COMMUNITY ENGAGEMENT PROJECT
NIMHE MENTAL HEALTH PROGRAMME
Report of the community led research project

THE IMPACT ASSESSMENT OF THE MENTAL HEALTH GUIDE PROGRAMME

A mental health community development project within Hackney's African and Caribbean communities

Social Action for Health and Mellow

HACKNEY
EAST LONDON

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PROFILE OF RESEARCH TEAM MEMBERS

Autherine Atkinson is 52 years old, single with 5 children and 3 grandchildren. She became involved in the Health Guide project because her son had become ill, and she wanted to find out more about mental health issues. She had previous experience in mental health, but wanted to find out more, to equip her to cope with everyday living and to help other people who are affected with this illness. Her work in the research team included interviewing people to hear their stories, designing questionnaires, facilitating focus groups and doing analysis.

Corrine Douglas is 45 years old. Corrine was unemployed for a year, and having done some work in the past as a mental health support worker, she decided to do the Mental Health Guide training. She got involved in the research where she has helped to run focus groups, develop questionnaires, analyse data and contribute in other ways. She has also carried out interviews for two other research projects.

Mark Laville is 46 years old. He was born in the Commonwealth of Dominica, came to England with his parents in 1975 at the age of 14, and later become a qualified electrician at Hackney College. Mark enjoys family life with his wife, son and two daughters. Two years ago he joined AKABA, the employment project at the Nile Centre, an African Caribbean mental health service. This year he has enjoyed working on the UCLAN project. Mark feels that by doing this research, he can give something back to a community which has given him so much.

Roxanne Rose is 40 years old and lives in Hackney, East London. She was born in Hackney Hospital and has lived in Hackney all her life. Roxanne is a service user of the City and East London Mental Health Trust and is part of their service user involvement programme. She goes around East Wing at Homerton Hospital, talking to people staying on the wards. She joined the Mental Health Guides training programme to learn about mental health and has contributed to the research, particularly with the statistical work.

Patience Seebohm is an independent researcher (53 years old) brought in by Social Action for Health and Mellow to facilitate and support the research team. The methods used during the project were chosen by the team, and to support this process Patience has learnt new skills in story-telling and statistics. She has gained a lot from being a part of the team and from the results of their work, and has really enjoyed the project.

Peter Smith is 33 years old. Born in Islington, Peter was diagnosed with bi-polar affective disorder in 1992. His identical twin brother shares his diagnosis. Peter has over 14 years experience of using mental health services. He has been involved in doing research for Mellow and Social Action for Health, where he has learnt a lot including interview techniques, understanding how to develop a

questionnaire, analysing and interpreting data, report writing and the importance of ethics and confidentiality. He now uses these skills on other projects.

Raymond Smith, 41 years old, was born and has lived all his life in Hackney. He is currently involved in being a Health Guide and researcher for Social Action for Health and Mellow in Hackney. Raymond is interested in being a Health Guide to help service users be more aware of health issues affecting their community and to provide information on improving services within the community. He hopes that by gathering statistics and information from service users, we can make a change in the way health services are provided.

Philip Vidal is a 24 year old British mixed race male born in Hackney. He joined the Health Guides because he wanted to learn how to help his community access public health services and make an impact on their day to day lives. He was unable to complete the course due to work commitments and becoming ill, but hopes to fulfil his goals if he can do the training another time. Before he left the course, Philip was an active member of the research team, helping to discuss the plans, do the research and present the early findings.

Mark Whyte, 35 years old, is employed at Social Action for Health as the Project Worker for Mental Health Guides. Mark has learned a lot of skills throughout this research project and has found the experience enjoyable, particularly when collecting the information from the community. He will find these skills invaluable when working within his community where he is very active. He has founded 2 theatre groups for young people, 2 youth football teams of different age groups and is also Chair of Clapton Park Tenants and Residents Association.

ACKNOWLEDGEMENTS

We would like to give special thanks to all the people who participated in focus groups and interviews, and also to the staff at Friends Lodge, Core Arts, Nile Centre, NACRO Housing Project, Hackney Football Club, Clapton Rangers, and Tuke ward, Homerton Hospital.

We would also like to thank all the members of the Steering Group, particularly Sue Balmer and Nicholas Garforth, for their time and support. Imran Mirza from UCLan has encouraged us and helped to solve many problems, for which we are very grateful.

We would like to thank Shabira Papain, Elizabeth Bayliss, Pauline Facey, Shanti Kar and Jeba Maleque at Social Action for Health and Sandra Griffiths at Mellow. The help and additional resources they have been able to contribute have made an important difference to the project.

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EXECUTIVE SUMMARY

Background to the study

This study is an impact assessment of a new community development model, the Mental Health Guide Programme, delivered by Social Action for Health (SAfH), in partnership with Mellow and funded by City and Hackney Teaching Primary Care Trust (CHTPCT). In its first year, 2006/07, the programme is targeted on Hackney's African and Caribbean communities, to identify and support ways of addressing the disproportionate numbers of African and Caribbean people in the mental health system. In the future it will be rolled out to other communities.

The impact assessment research is part of a national 'community engagement' programme managed and designed by the Centre for Ethnicity and Health at the University of Central Lancashire (UCLan). Each research project has the community at its very heart and contributes in a different way to the *Delivering Race Equality* Action Plan (Department of Health 2005).

SAfH is a community development charity focusing on health inequalities, promoting self determination, self management and community-led solutions. SAfH's approach is to work bottom-up, engaging local people, building networks and influencing policy. Mellow was set up to reduce the over-representation of young African and Caribbean men in mental health services and in 2004 became part of East London and City Mental Health NHS Trust.

The Mental Health Guide Programme

The Mental Health Guide (MHG) Programme has evolved from SAfH's Health Guide Initiative which trains and supports local people to act as health guides within their community, in their own language. They work in pairs to deliver sessions to groups of people from their own community, facilitating access to services by sharing information. At the same time, they hear the concerns of local people and these are reported back to NHS planning forums. In 2005, the project won the Department of Health's Health and Social Care Award for the London Region, in the category of *Improving Health and Reducing Inequalities*. The Mental Health Guide (MHG) Programme works in a similar way but with a mental health focus. All the Mental Health Guides (MHGs) in 2006/7 are from the African and Caribbean community and, to date, most session participants have been African and Caribbean but no one is excluded.

The MHG Programme in 2006/7 covered by this study included:

- Training 23 African and Caribbean men and women, including mental health service users, carers and concerned citizens (May – August 06).
- Delivering 14 MHG sessions within different settings (Oct 06 – Feb 07)
- Feeding back concerns of local people to the NHS (Oct 06 – Feb 07).

Research aims and methods

This study aimed to assess the impact of the MHG programme and had the following objectives:

- To assess the impact of the programme on the MHGs;
- To assess the impact of the MHG sessions on their participants;
- To gather feedback from mental health staff on the MHG programme;
- To draw out the lessons that can be learnt from training and supporting a specific community group within the mental health system;
- To support the personal development of the study's community researchers;
- To explore how the MHG programme can most effectively contribute to the objectives of *Delivering Race Equality*.

A participatory action research approach was adopted to enable those who took part in the MHG programme to develop, design and carry out their own study, rather than be the 'subjects' of an external academic institution. It was a circular process, with learning continuously fed back as part of the research process.

The impact assessment had two strands. First, it aimed to study the individuals engaged in the programme, as MHGs or session participants, to investigate the level of personal change that came about as a result of their engagement with the programme. For the MHGs, this included both statistical and qualitative 'before and after' measures. For the session participants, the study gathered qualitative data shortly after the sessions took place.

The second strand aimed to assess the potential impact of the programme on the experiences of local African and Caribbean people using mental health services in Hackney. This broader approach looking towards the future is comparable with a race equality or 'environmental' impact assessment. In order to help the reader understand this 'environment' where the MHG programme hopes to make a broad impact, the study drew on the personal stories of 8 local African and Caribbean people (MHG trainees).

A range of research tools were employed, including focus groups, semi-structured interviews and questionnaires. The study was approved by the Ethics Committee and Clinical Director for the East London and City Mental Health NHS Trust (ELCMHT), and by the Ethics Committee at UCLan.

The personal stories of local African and Caribbean people

The personal stories of 8 MHGs set the context for the study, illustrating aspects of life for African and Caribbean people in Hackney.

- All have strong local connections with East London, most having lived in the area for over 30 years. For 6 story-tellers, their family are from the Caribbean and for 2, their family are from Africa, but 4 describe themselves as African.

- Top personal priorities include family and friends, personal achievement, paid work and contributing to the community, all inextricably linked.
- The greatest concern is the education system and low expectations for Black children, followed by the ‘sense of exclusion’ caused by racism and unemployment. Other issues include drugs, crime and community divisions.
- The story tellers spoke of many achievements and resources within the community, which are insufficiently recognised by schools or the media.
- Causes of mental ill-health include the long term pressures of individual and institutional racism which lead to a sense of hopelessness and ‘going down the wrong road’. Stress without opportunities to talk could lead to crisis.
- Negative experiences of mental health services include lack of access to help when needed, poor quality services, and a failure to provide the kind of help which leads to sustainable recovery. This creates a sense of hopelessness, ‘self-medication’ with illicit drugs, ‘and then things just spiral out of control’.
- Helpful responses to distress include encouragement (which has come entirely from the family for these story tellers), talking, peer support, role models, activities in the community, self help and Black led services.

The impact on the Mental Health Guides

Twenty three people joined the training programme and of these 13 successfully qualified. Qualified MHGs were aged 30 and above, with equal numbers of men and women, born in the UK or abroad. Most describe themselves as Caribbean and half are Christian. The 13 MHGs include 4 carers and 11 with experience of mental health difficulties, including 6 who have received help from mental health services and 5 from primary care. Treatment has included medication (8) but not alternative therapy of choice (0). The emerging themes from their feedback are:

- People joined the programme in order to help others, to create change in mental health services and to develop their career.
- The MHG trainees found their training course enjoyable and useful, but they identified a number of areas for development. These included the level and nature of learning on mental health, enhancing the African and Caribbean focus, the size, organisation and delivery of the course.
- 13 people successfully qualified as MHGs and 8 people delivered 14 MHG sessions (Oct 06 – Feb 07). There was a positive impact on the 13 MHGs, particularly on the 8 who had delivered sessions. Qualitative and statistically significant statistical data shows that the 8 MHGs gained skills, self esteem and a belief in their ability to achieve. Some gained self awareness and strength as African and Caribbean people. They spoke of a sense of achievement and moving on through enterprise. However, expectations are only partially fulfilled as their ability to create change is not yet proven.
- Areas identified for development include increasing the ‘scale’ of the programme with a high standard of organisation and delivery, communication and payment systems, individual support and scope to do more paid work.

The impact on session participants

Feedback has been collected from 59 participants at nine MHG sessions which were held at Homerton Friends Lodge, Core Arts, Nile Centre, NACRO Housing project, Hackney Football Club, Clapton Rangers & Tuke Ward, Homerton Hospital. Most participants were over 30 years old, but the range extended from under 19 years to over 50. Most (69%) were male, over half were Black African or Caribbean, with just under a quarter of mixed ethnicity and similar numbers of White participants. About two thirds were born in the UK and most speak fluent English, but there are 9 different first languages. Two sessions took place outside the mental health sector, but most participants (75%) have experienced mental health difficulties, and most of these have accessed both specialist mental health services and primary care. Most have received medication, but less than half have had an alternative therapy of their choice. The emerging themes are:

- Participants felt encouraged and understood because MHGs shared their experiences. They valued the fact that MHGs were not professional staff: they were seen as role models with a personal commitment to help others.
- As service users, MHGs inspired hope and motivation to change.
- Where all participants were Black, the participants valued the fact that MHGs are African and Caribbean but some participants in mixed settings felt the ethnicity of MHGs was not important.
- Participants found coming together for the session made them feel closer and stronger as a group. They found relief in talking to people who listen, and they learnt from sharing different perspectives and coping strategies.
- Groups shared information from the MHGs and each other about their rights to help and how to get what they needed. Many wanted more information.
- Participants spoke of lacking control over their own care. They expressed hope, but some scepticism, that MHGs might have influence within the mental health system. Some feared there will be no change.
- Participants spoke of wanting a space where they can communicate directly with commissioners, mental health staff or others in positions of power.
- Some participants value the support they get from professionals, and several felt that MHGs and professionals should work together to improve services.
- The skills of the MHGs who facilitated the sessions were commended. Many wanted more frequent, regular sessions and some wanted longer sessions.

The feedback from mental health staff and managers

Interviews took place with a member of staff at six of the seven sites for sessions, a primary care trust commissioner and senior manager of mental health services, ELCMHT. Feedback was often similar, including:

- The MHG programme is enthusiastically supported as ‘brilliant’.
- It is seen as a way of enabling local people to contribute to service improvement. MHGs need to deliver regular sessions on the topics highlighted by the participants and be accountable to them. They need to fit into existing frameworks for service user involvement (where they tick

important boxes for CHTPCT). It is anticipated they will be catalysts for change, helping statutory authorities to achieve the objectives of DRE.
- It is considered that sessions provide safe spaces for participants to share their views and mental health problems. Regular sessions will enable MHGs to develop and maintain a relationship with the participants.
- MHGs are seen as role models because they prove to service users that there is 'life at the end of the tunnel'. Staff noted the significant impact of sessions on participants, and MHGs are seen as potential catalysts for change within individuals as well as within services.
- Some interviewees (notably the commissioner) value the independence of the MHG programme. Some look forward to close partnership working.
- It was said that programme development needs to be informed by the MHGs and extended to other communities.
- MHGs need to be adequately supported for their work and given the opportunity to further their careers.

The experience of being on the research team

The research team consisted of 7 MHG trainees, the SAfH project manager and a research manager. Five members of the team had used mental health services, and 3 had someone in the family with mental health problems.
- The six researchers who attended UCLan training all successfully passed their modules, and valued both the qualification and the skills gained.
- With weekly meetings, the team developed as a close-knit, stimulating and supportive group who enjoyed doing the research, analysis and report writing.
- The team is setting up a social enterprise to continue their research and other activities under shared leadership. Team members are publishing their work.

Conclusions

The MHG programme has made an impressive impact in Hackney. There is statistical and qualitative evidence to show that the African and Caribbean MHGs have personally benefited in many ways. Their experience of mental ill-health has inspired mental health service users and they are widely perceived to be role models. Their capacity to listen, inform and encourage local people suggests they could make a sustainable impact on the local mental health 'environment' if sessions are consistently delivered, making an important contribution to *Delivering Race Equality*. They could focus on mental health promotion or equally well, promote recovery from mental ill-health, or allocate resources to both. However, the appeal of the programme to local people and the MHGs own personal commitment arise largely from the hope that it will create change and improve the experiences of people in distress, particularly those from African and Caribbean communities. MHGs can be mandated representatives for local people but the commissioners and service providers' capacity to respond will determine the long term impact of the programme, and as commissioners and mental health staff fully support the programme, the outlook must be optimistic.

1. INTRODUCTION

1.1 Introduction to the report

This study is part of a national programme of research projects which puts the spotlight on local community groups and their perspective on mental health. Each project contributes in a different way to the *Delivering Race Equality* Action Plan (Department of Health 2005a). Our study looks at a new community development model targeted on the mental health concerns of African and Caribbean people in Hackney.

This report begins with information from UCLan about the national ‘community engagement’ programme (1.2), before we set the scene for our local study in Section 2 by describing the organisations involved, the Mental Health Guide Programme, the borough profile, the policy context and review of research literature. Section 3 sets out what the project aimed to do, and Section 4 describes how we did it. Section 5 covers the results of the study, in five parts, each part beginning with a summary. The discussion in Section 6 draws together the issues that have emerged and considers the questions we wish to answer to inform future development. Our recommendations are in Section 7. Details of the demographic data and some of the research tools we have used are in the Appendices.

1.2 Background information on the national project: The Centre for Ethnicity and Health’s Model of Community Engagement

Background to the community engagement model

We often hear the following words or phrases:

- Community consultation
- Community representation
- Community involvement/participation
- Community empowerment
- Community development
- Community engagement

Sometimes these terms are used inter-changeably; sometimes one term is used by different people to mean different things. The Centre for Ethnicity and Health has a very specific notion of community engagement. The Centre’s model of community engagement evolved over several years as a result of its involvement in a number of projects. Perhaps the most important milestone however came in November 2000, when the Department of Health (DH) awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire (UCLan) to administer and support a new grants initiative. The

initiative aimed to get local Black and minority ethnic community groups across England to conduct their own needs assessments, in relation to drugs education, prevention, and treatment services.

The DH had two key things in mind when it commissioned the work; first, the DH wanted a number of reports to be produced that would highlight the drug-related needs of a range of Black and minority ethnic communities. Second, and to an extent even more important, was the process by which this was to be done.

If all the DH had wanted was a needs assessment and a 'glossy report', they could have commissioned researchers and produced yet another set of reports that may have had little long term impact. However this scheme was to be different. The DH was clear that it did not want researchers to go into the community, to do the work, and then to go away. It wanted local Black and minority ethnic communities to undertake the work themselves. These groups may not have known anything about drugs, or anything about undertaking a needs assessment at the start of the project; however they would have proven access to the communities they were working with, the potential to be supported and trained, and the infrastructure to conduct such a piece of work. They would be able to use the nine-month process to learn about drug related issues, and how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity and Health Unit would provide, and they would learn from actually managing and undertaking the work. In this way, at the end of the process, there would be a number of individuals left behind in the community who would have gained from undertaking this work. They would have learned about drugs, and learned about the needs of their communities, and they would be able to continue to articulate those needs to their local service providers, and their local Drug Action Teams (DATs). It was out of this project that the Centre for Ethnicity and Health's model of community engagement was born.

The model has since been developed and refined, and has been applied to a number of areas of work. These include:

- Substance misuse
- Criminal justice system
- Policing
- Sexual health
- Mental health
- Regeneration
- Higher education
- Asylum seekers and refugees

New communities have also been brought into the programme: although Black and minority ethnic communities remain a focus to the work, the Centre has also worked with:

- Young people
- People with disabilities
- Service user groups
- Victims of domestic violence
- Gay, lesbian and bi-sexual and trans-gender people
- Women
- White deprived communities
- Rural communities

In addition to the DH, key partners have included the Home Office, the National Treatment Agency for Substance Misuse, the Healthcare Commission, the National Institute for Mental Health in England, the Greater London Authority, New Scotland Yard and Aimhigher.

The key ingredients of the model

According to the Centre for Ethnicity and Health model, a community engagement project must have the community at its very heart. In order to achieve this, it is essential to work through a host community organisation. This may be an existing community group, but it might also be necessary to set up a group for this specific purpose of conducting the community engagement research.

The key thing is that this host community organisation should have good links to the defined target community[1], such that it is able to recruit a number of people from the target community to take part in the project and to do the work (see section on task below).

It is important that the host community organisation is able to co-ordinate the work, and provide an infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day-to-day activities of the project. One of the first tasks that this host community organisation undertakes is to recruit a number of people from the target community to work on the project.

The second key ingredient is the research task that the community undertakes. According to the Centre for Ethnicity and Health model, this must be something

[1] The target community may be defined in a number of ways – in many of the community engagement projects it has been defined by ethnicity. We have also worked with projects where it has been defined by some other criteria, such as age (e.g. young people); gender (e.g. women); sexuality (e.g. gay men); service users (e.g. users of drug services or mental health service users); geography (e.g. within a particular ward or estate) or by some other label that people can identify with (e.g. victims of domestic violence, sex workers).

[2] This is not always possible, for example, where potential participants are in receipt of state benefits and where to receive payment would leave the participant worse off.

that is meaningful, time limited and manageable. Nearly all of the community engagement projects have involved communities in undertaking a piece of research or a consultation exercise within their own communities. In some cases there has been an initial resistance to doing 'yet another piece of research', but this misses the point. As in the initial programme run on behalf of the DH, the process and its outcomes have equal importance. The task or activity is something around which lots of other things will happen over the lifetime of the project. Individuals will learn and new partnerships will be formed. Besides, it is important not to lose sight of the fact that it will be the fist time that these individuals have undertaken a research project.

The final ingredient, according to the Centre for Ethnicity and Health's model, is the provision of appropriate support and guidance. It is not expected that community groups offer their time and input for free. Typically a payment in the region of £15-20,000 will be made available to the host organisation. It is expected that the bulk of this money will be used to pay people from the target community as community researchers[2]. A named member of staff from the community engagement team is allocated as a project support worker. This person will visit the project for at least half a day once a fortnight. It is their role to support and guide the host organisation and the researchers throughout the project. The University also provides a package of training, typically in the form of a series of accredited workshops.

The accredited workshops give participants in the project a chance to gain a University qualification whilst they undertake the work. The support workers will also assist the group to form an appropriate steering group to support the project[3].

The steering group is an essential element of the project: it helps the community researchers to identify the community they are engaging with, and can also facilitate the long term sustainability of the projects recommendations and outcomes. The community researchers undertake a needs assessment or a consultation exercise. However the steering group will ensure that the work that the group undertakes sits with local priorities and strategies; also that there is a mechanism for picking up the findings and recommendations identified by the research. The steering group can also support individuals' career development as they progress through the project

The community engagement team

The community engagement team comprises of senior support workers, support workers, teaching and learning staff, administration team and a communications

[3] Very often we will have helped groups to do this very early on in the process at the point at which they are applying to take part in the project.

officer. They work across a range of community engagement areas of specialisation, within a tight regional framework.

<table>
<tr><th colspan="4">National Programme Directors</th></tr>
<tr><th>Northern Team</th><th>Midlands Team</th><th>Southern Team</th><th rowspan="2">Senior Programme Advisors</th></tr>
<tr><td colspan="2">Senior Support Worker</td><td>Senior Support Worker</td></tr>
<tr><td rowspan="2">Support Workers</td><td rowspan="2">Support Workers</td><td rowspan="2">Support Workers</td><td>Drug Interventions Programme</td></tr>
<tr><td>Citizen Shaped Policing</td></tr>
<tr><td colspan="4">Teaching And Learning Team</td></tr>
<tr><td colspan="4">Administration Team</td></tr>
<tr><td colspan="4">Communications Officer</td></tr>
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Programme outcomes

Each group involved in the Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community. The qualitative themes that emerge from the reports are often very powerful. Such information is key to commissioning and planning services for diverse and ‘hard to reach’ communities. Often new partnerships between statutory sector and hard to reach communities are formed as a direct result of community engagement projects.

In 2005/-6 the Substance Misuse Community Engagement Programme was externally evaluated. This concluded that:

- the Community Engagement Programme had made very significant contributions to increasing awareness of substance misuse and understanding of the substance misuse needs of the participating communities. It also raised awareness of the corresponding specialist services available and of the wider policy and strategy context.

- the Community Engagement Programme had enabled many new networks and professional relationships to be formed and that DATs appreciated the links they had made as a result of the programme (and the improvements in existing contacts) and stated their intentions to maintain those links.
- most commissioners reported that they had gained useful information, awareness and evidence about the nature and substance misuse service needs of the participating organisations.
- all DATs reported positive change in their relationship with the community organisations. They stated that the Community Engagement Programme

reports would inform their plans for the development of appropriate services in the future.

- A significant number of the links established between DATs and community organisations as part of the Community Engagement Programme were made for the first time.
- The majority of community organisations reported their influence over commissioners had improved.
- Training and access to education was successful and widely appreciated. 379 people went through an accredited University education programme.
- A third of community organisations in the first tranche reported that new services had been developed as a result of the Community Engagement Programme.
- The vast majority of participants and stakeholders expressed high levels of satisfaction with the project.

The capacity building of the individuals and groups involved in the programme is often one of the key outcomes. Over 20% of those who are formally trained go on to find work in a related field.

The views expressed in the report are those of the group that undertook the work, and are not necessarily those of the Centre for Ethnicity and Health and the University of Central Lancashire.

2 THE FOCUS OF THIS COMMUNITY ENGAGEMENT PROJECT

2.1 The stakeholder organisations

The NIMHE mental health programme commissioned UCLan to manage this community engagement project, with a particular focus on supporting the aims and objectives of the DRE within Hackney, East London. The project is based within Social Action for Health (SAfH) in partnership with Mellow and City & Hackney Teaching Primary Care Trust (CHTPCT). Funding for the study has been provided by NIMHE/ Department of Health (£19,800) with additional resources (£4,800) from SAfH.

SAfH works with communities to address issues that affect their health and well-being. It is a community development charity focusing on health inequalities, set up in 1985, and now works in east and south east London promoting self determination, self management and community-led solutions.

SAfH's approach is to work bottom-up, within the framework it describes as the "spiral of participation": starting at the grass roots, engaging people who are strangers to each other, building networks and aiming to influence policy and thus contribute to the process of reducing inequalities

Mellow was launched in 2000 to reduce the over-representation of young African and Caribbean men in mental health services in East London. As well as developing alternative and sustainable responses to mental distress, Mellow works in partnership with statutory, voluntary and art-based agencies nationwide, both as a facilitator and a consultancy. Mellow became part of East London and City Mental Health NHS Trust in 2004, and plays a central role in the Trust's cultural diversity and race equality programme.

City & Hackney Teaching Primary Care Trust (CHTPCT) supports the Mental Health Guide programme and this assessment of its impact, to explore whether or not this community development approach is effective in meeting the needs of local people and achieving the objectives of DRE.

2.2 The Mental Health Guide Programme

The Mental Health Guide Programme is a new model of community development which has evolved from SAfH's award winning Health Guide Initiative.

The Health Guide Initiative was designed by SAfH to train and support cohorts of local people to act as health guides within their community, in their own language. The aim is to work with excluded groups, facilitating access to information and guidance about health services and health issues as well as promoting understanding and awareness of self care and self management.

The Health Guide Initiative began in 2003 as a partnership project with the North East London Strategic Health Authority. Since then, over 90 local people have been recruited to train as Health Guides from the Bengali, Somali and Turkish/Kurdish communities in Tower Hamlets, Newham and Hackney. They work in pairs to deliver sessions in community settings (community centres, schools, mosques, clubs) to groups of people from their own communities at different times of the day, evenings or weekends as required. In this way, they hear the concerns of local people at the grassroots.

Sessions are participative and interactive, enabling the group members and Guides to share information and explore solutions together. Health Guides then support NHS service development by feeding back frequently identified problems through formal consultation and planning processes to the providers and commissioners.

The Health Guide programme has reached over 5,000 local people so far (March 2007) and attracted a lot of attention from the NHS locally and more widely. In 2005, the project won the Department of Health's Health and Social Care Award for the London Region, in the category of *Improving Health and Reducing Inequalities*.

The Mental Health Guide (MHG) Programme works in a similar way but with a mental health focus. It is a partnership programme developed by SAfH with the support of Mellow and funded by CHTPCT. In its first year, 2006/07, the programme is targeted on Hackney's African and Caribbean communities, to identify and support ways of addressing the disproportionate numbers of African and Caribbean people in the mental health system. MHGs recruited from these communities facilitate sessions in a wide variety of settings inside and outside the mental health sector, to reach people with mental health problems as well as those at risk. It aims to promote well-being and recovery from ill-health.

It is hoped and anticipated that the programme will contribute to achieving the objectives of DRE by promoting leaders within African and Caribbean communities who 'engage' with service providers, supporting the development of more appropriate services and informing local people about sources of help. This process should reduce fear and increase satisfaction among service users, promote recovery and facilitate access to a greater range of therapies.

The MHG Programme in 2006/7 involved:

- Training 23 African and Caribbean men and women from East London, including mental health service users, carers and concerned citizens (May – August 2006).
- Delivering MHG sessions within different settings (October 2006 – March 2007).
- Using local planning and consultation processes to feed the concerns of African and Caribbean people back to the NHS (October 2006 – March 2007).

No one is excluded from MHG sessions and to date, most session participants have been African and Caribbean but many have not. During 2007/8, the programme will consolidate its work, and it is anticipated that in 2008/9 the programme will train a new cohort of MHGs who will reach out to people from selected local community groups in their own language, working alongside the experienced African and Caribbean MHG team.

In 2006 23 MHG trainees were recruited for a 14 week course, where they were joined by 20 generic Health Guide trainees. The generic Health Guide trainees were drawn from the Congolese, Turkish/Kurdish, Bengali and Somali community groups and were supported by the Black and Ethnic Minority Working Group (BEMWG). At the end of the course, 13 of the 23 MHG trainees successfully qualified and they attended two further training sessions dedicated to mental health issues. By January 2007, when data collection for this study ended, 8 of the 13 MHGs had delivered 14 sessions altogether in the community. Practice Development Meetings are taking place quarterly, to provide continued learning and support.

This study is an impact assessment of the MHG Programme as it operated in its first year, 2006/7.

Diagram 2 THE MENTAL HEALTH GUIDE PROGRAMME

Enrolment of 23 trainees in May 2006

Training Course
May – Aug 2006

Qualification
13 Mental Health Guides
August 2006

Delivery of MHG sessions
October 06 – March 07 and beyond

MHG sessions
2 Health Guides per Session

Community settings outside mental health
Eg football club, NACRO

5 -15 people per session

NHS

MHGs feed information from NHS to groups

MHGs feed information from groups to NHS

MHG sessions
2 Health Guides per Session

On The Wards
Tuke Ward

MHG sessions
2 Health Guides per Session

Mental Health Community Settings
Eg Drop In, mental health arts project

5—15 people

NHS

MHGs feed information from NHS to groups

MHGs feed information from groups to NHS

2.3 The London Borough of Hackney

Hackney is one of the smallest of London's 33 boroughs (19 square kilometres). It is situated in the East End of London and is just under a mile north of the River Thames. It is historically a place where travelling communities are passing through then decide to stay and settle. There is evidence that this course of action continues today.

Hackney has a population of approx 207,000 and is one of the most diverse places in the world with more than 100 languages spoken. Residents from white ethnic backgrounds make up 59.% of Hackneys population, with Black and Black British residents the second largest with almost 25% of Hackney's population, compared to 16% Black and Black British residents in Inner London as a whole.

Table 2 Hackney Borough Profile 2006

Ethnicity	Hackney	Inner London	London	England & Wales
White	59.4%	65.7%	71.2%	91.3%
Mixed	4.2%	3.9%	3.2%	1.3%
Asian or Asian British	8.6%	10.6%	12.1%	4.4%
Black or Black British	24.7%	16.4%	10.9%	2.2%
Chinese or other Ethnic Group	3.2%	3.4%	2.7%	0.9%

Source: http://www.hackney.gov.uk/xp-boroughprofile_chapter1.pdf (Census 2001 data)

Hackney is one of the most health deprived areas in the country. The majority of the borough falls within the top 30-40% of health deprived areas in the country and rates poorly on most health indicators.

Average life expectancy is less than 78 years which is below both the London and England averages, despite some narrowing in this gap over recent years. Hackney also has high levels of infant mortality (6.5 per 1,000) which disproportionately affects Black and minority ethnic groups.

Local residents are much more likely to suffer poor health than residents of other areas in the UK or London, with above average rates of limiting long term illnesses. In addition the local population has the highest incidence of schizophrenia and the second highest incidence of tuberculosis in Inner London.

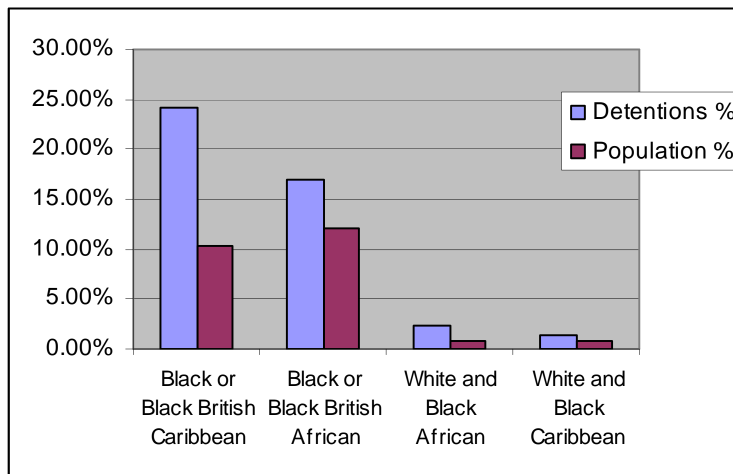
Black or Black British people make up nearly 25% of the population of Hackney but in August 2006 they made up over 57% of the population detained under the Mental Health Act (see Table 3).

Table 3 'Snapshot' of the detained population: August 2006

Ethnicity	Detentions %	Population %
Black or Black British Caribbean	29.9	10.3
Black or Black British African	24.6	12
Chinese	4.9	1.2
Any other Asian	2.9	0.8
Any other Black background	2.9	2.4

Source: Value Added Project East London & City Mental Health Trust September 2006

Diagram 4 The detained population in Hackney 2005 -2006 (sample)



Source: Value Added Project East London & City Mental Health Trust September 2006

The Value Added Project, now called The Alternative Pathways Project, has been set up to analyse the causes and explore ways of reducing this disproportionate representation in the detained population across the ELCMHT.

2.4 Policy review

This research is funded as part of *Delivering race equality* (DRE): 'an action plan for achieving equality and tackling discrimination in mental health services' (DH, 2005a). Two years into DRE, many people fear disproportionate detention of African Caribbean men will actually worsen if the proposed amendment to the

Mental Health Act is passed. Delivering equality will be a long journey, but the DRE is one of many policies that can, if implemented effectively, make a significant difference. Local projects can contribute to the DRE's three 'building blocks'- 'more appropriate and responsive services', 'better information' and 'community engagement', and to the 12 DRE Action Points, such as promoting recovery, reducing fear and creating a responsive workforce. As noted elsewhere (p.19 & 25), it is anticipated that the MHG programme will contribute to several objectives of DRE. Commissioners are reminded that 'good ongoing communication' is vital 'for race equality to evolve fully' (NHS Confederation/ CSIP, 2006) and statutory services are required to show they consult with people from BME communities on how to improve services (DH, 2004a).

Service users from all communities call for recovery-focused services, where recovery means not freedom from symptoms of ill-health (which may continue indefinitely) but gaining control over one's life and finding fulfilment, often through paid employment. The DH promotes this model of recovery (DH, 2004b; NIMHE, 200) but African and Caribbean men currently remain in services for longer than other groups as perceptions of risk and reliance on medication dominate. For one in three service users, dosage exceeds recommended levels (Healthcare Commission, 2007), but a host of policy drivers (e.g. SEU, 2004), emphasise that services need to deliver more than medication. Access to talking therapies, leisure, education, a social life and specialist support to get a job must be available (DH, 2004c, DH, 2006a) There is a right to choice and direct payments (DH, 2006b; CSIP, 2006). The NHS has a duty to promote recruitment of people with experience of mental ill-health within its own workforce (Disability Discrimination Act 2005; DH 2002). Where implemented, these policies are making a real impact, but in many areas progress is limited.

Mental health promotion is another policy area patchily implemented (DH, 2007). Enabling people to get help around their work, home or other basic need, is crucial to keeping them well (DH, 2004b). For young African and Caribbean men who under-achieve at school due to 'unwittingly' racist staff (DfES, 2006), mental health promotion has to do more than facilitate access to public services: they need the resources to deal with the discrimination in our unequal society and the skills to support their aspirations. Government is well aware that more has to be done in Hackney and elsewhere, and seeks creative ways of enabling role models to inspire positive pathways.

2.5 Review of research literature

Government places a strong emphasis on public participation as a lever to bring about improved services, but within mental health forums (and many others) those people from Black and minority ethnic communities most affected by services are rarely seen to play a key role, and are often absent altogether.

The main barrier to their participation is said to be a lack of trust that they will be listened to or that change will follow (Blakey, 2005). As service users, Black people experience little choice in their care and there is a vast literature describing their lack of a voice in a service widely perceived to be discriminatory (e.g. Footprints, 2003). These experiences and the lack of power they have as patients, informal or detained, shape their expectations. Blakey finds that many people do want to get involved, however, *if* they believe change will result from their efforts.

This belief can be fostered in many ways. Barriers of inadequate resources, capacity or leadership can be addressed, for instance by involving community organisations (Blakey *et al*, 2006). Flexible ways of communicating can be created outside rigid formal structures (Trivedi, 2002). Above all, service providers must be accountable, providing written feedback as to whether service user involvement made any difference, with precise details of what changes occurred and where (Trivedi & Keating, 2005). Finally, participants and providers have to learn how much can be achieved through working together when constrained by lack of time and competing national priorities.

Community development is one mechanism known to promote local participation, by developing the networks, capacity and leadership mentioned above, and in this and many other ways it can make a positive contribution to the mental health of local people. Some initiatives support small self help groups, where members offer peer support and mutual aid in 'safe spaces' (Seebohm *et al*, 2005). Service users and others can come together if they share commitment, empathy and listening skills (Borkman *et al*, 2005), breaking down barriers of stigma. People who support their peers gain therapeutically from what is known as the 'helper therapy principle' (Riessman, 1965). Being an active participant – in a self help group or any other community development activity – gives people a sense of value that being a passive recipient of services could never do (Borkman *et al*, 2005).

On a broader level, community development can help people learn about, understand and change the structures and systems that limit their contribution to society (Freire, 1972). It can create social capital which is associated with wider networks, greater trust among local people and more willingness to use local resources including statutory health services (Campbell *et al*, 1999). This is needed now as never before as the widening gap between rich and poor increases the incidence of racism, stigma and disrespect (Wilkinson, 2005). The differential between those who 'have' and 'have not' is perpetuated and widened as capital (economic, social or cultural) accumulates within certain groups (Bourdieu,1986). Using these arguments in the race equality/ mental health field, Campbell *et al* (2004) suggest that those with high status (symbolic capital), i.e. the planners, gain more respect by involving service users in their planning. The Black service user participant may, in contrast, lose status when joining a planning forum, by appearing to comply with an unsatisfactory system while in

reality lacking the power to change it. It is important to ask if, through community development, the credibility of Black service user participants can be increased, shifting passive compliance towards joint decision making. Their status would increase as their influence grows. The study will also ask if community development can increase social, economic and cultural capital within the African and Caribbean community, potentially making a real shift towards equality within the mental health sector.

3. AIMS AND OBJECTIVES OF THE STUDY

This study aims to assess the impact of the Mental Health Guide (MHG) programme piloted with a focus on Hackney's African and Caribbean community groups. In order to achieve its overall aim, the study has the following objectives:

Objectives

- To assess the impact of the MHG programme on the Mental Health Guides;
- To assess the impact of the MHG sessions on their participants;
- To gather feedback from mental health staff on the MHG programme;
- To draw out the lessons that can be learnt from training and supporting a specific community group within the mental health system with a view to developing recommendations for future programmes;
- To support the personal development of all those who take part as researchers in the study;
- To explore how, through its varied work with local people and public services, the MHG programme can most effectively contribute to the objectives of *Delivering Race Equality*. In particular, how it can contribute to:
    - the development of appropriate and responsive services, informed by mandated service users from local African and Caribbean communities;
    - informing local African and Caribbean people and others of available services, reducing fear and increasing confidence in accessing services when they are needed;
    - promoting recovery from mental ill-health for African and Caribbean and other people, for instance by increasing access to a wide range of community based resources;
    - community development by training and supporting a group of African and Caribbean service users, carers and others to foster self help / mutual aid activity among disenfranchised people.

4. METHODS

4.1 The Research Framework

Participatory action research

This study took a participatory action research approach, whereby the people within the situation (the MHGs) worked together towards a shared goal (the impact assessment of their programme). It was a developmental process, so that problems in the programme which emerged could be addressed as they arose. Participatory action research has a strong association with health, learning and community development (Freire, 1972, Barr, 2005), and has a strong resonance with the community engagement model described above. Participatory action research gives control to the participants to develop and design their own research, rather than be the 'subjects' of an external academic institution.

The process of feedback, reflection and learning typical of participatory action research also aims to bring about individual change as community researchers gain in confidence, skills and understanding, enhancing the benefits of the programme.

The Impact assessment

This impact assessment has two strands. First, it aims to study the individuals engaged in the programme, as MHGs or session participants, to investigate the level of personal change that comes about as a result of their engagement with the programme. For the MHGs, this includes both statistical and qualitative 'before and after' measures. For the session participants, the study gathered qualitative data shortly after the sessions took place. For both, the study also asked what could be done differently to enable them to benefit more.

The second strand aims to assess the potential impact of the programme on the experiences of local African and Caribbean people using mental health services in Hackney. This broader approach looking towards the future can be compared with an impact assessment prior to a new policy or urban development, such as a race equality impact assessment or an 'environmental' impact assessment. In order to help the reader understand the 'environment' where the MHG programme hopes to make an impact, the study draws on the personal stories of 8 local African and Caribbean people (MHG trainees). The discussion section will consider whether or not the MHG programme is likely to be successful and what further development might help increase its beneficial impact.

4.2 The research team

MHG trainees were invited to join the research team in May 2006, and 7 trainees joined up with their SAfH community development worker and a research manager. The five men and four women are all of African and Caribbean heritage, except for the research manager. Five have used mental health services and three have family members with mental health problems. The role of the research manager has been to train and support the team during the research process.

4.3 Ethics

The study was approved by the Ethics Committee and Clinical Director for the East London and City Mental Health NHS Trust (ELCMHT), and by the Ethics Committee at UCLan. It complied with the Research Governance Framework for Health and Social Care (DH, 2005b) in both the detail and overall purpose to ensure that the ‘dignity, rights, safety and well-being of participants’ were assured. Steps taken to ensure participant and researcher safety included:

- An ethos of mutual respect, regardless of faith, culture, ethnicity, age, health and gender.
- A clear purpose of the research to benefit the community.
- Voluntary participation based on informed consent.
- Respect for confidentiality even within a small group.
- Support for researchers who were trained to deal with sensitive issues.

4.4 The steering group

The MHG Steering Group had a remit to oversee and guide the research process through ethical approval, data collection and drafting the report. Finally, it seeks to ensure that the recommendations are appropriate and implemented.

The steering group has a wider role that continues after the completion of the research. It is responsible for recommending how the issues raised in MHG sessions are taken forward. These recommendations are based on the priorities of the MHG programme, as agreed with it’s funding body, CHTPCT. The steering group creates and identifies opportunities to feed the issues arising into the decision making processes. Membership currently includes representatives from the MHG programme, SAfH, Mellow, ELCHT, CHTPCT and UCLan.

4.5 Selecting the sample and accessing the community

There were three groups targeted for this study. In order to assess the impact on the MHGs themselves, all 23 people recruited for the MHG training course were invited to participate in the study and 21 gave consent. 13 people successfully completed the course, and 8 started work as MHGs during data collection and all of these gave consent.

To assess the impact on the participants of MHG sessions, all the participants at 7 sites where sessions took place were invited to take part in giving feedback on their experience. These sites were selected to provide a cross section of the potential range of MHG work, and included a voluntary sector drop in centre, a mental health arts project, a housing project for ex-offenders, a Black led mental health service, an NHS psychiatric ward, and two football teams, one for people using mental health services and one for local youth in an area of acute deprivation. A focus group took place immediately after the MHG session, to gather feedback on the experience of taking part. At two sites, where 4 sessions took place over a number of weeks, a focus group took place after the first and last session. In total, 59 people took part in focus groups giving feedback on the sessions.

Staff working at 6 sites where sessions took place, a commissioner and senior manager of mental health services were selected to assess impact on mental health and other professionals in touch with the programme. All of the 8 people invited to participate gave consent.

During the training, 11 trainees decided to tell their personal stories and some of the data from 8 of these stories, told by the qualified and working MHGs has, by consent, been included to describe the setting where the programme aims to make an impact.

The core research team of 7 people provided feedback on their experience of doing the research.

4.6 Research tools

To assess the impact on MHGs

- Focus group topic guides used with MHGs:
    - At the start of the training, May 2006, with 16 trainees, to explore why they joined the programme, what they hoped to achieve, and what they thought of the training so far.
    - Mid-way through the training, July 2006, with 16 trainees, to get feedback on the course.
    - In January 2007, with 6 working qualified MHGS, to explore the overall impact of being on the programme, what they liked about it and what they would like to be done differently.
    - In January 2007, with 5 members of the Research team to ask about the experience of taking part as a researcher.

  The focus group discussions lasted about 35 – 40 minutes.

- A visual analogue scale (VAS) survey to assess a range of skills and attributes associated with the MHG (Appendix 1). This included questions on

self efficacy, well-being, knowing where to go for help in Hackney and understanding of mental health issues.
The VAS is a tool where participants place a mark on a line to indicate how they feel in respect of a pair of statements and is usually repeated to indicate change over time. It has been found to be a reliable measure of how much and in what direction an individual's feelings change. Developed to assess chronic pain, the VAS is now widely used in the health field because of its simplicity, practical usefulness, and ease of completion. It was completed:
  - on entry to the programme (May 2006) by all new trainees
  - in January 2007 by those 8 people who had both qualified and worked as MHGs.

The SPSS analysis showed that the questionnaire overall based on the two raters (May and January) had a good reliability (Cronbach's Alpha 0.796). Three questions, when analysed on their own, showed poor reliability and this is discussed in Section 6 Discussion.

- A brief interview schedule was used with 5 people who had left the training course, to find out why they left, what they had liked and not liked.

To assess the impact on the participants attending the MHG sessions

- Two focus group topic guides:
  - After the *first* Mental Health Guide session at each of the selected sites.
  - After the *final* Mental Health Guide session at each of the selected sites.
  - Where only one session took place, the second topic guide was used.

  The focus groups lasted about 30 minutes, and were facilitated by two researchers.
- The UCLan amended demographic questionnaire (same as for MHGs).

To gather feedback from mental health professionals/ managers

- An interview schedule for either face to face or telephone interviews.
  The interviews lasted 15 to 30 minutes.

To describe the experience of local African and Caribbean people

A topic guide for the personal stories invited story tellers to talk about their connection with Hackney and East London, their heritage and culture, their personal priorities in life, the influences upon them and their weekly activities. A second section covered their experiences of mental ill-health, the MHG programme and their hopes for the future.
The stories took from 40 minutes to 2 hours, and three members of the research team took turns in facilitating the process.

4.7 Data recording

The focus group discussions during the training were recorded on a flip chart and hand written notes. Results were then written up and checked with participants. All other focus group discussions were tape recorded, fully transcribed, and summaries were checked for accuracy with contributors.

The personal stories were taped and fully transcribed. Transcripts were then shared with the story-teller for checking and permission to use.

The visual analogue scale survey and demographic questionnaires were designed for self-completion. Results were entered onto computer (Excel) by one researcher and checked by another.

Interviews with mental health staff were taped, transcribed and transcripts shared with interviewees for checking. amending and consent to use. Interviews with people who left the programme during the training were recorded by handwritten notes which were checked back with the interviewee.

4.8 Analysis of data

Thematic analysis (of taped group discussions, interviews and stories)

The interview transcripts were repeatedly read and data was progressively grouped, summarised and coded as themes were identified, revised and /or refined. Different topics within the study were analysed and written up by different researchers. Emerging findings were discussed, checked and further analysed with the team where time allowed. Draft reports were checked by the whole team.

Data on flip charts was analysed at team meetings before being drafted into reports by the research manager and reviewed again by the team.

Excel and SPSS (of visual analogue scale and demographic data)

The data from the demographic questionnaires were added up by Excel. Data from the visual analogue scale were transferred from Excel to SPSS for analysis.

Reflective discussion and feedback

From time to time there was reflective discussion within the research team on the issues which were emerging. Progress was discussed at five meetings with senior staff at SAfH and Mellow during the course of the study.

5. RESULTS

As outlined above, the results cover five areas of investigation. This section begins by setting the scene (para. 5.1) with a brief cameo from the 8 personal stories of local people and their experiences of mental ill-health, to help the reader understand the community and service context where the MHG Programme aims to make an impact. Following this, in 5.2, the experiences of the MHGs are described, including 23 trainees who enrolled in May 2006, 13 who subsequently qualified as MHGs in August, and 8 who both qualified and worked as a MHG by the end of January 2007. Next, in 5.3, the feedback from the 59 participants attending the MHG sessions is reported, and in 5.4, the interview data from 7 staff working within mental health services is set out. Section 5 concludes with the impact on the research team. The common strands which emerge across these different areas are drawn out and considered in the Discussion section (Section 6).

5.1 Personal stories from local African and Caribbean communities and their experiences of mental ill-health

This cameo of local people is drawn from eight personal stories told by MHG trainees who later qualified. This does not aim to be representative of the 23 MHG trainees, nor of the wider African and Caribbean population in Hackney, but it is hoped that the stories will help the reader to understand some aspects of life for African and Caribbean people in East London.

Local connections, varied identities

The eight MHGs have firm roots in East London. Four out of the eight people were born locally, three came to the UK as children and have lived in East London for over 30 years, and one came to the UK in 1995, moving to East London within a few years. All are residents of Hackney apart from one person living in Newham and another in Tower Hamlets. All have some family in the area, and most have attended local schools.

The families of six MHGs came from the Caribbean: Jamaica (5) and Dominica (1). The families of two MHGs came from Africa: Zimbabwe (1) and Nigeria (1). The MHGs themselves choose to describe themselves as African (4), African Caribbean (1), Afro-Caribbean (1) Black British (1) and Nubian (1).

> "*Personally, I describe myself as African, and then Nigerian British, if there was such a term.*"
>
> *"I'm a Jamaican, but … I see myself as an African. So everything to do with the African culture is what I teach my children."*
>
> *(MHG story tellers)*

Personal priorities

The family was described as particularly important by all the MHG story tellers, and some included in this their extended family and even their friends who together provide a network of support.

Nearly all the story tellers felt that personal achievement, paid employment, and actively contributing to their community are very important, and for many, these goals are inextricably linked.

The third most frequently mentioned priority was faith. For most, this is more to do with belief in a higher being than a specific religion. One spoke of her commitment to the Nation of Islam.

Physical health was said to be very important by three story tellers.

> *"Family is number one for me. I've got a big family and I've got a child myself….. Sometimes your friends could be like your family. They're supportive, I'm supportive to them."*
>
> *"Being an African Caribbean man and seeing what is going on over here and in … Africa, it has influenced me to take my culture more seriously and to be positive and to help [others]."*
>
> *(MHG story tellers)*

Perspectives on Hackney's African and Caribbean communities

Story tellers identified the main concerns and strengths of Hackney's African and Caribbean communities. Education emerged as the greatest common concern, as they spoke of low expectations and racism faced by Black children, which resulted in under-achievement at school. They also spoke of a 'sense of exclusion' which included negative portrayals of African and Caribbean people, unemployment and the drugs and crime which follow. The high level of mental health problems and of people seen in the streets who were clearly unwell was a major concern and seen as another consequence of the exclusion. There was also mention of the divisions and tensions within local communities, exacerbated by the lack of resources and 'run down' environment.

At the same time, the 'togetherness' and warmth of African and Caribbean communities were seen as their greatest strength. It was said that they have great potential for achieving change when they come together, which, it was said, they are increasingly doing.

The many 'resources' and talents of African and Caribbean people were also described, including fashion, music, sports and the many achievements in the

past (not sufficiently recognised in schools) which have contributed to British life and culture.

There was also mention of the capacity for ‘endurance’ among African and Caribbean people.

> *“African and Caribbean communities around Hackney, East London are beginning to become aware of who they are, where they can go, what they can achieve…. Aware of the difficulties they are faced with … and have become more adaptable at finding solutions.”*
>
> (*MHG story teller)*

The causes of distress

Five of the eight people telling their story have used mental health services in East London in the last 3 years, and two others have close family members with serious mental health problems. They described the causes of distress as broadly:

- Long term pressures of individual and institutional racism, bullying, worries about sexuality and lack of achievement, causing a lack of hope
- Intense stress, for instance one person was trying to bring up a family, hold down a job, and study while coping with a totally new environment
- Lack of the opportunity (or ability) to talk about the pressures with trusted individuals
- Going down the ‘wrong road’ as a response to the pressures or fashion, leading to drugs (and/or crime).

> *“There isn’t really any hope”*
>
> *“When people are looking at me like I’m lower than them, then it’s difficult*”
>
> *(MHG story tellers)*

What is not helpful to people in distress

The story tellers spoke about their negative experiences with the mental health services which broadly included:

- Lack of access to help before a crisis erupts
- The standard of service was poor / inappropriate
- The nature of the help provided was not likely to lead to sustainable change or recovery (in the NIMHE use of the word, Policy review above).

Two spoke of unsuccessfully seeking help in Hackney, one asking for help from a psychiatrist and the other seeking help at Accident and Emergency Services. The first received a successful re-assessment of his mental health needs after being

arrested by police shortly after meeting the psychiatrist. The second was successfully re-assessed after seeking help at a hospital outside East London.

All eight story tellers spoke about poor quality services, although some also spoke well of some of the help they received. One spoke of the poor environment on the ward where her son was referred from Newham: “All run down, messy and chaotic”. She felt the staff also had this worn out appearance, apparently lacking the motivation to provide the care she wanted for her son. One described his hospital experiences in Hackney as “inhumane” where he felt treated like a criminal. Another spoke of the “clash of culture” between mental health professionals and service users, which inhibited any “opening up” by the service users. One complained of the attitude of his community nurse.

Several (5) story tellers spoke of the lack of opportunity to talk about and share the problems which caused their distress. The focus was on medication to calm the individual and control the signs and symptoms of their illness. Pressure on bed-spaces meant that the least ill were discharged “patched up” without the underlying cause of their distress being resolved. Although the importance of talking was emphasised, it was said that not everyone wants to talk to a counsellor, where the “clash of culture” may re-emerge. Several (4) spoke about the lack of practical help to develop an active, fulfilling life on their return to the community.

As a consequence of these negative experiences, one spoke of losing confidence in the mental health system and another spoke of losing hope in his own future.

> *“I never thought that I would have the ability or opportunity to do the things that I wanted in life, I thought it was just over….that is the impression that people in mental health give you.”* *(MHG story teller)*

He felt that this hopelessness and bleak quality of life causes some to “self-medicate” with cannabis and other drugs, “and then things just spiral out of control.” Professional staff do nothing to inspire hope in a better future.

What has been helpful to people in distress

The eight MHG story tellers also have experiences of helpful interventions, which involve fostering hope and motivation in a range of creative (but not necessarily expensive) ways:

- Encouragement to instil hope
- Family support
- Talking to trusted people
- Peer support and role models
- Activities to progress life in the community
- Self help opportunities – taking control of your own problems

- o Black led services
- o Caring and practical mental health and GP support.

The main ingredient here is hope of a worthwhile future life, and this encouragement has come from family, friends, and for two people, from Black workers based at voluntary sector mental health projects. No one spoke of mental health professionals providing encouragement, so the family became hugely valued by those lucky enough to have one.

> *"Your family letting you know that … it is not the end of life."*
>
> *"My family being there for me,… telling me that I would get through it."*
> *(MHG story tellers)*

The family is valued both as a source of support and as a "guardian angel" making sure mental health professionals provide what is needed. Talking with family members is important, but can also be done with others who are trusted. One person valued his family counsellor, another valued two Black workers from different projects, and another would have liked a peer "helper" much like the Mental Health Guides rather than a professional. He argued that

> *"Where one [service user] is stronger,…. a bond seems to [lead to] an improvement in one who is not so strong."* (*MHG story teller)*

Activities which helped the individuals to get back into community life were valued, and information about these came through voluntary sector projects (THACMO and Tower Hamlets Mind) and key individuals from these projects. One person felt that there had been scope for his Care Plan to include much more on this area, and another noted it is important to "keep the momentum going". It was said that self help – being proactive in your own care – was vital, but not everyone is able to do that depending on their needs.

Good professional help had been available for some story tellers. One valued the specialist youth and Early Intervention Team (Newham) for the practical and regular help provided. One had found the GP looking after a close relation in Cheltenham provided intensive and well-judged support, enabling the patient to keep out of hospital so that he could keep his job, relying heavily on family support. One person found useful information on the ward in Tower Hamlets and the visits to the ward by local Black voluntary sector workers there enabled him to take up their offers of help on his discharge. They have "been there for me since then." Another person found the staff on the ward at North Middlesex Hospital "understanding". One person commented that there is always one worker who is able to help, however bleak the general situation.

5.2 The impact of the MHG programme on the MHGs

Demographic data

The detail of the demographic data is set out in Appendix 1. In brief, this shows the 13 qualified MHGs were aged 30 and above, with almost equal numbers of men (7) and women (6), born in the UK (7) or abroad (6). Those born in the UK have all lived here for over 11 years. Most MHGs describe themselves as Black or Black British or mixed Caribbean ethnicity but 2 are African. Most (11) are British citizens, and half (6) are Christian, with other religions including Rastafarian, Orthodox Coptic and Muslim. There are 4 carers and 11 with experience of mental health difficulties, including 6 who have received help from mental health services and 5 from primary care. Treatment has included medication (8) but not alternative therapy of choice.
There is data on 6 people who did not qualify as MHGs. Most are a similar age, British Citizens of Caribbean heritage born in the UK. All have experienced mental health difficulties, and 4 of the 6 have used specialist mental health services, received medication and help from the GP, but only one has had an alternative therapy of choice. There appears to be no significant difference between trainees who did or did not successfully qualify as MHGs.

Reasons for joining the MHG Programme

In total, 16 participants from the programme (9 men and 7 women) attended the two group discussions that covered this question. This was approximately 70% of those on the training programme at that time.

A commitment to help
Many spoke of a commitment to helping African and Caribbean people who experienced mental health problems. They felt that their experiences as service users and carers enabled them to help in a different way from professionals. Some trainees wanted to help on a broad range of health issues. Many wanted to increase other people's self esteem and confidence, so that they could speak up for themselves and get the help they needed from their CPN or doctor.

> "*Even if I help one person to get back on their feet in my lifetime, that's a great achievement for me."*
>
> *"This is like giving people the tools to become independent."*
>
> *(MHG trainees)*

A concern about mental health
Many were aware of the high numbers of African and Caribbean people in the mental health system. Several spoke about school-friends in Hackney or people seen on local streets who were not getting the help they needed. Many wanted to

get a better understanding of mental health issues, particularly the causes and the solutions.

To increase access to help
Some said that they themselves had not received the help they needed when they experienced difficulties, and they wanted to make the situation better for others. Some also hoped to gain information which would benefit themselves.

> *"To give someone the opportunity to talk that I never got."*
>
> *(MHG trainee)*

To create change in services and individuals
Many people wanted to create change in the mental health system and to challenge discrimination and stigma. They wanted to see greater access to talking and alternative therapies, less over-medication and side effects of medication, more Black-led services, better information, more help to get jobs, more resources in community services, better housing and changes in the mental health legislation to reduce the disproportionate impact on young Black men. Some said that they felt they could achieve more as a group than on their own, and could be a force for change, like the 'A Team' if working together.

> *"It's all about finding a solution."*
>
> *"I think I could make a difference, encouraging people to go to the right places."*
>
> *(MHG trainees)*

Some trainees hoped to inspire personal change and motivate others to help their community themselves. They felt that, by being a MHG, they can be inspirational to others, especially when others see that they have moved on from using mental health services to do this work.

To improve worthwhile career opportunities
The Programme was also seen as an opportunity to 'get out of the house', enhance skills and take up an active role in the community. They noted that in doing community work, the helper can benefit as much as the helped. Some saw it as an opportunity to get a qualification and a good job.

> *"It would be a step forward in my life."*
>
> *(MHG trainee)*

The training experience

Four group discussions were held with trainees during the course, attended by 70% -90% of trainees, to gather feedback on the training to date. Additional feedback was provided by 11 personal stories told by trainees after the end of the

course. There was a great deal of positive feedback, together with some strong views on how the course might be done better next time.

Enjoyable, interesting, with a good social mix
Most people found the course fun and interesting, with lots of variety in both the range of topics and teaching methods. There was a relaxed, welcoming atmosphere where people made new friends and acquaintances. Some said it was an opportunity to meet and get on with people whom they otherwise would not meet.

> *"A side of me came out in the group session that doesn't normally come out – it was making the house, it seemed childish, but I enjoyed it and found something new in me".* *(MHG trainee)*

Personal development and new skills
Trainees said that they had improved their skills and confidence in public speaking, team working and group facilitation. They learnt from each other in group sessions. By the end of the course, they felt ready to start work as MHGs – with support. Some of the exercises were challenging but helpful.

> *"I've been on a journey… a positive journey".* *(MHG trainee)*

Learning about mental health issues in a safe environment
Trainees valued the learning they gained about mental health issues, particularly from other trainees who were service users and during small group projects. At the start of the course a few people had little understanding of mental health issues and their discriminatory comments made others feel uncomfortable. This emphasized the need for more learning on mental health, with a greater focus on recovery and key issues such as procedures during a section under the Mental Health Act, medication, and the Care Programme Approach. It was said that the course could have given greater prominence to experiential knowledge by inviting mental health service users and carers on the course to contribute as trainers. Two additional training sessions about mental health were given to qualified MHGs in response to feedback.

A Black presence
The trainees particularly appreciated the SAfH MHG coordinator, partly because of his personality and the support he provided, and partly because he brought a Black male presence to the training. He was felt to be crucial to the success of the programme and gave trainees valued respect. Also, trainees valued the motivational Black speakers who had delivered training on a few occasions. It was said that a greater African and Caribbean presence would have been useful.

Individual learning support and space for communication
It was felt that trainees needed more support, and to some extent, they supported each other and with help from the SAfH coordinator. It was felt more was needed

to deal with any anxieties, misunderstandings or tensions which might arise. There was a tendency for trainees to discuss problems among themselves rather than share them with a member of staff and at one point tensions emerged which might have been averted if dedicated support and a channel for communication had been developed more vigorously. Through discussion, it was felt that SAfH need to allocate an approachable, available member of staff for each trainee, to keep in touch every week and to take any emerging issues up within SAfH. A shared gender and ethnicity might make the worker more approachable, but it was not felt this was sufficient or essential: personality, skill and a dedicated role are more important.

Design and delivery issues
Several of the trainers were felt to be very good, but it was said that several of those involved in delivering the course were not familiar with mental health issues and a better understanding would have helped to create a safe environment.

There were no trainers who spoke of their direct experience of using the mental health system, losing the opportunity to value of experiential knowledge.

Handouts varied in their usefulness and availability. Some trainees wanted more guidance on where to get further information (websites, book references etc). Some trainees would have liked a more structured approach with information about what they were learning and why, including clear learning objectives each week, together with time for reflection at the end of the day. A brief review of last weeks learning at the start of the day would help to retain the learning. Trainees valued the opportunity to do a practice session midway through the course, and many would have liked more opportunities to practice.

The lack of course accreditation was disappointing and said to be a serious omission.

Organisational issues
The number of people on the course (43) was felt to be too large. The venue for the training was not a good learning environment because of poor acoustics and constant interruptions from other people using the building.

Lack of clarity in the course publicity resulted in a number of false expectations, particularly regarding the accreditation, the amount of paid work available as a MHG, the focus on mental health and the recruitment restricted to African and Caribbean people. It is difficult to convey the complexities of the MHG programme, but in future, a ‘taster MHG session’ led by a current MHG could help. Many wanted more clarity about how people receiving incapacity benefits would be paid, with guidance and arrangements in place for ‘permitted work’.

It was a long course which overlapped with school holidays. Trainees suggested the timetabling be reviewed to help young families, and several people requested a more intensive course delivered over a much shorter period of time.

The course started each week with a good meal, but when the quality and quantity deteriorated due to a change of supplier, there was dissatisfaction.

Reasons for leaving the training programme
Ten of the 23 MHG trainees left during the training, and of these, six gave feedback. Three found the course was not what they had anticipated or wanted. One person was disabled and had difficulty arranging transport so had to withdraw. One person was under pressure from Jobcentre Plus to take up employment and another decided she did not want to work as a MHG. The two people who left because of travel and Jobcentre Plus expressed interest in future courses. In general, the comments from those leaving the course were similar to those above, both positive and negative.

Impact of being a Mental Health Guide

Qualitative data which describes the impact of being a MHG was collected from the 13 people who successfully qualified. The 8 MHGs who have already started work as a MHG describe their experience in terms of a journey, with personal development as they meet challenges with achievements, creating change and moving on through their social enterprise, Positive Visions. Their expectations are not all fulfilled yet, and they identify areas for programme development. Those who qualified but did not work as a MHG before the end of January 2007 were brief in their comments, both positive and negative.

Self development: skills, confidence and identity
Many MHGs gained confidence and new communication skills, particularly listening skills and the ability to talk to a large group of people. The benefits spilled over into other areas of their personal life. For instance, one spoke of gaining the confidence to do other things, another spoke of improved family relationships and several spoke of helping people outside MHG settings, on the street, with the family and friends. Two spoke of being able to talk about mental health issues more easily and openly.

Three men who have used mental health services spoke about developing their sense of identity. One described his increasing self awareness and another felt more assured as a Black person, communicating more easily with other Black people and consequently able to relate better with others. Another felt he knew more about his roots, and was glad to be able to ‘give back to’ his Black community.

> “*We are all Blacks and it feels good – like brothers and sisters.”*

“Gives me confidence to be someone in the community… I feel a lot more fulfilled now.”

“*I don’t feel I have to prove myself to nobody. I can just be myself, a Caribbean Englishman”.*

(MHGs)

Challenge

The role of a MHG, particularly going into a group of new people, getting them to listen to you and then you listening to them, facilitating a discussion and drawing in the quiet participants was described as very challenging. There is also the need to gather information that is wanted by the groups and to pass this on to them. It was described as hard.

“The very idea of being a Mental Health Guide is pretty daunting”

(MHG)

Sense of achievement

Meeting the challenge successfully gave a great sense of achievement, a word used several times. One was pleased with his success in encouraging quiet participants to speak, and another with her ability to listen to the participants. One spoke about her love of the research and her sense of achievement in that. There is a general feeling that the MHGs are making a positive difference to other people’s lives. The people they help do not have to go through the same experiences that they went through.

“I’ve really come away thinking that I’ve made a difference.”

“It’s given me a sense that I’ve put my stamp down on something.”

“Doing this has really inspired me…. I know I am doing something important for the community.”

(MHGs)

Creating change and challenging discrimination

The MHGs have some confidence that the programme ‘will work’ as a mechanism for feeding back messages from the community to the statutory services and they are glad to be part of this process. One spoke of how the MHG programme has enabled him to learn how services can be changed, and now as a MHG he can achieve his aspiration to improve services.

“I set out to take part in the MHG programme to help change things in the mental health setting and I think it has given me the opportunity to do that.

I think I've the ability to speak for [service users] in a place where they can be heard and what's been said can be taken on board and changes put in place."

(MHG)

Most of the 8 working MHGs felt they were better able to challenge discrimination and stigma, partly through talking within the Black community about mental health more openly and with more understanding, partly through working with others to reduce the disproportionate numbers of Black people in mental health services, and partly by sharing information. Through giving and receiving information, the MHGs could increase understanding, access to services and enable those services to be better designed and delivered.

Moving on

Moving on with the MHGs is an undercurrent in the focus group discussion. The personal development, opportunities to get involved in creating change, meeting new people and setting up the enterprise all contribute to a sense of a journey.

"It has opened different doors for me"

"I know there is going to be a change because of Positive Visions"

"It's given me, coming from a service user background, inspiration to say that even though you are a service user, you can go on to do good things."

(MHGs)

Expectations

As we heard above (Reasons for Joining the MHG Programme), people came with high hopes and the feedback above suggests that the experience has gone a long way to meeting these. Some people feel their expectations were fulfilled, but others are more cautious, speaking of 'work in progress' due to it being early days. For this group of MHGs, some expectations are fulfilled but a number of issues have yet to be addressed which are set out below (Areas for development). Two MHGs who are not yet giving sessions said their expectations are not fulfilled.

Quantitative data:

The 8 MHGs working on the programme completed the Visual Analogue Scale (described in Methods above). This group comprised six male mental health service users, one female carer, and one male 'concerned citizen'.

The Visual Analogue Scale showed a 'highly significant' overall positive change for the 8 Mental Health Guides (significance 0.000) across all questions. The good reliability for the questionnaire as a whole suggests the same result would be achieved for another similar group if given the same experience. However, the sample of 8 people is not representative of the trainee intake to the programme;

the benefit has been to a sample of predominately male mental health service users. The bar charts below illustrate the change found in 4 of the 11 questions.

Three questions showed poor reliability when analysed individually: ‘confidence in asking for help from professionals’, ‘understanding of mental health issues’ and ‘knowing where to go for help in Hackney’. There is no obvious explanation for the varied responses to confidence in asking for help. Three people gave a lower rate for the understanding of mental health issues in January, and this may reflect the qualitative data which indicated some trainees wanted more training to meet the challenge of delivering sessions. The data for ‘knowing where to go for help in Hackney’ showed an overall increase of 33%, but people varied in the amount their knowledge increased, starting from different levels, and one person knowledgeable from the start recorded a slight decrease, perhaps more aware of what he did not know. At the end, however, all 8 MHGs indicated a very high level of confidence in their knowledge of where to go for help in Hackney.

Areas for development in the MHG programme

The following issues arose in the feedback from the MHG’s:

- *More sessions, time and publicity, consistently delivered to a high standard*
  Several MHGs wanted the ‘scale’ of the MHG programme to be larger with more sessions effectively organised, publicised and delivered. There was concern that some sessions were poorly attended, and it was said that better publicity and consistency (not cancelling sessions at short notice) might help.

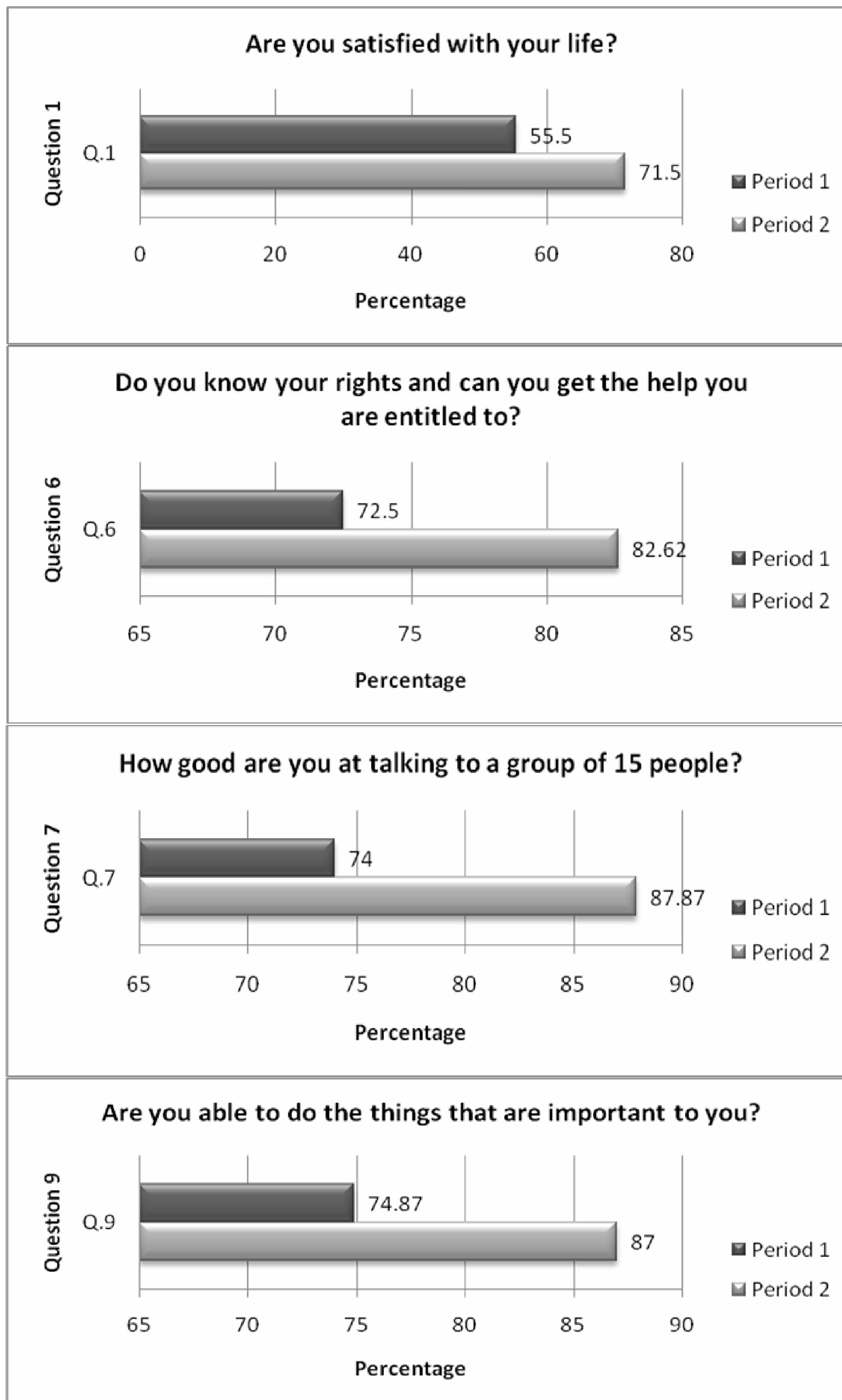
- *Improving the communication between SAfH and MHGs*
  Communication between the MHGs and SAfH was said to be variable, and MHGs wanted this improved with more forward planning. There was a request for a more systematic process whereby both a verbal debrief and written feedback was in place within a day of a session taking place. There is interest in a broader dialogue and relationship with SAfH, sharing views about what is working, what is not working and issues of common concern.

- *More individual support for MHGs*
  Several MHGs asked for more personal support and practical help, e.g. to gather the information needed for the following session.

- *Payment issues reviewed*
  There was a request to review the payment process, increase clarity and comply with the benefit rules for incapacity benefit claimants.

- *Access to ‘proper jobs’.*
  Several people had understood that the programme would offer regular work; they wanted more regular employment on or beyond the programme.

Table 5 Mental Health Guides Visual Analogue Scale Selected Results



5.3 The impact of the MHG sessions on those who took part

Demographic data

The tables in Appendix 2 show that most (71%: n.42) of the 59 participants were aged between 30 and 49 years old, and most of these were in their thirties. However, 17% of participants (n.10) were below 25 years old and 4 were over 50 years, showing the MHGs reached people with a good age range.

Most of the participants (69%; n.49) were male. Just over half (54%; n.32) were Black, Black British, Black Caribbean, Black African or Black other, including almost equal numbers describing themselves as African (13) or Caribbean (16). Just under a quarter were mixed Black/White ethnicity (24%;n.14), most of whom were Black African/White. Also just under a quarter (22%; n.13) were White, mostly White British.

About two thirds (63%; n.37) were born in the UK, and of those who were not, most (68%;n.15) have lived here for eleven or more years. Most (78%;n.46) are British citizens, with only 4 refugees or asylum seekers. Although most speak fluent English, there were 9 different first languages, indicating participants have a wide range of family backgrounds. Over half (56%;n.33) were Christian, but 19% (n.11) had no religion. Other religions include Rastafarian, Muslim, Buddhist and Jew. One person described himself as gay. Others were heterosexual or declined to answer the question.

Questions about disability and mental health showed that some of the 22 people who described themselves as disabled used the term to include mental ill-health while others did not. Three quarters (75% n.44) said that they themselves have experienced emotional or mental health difficulties, and 20% (n.12) were carers of people with mental ill-health. Most of the participants with mental health difficulties had received help with medication (40), from the GP (38) or from specialist mental health services (37). Fewer, (20) had received help from an alternative therapist.

MHGs are service users, carers and concerned citizens from the community

Participants felt encouraged and understood because MHGs shared their experiences. They valued the fact that MHGs were not professional staff: they were role models with a personal commitment to help others.

MHGs provide encouragement and hope

The MHGs gave inspiration and hope that life is not over just because of having a mental health problem. Participants saw and identified with service users and

carers delivering sessions, getting motivation and encouragement from their example. The service user led aspect of sessions and research was welcomed.

> *"This session made you realise that even though you're under the mental health, there's a way out and …there is hope. And support. That's what it's done for me."* *(Core Arts participant)*

> *"I've been in the service for 14 years - and I've never before seen people like you come in and make a stand for people with mental health issues. I never seen that before."*

> *"It was very encouraging and empowering for you to come in here - you have really given us all a great boost."* *(Tuke ward participants)*

> *"It's good that the research is being done by users. That's power!"* *(Core Arts participant)*

MHGs offer understanding and empathy

The participants spoke of MHGs showing understanding and being able to empathise with them, because of their skills and shared experiences. It was felt this enabled the MHGs to help them.

> *"If you've been through it yourself, it's easier to empathise with other people who have been through similar things."* *(Core Arts participant)*

> *"You have been through the system yourself, and understand exactly where we are, as opposed the people who are looking after us …. And therefore you are most able to help us in some ways".* *(Tuke Ward participant)*

> *"I feel comfortable speaking to both of you because you've made me feel comfortable."* *(NACRO participant)*

MHGS from African & Caribbean communities

In sites where all participants were Black (NACRO, Clapton Rangers and Nile Centre) the participants said that African and Caribbean MHGs had a good understanding of the issues that concerned them because of their shared experiences of being Black.

> *"They've come through the struggle as well…so they have an understanding".* *(Clapton Rangers participant)*

> "*For me, you're coming from where I'm coming from*". *(NACRO participant)*

"*It makes me feel like you're my friend and we belong together and you help each other*"
(*African and Caribbean participant, Hackney Football Club*)

In other sites, where ethnicity was mixed, some participants said that ethnicity made no difference to the job of being a MHG. Some expressed concern that participants who are not African and Caribbean might be excluded.

"*Ethnicity isn't important - it's the amount of knowledge they have and how much support they are going to provide … that is most important*".
(Tuke ward participant)

"*I don't think it's got anything to do with it... if they're speaking sensibly,… it doesn't make any difference, as long as they are … doing the job*"
(UK White participant, Hackney Football Club)

MHGs as personally committed non-professionals
Among the participants, the general consensus was that because the MHGs were not professionals, participants found it easy to relate to them, they felt comfortable doing so, and they appreciated their personal commitment and flexible approach (such as coming in the evening). Participants felt they got realistic, honest feedback from the MHGs.

"Feel more comfortable. … we're on a level…. I feel comfortable speaking to both of you because you've made me feel comfortable."

"*You're not doing it because you are sent, …you're doing it because in your heart, that's what you want to do*". … *(Nacro participants)*

"*They have more of a passion towards mental illness, because they've experienced it".* *(Core arts participant)*

"*A more realistic approach to the same issue…get more truth out of them for feedback.*" *(Friends Lodge participants)*

MHGs as role models
It was said several times that the MHGs were felt to be role models because of all these shared experiences. This inspired a few people to say that they too would like to help their community.

"*I think you are like a role model - when you mentioned [your experience]… you become more real and I relate to you a little bit more*".
(Hackney Football Club participant)

"Maybe in a future session, we could reverse the roles, we could go out and help somebody else…where I can say to somebody, 'Look, please don't do this because this is where you are going to end up".'
(NACRO participant)

The Group Approach

Participants find coming together has made them feel closer and able to understand each other more. They discussed how they found a new solidarity between themselves. They had an opportunity to learn from each other and the freedom to express what they wanted. It seems the majority of participants never had the opportunity to use a space to discuss their problems and issues.

Sessions bring people together
Individuals spoke of enjoying sessions, interacting and getting to know others from their own group. Some hoped future sessions would bring them more close together. Some spoke of the relief of being able to talk to others about their problems.

"*I feel closer to a couple of members here that I didn't feel before, because … there's not any place where we share any thing but creative art"*
(Core Arts participant)

"More intra-supporting network between ourselves where we can start to talk to one another .. in an informal way of supporting one another".
(Friends Lodge participant)

"*Most of us think at home [alone] unhappily about things … But the good thing about this is you can go back and you can say "Well at least I have spoken about this issue".* *(Friends Lodge participant)*

"*I've just got rid of it all. I haven't shouted out or lost my temper. Sitting down and talking about certain things, has got it all off my head. It's been a release*". *(NACRO participant)*

Participants learn and gain strength through peer support
Being able to share experiences with others was an important aspect of the sessions. Participants found they were able to learn from and support each other, gaining strength through group membership. Some said they were able to see themselves differently and gained new ways of dealing with their problems.

"Sharing my experience, how I dealt with it, and probably getting help from people who have similar problems to what I have, just being some kind of help". *(Tuke Ward participant)*

“I’ve heard a couple of things from a couple of people today that h*ave made me view them and myself a little bit differently, that’s all”..*
(Core Arts participant)

“*The advantages of a group are that you get lots of different ideas and experiences what people have had”.* *(Nile Centre participant)*

“*More solidarity, really, Just felt like a little bit stronger as a unit”*.
(Core Arts participant

MHGs as listeners and group facilitators
The MHGs showed they were able to listen and give valuable feedback. Their skills in facilitating the group discussion were praised by participants.

“*You did listen because you summed it up as well, you did a summary at the end and before you went on to the next point. ..Very good. A good experience”*. (*Hackney Football Club participant)*

“*Normally people ask you what you want but then they just tell you what they want to say. [The MHG] most of the time was listening to us and what we were talking about…. - must have been a good listener”*.
(*Friends Lodge participant)*

“*It was a friendly atmosphere. The atmosphere was brilliant. It wasn’t like, you felt you had to contribute. And it wasn’t like, you felt you didn’t need to contribute. You could put in a word when you needed to”.*
(NACRO participant)

Sharing Information

In addition to sharing personal experiences, groups shared information about how to get the help they needed and became more aware of their rights. Most information of this kind came from the MHG but some came from other participants. Participants found this aspect of the sessions very interesting and valuable, and they wanted a lot more.

MHGs improve access to services
Participants spoke of finding out where to get help when they or others close to them needed it. Some have more confidence in seeking help.

“*The information that I’ve got from the session, I can use it now. I can get more help that I needed. The help that I didn’t know I could get. I can get the help now”.* *(Friends Lodge participant)*

> "*Sometimes you don't know where to go and you don't know who to ask… So, I think it's been quite good because they have given us information – willing to give us information on things that we need to know".*
> *(Nile Centre participant)*

MHGs improve awareness of rights
Participants said they received useful information on their rights, but they need and want more.

> *"It will take away from our minds the confusion about who does what or where."*

> *"More explanation & understanding with the legal frame work about Mental Health Act, sections & medication*". (*Friends Lodge participant)*

> "*We [want to] know how to protect us more when it comes to medication and other criteria's like, going for walks – when they decide to let you go on walks in the grounds, or, they give you release, and let it go for longer and longer, until you're in the community again"*.
> *(Hackney F.C participant)*

Creating change through service user involvement

Participants raised some concerns that were discussed within the sessions, and these revealed a lack of control over their own care. They expressed hope, but some scepticism, that MHGs might have more influence within the mental health system.

Participants feel a lack of control
It has emerged that service users faced a lack of choice in the mental health system and felt powerless to have any say in important aspects of their care such as medication.

> *"We are up against the concrete wall really. They are not going to say to us 'Yes we can come off medication.' This is what we really should be searching for."* *(Friends Lodge participant)*

> *"You feel it's taken out of your hands. You'd rather have more control over what you're doing and where you're going to, got more choices, whilst you're not given that many choices."*
> *(Hackney Football Club participant)*

> *"We have a fear of the system which is a control factor "*
> *(Friends Lodge participant)*

Participants are afraid their voice will not be heard
Concerns were raised by participants as to whether the MHGs had the power to be heard and deliver information gathered to the relevant parties. Some individuals were concerned that no one will listen to the information they had given and there will be no change.

> *"I hope something is done about the stuff we are saying or otherwise it's all in vain. I'd like to see some papers." (Clapton Rangers participant)*

> *"I hope all this information doesn't fall on deaf ears, if it does get put into – a report." (Hackney Football Club participant)*

> *"I think its good, its good, because you can relate to us better, but the only problem is how much power is there going to be to actually change things? … How much power is this going to have with [people running the service], how much weight?" (Core Arts participant)*

Create a space for dialogue with those in power
Participants spoke of needing a space were they can communicate directly with commissioners, mental health staff or others in positions of power.

> *"It's down to the higher people. Information goes to researchers, …sometimes it don't make a difference, people don't seem interested in taking it to the higher, official people. That's why we've got to take it further ourselves."*

> *"Or maybe a facility where anyone from this group can put forward a question to any consultant or doctor or administrator or secretary or treasurer about issues, about support." (Friends Lodge participants)*

> *"Someone from the government. Anyone of a high position, anyone who is going to listen to what we have to say and be able to do something and say, Yeah, OK, I've got some power and I can use it. I'd like to speak to somebody that said that." (Core Arts participant)*

Build on what works within services

During the sessions it emerged there were good things that the participants liked with their services. Some felt that services could be improved further by working in partnership with MHGs on certain areas.

Aspects of the mental health service which are appreciated
A few participants spoke of how they appreciate the support they receive in the community.

> *"Key-workers make you go forward… they help you go forward in life. ….So this session just makes you realise how important your key-worker really is. And your social worker. And how important the support that you're getting is. When you listen to some people that says 'I haven't even got a key-worker'- It's not nice when you haven't got one and there's no support for you."* *(Core Arts participant)*

MHGs can work in partnership
It was discussed that service users and professionals should work together on developing and making improvements, each contributing their unique skills.

> *"It's the way forward, …. service users working with the rofessionals….this is breaking down barriers. Its doing what the government wants: inclusion, listening to the service users, and I think MPs are behind it, so I think we can take this forward. But we have to fight for it, based on evidence, collect all that, and it is a new break through and it is popular now, so we might go with it."* *(Hackney Football Club participant)*

> *"I think they need to work hand in hand with each other, because …you would have more control if you worked hand in hand with practitioners rather than an independent programme. You need to work together. Share experiences."* *(Tuke Ward participant)*

Areas to develop for the MHG programme

Satisfaction was very high, but some participants were concerned that the MHG programme would need more funding to continue its good work and sustain results. Also, during the feedback from participants it was noted that the presentation, level of information, and number of sessions had to be tailored carefully for the target audience. This is a key part of the normal session planning process, and most participants expressed satisfaction, but occasionally the MHGs did not satisfy all of them.

Funding and support for the MHG programme
When asked how the programme could be improved, several participants spoke about the need to secure the programme with adequate funding and support so it could continue.

> *"You might need more support with funding."*
> *(Tuke ward participant)*

MHGs tailor sessions for their audience
Several participants wanted more information, others less, and two participants felt some information they were given was incorrect. Several groups wanted more sessions given regularly.

"I think the sessions could be a bit longer…sometimes there are things you want to talk about but you don't get the chance to say."

"I got the wrong information on certain things."
(Friends Lodge participants)

"I think it was too much information, actually, it got extended to a certain level where you don't really understand what's going on."
(*Hackney Football Club participant)*

5.4 The feedback from mental health managers and staff

Interviews took place with a member of staff at six of the seven sites for sessions, a primary care trust commissioner and senior manager of mental health services, ELCMHT. The relevant member of staff at one site had left the organisation.

There was a lot of similarity in the interviewees' views, particularly in their full and enthusiastic support of the sessions, the MHGs themselves and their success as role models. There was an acknowledgement that they could be a catalyst to change, through service user involvement (where they help to tick important boxes) and partnership working, and all agreed this would make an important contribution to *Delivering Race Equality*. There were several comments about the future and what is needed to make sure the early success is consolidated with the MHGs informing future development.

Views on the sessions

The MHG sessions are seen a 'worthwhile', 'brilliant' and important contribution to mental health service user engagement. It was said they identify and help to realise issues and concerns from local community groups, by providing a good outlet where participants can open up and bond together. It is considered that sessions provide safe spaces for participants to share their views and comments on services and their mental health problems. It is felt that sessions should be delivered on a regular basis, as a consistent and flexible approach, so that MHGs can develop and maintain a relationship with the participants. Staff interviewees said it is important that the MHGs deliver sessions on the topics and issues highlighted by the participants and that they make the session timetable available to the group for accountability.

"It seems really worthwhile and people get a lot out of it."   Football manager)

"It was brilliant."   (Mind Drop In Centre manager)

"[The patients] were completely ecstatic about it because they found it very useful and we had lots of positive feedback. " *(Ward manager)*

"They really started to bond with one another, … it's an outlet for them to open up and really break down that awareness of their mental health and to understand their mental health and to share it as a team. I noticed after [the session] more of a bond - a team spirit."
(Occupational Therapist and Football Team manager)

"I think it's an exciting, creative programme, which from what I've seen of it has had a big impact on the people involved with it"
(Director of Mental Health Services)

"I think it's fantastic. Fantastic idea, fantastic initiative, and it's what's needed"
(Occupational Therapist and Football Team manager)

MHGs as role models

A strength of many MHGs is perceived to be their personal experience in using mental health services. Interviewees felt they bring an awareness, intelligence and knowledge of the system and how it actually feels like for the service user. MHGs willingness to share their experience enables them to build trust and credibility with participants. They are seen as role models because they prove to service users that there is 'life at the end of the tunnel'.

"The fact that [the MHGs] are service users and carers is just fabulous for the patients to see, that they could move onto that."
(Director of Mental Health Services)

"At the end of the day, everything is based towards evidence based practice, and if you have service user MHG's, now they've been there, they've done it, they've proved that certain things worked and they are on recovery, what more evidence do you want than that?"
(Ward manager)

"When [MHGs] left last week, some of the male patients were going. 'Yeah,yeah'. It made them feel well, thinking, 'If they can do it, I can do it'."
(Ward manager)

"One of your chaps came here the other day - everyone recognised him and everyone was 'When are you coming back?" which I think was really positive." *(Mind Drop In Centre manager)*

MHGs as agents of change and potential partners

MHGs are seen as a practical group who can act as a bridge between service users and staff, feeding issues into existing frameworks, promoting partnerships between the voluntary sector and statutory bodies. The independence of MHGs is seen as an important aspect of the programme which needs to be maintained. There is an expectation that MHGs will contribute to incremental service change in City and Hackney, helping to achieve the objectives of DRE. This will be achieved by feeding into the consultation process and acting in a representative role, sometimes promoting partnerships between local people and services. Senior managers expressed a personal interest in the MHGs progress and one suggested direct dialogue outside the formal planning meetings to learn from their experience.

> *"I think that the MHGs have got a lot to teach us and I think we have to do it in partnership with you"* *(Director of Mental Health Services)*

> *"I think it's the best model we could have for the service user involvement here……. For me, the independence is key"* *(Commissioner)*

> *"They could meet with us – the staff- to raise issues."*
> *(Community arts project)*

> *"North East London is a FIS for the DRE programme and as part of that City and Hackney PCT has an action plan which contributes to the over-arching North East London programme, and I would refer in it to the MHGs as a key aspect of that action plan, particularly given the MHGs are from the communities which are disadvantaged in City and Hackney"*
> *(Commissioner)*

> *"If you look in the HIMP – the Health Improvement Programme – one of the targets in that is to reduce the numbers of people from African and Caribbean groups who are detained under the Mental Health Act, because its about 45%, double what it should be, and that is a huge task, and this is one element of trying to get some change in that."*
> *(Director of Mental Health Services)*

Looking for continuity and development

The need for ongoing sessions and project development was said to be important, extending it to other communities. It was felt that the MHGs delivered the type of information needed by both sides and stimulated much needed dialogue. There was concern that they should be adequately supported for their work, given the opportunity to contribute to the programme development and also the opportunity to further their own careers through employment support.

"I just want you to continue to do this work and continue to have this partnership which will effect change" *(Commissioner)*

"I think where service users are taking part in something that improves people's understanding, it is going to improve decision making"
(Ward manager)

"It's a better way for [MHGs] to work with health professionals, … for them to work together, as part of the package of going out to the community …part of their infrastructure, so that [MHGs] should be there…all the time."
(Occupational Therapist and Football Team manager)

5.5 The experience of the community researchers

Learning, qualifications and UCLan

Learning about all aspects of the research process was a highlight for team members. Similarly, the opportunity to go to UCLan and successfully gain qualifications at a university was hugely important. One plans to take the certificates with her to Jamaica and make use of them there. For another, it is the skills gained which open up new avenues.

"Going to UCLan, that really was a challenge for me, because I've never done university work before…. That was very stimulating and motivating."

"I got distinction. When I told the children, they said: 'Well done Mum, at your age'!"

"I feel confident that I could pull off a research project in all its 8 stages… and I will do one in the future."
Community researchers

UCLan was appreciated for the opportunity it offered, and the first two workshops were found to be inspiring but later workshops were said to be too long. The food and heat at the workshops came in for criticism.

A stimulating and close knit team

Much of the stimulation and learning came from within the research team, particularly during their debates at the Monday morning meetings. The sharing of expertise between the research manager and community researchers was valued on both sides. The commitment and enthusiasm of the team over the year, regularly turning up on a Monday morning (despite it being Monday) were felt to be unusual and one factor in their success.

It was felt that the team worked well together and became very close. It benefited from being a small group and ‘all Black people together’. It was said that it was ‘good for the soul’ to learn about each other, and in this process to learn about ourselves, as the same but different.

> *“We made it like a second family”*
>
> *“We were well knitted, we well understand each other; we might have our good and bad days, but we are all together”*
>
> *Community researchers*

What did not work well

The research had been very hard work, and this created pressure. Over the course of the project, there was a certain amount of absence caused by illness, travel and bereavement. The illness was not related to the research, but those that remained were aware of the amount of work to be done and it would have reduced the pressure if the workload could have been shared more widely.

Communication between the research team and the Social Action for Health / Mellow management team was said to be poor. A meeting set up at an early stage in the project had been poorly attended by the management and was not repeated, but in hindsight greater effort could have been put into making this channel of communication work more effectively.

As the report writing and presentation phase began, this work was not always successfully shared out. Time constraints were thought to be large part of the explanation. One person felt that an opportunity to learn was being missed, and following the discussion more effort was made to enable him to contribute as much as he wanted. Others had contributed as much as they wished or as much as they could given their personal circumstances.

For one researcher, the travel to the Monday meetings was hard but she had persevered. For another, tiredness caused by his physical health and lack of sleep limited his capacity to contribute.

The impact of having a White research manager for an African and Caribbean research project

This issue was explored at the request of the research manager, to increase understanding of cross-cultural research. There were three strands to the response. First, the team felt comfortable with the particular person concerned. They felt respected and communicated well. She was said to be a friend and, by one, included as member of an all-Black team. (It has to be said that her presence at this discussion may have influenced what was said).

> *"It's not about skin colour, it's about the person's vibes, what they can do, how they treat people."* *Community researcher*

The second strand in the response was about the need to be cautious when considering the ethnicity of a worker. It was said that some people from a Black or minority ethnic background do not identify with a Black cause or struggle in the same way as many members of the team and MHG session participants. Class differences or the need to survive in a white dominated profession may make them feel and behave differently.

> *"If you're Black, you don't necessarily come from where all Black people come from."* *Community researcher*

The third strand concerned skills. It was agreed that if there were a person who shared an identity with the group, who had the necessary skills, then they should be appointed in preference to a white person. Sometimes, it was said, it may be necessary to appoint someone who is a bit less experienced, in order to give them the opportunity to learn. It is hoped that Positive Visions will enable the research team and other African and Caribbean people to take a lead role in research projects in the future.

> *"We need to make changes to benefit ourselves as a group.… To motivate us and stimulate us so we can pass it on richly to our children."*
>
> *"The skills and the experience – how they going to get it, if you don't give them the chance to get it?"*
>
> *Community researcher*

Outcomes

Six people gained qualifications at UCLan. Five took both the *Community Based Research* and the *Mental Health Policies and Practices* papers, and passed (all gained at least one distinction, and two gained a double distinction). The sixth person was admitted to hospital during the project, and from there successfully took the *Certificate of Achievement in Research*. None had previous experience at university.

'Positive Visions', a social enterprise, was the outcome of discussions at an early stage in the research. As the research drew to a close, a bank account and an unconstituted group structure were being established. Positive Visions has now been accepted for enterprise support through the **engage** programme at UCLan and will receive continuing support from SAfH. They completed their first commissioned work in March 07, a session of facilitation for Mellow.

It was also felt that the team had gained a lot of credibility within the mental health services. Positive Visions is recognised as a new resource within the Trust.

Members of the research team have been recruited to work part-time on two other research projects within East London. As the research draws to a close, one researcher has been offered a job, and another is applying for a job.

The researchers gathered eleven personal stories from MHG trainees during the project. Some of the data has been used for this report but the main purpose of the story telling is to publish a story book and a journal article of their 'community narrative'. Funding for the story book has been acquired through Mellow and work on both publications will begin when the research comes to an end.

During the course of the project, one researcher published an article in a national journal and another is due to publish an article in April 07. A third researcher is working towards the publication of her creative writing.

6. DISCUSSION

The impact of the MHG programme

The impact on MHGs

The impact of the MHG programme on the 13 African and Caribbean Guides has been shown to be extremely positive. For the 8 Guides already delivering sessions - mostly men who have used mental health services - both the qualitative and statistically significant data demonstrate there has been an impact on their lives beyond the programme. They have developed transferable skills, greater self esteem, understanding of the issues important to them, and a role which enables them to help others and they hope, in time, to create the changes in mental health services that they know are needed. In economic terms, they have initiated a social enterprise and some are actively seeking a job. As African and African Caribbean people, the programme has been a source of strength and increased awareness. Those who have taken forward information to the planning forums have felt that they have greater credibility there than before. They are all highly committed to creating change, they have become skilful in their work and they have made a strong impression on participants and staff where they have delivered sessions.

The impact on session participants

There was a wide range of session participants from under 19 to over 50 years old, speaking nine different first languages. However, most participants described themselves as Black or Black mixed ethnicity, and most experienced mental health difficulties.

The impact of the MHG programme on session participants has been extremely positive and often therapeutic. Participants spoke about getting encouragement, empathy and relief from the opportunity to talk to a group of peers who listen. This provides a striking contrast to the despair and medical focus described in the personal stories. Participants speak of being able to talk openly, gain confidence from the Guide as a role model, and receive useful information about their rights and where to get help. In time, if further sessions encourage participants to act on the information, it is possible more service users will get the choices to which they are entitled and move on to recovery. Black participants value the fact that the Guides ‘shared the struggle’, and seeing the Guides’ success helps others to deal with the racism described in the stories.

All participants valued the MHGs obvious personal commitment. Participants started to make connections with each other in new ways, opening up and sharing their experiences of mental ill-health and their coping strategies. The

group discussions were skilfully facilitated as MHGs drew out quieter members enabling all to contribute.

The impact on the mental health ‘environment’

The MHG programme appears to have the potential to create sustainable sources of peer support and a broad impact on the experiences of the wider service user population. It could create pockets of improved social capital across the community and channels of communication between the community and providers. However, evidence for this potentially beneficial impact was based on an immediate response to a MHG session, and we know from evaluations of training (Kirkpatrick,1998) that more is needed if the immediate benefits are to be sustained. Consistent delivery of sessions over a period of time is what participants, MHGs and mental health staff clearly want, and this consistency is much more likely to create sustainable positive impact.

There is good evidence that the MHG programme has contributed to the objectives of DRE as intended, both in the ‘building blocks’ of community engagement, more appropriate services and better information, and also in a number of ‘action points’ such as reducing fear, promoting recovery, and increasing access to a range of therapies and services.

The feedback from mental health managers/ staff

The response of the mental health professionals who have come into contact with the programme and the Guides has been universally enthusiastic and in every case they wish to see more. They feel the programme can make an important contribution to service improvement and will contribute to the objectives of *Delivering Race Equality* by promoting recovery, increasing the voice of the Black service user, reducing fear and increasing information to both the community and service provider. Here again there is scope for a broad impact on the wider service user population, if it continues to develop as it has begun.

A project in development

The programme has been highly successful but everyone involved admits it is in its early days and there is much to learn. The role of the MHG is very challenging and the programme is complex; training and management has to be adequately resourced. Extending the Health Guide initiative to the mental health sector with African and Caribbean people in Hackney has been a learning experience for SAfH. There is more to learn and questions remain.

Can the MHG programme contribute to a recovery focused service?

The programme has created a vocational pathway for a group of people often hopelessly stuck within services, and it has enabled them to be role models who

inspire others to follow. Can this pathway be enhanced with training opportunities with access to specialist employment support – designed and delivered as required in the commissioning guidelines (DH, 2006a)? A Black led employment project of this kind could prove more cost effective than the reliance on 'risk assessment and ensuring compliance with medication' which is known to fail (Alternative Pathways Project, ELCMHT, 2007).

Can the MHG programme retain an African and Caribbean group identity?

How can the powerful impact of belonging to an African and Caribbean cohort of Guides be retained as the programme is rolled out to other groups? The MHGs, gained strength from belonging to an African and Caribbean programme and the shared experience of being Black contributed to their success with young men (Clapton Rangers), ex-offenders (NACRO) and mental health service users (Nile Centre and elsewhere). Loss of the African and Caribbean group identity will greatly reduce the programme's impact. At the same time, there are obvious benefits of extending sessions to other communities and enabling the MHGs to work alongside other groups. Setting up opportunities for diverse MHGs to work together and separately would require time, resources and commitment.

Should the programme target health promotion or recovery from ill-health?

The sessions could be held for the purposes of health promotion, promoting recovery for community based service users, and/or improving the experience of staying on acute wards. If there is a targeted approach in a few sites there is more likelihood of a sustainable impact. Although a brief presence at scattered sites may be a useful spark to initiate change, it is likely the impact will whither away without a continued impetus of some kind. In planning the delivery of sessions, the steering group may wish to bear in mind sustainability as well as the priorities of the MHGs, commissioners, service providers, and local people.

A learning process from the grassroots

As the MHG programme evolves, some practices used within the generic Health Guide programme may need to be adapted. SAfH and Mellow are committed to learning from the Guides as the programme rolls out. Improved communication systems to facilitate this will be an important area for development.

The response of statutory services

Service user involvement

The MHG programme is valued for its contribution to service user involvement: it enables the primary care trust to tick an important box. Community development in mental health has this potential to articulate, explain and share the experience of minority voices and can insist that statutory services listen and respond. If they

do not both listen and respond, the purpose of the programme and motivation will be lost (see review of research).

The Guides have been invited to join the Local Implementation Plan (LIT) team meetings and no doubt other doors will open. The DRE challenges mental health services to make fundamental changes in the way they listen and respond to service users from Black and minority ethnic communities. New ways of sharing experiences are needed, in addition to the formal processes, if commissioners, managers and practitioners are to comprehend other perspectives, feel their pain and respond with better ways of working. Experiences could be shared through open dialogue, creative expression, drama or service user led training. There could be partnership initiatives where MHG and staff work side by side. Above all, there has to be accountability from the NHS back to the local community groups, to explain what has been done in response to their views.

7 CONCLUSIONS AND RECOMMENDATIONS

The MHG programme has made an impressive impact in Hackney. There is statistical and qualitative evidence to show that the African and Caribbean MHGs have personally benefited in many ways. Their experience of mental ill-health has inspired local mental health service users in the community and on the ward, and they are widely perceived to be role models. Their capacity to listen, inform and encourage local people suggests they could make a sustainable positive impact on the local mental health 'environment' if sessions are consistently delivered, making an important contribution to *Delivering Race Equality*. They could focus on mental health promotion or equally well, promote recovery from mental ill-health, or allocate resources to both.

However, the appeal of the programme to local people and the MHGs own personal commitment arise largely from the hope that it will create change and improve the experiences of people in distress, particularly those from African and Caribbean communities. MHGs can be mandated representatives passing on the concerns of local people to commissioners and service providers. The decision makers' capacity to respond will determine the long term impact of the programme, and as commissioners and mental health staff fully support the programme, the outlook must be optimistic.

The following recommendations arise from the evidence collected.

(A) MHG model development
Maintain and further develop:

- The MHG programme in Hackney with an African and Caribbean core group of about 10 - 15 MHGs
- A high proportion of MHGs with direct experience of distress; a smaller proportion of MHGs with carer experience and a small number of MHGs who are 'concerned citizens' with exceptional talents relevant to the programme (eg in youth work)
- MHG sessions at the full range of sites from hospital to mental health community sites to mainstream community sites outside the mental health sector (e.g. sports and educational venues) i.e. promoting mental health and promoting recovery from mental ill-health
- A limited number of partnerships with mental health professionals in specific agreed areas, e.g. Hackney Football Club, Homerton Hospital wards
- The principle of excluding professional staff except where participants invite them in or in the partnership initiatives (as above)
- A continuous process for evaluation and review, designed and carried out together with MHGs, combined with improved communication systems between all levels of management and MHGs to ensure the experience on the ground informs programme development

- SAfH staff awareness and understanding of mental health issues, to ensure training, management, payment and delivery of sessions is safe and respectful.

Explore potential for:
- Extending the programme to other parts of East London and further afield
- Extending the programme to other minority communities
- Developing opportunities for African and Caribbean and other MHGs to meet both separately and together, to allow cross cultural learning while maintaining the group identity
- Developing strands of focused work, e.g.
    - Promoting recovery for mental health service users on wards and in community based services
    - Improving staff/patient dialogue on acute wards
    - Mental health promotion for Black youth and others
- Confining single sessions to those sites where a brief presence is likely to be a spark to sustainable change.

Responsibility for implementation: The MHG Steering Committee (SAfH, Mellow, CHTPCT, ELCMHT) to refer to appropriate bodies, including the BME LIT, Recovery Programme Working Group and Service User Reference Group.

(B) MHG programme funding, management and delivery

- Improve administration, planning and communication systems between the MHGs, their Project Manager and SAfH/Mellow senior management
- Enhance flexible support for MHGs, with constructive feedback, prompt debriefs and practical assistance with finding information for sessions
- Develop ways of ensuring MHG sessions are well publicised in advance
- Liaise with Jobcentre Plus to set up a procedure which enables MHGs and trainee applicants to make an informed choice about the offer of paid work.
- Link the MHG programme to training providers and specialist employment support services (see 'Vocational pathway' recommendations below).

Responsibility for implementation: The MHG Steering Committee (SAfH, Mellow, CHTPCT, ELCMHT)

(C) The voice of African and Caribbean communities and service users

- MHG representatives be enabled to contribute to consultation and planning meetings such as the LIT on an equal basis with other members
- Measures be put in place to ensure their voice is heard, e.g. enabling MHGs to contribute to the agenda and regularly present the views of local people

- The people who chair the meetings be required to respond to MHG presentations within an agreed timescale with information about action taken, action planned or reasons for not taking action (see E Service Development)
- SAfH put in place systems for MHGs to be mandated to represent their colleagues and communities, through election procedures and consensus on the information to be fed up from the community, based on the feedback from MHG sessions
- MHGs receive training and support to enable them to present their case effectively, speak up in a formal meeting and understand the decision making processes within the mental health services and primary care trust
- Unwaged MHG representatives be paid for this work, including their preparation time, either directly by the trusts or by SAfH
- Channels for communication and an exchange of perspective outside of formal consultation processes are developed, to include
    - open dialogue between commissioners/senior managers and MHGs
    - facilitated dialogue between managers/practitioners and local people where MHG session participants have requested this
    - Creative expression including drama
    - MHG and service user led training for practitioners.

Responsibility for implementation: The MHG Steering Committee (SAfH, Mellow, CHTPCT, ELCMHT) to refer to appropriate committees.

(D) Establishing a vocational pathway for those on the MHG Programme

- Commissioners and the mental health services acknowledge and fund accordingly the role of the MHG Programme as an 'alternative pathway' to recovery and employment for African and Caribbean service users
- Commissioners and mental health services ensure that Hackney offers a specialist employment support service, using the 'Individual Placement and Support Model'[4] which is known to be effective across gender, ethnicity and diagnosis, as required by the DH commissioning guidelines (DH, 2006a). A Black led employment service adopting this model would have advantages.
- SAfH facilitate access to this and other vocational opportunities for all MHGs so personal development planning can take place from an early stage. MHGs be supported to raise skills to a high standard in presentations, research and delivering training, leading to full time work where this is wanted.
- Social enterprise development support is made available to groups of mental health service users, commissioned by the primary care trust.
- Commissioners and mental health services comply with the Disability Discrimination Act 2005 and DH policy (DH, 2002) by making available

[4] As described in the Social Exclusion Unit Report (2004) *Mental Health and Social Exclusion*

employment opportunities at all levels within mental health services to people who have used mental health services.

Responsibility for implementation: CHTPCT, ELCMHT and Steering Group.

(E) Mental health service development

- Statutory bodies listen and respond to the views of the African and Caribbean communities as presented by the MHGs
- The people who chair the planning meetings attended by MHG mandated representatives (e.g. LIT) provide a written response within an agreed timescale with information about action taken, action planned or reasons for not taking action (see C above) so MHGs can feed this back to local people.
- Statutory bodies draw on the MHG Programme and the emerging social enterprise, Positive Visions, where possible to explore ways of working which deliver the requirements of *Delivering Race Equality*. This might include management support for MHG sessions on the wards and elsewhere.

Responsibility for implementation: The MHG Steering Committee (SAfH, Mellow, CHTPCT, ELCMHT) to refer to appropriate committees and the London Borough of Hackney

(F) The MHG Training Programme

Maintain and further develop:
- Variety of teaching methods particularly group work
- Welcoming, friendly atmosphere
- High proportion of trainees with direct experience of distress
- A smaller proportion of trainees with carer experience
- A small number of trainees who are 'concerned citizens' with exceptional talents relevant to the programme
- African and Caribbean trainees, trainers and staffing[5]
- Good quality trainers
- Comprehensive training on mental health issues, e.g. Care plans and what should be in them, the purpose and practice of ward rounds, direct payments
- Training on mental health to have a focus on recovery and empowering the service user, for instance in negotiating with their psychiatrist, community psychiatric nurse and others.

Areas for review:
- Reduce size of trainee group to 15 – 20 participants max.
- Accreditation for those who complete course

[5] Overlap with other recommendations

- Ensure there is an approachable, available, source of individual support for each trainee and MHG
- Value experiential knowledge of mental ill-health in choice of trainers and in facilitation of all sessions to ensure safety and well-being of trainees with direct experience of distress
- Programme planning and consultation, with stated learning objectives and weekly review of progress with trainees
- Enhance learning opportunities by providing guidance for trainees, where they wish, to carry out further research
- Organisational arrangements, e.g. ensure timely handouts, appropriate venue and food arrangements, scheduling to suit parents of young children
- Improve understanding of the MHG programme to potential trainees, through clear advance publicity, one to one talks, and MHG taster sessions
- Clarity from the start about payment arrangements for MHGs (see above, A, Model Development)
- Reduce length of course by increasing intensity of learning
- Increase opportunities for practice sessions where possible.

Responsibility for implementation: SAfH, Mellow and the Steering Group.

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APPENDIX 1

Demographic data for the Mental Health Guides and Trainees who did not successfully qualify

Table 6 Age

	19-21	22-24	25-29	30-39	40-49	50+	No response
Qualified MHGs				6	2	2	3
Other trainees		1		3	2		4
Total		**1**		**9**	**4**	**2**	**7**

Table 7 Gender

	Male	Female	Transgendered or Transexual	No response
Qualified MHGs	7	6		
Other trainees	4	2		4
Total	**11**	**8**		**4**

Table 8 Ethnicity

	Mixed White & Black Caribbean	Mixed White & Black African	Mixed Other	Black or Black British Caribbean	Black or Black British African	Black or Black British Other	Other	No Resp.
Qualified MHGs	1			6	2		4	
Other trainees			1	5				4
Total	**1**		**1**	**11**	**2**		**4**	**4**

Table 9 Residency

	Born in UK?		If no, how long have you lived here?			
	Yes	**No**	**Less 1yr**	**1-5 yr**	**6-10 yr**	**11+**
Qualified MHGs	7	6				6
Other trainees	5	1				1
Total	**12**	**7**				**7**

Citizenship: Of the 13 qualified MHGs, 11 are British Citizens, none are refugees or are asylum seekers, but 2 describe themselves as 'other'. Of the 6 other trainees who completed questionnaires, all are British Citizens.

Language: Of the 13 qualified MHGs, all write English fluently, and all but one describe themselves as speaking English fluently. The first language of one is Creole and of another is Palais. Of the 6 other trainees, all speak English fluently and one has some additional French skills.

Religion: Of the 13 qualified MHGs, 2 have no religion, 6 are Christian, 1 Muslim, 2 are Rastafarian and 2 describe themselves as 'Other'. Of the 6 other trainees, 4 are Christian, 1 has no religion and 1 describes themselves as 'other'.

Sexuality: Of the 13 qualified MHGs, 11 are heterosexual and 2 decline to answer. Five of the other trainees are heterosexual, and 1 described himself as 'other'.

Disability: Of the 13 qualified MHGs, 4 have a disability, 8 do not. 1 did not answer. Two of the others had a disability, 3 did not. One did not answer.

Table 10 Mental Ill-health

	Do you care for/live with anyone with mental ill-health		**Have you ever experienced depression, anxiety or emotional difficulties?**	
	Yes	**No**	**Yes**	**No**
Qualified MHGs	4	9	11	2
Other trainees		5	6	
Total	**4**	**14**	**15**	**2**

People who said they had experienced difficulties were asked what help they had received, if any.

Table 11 Help received for mental health difficulties

	Medication		**Help from GP**		**Mental Health services**		**Alternative therapist**	
	Yes	**No**	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
Qualified MHGs	8	3	5	5	6	4	0	10
Other trainees	4	2	4	2	4	2	1	5
Total	**12**	**5**	**9**	**7**	**10**	**6**	**1**	**15**

APPENDIX 2 Demographic data on the session participants

Table 12 Age

Total	16-18	19-21	22-24	25-29	30-39	40-49	50+
59	6	3	1	3	26	16	4

Table 13 Gender

Total	Male	Female	Transgendered or Transexual
59	41	18	0

Table 14 Ethnicity

Total	Mixed White/ Black Caribbean	Mixed White/ Black African	Mixed Other	Black or Black British Caribbean	Black or Black British African	Black or Black British Other	White Brit.	White Irish	White other
59	4	7	3	16	13	3	11	1	1

Table 15 Residency

Total	Born in UK?		If no, how long have you lived here?			
	Yes	No	Less 1yr	1-5 yr	6-10 yr	11+
59	37	22	0	2	5	15

Citizenship: Of the 59 session participants, 46 are British citizens, 2 are refugees, 2 are asylum seekers and 5 describe themselves as ‘other’. (4 non-respondants)

Language: Of the 59 participants, 11 did not give English as the first language. Their first languages included Amharic, Shona, Twi (Ghanaian), Lingala, French, Tgtina Dutch, Turkish, Hungarian and Spanish. Five indicated they were not fluent in English. Five could speak and write two languages fluently, including one who could speak and write the Jewish language.

Religion: Eleven participants had no religion. Of the others, 33 were Christian, 3 were Rastafarian, and there was one Buddhist, one Jew, one Muslim and 7 ‘other’. (2 non-respondants)

Sexuality: 41 participants were hetero-sexual, and one was a gay male. Ten selected ‘choose not to answer’. (7 non-respondants).

Disability: 22 participants had a disability (but few gave further information). 31 did not have a disability. (6 non-respondants). Some people who use specialist mental health services indicated they did have a disability but most did not.

Table 16 Mental Ill-health

Total	Do you care for/live with anyone with mental ill-health		Have you ever experienced depression, anxiety or emotional difficulties?	
	Yes	No	Yes	No
54 - 57	12	42	44	13

People who said they had experienced difficulties were asked what help they had received, if any, and Table x shows that the results.

Table 17 Help received for mental health difficulties

Total	Medication		Help from GP		Mental Health services		Alternative therapist	
	Yes	No	Yes	No				
51 - 46	40	11	38	12	37	11	20	26

APPENDIX 3 Visual Analogue Scale Questionnaire

Mental Health Guides Impact Assessment: Final Survey

SAFH and Mellow are grateful to you for agreeing to take part in this research. It aims to find out if taking part in the Mental Health Guide programme has made any difference to *you*.

This questionnaire repeats an exercise you carried out in May 2006, at the start of the training programme. We want to know if you feel any differently now that you are working as a Mental Health Guide.

To remind you, below are some statements about feelings together with 10 centimetre lines. All we want you to do is to put a cross on each line to show you feel now.

For instance, if the statement on the left describes best how you feel, put a cross on the left. If the statement on the right describes how you feel, then put a cross on the right. If you feel somewhere between the two, put it in the place which is right for you.

Your name will not be given with this form. No one will know who filled it in except the research manager who will do the analysis. She will need to know, so that the forms you complete can be matched up to measure the change in your feelings over the time of the programme. Your name will not be mentioned in any report about this form.

If you want some help, please ask a community researcher, Mark from SAFH or Patience.

Your answers will be treated in confidence.
Thank you for your help.

<u>Now that you are working as a Mental Health Guide</u>,
Please tell us how you feel about the following:
(please make a cross on the line at the place which you think is right for you)

Q1

I am not satisfied with my life	--	**I am satisfied my life**

Q2

I believe that I will be able to achieve what I want in my life	--	**I do not believe that I will be able to achieve what I want in my life**

Q3

I can help people in Hackney worried about mental health	--	**I cannot help people in Hackney worried about mental health**

Q4

I am not confident about asking for the help I need from professionals (GP, Jobcentre, housing, etc)	--	**I am confident about asking for the help I need from professionals (GP, Jobcentre, housing, etc)**

Q5

I know where to go for help in Hackney	--	**I do not know where to go for help in Hackney**

Q6

I know my rights to help and can get the help I am entitled to	--	**I do not know my rights to help, & cannot get the help I am entitled to**

Q7

I am not good at talking to a group of 15 people	**I am good at talking to a group of 15 people**

Q8

I have a good understanding of mental health issues	**I do not have a good understanding mental health issues**

Q9

I feel able to do things that are important to me	**I do not feel able to do things that are important to me**

Q10

I have good self esteem	**My self esteem is not good**

Q11

I do not feel ok about my mental well-being	**I feel ok about my mental well-being**

Thank you very much for your help