

**Community Engagement Project
NIMHE MENTAL HEALTH PROGRAMME**

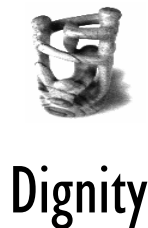
**REPORT OF THE COMMUNITY LED RESEARCH PROJECT FOCUSING
ON THE ROLE FAITH COMMUNITIES CAN PLAY IN THE MENTAL
HEALTH SERVICE NEEDS OF THE AFRICAN CARIBBEAN COMMUNITY
IN LUTON**

**By Dignity Mental Health Service
Luton**

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Aretha Gonzales, George Williams, Lorna Markland**

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Managed and supported by
The Centre for Ethnicity and Health, University of Central Lancashire.***



PERSONAL PROFILES

The following people were involved in the development and delivery of this project:

Paulette Adams: who is 42 years old and married to Pastor Trevor, Director of the Family & Relationship Crisis Centre (FRCC) which houses the Dignity Project. They have one daughter who is 16 years old. Paulette works part-time as a medical secretary, and as a life-skills Coach for FRCC. She became involved in the Research project because she has a passion to see "broken lives restored" and felt that she could make a difference to her community by engaging in a dialogue which could ultimately give a voice to the needs of the African and Caribbean Community in Luton.

Jane Litchmore-Grant: who is aged 39 and married to Rev. Linton Grant. Jane is a teacher by profession and also a Sign Language Interpreter. She has been teaching for the past 15 years - 12 years in Jamaica and 3 years in England. She came to the project by the invitation of Pastor Trevor Adams, her pastor and Director of the Family & Relationship Crisis Centre (FRCC), with some knowledge of Research Writing and has found it quite interesting, challenging and informative. Having served in voluntary services and in various capacities for a number of years, Jane came to the project with a sense of purpose and commitment to seeing "broken lives restored". Along with working with her husband as the pastor for two churches over a 7 year period (whilst in Jamaica), she also served her community as a member of the Red Cross Society, a Warranted Guider of the Girl Guides Association, a member of the Optimist Club International, among others. Jane feels that the knowledge and experiences gained from being involved in this project have motivated her to become more engaged in the welfare of the African and Caribbean community in Luton and specifically, in the area of mental health, where support is sadly lacking.

Gladys McKoy: aged 65 is married to Leslie who acted as her chauffeur to take her to the various meetings for the project. Gladys is a retired Clerk Typist with 5 children (3 boys and 2 girls). She became involved in the project out of a passion to help people. The project provided the opportunity for learning about dealing with people, through the project team working together. It is Gladys' intention to use the skills gained from the project to help other people and to see broken lives restored.

Aretha Gonzales: is aged 26 and describes herself as 'famous-to-be.' She currently holds a position as a youth leader at her local church. Her passions include the work of God, helping young people, writing poems, and praying for the Nations. Aretha says, "*The project has given me an opportunity to see life on a wider basis and to gain a better understanding of mental health issues. It has also helped me develop as a person.*"

George Williams: is a social entrepreneur who has an interest in his community in terms of its mental, social and economic betterment. Being involved in the project has enabled him to gain an understanding of how things are constructed. It has also enabled him to overcome a block to his personal development. He hopes that the powers that be will look at this report and act with the community to bring about change.

Lorna Markland: was the Lead Researcher for the final trimester of this project. - She is 38 years old and married with 4 children. She has been an active volunteer in community regeneration since leaving her career as a Legal Secretary (8 years ago). Her voluntary work is juggled alongside her church duties and raising a family! She has a strong desire to see people's needs met in a real way and was delighted to be able to use her skills on a project which could eventually help achieve this. This project has provided her with an improved knowledge of how the mental health system works and has also equipped her with new skills to carry out further community studies.

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Dignity Mental Health Research team would like to thank all those who helped with this research project.

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Pam Howard - Senior Lecturer

The Family and Relationship Crisis Centre (FRCC) Team:-

Pastor Trevor Adams - Centre Director

Denise Wellington - Administrator

Board of Trustees (Herbie Burton (Chair), Howard McCalla, Jones Alfred)

Former members of this Research project;

Ama Adu-Gymiah - Project Manager (2005)

Leonie Gordon - Lead Researcher (2005)

We also send a very special thank you to;

Each Respondent, who gave of their precious time

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EXECUTIVE SUMMARY

This report stems from a Research conducted by Dignity on the mental health needs of the African/Caribbean community in Luton.

Dignity Mental Health Service is an initiative of The Church of God of Prophecy. We were one of the community groups selected to take part in this Community Engagement Pilot Programme which was funded by The Department of Health's (NIMHE) and supported by The University of Central Lancashire.

The programme is a direct action from the Government's Delivering Race Equality document (DRE) which has a national aim to deliver improved equality of access; experience and outcomes for Black and minority ethnic mental health service users.

We chose to research whether faith organisations could play an important role in mental health promotions, awareness raising and culturally appropriate service provision. Interviews were conducted with members belonging to various Christian faith organisations, the general public, a group of service users and local mental health service providers.

We used the Focused Implementation Site (FIS) Board that comprised of key service providers and commissioners as our steering group to ensure that our findings and recommendations would be picked up and linked into the wider picture.

We used the following definitions from the World Health Organisation (WHO) to help us assess our findings about mental health terms.

Definition of 'Mental Health'¹

"The successful performance of mental function, resulting in productive activities, fulfilling relationships with other people and the ability to adapt to change and cope with adversity; from early childhood until late life, mental health is the springboard of thinking and communications skills, learning, emotional growth, resilience and self-esteem".

Definition of 'Mental Illness'²

"Mental illness is extremely common - far more prevalent than most realise. Research suggests that 1 person in 4 will experience some kind of mental health problem in the course of a year. This kind of illness therefore ranks alongside cardiovascular disorders and cancer as one of the nation's biggest health problems.

Mental health problems can take many forms including depression, schizophrenia, eating disorders, anxieties, phobias, drug and alcohol abuse, post-traumatic stress disorder, and dementia.

*Many of us may already have experience of mental health problems; we may have a relative, friend or partner suffering from depression, or who has had to deal with the effects of bereavement, marital difficulties, misuse of drugs or alcohol, or take responsibility for old people suffering from memory loss, or children with painful emotional problems. **These are issues which could affect any one of us".***

Findings:

1. Misinterpretation

- One of the main findings of this study was the significant amount of people who misunderstood the terms 'mental health' and 'mental illness.' (32% from the faith group, 32% from general public and 100% of focus group)
- People thought that the terms 'mental health' and 'mental illness' meant the same thing and said they referred to people who were not in their right mind.
- We found that the term 'mental health' was often being used as a short way of saying mental health problems.
- Many people felt that the term 'mental illness' referred only to severe symptoms such as schizophrenia and depression. Many people did not agree that things like loss of appetite, inability to sleep, fear and stress should be classed as a mental illness.

2. High incidences of Mental Illness and Coping Strategies used

- 76% of people from the faith group and 72% of the general public said they had personally experienced mental illness.

Faith Group's main experiences:

- Stress,
- Depression and
- Anxiety

General Public's main experiences:

- Stress,
- Depression and
- Insomnia

Work-related stress was the most frequently mentioned problem.

- Most people chose to turn to Friends to help with their issues (25%). GP's were used by 24% of people and Relatives were used by 20%. 96% of the faith community said that their faith played a very significant role in maintaining their own mental health and well being. They said prayer helped to unburden them and the knowledge of a bigger source being in control gave them a great sense of peace.

3. Low take up of Services

- 84% of people from the general public group had never accessed any local mental health service (this figure included people who said they had experienced mental health problems).
- 68% of people said they were aware of local mental health services and were able to name 20 services between them. (See *General Public Question 3*).

- 16% of people said that they had accessed mental health services. GP and counselling services were accessed but people were unhappy about having to be referred and the long waiting lists.
- Only one person from the focus group had voluntarily accessed another mental health service. They tended to stick to one specialist service in particular, saying that it made them feel, “*At home*” because it was culturally relevant to them.

Improvements

Respondents said the following things could be done to improve service provision for the black community:-

- Listen to the patients
- Less stigma
- More awareness needed about signs of illness and help available
- Joint up working between agencies
- Effective engagement strategy needed
- Implement a middle-man service which provides someone to talk to before things get out of hand – something with a non-stigmatising name, such as ‘Healthy Living’ so everyone can use it.
- Establish more preventative measures
- More Counselling services to shorten waiting times
- Advocacy service for black mental health patients should be available
- More services and awareness aimed at Black men
- Community Groups and existing social networks to play a larger role
- More bereavement services in place
- Mainstream services to become more culturally competent
- More BME people to sit on trust boards and at local government

Service Providers who took part in this study said they felt the following were gaps/barriers in service provision for the African Caribbean community:-

- Stigma
- Services lack of understanding of cultural issues
- Services that can provide are not given funding to do so
- Poor access to information.
- Capacity resource problems
- Structural barriers (All the different NHS Trust)
- Bureaucratic nonsense
- People above are not listening
- Best Value protects funding not to help people
- Mistrust giving black people money
- Lack of commitment from commissioners
- A lot of institutional racism still exists within services
- Junior managers
- Short staff

Church Facilities:

People said that the named facilities provided by churches and the benefits they produced meant that churches were in a good position to help with mental health issues. They said they would like to see churches more involved with;

1. Providing spiritual and emotional support to people with mental health issues; and
2. Educating their communities about mental health issues.

It was also reported that churches needed training to reduce fear amongst their members.

RECOMMENDATIONS

Our recommendations are as follows;

- That true partnerships be formed between African/Caribbean community organisations and statutory mental health bodies.
- The need to accept and acknowledge the potential of faith establishments in providing support for mental ill health sufferers from BME groups. The spiritual needs of the BME community must be continually taken into account when designing mental health services.
- That commissioners of mental health services utilise black-led organisations other than faith establishments to help deliver services that will address the mental health problems of the African Caribbean community.
- Mental health promotion and awareness-raising, in the form of educational flyers, outreach workshops and specific events, needs to start immediately to address the lack of awareness evidenced in this research.
- Dignity needs to access appropriate funding over the long term (capital as well as revenue) to enable the setting up and delivery of a non-stigmatising, easy to access service within the community which will help encourage 'the ordinary person' to look after their mental health. Stress management, and general opportunities for people just to talk could be some of the things included to provide early intervention strategies.
- Link or advocacy workers from the target communities are needed to work alongside both statutory agencies and mental health sufferers to help break down fear
- One of the Government's proposed community Development Workers should be employed from the black community and have a remit to work

within Luton to help capacity build faith and other non statutory organisations so they can help with delivery of services

- Dignity should be invited to sit on the Local Implementation Team (LIT) to ensure focus on BME issues is on the agenda
- There is a strong need for local mainstream services that exist to provide a culturally competent service, incorporating West Indian meals and staff that represent the cultural make up of potential users. The black community should be consulted on measures needed for services to be more user friendly for members of the African/Caribbean community.

INTRODUCTION

Background Information about the National Project:

The Centre for Ethnicity and Health's Model of Community Engagement

Background:

We often hear the following words or phrases:

- Community Consultation
- Community Representation
- Community Involvement/Participation
- Community Empowerment
- Community Development
- Community Engagement

Sometimes they are used inter-changeably to mean the same thing. Sometimes the same word or phrase is used by different people in the same meeting to mean different things. The Centre for Ethnicity and Health has a very specific notion of Community Engagement, and this section is an attempt to describe it.

The Centre's Model of Community Engagement evolved over a number of 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 awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire 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 Department of Health had two key things in mind when it commissioned the work; first, the Department of Health 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 Department of Health had wanted was a needs assessment and a 'glossy report', they could have directly commissioned a number of researchers who could have gone into local Black and minority ethnic communities, talked to them about their needs, written up a report, and produced yet another set of reports that potentially do not have any long term impact.

This scheme was different however. The Department of Health 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; what they would have is 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 six month process to learn about drug related issues and about how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity & 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. 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 or domains of work. These include:

- Substance Misuse
- The Criminal Justice System
- Sexual Health
- Mental Health
- Regeneration
- Higher Education
- Asylum

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 people
- Women
- White deprived communities
- Rural communities

In addition to the Department of Health, 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 and Aimhigher.

The Key Ingredients:

According to the Centre for Ethnicity and Health's 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 a real or virtual group up where one does not already exist. The key thing is that this host community organisation should have good links to the target community¹ (whoever this is) such that it is able to recruit a number of people from the target community 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 provide a co-ordination and infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day to day activities that will be undertaken once the project is underway. One of the first tasks that this host community organisation undertakes will be to recruit a number of people from the target community to work on the project.

A Host Community Organisation	With Good Links To The Target Community	To Provide Basic Infra-structure For The Project (Recruit And Co-ordinate Project Team; Provide Office Space, Phones And Computers; Look After The Finances)	To Recruit A Number Of People From The Target Community To Do The Work
A Task	Time Limited Meaningful Manageable	A Piece Of Research Into Key Needs/Gaps/Issues For The Community	Learning And Development Of Key Individuals; Access Hard To Reach Groups; Raise Awareness and Debate; Community Ownership
Support	Financial (Typically Up To £20,000)	Training And Workshops; On-Going Support And Guidance; Personal Tutor	Statutory Partnerships; Steering Groups; Sustainability

The second key ingredient is the task that the community is to be engaged in. According to the Centre for Ethnicity and Health's model, this must be something that is meaningful, time limited and manageable. Nearly all of the community engagement projects that we have run have involved communities in undertaking a piece of research or a consultation exercise within their own communities. Sometimes we have been met with an initial resistance to doing 'yet another piece of research', but this misses the point. As in the initial programme that we ran on behalf of the Department of Health, *the process (i.e. of getting ordinary people involved in doing the work) is as important, if not more important, than the report that they produce at the end of the day.* 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 first 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. We do not expect community groups to become involved for nothing. Typically we would make

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

in the region of £15-20,000 available to the host organisation. We would expect that the bulk of this money would be used to pay people from the target community as community researchers². We then allocate a named member of staff from our Community Engagement Team 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 through the project. We also provide 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 pull together a steering group for the project³. The steering group is an essential element of the project: without one, it is difficult to see who the community are engaging with and it is unlikely that anything out of the project will be sustained in the longer term. The group will be doing a needs assessment or a consultation exercise, but for what purpose? It is the role of the steering group to ensure that the work that the group undertakes sits with local priorities and strategies, and that there is a mechanism for picking up the findings and recommendations that the group may make. It is also their role to help to pick up the key individuals who are developed through the project process to help them to take their ‘next steps’.

The Community Engagement Team:

The Community Engagement Team comprises of 25 members of staff. They work across a range of Community Engagement areas of specialism, within a tight regional framework.

National Programme Directors			
Northern Team	Midlands Team	Southern Team	Senior Programme Advisors
Senior Support Worker	Senior Support Worker	Senior Support Worker	
Support Workers X 3	Support Workers X 3	Support Workers X 6	Drug Interventions Programme
			Regeneration
			Mental Health
Teaching And Learning Team			
Administration Team			
Communications Officer			

Programme Outcomes:

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.

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.

Each group involved in any of our Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community that it consulted with. The qualitative themes that emerge from the reports are often very powerful, particularly when taken together with other reports produced by groups involved in the same programme. 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.

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 at the University of Central Lancashire.

The Focus of This Particular Report:

This report focuses on the mental health stream of the Community Engagement Work Programme, which falls under the remit of the National Institute for Mental Health in England (NIMHE). In particular, it details the work of Dignity Mental Health Service in delivering the community engagement research amongst the African/Caribbean Community in Luton, Bedfordshire.

Dignity Mental Health Service was one of 11 community groups who took part in the NIMHE Community Engagement Pilot Programme in 2005. The objectives of the programme were to deliver improved equality of access, experience and outcomes for Black and minority ethnic mental health service users by:

- Building capacity in the non-statutory sector
- Encouraging the engagement of Black and minority ethnic communities in the commissioning process
- Ensuring a better understanding by the statutory sector of the innovative approaches that are used in the non-statutory sector.
- Involving Black and minority ethnic communities in identifying needs and in the design and delivery of more appropriate, effective and responsive services
- Ensuing greater community participation in, and ownership of, mental health services
- Allowing local populations to influence the way services are planned and delivered
- Contributing to workforce development, and specifically the recruitment of 500 Community Development Workers

Specific Aims and Objectives:

Dignity, is a project of the Family and Relationship Crisis Centre, an initiative of the Church of God of Prophecy, a black majority-led Church. The project was set up in 2001 to deliver a culturally sensitive independent mental health advocacy service. This was in response to a request by Luton Borough Council Housing and Social and Luton PCT, who were challenged by the African/Caribbean community over the lack of such a service, despite the need for the service being highlighted in the National Service Framework.

Our primary objective in this community engagement project was to engage the African/Caribbean Community and service providers in Luton around the specific issues of mental health promotion, awareness, and culturally appropriate service provisions for mental health in order to carry out a needs assessment.

There were four main reasons for the rationale surrounding the choice of mental health promotion;

1. Firstly, under the mental health National Service Framework, all localities should have a local mental health promotion strategy and embark on active health promotion, usually covering the same boundaries as the Primary Care Trust. The research would enable Dignity to identify the local strategy for mental health promotion and the gaps in mental health promotion as it pertains to the African/Caribbean Community. It would also provide opportunities for Dignity to point out good practices for effective mental health promotion and culturally sensitive service provision.
2. The second reason for the rationale emerged from the DOH (Department of Health) Delivering Race Equality Strategy which incorporates the responses made to the David Bennett Enquiry and highlights 12 points as indicators for change. These being:-
 - i. Less fear of mental health services among BME communities and service users
 - ii. Increased satisfaction with services
 - iii. A reduction in the rate of admission of people from BME communities to psychiatric inpatient units
 - iv. A reduction in the disproportionate rates of compulsory detention of BME service users in inpatient units
 - v. Fewer violent incidents that are secondary to inadequate treatment of mental illness
 - vi. A reduction in the use of seclusion in BME groups
 - vii. The prevention of deaths in mental health services following physical intervention
 - viii. More BME service users reaching self-reported states of recovery
 - ix. A reduction in the ethnic disparities found in prison populations
 - x. A more balanced range of effective therapies, such as peer support services and psychotherapeutic and counselling treatments, as well

- as pharmacological interventions that are culturally appropriate and effective
- xi. A more active role for BME communities and BME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services; and
 - xii. A workforce and organisation capable of delivering appropriate and responsive mental health services to BME communities.

In 2004, Dignity organised a mental health conference in Luton, with Dr Joanne Bennett, the sister of David (Rocky) Bennett, as the key note speaker. The conference called “Mental Health and the African/Caribbean Family,” was aimed at the African/Caribbean community and service providers. The Conference objectives were two-fold. Firstly, to provide a platform for the mental health service providers to share with the community their plans for implementing the recommendations outlined in the David Bennett Inquiry and secondly, to promote and raise awareness, amongst the African/Caribbean community, with regard to the nature and impact of mental ill-health on individuals, family and the wider community.

The Conference highlighted that;

“There was a general surprise that issues around mental health had not moved any further forward”⁴

3. The third reason for the rationale stems from Dignity’s four years experience as a community led mental advocacy service. We found that there were misconceptions and stigma attached to mental ill-health in the African/Caribbean community. Individuals and families where there was mental ill-health often found themselves isolated and excluded through a general lack of awareness of the nature, origin, scope and general support available. This has resulted in individuals and family members feeling ashamed to seek culturally appropriate and sensitive help for themselves or their family member. Unfortunately, where there has been a lack of willingness to seek help there has also been a lack of awareness by the individual or family members of the type of provisions that is available and opportunity for prevention or early intervention is often therefore missed. The community engagement work would provide the basis for mental health issues to be shared and discussed openly in the community and with service providers.
4. The final reason was that the community engagement, around mental health promotion, would provide an opportunity for local people to have a direct involvement, in effecting changes. This would be achieved through building their capacity to identify needs and devise strategies with service providers for effective sustainable changes.

⁴ Dignity Mental Health Advocacy Service, Mental Health and the African Caribbean Family Conference Monday 26th April 2004, Conference Report, p11

In designing our community engagement project Dignity specifically chose to explore the link between faith communities, local mental health issues and services. The very high percentage of African and Caribbean's who are affiliated to local churches and deeply rooted in the Christian faith, specifically justified this. Another reason is highlighted in a report from America by Larson et al.⁵ The report draws attention to the positive impact of faith on a person's mental well-being especially with regards to recovery and general health.

Dignity's community engagement project was designed to find out whether Faith organisations could play an important role in mental health promotions, awareness raising and service provision.

Contrast was to be drawn by exploring the view of the general population alongside the African Caribbean Faith community in Luton to formulate an overall local picture.

Demography:

Luton in Bedfordshire is a town made up of mixed nationalities. According to the census for 2001, Luton's population is approximately 184,000.⁶ The Black and Ethnic Minority community form a quarter of the population with African/Caribbean's making up 6.1% of the population.

Luton has in recent years seen the influx of Congolese and Zimbabwean, refugees and asylum seekers in addition to large numbers of people arriving from Jamaica and other Caribbean Islands. Thus raising the number of African/Caribbean residents in Luton even higher. Caribbean's have long lived in Luton since the 1950s.

⁵ 'The Patient's Spiritual/Religious Dimension: A Forgotten Factor in Mental Health' by David Larson, Susan Larson and Harold Koenig, first published November 2001 in Directions in Psychiatry, Vol. 21. Lesson 21.

⁶ 2001 Census –Luton Borough, *Source: 2001 Census, [Key Statistics for Local Authorities]*

METHODOLOGY

The team:

The work was delivered by 2 separate teams of researchers.

Several student volunteers from the University of Luton were recruited in the first instance to undertake the work. The assumptions made were that the students would have the time and access to a wide range of people from the African/Caribbean community. Unfortunately, several factors contributed to the original research team not being able to undertake the research field work. This included the timing of the project, changes in personal circumstances amongst team members, and changes in lead researchers.

In order not to jeopardise the valuable work started by the initial research team, another team was recruited to replace the first team that had completely left the Project. This was achieved through existing links within the community that the Project was able to access.

Recruitment of the team:

The University of Luton has an “employment agency” style service that tries to link students to local community organisations. Dignity contacted the University and interviewed several students that had been referred by the University. The initial team of students were selected on the grounds that they had an interest in mental health and felt that the Project would be of benefit to them in terms of their development.

The students were appointed as researchers under the leadership of a lead researcher who had background knowledge and experience in mental health, and mental health promotion.

The second team was recruited by identifying several people from the local community and inviting them to a briefing meeting. A senior support worker from UCLAN explained the nature of the work, timescale and commitment needed to complete the Project. 6 people were recruited from the target community.

Training and Support:

Training was provided by the University of Central Lancashire in specialist areas such as community research and research methods. A Support Worker was assigned to Dignity by the University.

The first research team attended workshops provided by UCLAN in central London. They were given training in research design and mental health. Support to this team was interrupted during a change of Support Workers.

The second team because of the time they were recruited received customised training based on their specific needs, around research, mental health and report writing. The training was delivered in-house, within the community at Dignity's base.

Intensive weekly support was also provided to this team by UCLAN.

Researchers' Duties:

Researchers were responsible for designing the framework and approach for conducting the research. The methodology was based around the nature of their enquiry and strategy for engaging with their community around mental health promotion and awareness.

Steering Group role:

Dignity utilised the Focused Implementation Site (FIS) Board that comprised of key service providers and commissioners as its steering group. The Board provided an accountability structure whereby Dignity was able report to the Board periodic progress made in undertaking research.

Utilising the FIS Board rather than setting up a separate steering group, proved to be prudent, time saving, and advantageous in linking Dignity community engagement work into the wider work of service providers.

The FIS Board enabled Dignity to be part of the decision making process and planning that addresses mental health issues in Luton and Bedfordshire, as it pertains to equality issues.

This link with the FIS Board has ensured that local strategic planning and commissioning bodies have a greater awareness of Dignity and the mental health issues it is seeking to address. Dignity is now part of the community engagement, workforce, and information strand of the FIS Board.

How Community was accessed:

Researchers came from the same community as the respondents. They were therefore able to use their connections to access respondents from within the community.

Types of Interviews used:

Questionnaires were developed and piloted on the community in the first instance. Once satisfied, the field work was undertaken using questionnaire interviews with the faith community (which consisted of members from various Christian churches), the general community and local service providers. Service provider questionnaires were either sent out by email or completed during personal visits. A focus group was also held with users of a local mental health service.

Recording of Interviews:

Responses from the respondents were recorded on the questionnaires. Additional notes were made where appropriate to ensure researchers accurately captured the respondents' responses. Two note takers were used for the focus group session.

The researchers operated under a code of ethics which meant that a consent form was given to each respondent at every interview. The team also received ethics approval from the Ethics Committee at UCLAN.

Analysis of Interviews:

The responses from individuals were collected and recorded on summary sheets highlighting answers that were obtained for each question. These responses were then further coded to enable key emerging themes to be identified.

FINDINGS

The results of our interviews are presented in 3 categories:-

1. Core Data - from the 50 Questionnaires (25 Faith and 25 General Public)
2. All Quantitative Answers
3. All Qualitative Answers

CATEGORY 1: CORE DATA

Table 1: Age

Age	No. of Respondents	%
18 +	0	0
19-21	0	0
22-24	1	2
25-29	6	12
30-39	17	35
40-49	25	51
50 +	1	2
TOTAL	50	100

Table 2: Gender

Gender	No. of Respondents	%
Male	16	34
Female	34	68
TOTAL	50	100

Table 3: Ethnicity

Ethnicity	No. of Respondents	%
Black Caribbean	44	88
Black African	4	8
Mixed Black + White	2	4
TOTAL	50	100

Table 4: Born in UK

Born in UK	No. of Respondents	%
Yes	24	48
No	26	52
TOTAL	50	100

Table 5: Length of residency in UK
(Out of the 26 residents who were not born in the UK)

No. of Years lived in UK	No. of Respondents	%
1-5	4	15
6-10	3	12
11 years or more	18	69
Not answered	1	4
TOTAL	26 (not born in UK)	100

Table 6: Citizenship

Citizenship	No. of Respondents	%
British	44	88
Refugee	6	12
Asylum	0	0
Other	0	0
No answer	0	0
TOTAL	50	100

Table 7: Languages fluent in

Language	No. of Respondents	%
English	50	100
Additional (Various African dialect + Jamaican Patois)	11	44
TOTAL	50	

Table 8: Religion

Religion	No. of Respondents	%
Christian	36	72
None	13	26

Other	1	2
TOTAL	50	100

Sexuality: All 50 respondents said they were heterosexual

Disability: All 50 respondents reported that they had 0 disabilities.

CATEGORY 2: QUANTITATIVE ANSWERS

Faith Group Questionnaires:

Figure 1. Have you ever experienced any mental health issues?

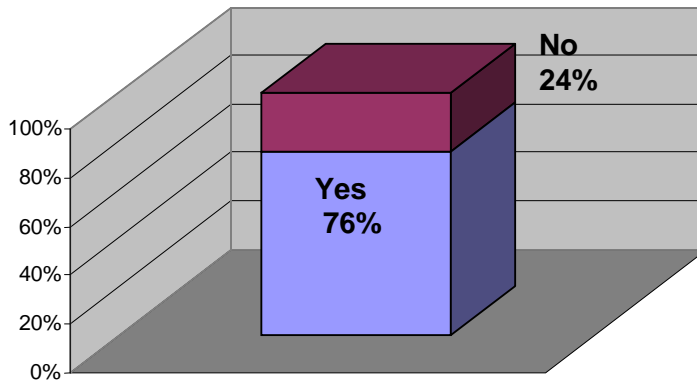
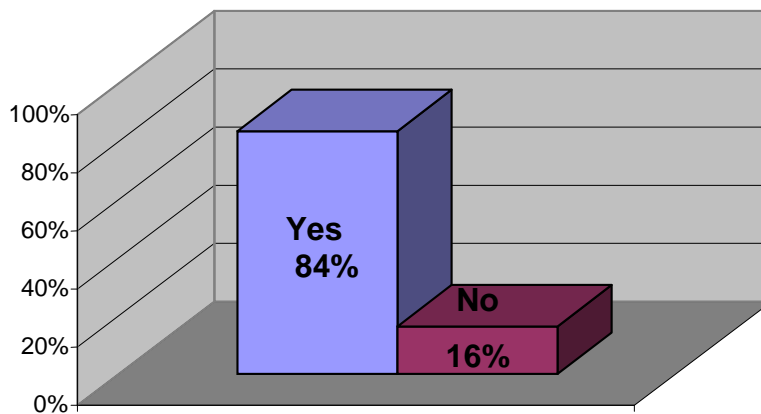


Figure 2. Does your place of worship have any facilities to cater for mental health issues?



**Figure 3. How are these facilities/services advertised?
(Please tick all that apply)**

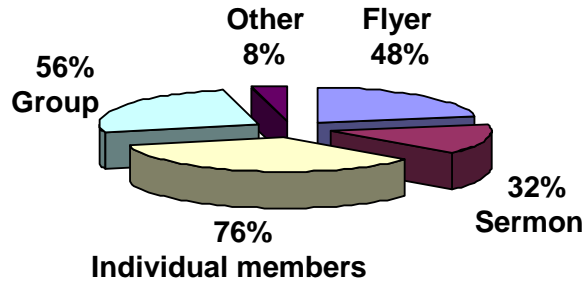
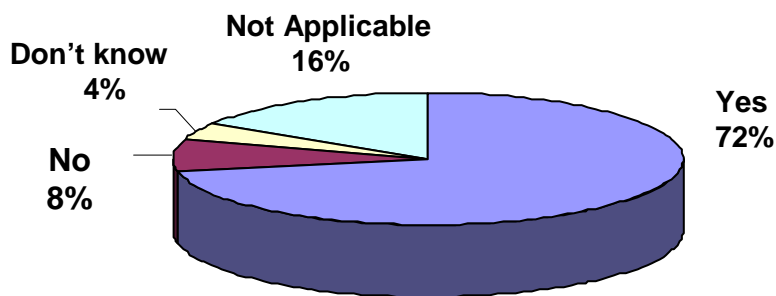


Figure 4. Are these facilities/services confidential?



**Figure 5. How does someone access these facilities/services?
(Please tick all that apply)**

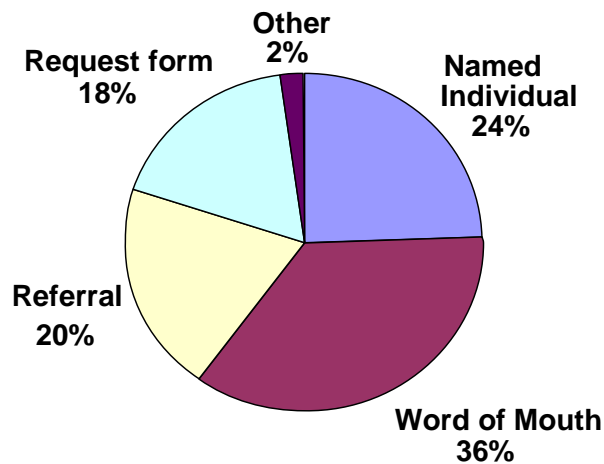


Figure 6. Who leads these facilities/services?

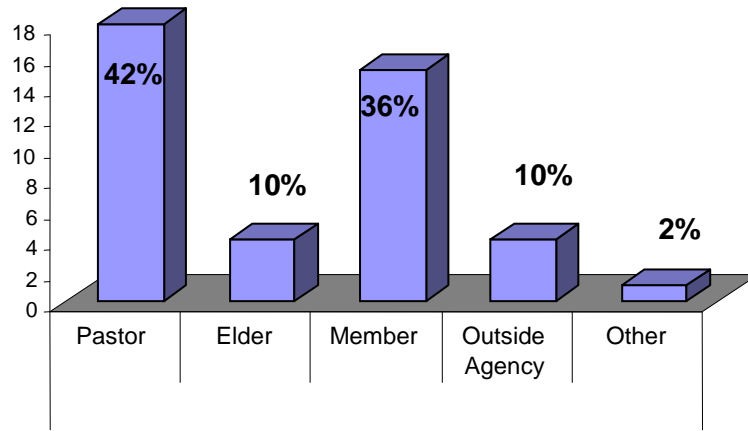


Figure 7. Has someone you know benefited from this service?

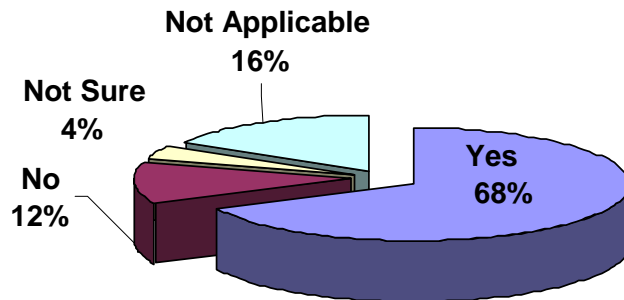


Figure 8. Are you aware of any links your place of worship has with mental health services in Luton?

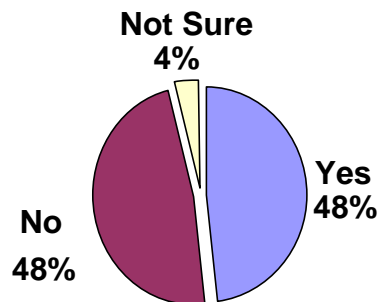


Figure 9a. Do you think places of worship should have a role to play in the services which address mental health issues?

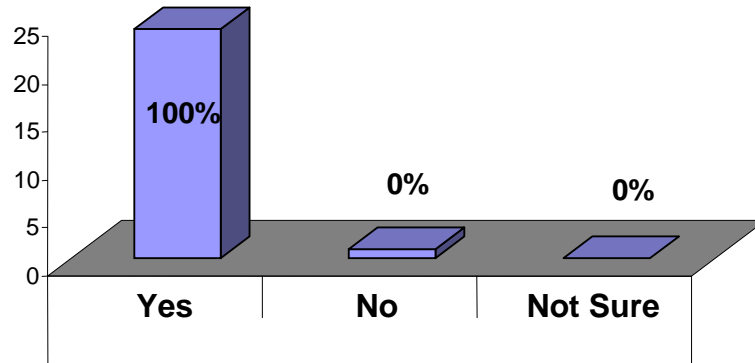
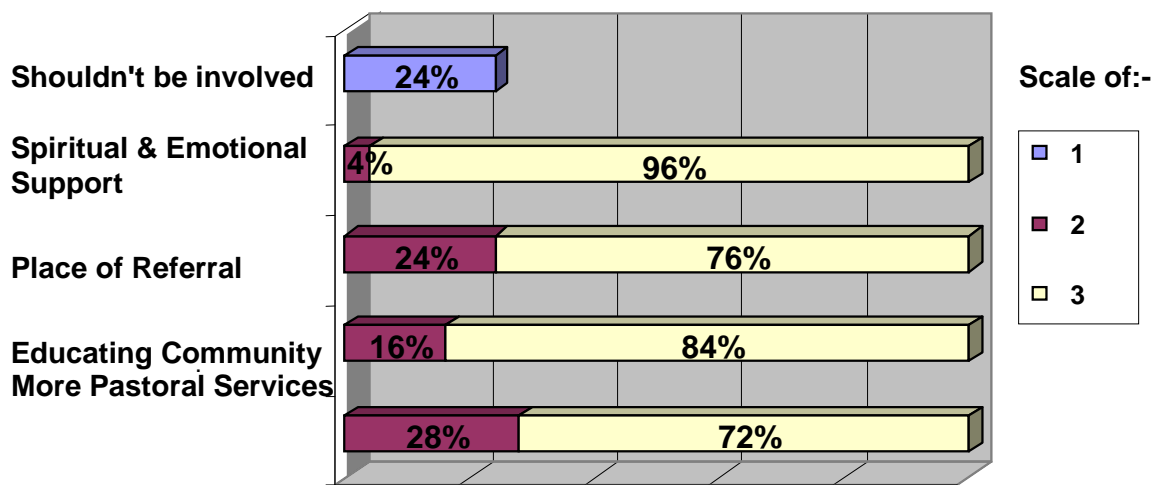


Figure 9b. If yes, how important do you think this role is?

Very Important	Important	Not important
96%	4%	0%

Figure 10. How, on a practical level, would you like to see places of worship involved in delivering mental health services if at all? (Please indicate on a scale of 1-3) (3 being highest)



General Public Questionnaire:

Figure 11. Are you aware of any local mental health services in Luton?

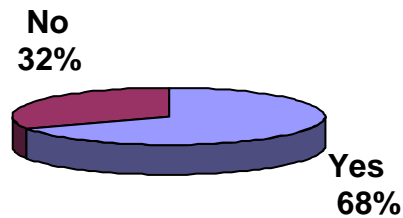


Figure 12. Have you ever experienced any mental health issues?

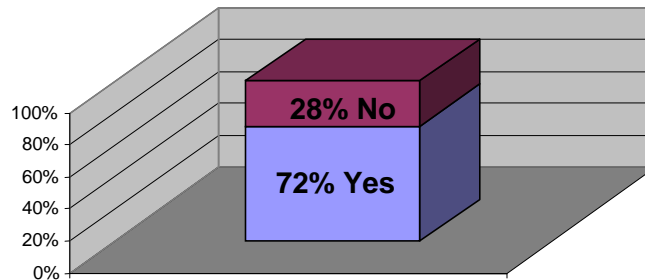


Figure 13. In what ways did you seek to get help for your mental health issues? (Please tick all that apply)

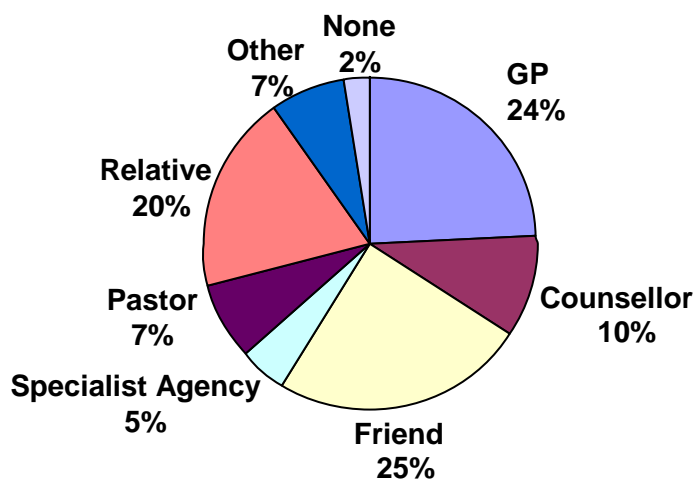


Figure 14. Were you given any treatment for your illness?

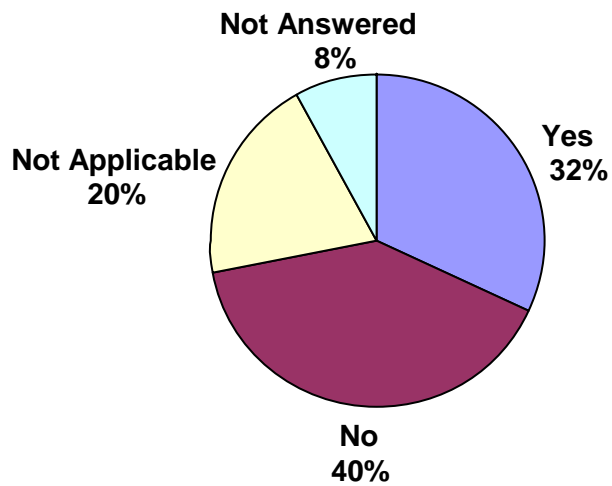


Figure 15. Were you happy with the treatment given?
(Of the 32% who said they received treatment)

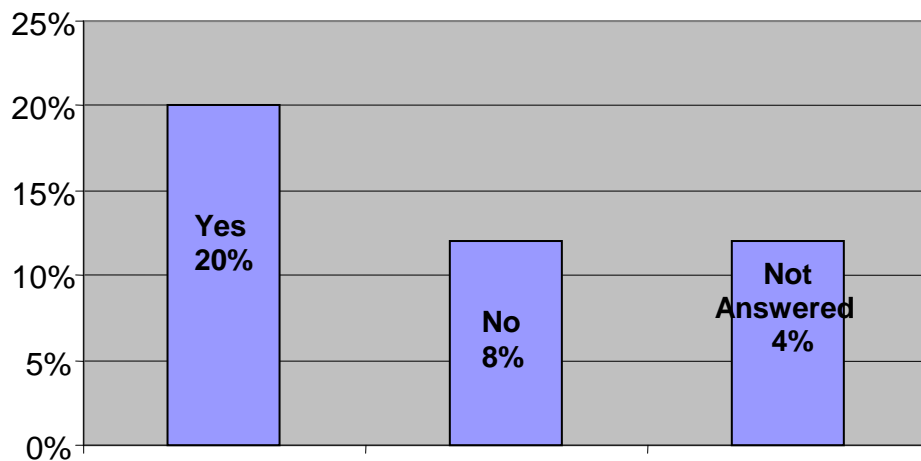


Figure 16. Have you ever directly used or accessed any mental health services in Luton?

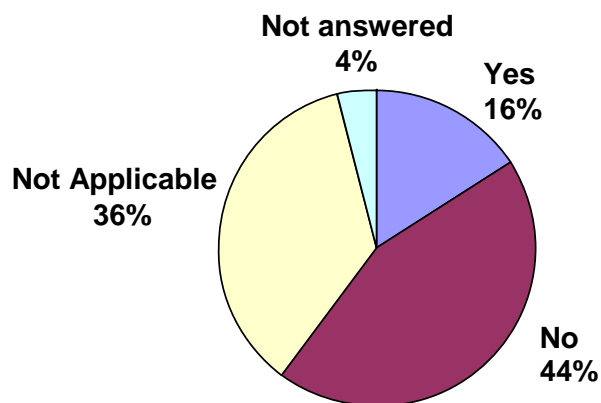


Figure 17. How did you access these services?
Of the 16% that answered yes

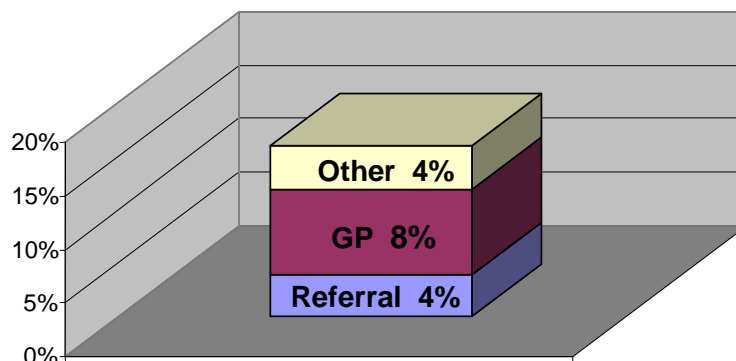


Figure 18. Were you happy with the service provided?
Of the 16% who had accessed services

Yes	No
16%	0%

Figure 19. How would you rate the quality of the service provided?

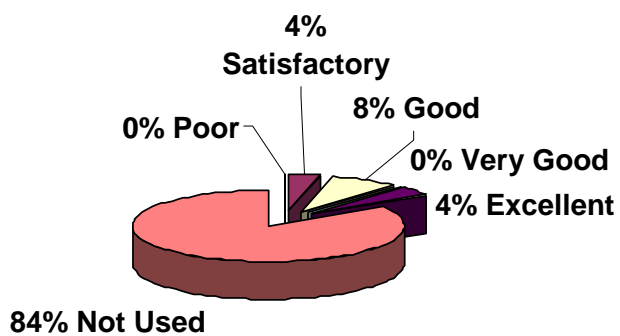


Figure 20. Have you any ideas or thoughts on how mental health services in Luton can be improved?

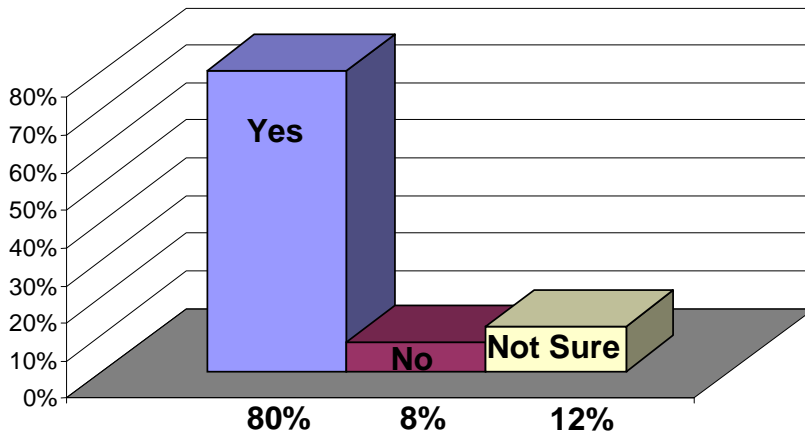
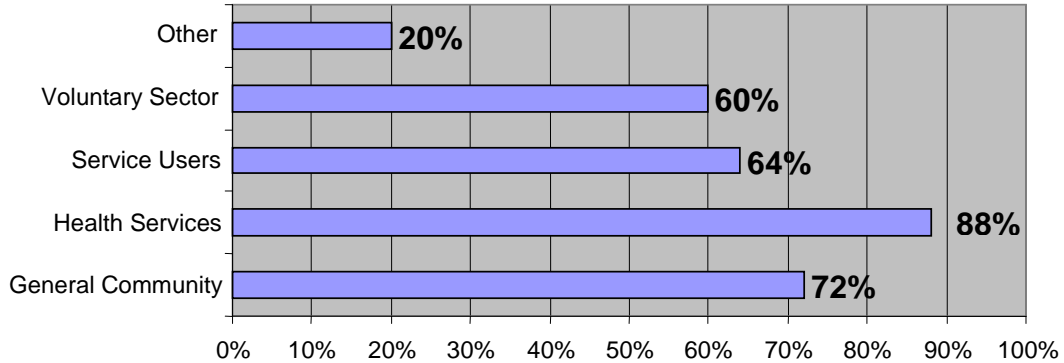


Figure 21. Who should be responsible for making improvements and changes to local Mental health services? (please tick all that apply)



Service Provider Questionnaire:

1. On average how many people will use your service in any week?

Figure 22

Amount of Weekly Users	Service Provider 1	Service Provider 2	Service Provider 3	Service Provider 4	Service Provider 5
0-5					
6-10					
11-15			11-15		
16-20					
21-25				21-25	21-25
26-30					
31-35					
36-40					
More	90	150			

2. How do people access and use your service?

Figure 23

Access via	Service Provider 1	Service Provider 2	Service Provider 3	Service Provider 4	Service Provider 5	%
Word of Mouth		✓		✓	✓	60%
Referral	✓	✓	✓	✓	✓	100%
Drop-in		✓		✓	✓	60%
Voluntarily		✓		✓	✓	60%
A Statutory Agency	✓	✓	✓	✓	✓	100%
Other						0%

3. Do you have an Ethnic breakdown for all the people who use your service?

Figure 24

Ethnic Breakdown	Yes	No
Service Provider 1	✓	
Service Provider 2	✓	
Service Provider 3	✓	
Service Provider 4	✓	
Service Provider 5	✓	
Total	100%	

4. Do you have a breakdown of Faiths for all the people who use your service?

Figure 25

Breakdown of Faiths	Yes	No
Service Provider 1		✓
Service Provider 2		✓
Service Provider 3	✓	
Service Provider 4	✓	
Service Provider 5	✓	
Total	60%	40%

5. Does your service have any links with voluntary/community groups to aid or enhance your provision?

All 5 of the service providers interviewed, said they had existing links with voluntary/community groups to enhance service provision. They also reported having links with a variety of statutory agencies.

CATEGORY 3: QUALITATIVE ANSWERS

Faith Questionnaire:

1. What does the term 'mental health' mean to you?

The majority of respondents (68%) said the term mental health meant 'the state or condition of the mind. Many of the comments referred to the condition of the mind as being "healthy," "balanced," and "stable. "

The remaining 32% used the following quotes to explain what mental health meant to them,

- *"Mental health is when people have got the symptoms of mental illness."*
- *"Not in their right mind".*
- *"Hearing voices."*
- *"Not got full control of their mind."*
- "Things like depression"

2. What does the term 'mental illness' mean to you?

The general themes drawn from the responses given to this question were:-

- Disturbed mind
- Unhealthy state of mind
- Inability to cope
- Depression
- Schizophrenia
- Stress
- Anxiety

3. Please give details of any mental health issues you have experienced?

- Depression,
- Stress (with a large amount being work related)
- Anxiety.

4. In your faith, what do you think the attitude is towards mental health / mental illness?

Many respondents spoke about attitudes that were sympathetic and caring. Help, support, love, prayer and feelings of optimism about recovery were recurring points.

Responses also revealed that the issue of mental health and mental illness was taboo due the lack of understanding and fear surrounding it. Some people felt it was viewed as a test of a Christian's faith and others associated it with torment of the mind due to demon possession.

Comments included,

"It upsets me to see people out of their mind like that. We see them as just having another illness and we need to give them the support they need to make them better."

"Want jobs in the places that tend to them so we can give them the right care that they need."

"We Christians have a hope that they can be healed. We pray to our Lord to deliver them and set them free and He does."

"On a whole my faith is generally caring and understanding towards people who suffer mental illness but there is still a lot of misunderstanding and fear about their behaviour."

5. What role does your faith play in your own mental health and wellbeing?

"Sometimes when I'm stressed faith centres me, draws me back. If I keep my mind focussed on Him instead of the problem I have peace. The situation doesn't change but my perception changes."

96% of respondents felt their faith played an important role in their own mental health and wellbeing with 4% stating that they did not know. The overriding themes were, that having a faith provided them with:-

- Mental strength
- Help and guidance through problems
- Real peace of mind
- Comfort and reassurance in the knowledge that there is a bigger source

6. What facilities does your place of worship have to cater for mental health issues?

84% of respondents said their place of worship had facilities to cater and 16% said theirs' did not (see Fig 2). The facilities mentioned in order of frequency were:

- Trained Counsellors
- Prayer support
- General befriending and socialising
- Pastoral care
- Care groups and Help teams
- Church departments dealing with varying aspects of life (i.e. Youth, Community, Family life, Finances, Health and temperance).

7. Describe what is done to ensure confidentiality.

72% said the facilities/services were confidential, 4% did not know, 8% said they were not and 16% said not applicable (see Fig 4)

The following answers were given to describe measures taken to ensure confidentiality;

- *"I don't know"*
- *"Expected code of conduct"*
- *"It depends on the information shared"*
- *"Communicated verbally - no paperwork"*
- *"By confidential agreement"*
- *"By agreement"*
- *"Expected and policy"*
- *"People keep their mouth shut and have learned how to respect people's privacy and deal with sensitive issues"*
- *"Confidentiality policy"*
- *"Take them to a private place to pray for them"*
- *"People who tend to them know not to take it out of their group just like doctors and nurses have patient confidentiality"*
- *"Don't reveal it to anyone else"*
- *"Whoever the Lord uses to counsel"*
- *"Because we have a confidentiality policy when dealing with sensitive issues"*
- *"Confidentiality mean if something is said in confidence, it mean it stays in confidence with that person and that person only"*
- *"By signing non disclosure agreement"*
- *"Verbal contract not to disclose information"*
- *"Not aware"*
- *"Trust and respect for each other"*
- *"State that everything is confidential"*
- *"Contract of agreement, one to one"*

8. How are these services/facilities organised?

Respondents said the facilities were organised as both one-to-one sessions and group discussions.

9. Has someone you know benefited from this facility/service? If yes, how and what are you aware of?

68% said they knew someone who had benefited from this facility (*See Fig 7*).

Respondents said they knew about the benefits because they had seen positive changes in people's lives and heard personal testimonies of how individuals had come through certain issues.

The main benefits reported were:-

- Improved mental stability on a whole
- People being able to cope with everyday life better
- People looking better and saying they felt better
- People who had suffered a breakdown being able to go back out to work and hold down their job.
- Overcoming depression and having a positive outlook

General Public Questionnaire:

1. What is your understanding of 'mental health'?

68% of people said it was to do with your state, condition and peace of mind. The term was associated with being mentally stable and having mental wellbeing. The other 32% said it was to do with the following,

- *"Not being right in the head"*
- *"Inability to cope"*
- *"Depression, Stress, Breakdowns and Schizophrenia"*
- *"Psychotic illness"*
- *"Illnesses affecting the mind"*
- *"People who keep doing wrong things"*

2. What is your understanding of 'mental illness'?

Respondents' answers fell into the following themes, with 32% saying that they understood the term 'mental illness' to mean the same as the term 'mental health'.

General themes:-

- Mentally disturbed
- Mentally unstable
- Abnormal state of mind
- Inability to cope mentally
- Schizophrenia
- Depression
- Anxiety
- Stress

3. Which local mental health services in Luton are you aware of?

(See Fig. 12)

32% of respondents were not aware of any services whilst 68% named the services they were aware of. The majority named between 1-4 local services, whilst a very small percentage of respondents were able to name approximately 10 services each.

The following services were mentioned frequently by the majority of respondents:

- Ashanti
- Nyabingi
- Dignity
- Befrienders

- GP
- Luton & Dunstable Hospital
- NHS Mental Health Services
- Bedford & Luton Partnership Trust
- Lewsey Community Care Centre

The following services were mentioned once

- Roshni
- CMSU
- Care in the Community
- ACE
- Supported living services
- Cherrywood House
- Early intervention service
- BLPT
- Reach out
- Mind
- Charter House

4. Please give a brief description of the mental health issues you have experienced.

Some respondents had experienced more than one of the following issues.

- Stress (46%)
- Depression (18%)
- Insomnia (18%)
- Anxiety (6%)
- Fear (6%)
- Eating problems (6%)

5. What treatment were you given for your illness and did it help?

32% of people were given treatment for their illness (See Fig 15). The majority said they were given tablets whilst the others received counselling.

“The medication helped me in the sense that it kept me calm and made me well.”

Everyone who received counselling said it helped. Comments included,

“The counsellor was very supportive and she seemed to understand my culture.”

5. Were you happy with the treatment given? Why / why not?
(See Fig. 16)

Of the 32% who received treatment 20% said they were happy. Reasons given were due to the non judgmental attitude of the counsellor and medication which helped to calm their mind.

Others felt unhappy with the high dosage of medication and the effects of tablets that were said to be either too calming or too strong with zombifying results.

7. Please describe mental health services in Luton that you have directly used or accessed.

16% of respondents (See Fig. 17) had accessed the following services:-

- Counselling clinic at Liverpool Road
- GP Mental Health Team
- GP/Doctor
- Ashanti – (*Specialist African Caribbean Mental Health Service*)
- Specialist Bereavement Agency

8. Were you happy with the service provided? What were you particularly happy with?

People who had accessed services said they were particularly happy with;

- The unbiased treatment received
- The counsellor
- Having someone to talk to
- The fact that it made them look at things in a different way

9. How would you rate the quality of service you received? Describe why?

Respondents ticked the 'satisfactory', 'good' and 'excellent' ratings (See Fig. 20) but explanations were only given for why they felt services were good.

Comments included:

- *"Being able to talk to people"*
- *"Counsellors being very understanding and open to listen"*
- *"Being able to do activities"*

10. Have you any ideas and thoughts on how mental health services in Luton could be improved?

The following suggestions on improvements were given:-

- Listen to the patients
- Less stigma
- More awareness needed about signs of illness and help available
- Joint up working between agencies
- Effective engagement strategy needed
- Implement a middle-man service which provides someone to talk to before things get out of hand – something with a non-stigmatising name, such as 'Healthy Living' so everyone can use it.
- Establish more preventative measures
- More Counselling services to shorten waiting times
- Advocacy service for black mental health patients should be available
- More services and awareness aimed at Black men
- Community Groups and existing social networks to play a larger role
- More bereavement services in place
- Mainstream services to become more culturally competent
- More BME people to sit on trust boards and at local government

Service Provider Questionnaire:

These are responses from the 6 local Mental Health Services who took part in this study.

1. What services do you provide and for whom?

Service Provider 1:

Provides an employment and day service which is recovery orientated for people with mental health problems.

Service Provider 2:

Provides a range of services for people with mental health difficulties. including; individual support, learning opportunities, social interaction, social inclusion, aspiration, going back to work.

Service Provider 3:

Provides a range of care for inpatients and outpatients aged 16-65; including crisis service/support, early intervention, care for depression and eating disorders.

Service Provider 4:

Provides a holistic aftercare service for mentally ill clients. Covers a whole range of culturally relevant and practical activities, such as; social support, advice with benefits, assistance in independent living skills, counselling, advocacy and support for carers. Also provides a link between service users and professionals - giving other professionals advice on user's cultural needs. Conducts joint assessments on how to deal with certain clients and helps people to use the mental health system effectively.

Service Provider 5:

User led service was set up to raise self-esteem in users', build confidence and self-development. Currently consults with professionals in order to share its successful working model. Formal counselling also provided through this service.

2. How long has your service been available?

SP 1: 14 years

SP 2: 16 years in Luton (Bedfordshire 27years)

SP 3: 5 years in current form

SP 4: 10 years

SP 5: 5 years

3. Why was your service set up?

SP 1:

Initially, to support people moving from psychiatric units into the community. It now exists to provide an employment and day service which is recovery orientated.

SP 2:

To reduce social isolation and support mental health sufferers to recover and move on. To build self esteem and confidence and to encourage patients to try new things and take responsibility to improve themselves.

SP 3:

To provide an innovative way of treating patients who would have formerly gone into large psychiatric hospitals. To provide care closer to families and bring patients back into the community.

SP 4:

Due to concern about the large number of African Caribbean males in the mental health system. Luton was higher than the national average. A specific culturally competent resource was required to respond to their needs.

SP 5:

User led service set up strategically to address suppressed mainstream service. Users needed to have some level of control.

4. How do you involve service users?

SP 1:

- User led action planning
- Client forums
- User led activities i.e. craft group

SP 2:

- Member forums
- 3 users included in management meetings
- User led Self run café
- Driver

SP 3:

- At time of admission – fully involved
- Involved in treatment care plan
- Involved in discharge plan
- Involved in care plan

SP 4:

- In management of user led service which has emerged
- Train them to be critically objective to give useful feedback
- In development of their own care plans
- In running services and activities to meet their own needs

SP 5:

- Users are involved in every aspect of this service
- User led Management Committee
- Planning and participation of activities

5. Which voluntary/community groups do you have links with in order to enhance your provision?

The 6 Service Providers said they had links with the following services in order to enhance their provision:-

- Ashanti (specialist African Caribbean mental health service)
- Roshni (specialist Asian mental health service)
- Rethink
- Volunteer service
- Employment service
- Befrienders
- African Caribbean Community Development Forum (ACCDF)
- Other community groups
- Individuals with specific skills
- On track
- Bedford African Caribbean Community (BACC)
- Dignity
- Caroline Eating Disorder
- 'Lots of other statutory services'

6. What do you think are the gaps/barriers in providing mental health services to African and Caribbean communities?

The following points were given as perceived gaps/barriers to service provision for African Caribbean people:-

- Stigma
- Services lack of understanding of cultural issues
- Services that can provide are not given funding to do so
- Poor access to information.
- Capacity resource problems
- Structural barriers (All the different NHS Trust)
- Bureaucratic nonsense
- People above are not listening
- Best Value protects funding not to help people
- Mistrust giving black people money
- Lack of commitment from commissioners
- A lot of institutional racism still exists within service
- Junior managers
- Short staff
- Cultural differences of all ethnicities
- Delivery of care
- Treatment tends to be more aggressive possibly fear of subject aggression/verbal
- They don't seem to know exactly what they want
- They seem to require help from their own kind
- They seek help quite late
- Lack of counselling services
- Diagnosis treated differently

7. Which mental health services do you think African and Caribbean's are currently using?

- Ashanti
- Beds and Luton Partnership Trust Services
- Nyabingi
- Community Mental Health Service – forced to use through admission process or when family cannot cope.
- Not many
- Inpatient services
- Community mental health team
- Care Co-ordinator
- Individual support from statutory agencies.
- Psychiatric nurses etc.
- Informal services from church and communities.

Focus Group Interview:

We held one focus group with 5 African/Caribbean users of a local mental health service. The group consisted of 4 men and 1 female. The emerging themes were as follows:-

Definition of Mental Health

All respondents in this group felt that the term 'mental health' meant an inability to cope with life. They said it meant the same as the term 'mental illness' and described things such as "*hearing voices*" and "*sickness of the mind.*"

Experiences within the mental health system on a whole

They gave descriptions of very negative experiences in their past, which detailed being sectioned against their wishes and the harsh treatment received in institutions as inpatients under section. They spoke of being treated disrespectfully and insensitively and of over powering medication which had very unpleasant side effects. The majority reported that they had little or no support during their illness.

Experiences of local services

Although reporting to know of other services in the town, members of the group told us that they did not feel comfortable to use them. People reported accessing only 3 of the local mental health services available. The majority of this group tended to stick to one specialist service and most said that they were not using any other service prior to coming here. Some were referred to this service by their GP's, after being institutionalised and others accessed this service after parents or family members made enquiries on their behalf. Others had self referred. They described how this service had adapted to accommodate their needs and felt it catered for them culturally. Many expressed that they had built up a good relationship with the staff, who were described as being, "*Extremely helpful*" and were said to, "*Treat us nicely*". They enjoyed being in an environment where staff and other users were the same colour as themselves and said this made them feel, '*At home.*' They also felt that the activities were relevant to their way of life and helped them to get back on track.

One person said that he also attended a service which provided literacy and IT skills for mental health patients. He enjoyed this facility and said, "*The staff are friendly, but they don't provide any cultural meal options.*"

The role of faith in their own mental health

Members of the group said that attending church provided them with positive guidance. They felt that faith establishments could potentially provide a very useful service in addressing mental health issues, but felt that training and a change in certain attitudes was also needed, to address in particular the fear element which existed amongst some faith group members.

DISCUSSION

The average age of respondents in this study worked out to be 39. As the research was specific to the experiences of African/Caribbean's, all respondents were of African/Caribbean descent with a small percent being of dual (Black and White) heritage. The gender split of people interviewed, including those from the focus group, was 36% male and 64% female.

We noticed three main points emerging out of this research along with a number of smaller issues. These are explained below;

1. Misinterpretation

The first thing that stood out to us was the large amount of people who did not have a clear understanding of the terms 'mental health' and 'mental illness' (*according to the definitions used on page 8*). Many people felt the terms meant the same thing.

When asked what the term 'mental health' meant to them, 32% of people from the faith community, 32% from the general public and 100% from the focus group described conditions such as schizophrenia and depression. Prevalent quotes referring to this included;

"People who are not in their right mind."

"Sick in the head." and

"Hearing voices"

We noticed that being from a faith, general public or user group background made no difference to the level of understanding respondents had concerning this issue. We felt that people were being thrown by the word '*mental*' in the term '*mental health*.' Instead of looking at it in its intended sense, which means '*Of the mind*' many people were interpreting it by its slang usage which has grown to be commonly associated with insanity. **A lack of awareness surrounding mental health and its terminologies was highlighted here as well as issues around the way we speak as black people.** It became apparent during the research that people were using the term 'mental health' as a short way of saying mental health problems. I.e, when some people said, "*He's got mental health*" they actually meant that the person had mental health problems. **We wondered about the impact this language issue placed on communications between the black community and statutory bodies.**

When asked what the term 'mental illness' meant, the majority of respondents tended to describe severe symptoms, focussing on illnesses needing medication or institutionalisation. During the interviews, researchers gave feedback of respondents expressing surprise at the question which asked about the types of mental health issues they had experienced. Some

respondents initially queried whether some of the conditions appearing in this question, such as, loss of appetite, loss of sleep, fear and stress should be classed as mental health issues. Some disagreed outright, saying that they did not see these things as mental illnesses. Comments such as, “*Well if that’s the case everybody suffers from mental illness at some point.*” were expressed, revealing that our intention of raising mental health awareness through this project had already begun! **Undoubtedly, a more thorough understanding of mental illness is widely needed. We saw the need for literature containing the clinician’s definition of mental health and mental illness to be easily accessible and widely available to the community. We feel this would help to raise awareness and de-stigmatise the issue which could in turn encourage people to look after their own mental wellbeing.**

2. High incidences of Mental Illness and Coping Strategies used

The next point we noted was the amount of people who considered themselves to have experienced mental health issues (76% of the faith group and 72% of the general public told us about theirs). The ways in which people coped was also of significance.

Similarities were found between the issues experienced by both groups. In the faith community, the most frequent conditions were; stress, depression and anxiety, whilst in the general public, stress, depression and insomnia were recurrent. Work-related stress was the biggest problem and the issue for which most of the respondents sought medical intervention through therapies such as counselling. Promotion and awareness in stress management would help people to intervene early enough to address and control things before they got out of hand. We also feel that additional work could be done around understanding depression and recognising the signs, including those associated with post natal depression. Workshops should be aimed at the ordinary person as well as those who have already been diagnosed with this illness. We would like people to more fully appreciate how the everyday experiences of life can build up and lead to depression and equip people to better deal with life’s little losses and disappointments more effectively.

Most people chose to turn to Friends to help with their issues (25%). GP’s were used by 24% of people and Relatives were used by 20%. The remaining people said they used counselling methods, Pastors, specialist services (such as Bereavement Agencies) and other methods namely unions, health visitors and taking time off work. A small percentage of people said that they did not use any measures but, “*Just got on with things*”.

96% of the faith community said that their faith played a very significant role in maintaining their own mental health and well being. They said prayer helped to unburden them and the knowledge of a bigger source being in control gave them a great sense of peace.

3. Low take up of Services

The third issue was around the low numbers of people who actually used mental health services. 84% of people from the general public group had never accessed any local mental health service, this figure included people who said they had experienced mental health problems. We felt the disassociation here could be due to the lack of knowledge about conditions classed as mental illnesses.

72% of people from the general public said that they had experience of mental health issues, 68% of these said they were aware of local mental health services and were able to name 20 services between them. (See *General Public Question 3*). Although 32% said they had received treatment, respondents' answers revealed that some of these people did not view receiving counselling or medication as accessing a mental health service. This explained why only 16% said that they had accessed services. GP and mainstream counselling services were accessed but people had to endure long waiting lists to receive counselling after being referred. This information raised questions about how the ordinary person looked after their mental health. We felt that additional counselling services that were easy-to-access and the setting up of 'general talking sessions' within the community would help people to better deal with the every day problems of life.

Only one person from the focus group had voluntarily accessed another mental health service. They tended to stick to one specialist service in particular, saying that it made them feel, "At home" because it was culturally relevant to them. They said that, although other services offered useful facilities, they did not feel comfortable using them because they did not cater for them culturally or religiously. This group also gave reports of their bad experiences, which included being forced into institutions against their will, after reaching a critical stage in their illness. We believe that these negative experiences have brewed a lot of fear and mistrust of the mental health system on a whole and of some of the people working within them. We feel it contributes to this group being reluctant to access services. This finding coincides with information that already exists within the public domain. A report called 'Breaking the cycles of Fear' reports on this. We feel a link or advocate between statutory service providers and the local community could do some work to develop both sectors and help to break down this fear.

Improvements:

Although the few people who had used mental health services said that they were happy with them, when asked what improvements could be made, these same people produced the long list of suggestions below;

- Listen to the patients
- Less stigma
- More awareness needed about signs of illness and help available
- Joint up working between agencies
- Effective engagement strategy needed

- Implement a middle-man service which provides someone to talk to before things get out of hand – something with a non-stigmatising name, such as 'Healthy Living' so everyone can use it.
- Establish more preventative measures
- More Counselling services to shorten waiting times
- Advocacy service for black mental health patients should be available
- More services and awareness aimed at Black men
- Community Groups and existing social networks to play a larger role
- More bereavement services in place
- Mainstream services to become more culturally competent
- More BME people to sit on trust boards and at local government

The service providers in this study produced the following list of things that they felt were gaps/barriers in providing services for the African Caribbean community;

- Stigma
- Services lack of understanding of cultural issues
- Services that can provide are not given funding to do so
- Poor access to information.
- Capacity resource problems
- Structural barriers (All the different NHS Trust)
- Bureaucratic nonsense
- People above are not listening
- Best Value protects funding not to help people
- Mistrust giving black people money
- Lack of commitment from commissioners
- A lot of institutional racism still exists within service
- Junior managers
- Short/no staff

Church Facilities:

The facilities that churches had in place to cater for people's mental health issues were;

- Trained Counsellors
- Prayer support
- General befriending and socialising
- Pastoral care
- Care groups and Help teams
- Church departments dealing with varying aspects of life (i.e. Youth, Community, Family life, Finances, Health and temperance).

The benefits reported as a result of people using these facilities were:-

- Improved mental stability
- People being able to cope with everyday life better

- People looking better according to their friends and people around them
- Self reported states of feeling better
- People who had suffered a breakdown being able to go back out to work and hold down their job.
- Overcoming depression and having a positive outlook

The two things people from the faith group said they wanted to see churches provide were; spiritual and emotional support for people with mental health issues and education for the community on mental health issues.

Discussions with members of our focus group and responses to the question about attitudes of people's faith toward mental health / mental illness revealed that people generally felt that faith groups were in a good position to address mental health issues. It was also expressed that churches needed training to change attitudes of fear amongst some of their members.

In the United States a National Institute of Mental Health funded research project⁷ highlighted that the black community viewed their churches as being in a prime position to "alleviate social problems that plague their communities".

Our study also revealed that whilst churches had facilities in place that produced stated benefits to people's mental health issues, questions were raised about how confidentiality was maintained. 72% said the facilities were confidential, 4% did not know and 8% said facilities were not (the question was not applicable to 16% of people). It was found that confidentiality policies within church establishments were more often an expected code rather than a written one. We see a need for related churches to update certain operational frameworks by putting written policies in place. We noticed from our research that projects which came out of some of the churches functioned with the relevant written policies in place.

REFLECTIONS

WHAT WENT WELL:-

The team managed to work within a very tight timeframe to complete the work and save this project which was in danger of folding. We are very pleased with the level of engagement we have managed to achieve. We feel we have engaged well with real people, who opened up and shared sensitive issues with us. We were very impressed by the level of input received from our focus group members and are confident that we will be able to use this experience to effectively engage with the wider community who are sometimes considered 'hard to reach.' We have also made good links and partnerships with the wider mental health strategic bodies.

PROBLEMS ENCOUNTERED:-

Due to the time restraints some parts of the process felt a bit rushed. Members of the team were willing to help and therefore had to sacrifice their other important commitments in order to be involved.

OTHER OUTCOMES:-

As a direct result of skills gained through this project, we have been asked to help with another BME mental health research by the Marsh Farm Community Development Trust (MFCDT), which is a local strand of the Government's New Deal for Communities regeneration scheme.

- Dignity now sits on the FIS – community engagement and Information sub groups
- We have also been asked to be members of a BME Network by Csip (care services improvement partnership).
- We feel we are in a better position to effect change and assist with improvements.
- Experience of working towards a University degree and hopefully the qualification.

INDIVIDUAL DEVELOPMENT/LEARNING:-

The whole process was invaluable in terms of the new skills it taught us in;

- Community research
- Mental health system
- Community engagement.
- Assignment writing – a first for some of the group.
- Report writing
- Meeting deadlines!

RECOMMENDATIONS

Our recommendations are as follows;

- That true partnerships be formed between African/Caribbean community organisations and statutory mental health bodies.
- The need to accept and acknowledge the potential of faith establishments in providing support for mental ill health sufferers from the BME groups. The spiritual needs of BME community must be continually taken into account when designing mental health services.
- That commissioners of mental health services utilise black-led organisations other than faith establishments to help deliver services that will address the mental health problems of the African Caribbean community.
- Mental health promotion and awareness-raising, in the form of educational flyers, outreach workshops and specific events, needs to start immediately to address the lack of awareness shown by this research.
- Dignity needs to access appropriate funding over the long term (capital as well as revenue) to enable the setting up and delivery of a non-stigmatising, easy to access service within the community which will help encourage 'the ordinary person' to look after their mental health. Stress management, and general opportunities for people just to talk could be some of the things included to provide early intervention strategies.
- Link or advocacy workers from the target communities are needed to work alongside both statutory agencies and mental health sufferers to help break down fear
- One of the Government's proposed community Development Workers should be employed from the black community and have a remit to work within Luton to help capacity build faith and other non statutory organisations so they can help with delivery of services
- Dignity should be invited to sit on the Local Implementation Team (LIT) to ensure focus on BME issues is on the agenda
- There is a strong need for local mainstream services that exist to provide a culturally competent service, incorporating West Indian meals and staff that represent the cultural make up of potential users. The black community should be consulted on measures needed for services to be more user friendly for members of the African/Caribbean community.

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⁴ Dignity Mental Health Advocacy Service, (Monday 26th April 2004) **Mental Health and the African Caribbean Family Conference**, Conference Report, p11

⁵David Larson, Susan Larson and Harold Koenig (November 2001) **The Patient's Spiritual/Religious Dimension: A Forgotten Factor in Mental Health** in Directions in Psychiatry, Vol. 21. Lesson 21.

⁶2001 Census – Luton Borough, *Source: 2001 Census, [Key Statistics for Local Authorities]*

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APPENDICES