic communities in England*,¹⁴ sets out an agenda

for improving mental health services for Black communities. It has three key objectives; to reduce and eliminate ethnic inequalities in mental health services; to develop a mental health workforce that is able to deliver an effective service to a multi-cultural population; and to build capacity within black and minority ethnic communities and the voluntary sector to deal with mental health issues.

In the foreword, health minister, Jacqui Smith, states: 'Tackling ethnic inequalities within mental health services, in terms of prevention, early detection, access, diagnosis, care and quality of treatment and outcome is one of the greatest challenges facing us.' She sees this report as the 'beginning of a historic dialogue'.

Another report out last year suggests there is a lot of talking to do as the problems run deep for both service users and mental health service staff. The Sainsbury Centre for Mental Health produced a research report, *Breaking the Circles of Fear*, looking at the impact of racism, cultural ignorance and stereotyping on the delivery of mental health services to African-Caribbean people.⁹ The report states: 'When prejudice and the fear of violence influence risk assessments and decisions on treatment, responses are likely to be dominated by a heavy reliance on medication and restriction.'

'Service users become reluctant to ask for help and or to comply with treatment, increasing the likelihood of a personal crisis, leading in some cases to self-harm or harm to others.' The report says that this can reinforce prejudices and in turn lead to more coercive responses by people delivering mainstream mental health services. It calls this downwards spiral, 'circles of fear', in which 'staff see service users as potentially dangerous and service users perceive services as harmful'.

The research report documents these 'circles of fear', finding that Black service users are not given a voice in mainstream mental health services and at the same time Black-led community initiatives are not given enough secure funding.

The report recommends empowering the Black community to develop 'gateway organisations' which can build bridges between the community, services and individuals. It also suggests a programme of mental health promotion aimed at and owned by the Black community, as well as more support and training for Black primary care staff.

It says that the government should create more funding opportunities for national and local Black mental health organisations.

The recommendations from this report and the plethora of research material point to the need for Black spaces where people from Black groups can find a mental health service tailored to their needs and culture.

The Black Spaces Project looks at some existing Black organisations currently operating in the field of mental health and asks how they can build the bridge between the community, mental health services and individuals. It should be noted again, that this project adopted a wider definition of 'Black' than the Sainsbury Centre report, which addressed the particular relationship between African-Caribbean people and mental health services. Different ethnic groups experience mental health services differently, albeit there are commonalities of racism, inappropriateness and poor access.

What happens at seven Black spaces?

A brief summary of the seven projects visited by the Mental Health Foundation and user consultants

Project 1

African-Caribbean Community Initiative (ACCI)

Based in Wolverhampton in the Midlands this project was set up in 1987. A group of Rastafarians founded the organisation because they were concerned about the over-representation and treatment of African-Caribbean people in the psychiatric system.

ACCI is committed to increasing the quality of life for African and Caribbean people who are experiencing or recovering from mental ill health. It refers to users as members and develops and delivers user-orientated, structured and unstructured activities. ACCI also offers the services of a proactive outreach staff team to assist in meeting the needs of its members.

ACCI operates a day centre every day of the year except Boxing Day. It opens on Christmas Day in recognition that this is one of the loneliest days of the year. At the time of the research ACCI managed a total budget of £175,000 and ten staff.

ACCI's services include:

- A mini-bus to take people to community activities in Wolverhampton.
- Computer classes held on a weekly basis.
- Physical activities including football, bowling and keep fit.
- Regular forums including carers' meetings and women's groups.

Housing provision includes:

- Eight self-contained flats for people who need very little support.
- Medium level management support within a two-bedroom house.
- Three bedsits for people who need a high degree of support.

Project 2

AWAAZ Manchester Limited

AWAAZ was set up over 10 years ago and is based in a predominately Asian area of Manchester, where 40% of the population is Asian or Black.

The idea to set up the organisation came from one of the current management committee members who had used psychiatric services and realised the importance of delivering services that addressed Asian people's needs. AWAAZ targets Asian men and women but it also reaches out to other groups including Africans and white

people. Over the years AWAAZ has moved away from a sole emphasis on mental illness as they have found this stigmatising in the Asian community.

The senior team at AWAAZ sees the needs of Asian people as much wider than mental health, addressing health and social needs, for example employment and training. The high street office has a shop front and is equipped with computers and desks where people can access learning.

The organisation also has an employment team to work with the local job centres to help Asian people whose first language is not English. There is a male and female member of the team to help with gender specific enquiries. They have developed training packages that incorporate:

- Identification of skills.
- Confidence building.
- Development of language skills.
- Maths and English.
- IT skills.

Project 3

AWETU

AWETU, which means 'unity', is based in Cardiff in a self-contained house on a residential street. It was set up 12 years ago as a befriending scheme in response to concern at Black over-representation in the psychiatric system. AWETU is currently the only Black mental health group in Wales.

The organisation strives to support all Black people confronted by mental illness, through the delivery of its own services. It also aims to influence the services provided by others, so that they are effective and sensitive to the needs of their Black users.

AWETUs budget totals just over £50,000 allowing for a full-time project manager, a three-day-a-week volunteer co-ordinator and one full-time administration and information officer.

The service provides:

- A regular newsletter.
- Advocacy.
- Advice and information.
- Representation on strategic forums and working groups.
- Workshops and training for organisations such as the police, probation service and learning disabilities services.
- A drop-in group for women.
- A mixed group drop-in.

Project 4

The Forward Project

The Forward Project is based in West London and works with people of African and African Caribbean descent aiming to keep them out of psychiatric hospital whenever possible with care and support in the community.

The organisation began its mental health work in the early Nineties springing out of political work that was started by women living on some of the estates in Hammersmith and Shepherd's Bush. Forward came into being as a reaction to the large numbers of young Black men being picked up by the police, which often led to their admission to psychiatric hospitals.

The Forward Project has 17 paid posts and in addition uses the skills of students on placement and volunteers. It has a residential care home in Shepherd's Bush, called Nia House. This has eight single bedrooms usually occupied by men, although the project has resisted stating that the facility is for men only. The Forward Project also runs a resettlement scheme.

Other work carried out by the Forward Project

Floating Support Scheme

This area of the Forward Project's work entails supporting up to 12 tenants who are living independently in their own homes within the community. The work involves taking on practical problems such as sorting out benefits and repairs. In future, the plan is for the scheme to address people's longer-term needs such as getting back into education or work.

Family Support

The Forward Project has a dedicated worker to offer information, advice and support to the families of people with a mental illness.

Counselling and Psychotherapy

Counselling and psychotherapy are offered free to people living in the boroughs of Ealing, Hammersmith and Fulham with sliding-scale fees on offer to those outside these areas. In most cases clients can choose a male or female worker and the service is able to offer several languages.

Advocacy Services

The advocacy worker was new in post at the time of the Black Spaces Project visits but had already begun developing partnerships with the local Mind organisation and making strong links with people using the Charing Cross hospital.

Project 5

Family Health ISIS

The project was started in 1986 by a steering group who were responding to the reality of African and Caribbean people, especially men, being over represented in the psychiatric system.

This project is based in the main shopping area of Catford in the south London borough of Lewisham. The centre was purpose built with joint funding from health and social services.

The organisation has two sites, a day centre in Catford with 11 staff and an assertive outreach team of six in Deptford. The organisation also has a number of students who are training to be community workers, social workers and community psychiatric nurses.

The day centre runs the following activities:

- Sewing workshop.
- Women's group.
- Social gathering.
- Men's group.
- Creative writing workshop.
- Music workshop – incorporating an in-house band.
- A one-to-one counselling service.
- Advice and information.
- Literacy classes.
- Benefits advice.

Offsite activities co-ordinated from the Catford centre include:

- Hospital liaison work.
- Gym sessions at the local leisure centre.
- Outreach work.

The assertive outreach service work includes:

- Making and keeping contact with hard to reach Black people.
- Liaising with community mental health teams.
- Resolving practical problems.
- Keeping people out of hospital.

Project 6

Newham Asian Women's Project (NAWP)

Newham Asian Women's Project (NAWP) is based in Newham, East London, in an area with a large Asian population. It was set up in 1987 to provide advice and support for Asian women and their children who were experiencing domestic violence. It has now expanded its range of services to include:

- Housing.
- Refuge and safety for women and children who are abused either physically or emotionally.
- Counselling in mother tongues.
- Legal advice and information on immigration and financial issues.
- Support groups for young women.
- Befriending for people with mental health needs.
- Training skills and education classes for unemployed women.

NAWPs main office provides the majority of the advice, information, mental health and training sessions. NAWP services are also based in different facilities within the community. For example, the support groups for young women are based in a community centre, which is walking distance from the main premises. The housing and refuges are based in different parts of East London and are only visited with prior permission from the residents of the facilities as well as the management committee and director of the organisation. The priority area for NAWPs work is Newham with a fairly recent extension into Haringey in north London, where it manages a further hostel.

NAWP has approximately 30 staff and a number of volunteers. It has a combined budget of around £1 million. It runs a number of projects including the Zindaagi Project and Teens work.

The Zindaagi Project

The Zindaagi project is a partnership initiative that is funded by East London Health Action Zone. The worker is based in the East London and City Mental Health Trust (ELCMHT) and managed by NAWP.

The aim of the Zindaagi Project is to:

- Develop and co-ordinate support services for young Asian women who are vulnerable to suicide and self-harm in East London.
- Develop specialist counselling services.
- Offer support and information for Asian women's voluntary sector organisations in providing support to young Asian women in distress.
- Provide training and awareness workshops to frontline health, social care and educational professionals.
- Establish a specialist crisis refuge for young Asian women vulnerable to suicide and self-harm.

Teens work at NAWP

This group is for teenage girls, many of whom are vulnerable to self-harm and suicide. It runs activities to increase the girls' trust and confidence and operates a mini bus service to ensure safe transport home. This service is sensitive to the Asian family culture that would normally frown upon young, unaccompanied girls being out after school hours.

Project 7

Qalb

Qalb is based in east London and began in 1993. It operates over three sites with a day centre in Walthamstow on the ground floor of an industrial site. It was developed after professionals realised that there was no provision in the area for the Asian community. The service began by developing a counselling service. In 1995 it was agreed that Qalb needed to develop a rehabilitation centre, which operates from the day centre.

The aim of the project is to provide daytime opportunities for Asian people who have severe or enduring mental illness. Qalb's philosophy is to ensure that people using the centre have the chance to do something useful and productive.

In 1998 the alcohol and drug counselling service was established and in 1999 Qalb developed Quality Protects, which is a service that provides short breaks for young children. Quality Protects also provides after school clubs.

Qalb employs a director of the organisation and each service area has its own manager. There are also three part-time workers, administration staff and volunteers.

Qalb offers classes including maths, English and computer studies. Asian meals are provided at low cost to users. Other activities include screenings of Asian films and art classes with some groups running as single gender and others mixed.

At least twice a week there are therapists who come in and offer Indian head and shoulder massage and reflexology. People who use the service also have access to the counselling service, which is off site.

How the Black Spaces Project established itself

- The Foundation set up a steering group comprised of service users, people with experience of developing initiatives on race, Foundation staff and a consultant researcher.
- This group established the terms of reference of the project. These included the consultant spending at least three days with each agency shadowing their various work areas and acting as an observer/student. A separate two-day visit would also be organised for user consultants who would provide service user feedback and observations from a user perspective.
- Appointments were then made with various agencies for an initial face-to-face consultative meeting. Letters were written to agencies clarifying the expectation of organisations.
- The subsequent visits to the agencies included spending time with the senior worker, observations and discussions with staff, and attending staff and service user meetings as well as community visits.
- Shadowing visits included a seminar in Cardiff with the AWETU Project on the needs of Black people with disabilities and a visit to a hospital in Lewisham to advocate for people on psychiatric wards.
- Similar information was collated about each agency, for example, location and suitability of the building; target population; services on offer; number of staff; number of volunteers; number of students involved; funding; brief history of the set up of the organisation.
- It was agreed that the user consultants would visit the agencies and ensure that the people they were consulting were comfortable enough to talk and share their often difficult and traumatic experiences.

It was therefore agreed that user consultants should focus on:

- People's lives before they had a mental health experience.
- Initial feelings when arriving at the service.
- How the project helped them.
- How staff at this project dealt with them.
- How they saw their future.

Action on the ground

Key themes that emerged from visits made by the Black Spaces Project, with examples of work in practice

The importance of partnership working

ACCI's success within the community is based on partnership working. For example, much of the housing support and management at ACCI has been made available through working with two housing associations. Rather than being overtaken by mainstream organisations, ACCI knows and uses its power which lies in its ability to work well with Black men, who some of the mainstream organisations have given up on. The agency works with the psychiatric hospital, negotiating care and discharge packages as well as the Benefits Office, getting money for its members.

Staff at the Forward Project sit on the local housing referral panel. This proves a useful networking opportunity as other members of the housing panel include representatives from the local housing association, the local housing department and the liaison worker from the local hospital. Each representative ensures that their input benefits the clients. This involvement means that they can quickly refer appropriate individuals who are looking for housing to the Forward Project. It also means that when vacancies come up the organisation can have a clear picture of who would suit the vacancy.

Advocacy Work proves vital to secure Black people's rights

Many of the Black users of ACCI have found themselves on the receiving end of harsh treatment either from the psychiatric system or the penal system. Advocating on behalf of clients and their families has therefore become commonplace and is an integral part of much of their work.

At AWAAZ, advocacy workers negotiate with health professionals around diagnosis and treatment and ensure that interpreters are appropriately versed in mental health issues to represent their clients' wishes. Interpreters' mental health knowledge is particularly important when explaining psychiatric terminology and sections of the Mental Health Act.

However, AWAAZ's staff are keen to ensure that their work with clients does not foster a culture of dependence. Therefore time is spent developing people so that they advocate for themselves, with AWAAZ operating as a support during that transition.

When people are admitted to hospital, AWAAZ interprets people's rights and clarifies the situation they may find themselves in. At other times, hospital units may call AWAAZ in to offer a different angle and perspective around assessments.

AWAAZ has adopted a role in interpreting people's rights under the Mental Health Act, for example, relevant information about treatments and prescribed medication as well as possible side effects. The statutory sectors have included AWAAZ in a number of cases involving Asian people, not only as interpreters but also

as independent advisors to their services, and to assist the multi-disciplinary teams in devising more appropriate care packages.

Unsuitable premises cause problems for service users and staff

ISIS staff talked about the restrictions of their building, causing separation between the staff team and members as well as raising safety issues. Some staff were able to get on with their paper work more easily; however, because of the layout, more staff had to be on hand for security reasons.

For AWETUs long-term future, it would be good if it could secure appropriate premises to offer on-site services.

The Forward Project has many sites, so the co-ordination of the users' voice can be quite challenging. Some buildings were not designed to enhance integration for example, some had codes to open doors, security cameras or staff offices upstairs – others had good facilities but felt clinical.

User consultants felt that Qalb's building was bright, light and airy with a sizeable resource in the day centre. The arts and craft therapist had achieved a lot for the users and the centre, with much of the work undertaken adorning the walls.

A good building block: Feedback from service user consultants on ISIS

- It's very clean with lots of information on the walls.
- There were also lots of Black pictures and posters with poetry on the walls.
- There is disabled access to the building and a lift goes to the two floors and has ample room for anyone with a wheelchair.
- There is a shower room with a washing machine and dryer.
- There are rooms for counselling and lots of storage space.

The importance of empowering users

Feedback from the user consultants showed that ACCI seems to have an interactive and vocal user group, giving people some power and confidence in themselves. Consultants said this could be further improved by having user groups that are run totally by people using the service.

The user consultants thought ACCI was seeped in 'Blackness' and professionalism, with a high regard for the people who use the service, who in turn totally respect the organisation. Consultants said it felt like a safe environment with a warm atmosphere.

Very early on in its development, ISIS undertook to discuss with the people who frequent their services, what they thought about using the term 'users'. They found out that users was a term that their members couldn't relate to especially as they stated that everyone uses health and social services at sometime or other. The term that people who use the service and the staff find comfortable is the term 'members'. People feel that this way they belong to an organisation with which they have chosen to be involved.

User consultants felt that in some organisations, user groups were not always effective in obtaining users' views and feedback. For example, while attending one users' group the consultant noticed how the staff did all the talking and the users were very quiet. The worker facilitating had many 'business' and practical house items to go through. However, in the kitchen, when no staff were present, the users were complaining about the food and saying that they didn't get the things they were asking for and that the organisation needed to address more Black aspects of their lives.

On a more positive note, the Zindaagi Project work was prioritised as the result of some direct consultation and feedback from Asian women. This was also prompted by evidence, which showed that Asian women were three times more vulnerable to suicide and self-harm between the ages of 15 and 35 years of age than their non-Asian counterparts.

Coping with expansion while not losing focus on core services

The expansion of organisations can put pressures on staff time as they are called on to play a wider role by funders and planners.

One of the strengths of the Forward Project is its ability to have transformed itself from a relatively small voluntary sector organisation into a relatively large one, but not so large that its transition has threatened its core service areas.

ISIS has also grown from a relatively small to quite a sizeable organisation. However, this has increased the call on staff time to attend meetings with funders and planners who often call on the organisation's time and input in a range of ways. These external expectations and demands from funders can sometimes exert added strains on already pressurised agendas. It is a delicate balance between these pressures and not losing the one-to-one time that users value so much.

NAWP seems to have managed to make the transition from a relatively small organisation in 1987 to a large voluntary sector organisation in the new millennium with its infrastructure and political beliefs still intact. Politically NAWP seems well placed to continue to make great strides in its work with Asian women. It is very well respected as an organisation and has become an ambassador for Asian women in the area.

Strategies for preventing people from unnecessarily entering the mainstream mental health system

'The Forward Project is a sanctuary in the community. Without our service many of the people we work with would be in hospital. With the Forward Project's input people remain in the community much longer than before our intervention.' (Director of the Forward Project, Geraldine Huka)

A good example of prevention work is NAWPs befriending scheme. This work developed out of the understanding and knowledge that in order to have an alternative perspective for Asian women there needs to be on-going support. The befriending scheme is there to offer women with a mental health need the opportunity to meet together to gain strength from each other's experiences. The women who attend this group are around 40 years of age.

The befriending scheme is facilitated by an Asian user from South London who gives the women autonomy, letting them decide what they want to do in the sessions.

This practice is highlighted in the government report, *Inside/Outside*, which suggests that all mental health services should have access to alternatives to hospital admission at times of crisis.

Cultural sensitivity is vital to Black users

It is important for Black organisations to employ Black staff who understand the social and political experiences of Black people's lives in the UK. For example, at ACCI the user consultants observed a commitment to improving Black people's lives in wider society – planning a future for Black people and believing in their ability to grow. Awareness of the need for a wider approach springs from staff coming to an understanding that the experience of mental distress in Black people is intimately linked with disempowerment, exclusion and racism they or their families have experienced.

One of the important aspects of the work of AWAAZ is that between them, the staff speak the local Asian languages and understand the customs and dynamics that operate as part of their culture and within their extended families.

Case study – cultural sensitivity in action

The NAWP teens support groups are held in a local community centre. In order to set up the support group and in keeping with Asian lifestyles, the workers had spent time going to meet the families of the teenagers. The workers reassured families that they were respectful of their culture and this enabled the girls to attend on a weekly basis without parents feeling estranged. However, some parents were worried about their daughters going out after school and coming home unchaperoned. NAWP therefore provided a mini-bus and driver to transport them. For many of the young girls this would be the one event in the week where they could just be themselves. A place where they could support each other by exploring and discussing family issues, as well as noticing and keeping up with each other's educational and social lives.

Visiting the group where the teenagers meet straight from school and where they get their social support was one of the highlights of the Black Spaces project. The content of the work varies, and is often propelled by the girls' wishes and needs and partly organised by the workers and volunteers who offer some structure and educational stimulation so that the girls are constantly developing.

One session included a female DJ teaching the teenagers how to mix music and to 'scratch'. This session ended up as a Bangrah dance with the girls being relaxed enough to take on more strenuous aspects of the dance, which are usually the domain of males at family weddings. The girls offer each other genuine affection, challenging each other's moods and experiences and behaviour in a way that is safe and which may not have been allowed elsewhere in their community settings.

For example, one girl spoke negatively of going to school, doing her homework and disassociating herself from her family. This negativity seemed so out of keeping with the bubbly personality she displayed at the teen group, giving the impression that this was somewhere she felt more positive about herself.

It would seem that the work of NAWPs teens group is particularly important in terms of mental health promotion for young Asian people.

Cultural stigma around mental illness impacts on Black services

AWAAZ deliberately chose not to have a name that identifies it with mental illness as this carries a particular negative meaning for many within Asian communities. It is also trying to provide a wider range of services so it is not automatically associated with mental illness.

However, this a delicate balancing act to ensure that the original target group – people who have a mental illness, does not get pushed off the agenda while others get to use the facilities that are available.

Many of the people who are supported by the Forward Project have the label or diagnosis of severe mental illness. The Forward Project realises that it has a lot of work to do to turn around people's often negative experiences and to plan a positive future.

'Being here helps me to be comfortable with myself. I don't have to worry about what other people think of me by coming to a Black group. I enjoy the Black bit, I am not keen on the association with mental health.' (quote from a female member of ISIS)

Dancing to the funders' tune

User consultants felt that some projects were in danger of losing their focus on mental health or Black issues in the search for funding.

AWAAZ, like many voluntary organisations, has not been able to attract core funding. This has some advantage, as it is not dictated to in terms of service delivery. However, it constantly has to search for funding which can sometimes mean taking on work that moves it away from its original aims.

The Black voluntary sector is beginning to dance to the statutory funders' tune rather than maintaining its independence. This was always one of the concerns that some voluntary sector organisations expressed about funding – striking the balance between not being left out in the wilderness and fighting for survival. Funding needs to allow organisations to feel more homely and friendly and embrace the social and spiritual needs of its clients.

The director of Qalb has a background in working with the statutory sector so is well able to negotiate and obtain funding for the organisation. The director will always ensure that money is made available from the statutory services before the organisation progresses to its next stage of development.

Funding for NAWP comes from a range of places, which include local funding from:

- health and social services.
- leisure services.
- housing.
- community education and youth services.

In addition funding from further afield comes from:

- Comic Relief.
- BBC Children In Need.
- City Parochial Foundation.
- London Borough Grants.
- Creative Training Association.
- Jack Petchey Foundation.

NAWP attracts funding from a range of sources, which enables the organisation to keep some autonomy and independence from mainstream funders.

Three to five year funding for AWETU would enable the workers to plan their work over a longer period of time and would offer some security to the project. The outcomes for the project would be sustained such as improved services and campaigning on behalf of Black people on psychiatric wards.

Problems with funding have been recognised in the report *Inside/Outside*, which says that the sustainability of voluntary sector initiatives has been problematic because of the lack of long-term funding.

Outreach work is an essential part of the service

Staff and volunteers at AWAAZ visit people in the community via appointments. This can ensure privacy or choice of location, which can be important for some of the women. The outreach work is varied and can involve interpreting letters and forms, through to issues of separation and domestic violence. Attention to children was a key priority ensuring that they are not taking time off school to help at home.

The Forward Project also runs a resettlement scheme. The more formal parts of the resettlement job entail settling and sustaining people who live in the community. The Forward Project provides single sex hostels for people who usually stay for around two years. After this period and as part of the local housing quota with a local housing association people are moved onto their own accommodation. The resettlement worker may then continue to have contact for three to six months.

The resettlement worker tries to develop trusting relationships between the clients, so residents are free to come and go as they please.

AWAAZ also ensures that the local Asian community is informed about issues such as depression using videos and discussions. Their outreach role extends to having Eid parties where service users, carers and friends are invited as a way of tackling and breaking down the fear and anxiety associated with mental illness.

Much of AWETUs time is spent raising awareness in other organisations around race and mental health.

The importance of involving family and community in the care of users

AWETU, for example, is very much a community project with family members passing through – children are encouraged to attend with their parents. Inside there is a flexible approach to what people want to do.

The Forward Project has a community worker, who is well known in the area, and people alert him to community problems and individuals that may need help.

The report *Inside/Outside* suggests a new national standard for individuals to be assessed with carers or family members present, and if necessary, with the support of an interpreter, translator or advocate.

Creating organisations with a sense of Black identity

‘What makes our service relevant to Black people is that we speak the same language, we understand what’s happening in people’s homes and what’s happening on the streets and we communicate from the same or very similar standpoints.’ (Isis staff member)

The Forward Project ‘feels’ Black because it:

- acknowledges and involves the family which is the foundation of all Black communities, but which has not been sufficiently acknowledged by mainstream services.
- recognises that issues underlying people’s brush with psychiatry stem from social and psychological reasons so counselling and psychotherapy are often a relevant intervention.
- recognises and acknowledges the effects of racism both internally for the individual and externally.
- incorporates cultural themes and values, such as music, art and belief systems into the services that are delivered.

The resettlement officer at the Forward Project offered feedback regarding some of the factors surrounding the mental health of the local Black community.

- Many first generation Black people living in England may have come from semi-urban or rural environments and are now living in the inner cities and large towns – this may have an effect on emotional and mental health, social perceptions and lifestyle. For these reasons many Black people have been re-conditioned to see themselves as ‘townies’ – we need to look at the pressure caused by this reconditioning (which is similar to the pressure experienced by all first generation city dwellers, but takes place in the context of racism and exclusion).
- The urban environments that many Black people are moving in to can now include a high prevalence of guns, police, drugs and violence. This can create a range of stresses depending on the individual reaction to and engagement or disengagement from this culture.
- Black history and a reminder of where we came from and a vision of where we need to be going is one of the solutions for raising Black consciousness and Black self-esteem.

An organisation that feels Black:

- It feels like an extension of people's homes – a place where they come to socialise.
- The staff are always interacting with the clients.
- There were at least 30 people there by lunchtime.
- The age range was from 20 to 82!
- People just looked happy to be there.
- People are given a sense of ownership.
- Staff are street-wise.
- People say they go to ACCI because it's a safe place and there are no judgements.
- The premises are open to the wide spectrum of Black expression by both Africans and Caribbeans.
- Staff and students are encouraged and nurtured to be very Black conscious.
- The clients are plugged into other systems and other resources as a way of ensuring that they get their needs met.
- The project manager appears to be well placed within the community and gets things done for and on behalf of the people who use the service.
- The manager conveys warmth and authority and the people who use the service talk to her as the figure who gets things done and resolved on their behalf.

(User consultants' impressions of ACCI)

Forward thinking

Useful learning from the Black Spaces Project

Conducting outreach work

Community involvement and interaction gives organisations a wider knowledge base about their targeted clients. Outreach work can be very useful as both casework and to keep in contact with people who have not attended a centre for a while. This is fundamental to modern mental health policy as outreach fulfills a number of functions including keeping in contact with people who are hard to engage and preventing people from entering services through a custodial or forensic route. Some projects also used members of the community to alert staff when certain people with a psychiatric history were not functioning well.

Respecting clients as adults

Projects found that clear and continuing communication with clients was essential, so that everyone understands expectations and roles.

A case at ACCI was a man known to take illicit drugs who was given a sizeable sum of money to re-furnish his property. The manager spent time with him to negotiate a system so that when he wanted to purchase something, a cheque would be made out to the appropriate store. That way he got what he actually needed and the temptation to spend on his habits was lessened. ACCI's management said it would have been too easy to have given him the money and allow him to live with the consequences of his actions, but they do not want vulnerable people to risk falling back into drug habits.

Promoting adult education classes and learning

Attending classes helps with integration in the local community. Isolation and a lack of educational opportunities is one of the factors underpinning social exclusion. Combatting this can improve mental health and resilience and allow users or clients to take up valued opportunities.

ACCI staff take people who are unable to travel themselves to adult education centres. The high street office at AWAAZ is equipped with computers and desks where people can access learning, through a government backed initiative called Training Wise. Agencies who have computers as a resource can receive learning packages and a grant to provide the service to a particular catchment area.

Many of Nia House residents at the Forward Project are encouraged to attend college or work during the day and return home in the evenings.

At AWAAZ sessions may include computer work, job search courses, sewing classes and English as a second language.

Attaining tangible quality standards

ACCI has gained a Beacon Award, which acknowledges the work it does and allows other organisations to learn from its experience. It also allows ACCI staff to re-evaluate and reflect on their practices.

Setting tangible quality standards is a practice endorsed by the recent report, *Inside/Outside*, which advocates establishing accountability for mental health organisations. It recommends that organisations undertake self-assessment of the cultural and linguistic competencies of staff and that there should be annual reports on an organisation's progress in relation to ethnic matters. It also suggests there should be mechanisms to allow consumer and community feedback to establish user satisfaction with services.

The report also recommends setting national standards to improve mental health services. These include monitoring of ethnicity of service users, assessments in a client's preferred language and crisis plans that minimise the risk of coercive interventions. It says that these should be implemented nationally and monitored systematically.

Influencing the design of buildings

The physical layout of buildings to ensure safety as well as integration between staff and users are considerations that both planners and the voluntary sector need to consider for the future. As well as planning the physical aspects of the building, the voluntary sector needs more security around buildings and ownership but this cannot be achieved in many cases without long-term commitment and partnership from the statutory sector.

Co-ordinating volunteering and allowing users to volunteer

Many of the projects rely on volunteers but their work needs to be valued and nurtured. At AWAAZ, for example, there is a volunteer co-ordinator, who trains and supports volunteers.

Volunteer work is an integral and important role that enables AWAAZ to operate and offer its range of services. There is a volunteer co-ordinator whose role is to train and support volunteers. There are currently eight volunteers at AWAAZ who are involved in many aspects of the work including outreach and home visits.

From time to time some of the people who use ISISs services volunteer which develops and enhances their confidence and work experience.

Respecting cultural differences

One of the key benefits of a Black voluntary organisation is its focus on cultural difference. There are important elements of some services that show respect and could be adopted by mainstream organisations.

At AWAAZ, for example, there are targeted gender services, which show an understanding and respect of Asian culture, where men and women, particularly those who are unmarried, often work or socialise separately.

Having staff who speak and understand local languages is very important especially if people are in mental distress.

Activities should be planned with an understanding of people's religion and the time and space needed for prayer and other religious observances. It is important to have an understanding that Asian people's needs are varied but often focus on having a future, education and occupation. For example at Qalb the women would get together and knit while the men played pool or educated themselves on the computer.

A culturally appropriate diet provided on a daily basis is important for Black and Asian people, as is the atmosphere created and the colloquial language used in a service. It is also important that staff understand the behaviour and mannerisms of Black and Asian people.

The report *Inside/Outside* also suggests a national standard for assessments of Black people. It says that these should 'establish a care plan that will include individual religious, cultural and spiritual beliefs with clear identification of recovery and outcome'.

Focusing on wider issues

Projects found that helping to resolve people's practical lifestyle issues is important as well as offering education or work-related advice and information.

Producing and distributing information

Producing and distributing information targeted specifically at the community can be very useful; AWETU for example, produces its own newsletter and resource material.

AWAAZ offers an information service, for example, on medication, drugs and their side effects.

These examples could be at the vanguard of development if a national standard for the provision of information is implemented following a recommendation in the report, *Inside/Outside*. It states that users and their families and carers should receive written information on legal status and rights to advocacy, interpreting services, professional roles and responsibilities and details of complaints procedures.

Community counselling and psychotherapy – importance of working with culture

- Use of music tapes to get people relaxed and to build up a rapport.
- Possibly offering sessions that are not time limited.
- Spending time to build up Black people's confidence before attempting to tackle deeper issues.
- Using people's creativity, art and culture as a backdrop for discussion.
- Acknowledging the role that politics, oppression and racism has played in people's lives socially and personally.
- Openness and understanding of the depth and range of Black belief systems in their diversity and ancestry.

Empowering users

Sometimes Black projects can make assumptions about individual abilities and their understanding of the concept of empowerment: this needs to be carefully explained. When each manager is clear about the task and expectation of empowerment, then they need to develop a plan of implementation and measure progress in their staff team or service area.

Personnel and management need to understand that talking on behalf of others does not empower or involve people effectively. User consultants felt that some organisations needed to put the person who uses the service at the centre of its work.

By empowering users to do more for themselves in a residential or day care setting, there could be huge benefits for an organisation in terms of freeing up staff time to work on wider issues. For example in one centre, a lot of the staff time was taken up serving meals. Users could serve themselves or be trained to take on such tasks as cooking and for this they could be paid therapeutic earnings.

Internalised racism can be a major block to empowerment. This can happen in two main ways. Firstly through internalised racism lowering the self esteem of users and secondly through it lowering staff expectations of users. The latter process is hard to contemplate but has been widely reported as occurring in statutory services. It needs to be systematically challenged at all levels within organisations working with Black people, and staff need a safe place in which to discuss their concerns.

Effects of internalised racism identified in counselling at one project

- Some Black people feel so bad about themselves that they will not even ask white people a question, in case they are seen as 'that stupid Black man who knows nothing'.
- One woman who has been treated so badly over the years said that she believes she has no skills.
- Another woman who wrote short stories and poetry used to say really negative things about herself and other Black people all the time.

Using and training of students

The director of ISIS, for example, puts a lot of emphasis on taking on students because she feels it's important that more practice professionals take the opportunity to work with Black people outside the psychiatric setting. In this community setting there is less opportunity for workers to fall into the usual expectation and responses to Black people based on their diagnosis. A number of workers within ISIS are experienced and qualified to act as supervisors. An added benefit of having students is that they sometimes come with a small budget.

Feedback from user consultants on Newham Asian Women's Project (NAWP)

Befriending Project

- The women attending this group spoke at least three different Asian languages between them. This was a challenge for those women unable to communicate and share their issues with the whole group.
- Lots of issues were raised which involved family problems.
- The women at the scheme were very accommodating of new people – they were always particularly supportive of each other.
- The volunteer facilitator was very keen and interested for the user consultants to share some of their good practice in order to expand and develop the work being offered.

Recommendations for future work for organisations

Training and support

Students training for mental health work should be encouraged to undertake placements within the Black voluntary sector. This recommendation dovetails with the report *Inside/Outside*, which states that ‘culture and mental health’ should become part of GP training. It also suggests that training in ‘cultural competency’ should occur at all levels of training for professional staff.

There should be support and development training for Black voluntary sector organisations moving from being small providers to medium or large organisations. This should also take into account the effects of such developments on the people using the service.

Focus on the future and realise users’ potential

Encourage people who use services to realise their own inner potential:

- Pay more attention to giving people a sense of a future with more focus on where people were before they had a psychological problem.
- Put more attention on re-training people and getting them into part-time jobs and if required full-time jobs.
- Encourage people to get back to evening or daytime classes.

Black and mainstream organisations should engage in collaborative work

Different projects should be encouraged to connect with each other so that they could develop new ideas and different ways of working.

This is echoed in the report *Inside/Outside*, which says that statutory mental health providers must work collaboratively with local voluntary sector groups. The Department of Health admits in the report that the voluntary sector has led the way in developing culturally sensitive services and that statutory care providers have often failed to follow this example.

It further suggests establishing consultation between mental health agencies and other key stakeholders. It states that ‘every Mental Health Local Implementation Team should set up formal mechanisms for community and consumer involvement from minority ethnic groups’.

It also recommends investment in community development workers (CDWs) to ‘build on the inherent strengths and capacity of minority ethnic groups in dealing with mental health issues’. It says community development should go beyond ‘establishing a “link” between disaffected communities and governmental agencies’. The aim of CDWs would be to provide support for local groups so that they can become partners in developing services and identifying gaps in current provision.

A team of user consultants

The development of a team of African-Caribbean, Asian and African service user consultants will help with organisational development within the Black voluntary sector.

The aim of the team would be:

- To help staff teams to understand the benefits of service users' voices in organisational development.
- To enable staff teams to look at their own prejudices even though they may be Black, working in the voluntary organisation and working in the field of mental health.
- To develop independent user voices within the membership of the services being used. This may entail setting up user groups or it may be a creative forum that accesses the strength and creativity of people who use services.
- To make suggestions and give feedback to organisations regarding how things can be changed.

Support and funding for the above initiative needs to be developed over a realistic time span. This suggestion may be more effective if done in partnership or in conjunction with influential national mental health organisations with experience in this field.

Conclusion

The Black Spaces Project found evidence of some excellent work in the Black voluntary sector, empowering users, providing culturally sensitive spaces and developing first class mental health services. They are also having an impact on mainstream mental health services through advocacy and outreach work. However, many are struggling with scant resources and there needs to be more support to allow them to reach their full potential. The Black Spaces Project hopes to continue its work, if funding allows, to encourage the dissemination of learning from these pioneers' experience. The ultimate aim is to improve the lives of Black people with mental health problems and to combat the injustice and discrimination some have experienced in the mainstream mental health system.

Here are just some of the reasons why this work is so important and needs to continue.

'The Forward Project is a sanctuary in the community. Without our service many of the people we work with would be in hospital. With the Forward Project's input people remain in the community much longer than before our intervention.'

'For many of the young girls the NAWP teens group would be the one event in the week where they could just be themselves. A place where they could support each other by exploring and discussing family issues, as well as noticing and keeping up with each other's educational and social lives.'

'Being here helps me to be comfortable with myself. I don't have to worry about what other people think of me by coming to a Black group.'

'The issue of funding appears to be a crucial one in many of the organisations involved in the Black Spaces Project – the funders calling the tune and the voluntary organisations are having to dance to the beat of an unfamiliar and undesired rhythm.'

'What makes our service relevant to Black people is that we speak the same language, we understand what's happening in people's homes and what's happening on the streets and we communicate from the same or very similar standpoints.'

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Appendices

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Notes



The Mental Health Foundation is the UK's leading charity working to promote mental well-being and the rights and needs of people with mental health problems and people with learning disabilities. We aim to improve people's lives, reduce stigma and discrimination and to encourage better understanding. We undertake and support research and encourage improvements to local services. We provide information to the public and people working in relevant fields. We aim to maximise knowledge, skill and resources by working with service users, government and service providers.

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