COMMUNITY ENGAGEMENT PROJECT, NIHME MENTAL HEALTH PROGRAMME

REPORT OF THE COMMUNITY LED RESEARCH PROJECT FOCUSSING ON THE MENTAL HEALTH SERVICE NEEDS OF AFRICAN AND AFRICAN CARIBBEAN WOMEN

BY ACCI AND NYELA (WOLVERHAMPTON)

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MARCH 2006

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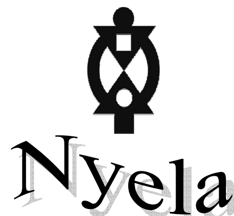

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FOREWORD

The African Caribbean Community Initiative (ACCI) was established in 1987 in response to community concerns about the disproportionate number of African Caribbean's within the mental health system and the lack of appropriate aftercare/day care facilities.

Twenty years on there is still cause for concern. The most recent 'Count Me In' National Mental Health and Ethnicity Census 2005/06 confirmed the well known fact that African Caribbean's are still disproportionately detained on Section. 'Inside/Outside' A Department of Health report on improving mental health services for Black and minority ethnic communities and its implementation framework document 'Delivering Race Equality (DRE) in Mental Health Care' make recommendations for action in the following areas to improve services for BME communities:-

- Better access and information;
- More appropriate and responsive services;
- A culturally competent workforce; and
- Community engagement and development.

If successful the DRE strategy should result in:-

- Equality of access;
- Equality of experience; and
- Quality of outcomes

Principles within the DRE framework have helped to underpin this research which focuses on the care pathways and experiences of African Caribbean women in the mental health system in Wolverhampton.

The approach employed in developing this research project directly supports ACCI's ethos and principles of working. This was achieved by enabling and empowering our service users to lead and undertake research about their needs, on their terms, and report it using their own words.

When the Universities Mentor advised that the participating groups could give a name to their research project the ACCI team grasped the opportunity to give individuality and ownership to their efforts. The team chose to name the project **Nyela,** meaning "one who will succeed" and joined this together with a West African proverb Boa Me Na Me Mmoa Wo which translates to "Help me and let me help you" and its Adinkra symbol means 'cooperation and interdependence**.**

In undertaking the research we have been greatly assisted by a number of individuals, organisations and services. We hope this report truly reflects the input and commitment from all those involved.

We recognise that partnership, commitment and resources will be required to effectively implement the reports recommendations. However we believe that implementation of the recommendations will lead to provision of more appropriate and responsive services, provided by a culturally competent workforce, effectively engaging with the community, thereby enhancing their development.

Alicia Spence
ACCI - Service Manager

The Research Project Team

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

Lenomie Valententina Myrie - I am part of the research team. I have been involved with Mental Health Services for 14 years. I became invloved with the research team by asking the manager of ACCI for some work I could do, because I wanted to start working again. So this is how everything came about and how I became a part of the project team.

Shirley Williams - I have lived in Wolverhampton, West Midlands most of my life. I am now middle aged. Mrs Alicia Spence, the manager of the African Caribbean Community Initiative (A.C.C.I) resource centre for people with Mental health issues, carers, and relative community members felt from the earlier stages of this work that it is a project I would find useful and rewarding to be a part of. I have had long term contact with NHS and Social Services and I see areas where changes need to be made. I feel that by contributing to this project I can make a small amount of change. I am privileged to take part.

Angela Wilson - My name is Angela. I experienced Mental Health problems due to bullying in the workplace. The African Caribbean Community Initiative was a great source of help and they enabled my recovery. I am pleased to participate in this research project, as I feel we need to raise awareness of the mental health issues of African-Caribbean women in Wolverhampton.

Mary-Ann Collymore - I have worked within Menal health for over 5 years and currently hold a postion at Yahimba House, supporting women who have experienced mental ill health. I was seconded to the research project 6 weeks after the previous Project-Coordinator left.

Ebony Lewin - Social work student on placement with ACCI for 6 months during the final year of her 3 year social work BA honours degree. Her degree dissertation focused on Women in Mental Health. The onset of the project came about as Ebony completed her degree and placement at upon which she welcomed the role of Project Coordinator and attending the mental health training sessions with the research team. On completing the project plan, some project promotion and supporting the research team in gathering information for literature review she was offered a very good full-time employment opportunity, and therefore was forced to leave the project.

Janet Clarke-Lewis - ACCI Administration and Finance Officer undertook responsibility for the administration and finances of the project. When the project lost the first Project Coordinator it was helpful to the project that Janet had attended some of the training sessions, as she was able to complete the Universities Ethics Form required for approval of the planning, methods and monitoring of the project. Janet also assisted in arranging meetings and providing information to the Steering Group.

Alicia Spence - ACCI Director of Services, who despite a very busy schedule running the day-to-day business of the organisation provided support, guidance and hands-on management to the project.

ACKNOWLEDGEMENTS

The community engagment researchers would like to thank all the women who took part in this research. It has been a privilege to share their experiences and personal journeys. Without these women the project would not have been possible. Our thanks also go to the University of Central Lancashire's Centre for Ethnicity and Mental Health mentor, all of the steering group members for guidance and support thoughout this reseach project and of course our sponsors, funders and other unnamed supporters. Without your resources, support and confidence in the team to deliver, this important project would not have been possible.

A MENTAL HEALTH SURVIVOR'S GIFT TO THE REPORT

If I Was Healed

If I was healed - I would be free.
My fragile wings would courageously open,
As I would soar, soar, soar up into the sky and fly into the distant horizon
Where the sun sets burnt orange, fiery red and fluorescent pink.

If I was healed - I would sing without fear.
I would tell of all the terrible experiences that destroyed my heart, body, mind, soul and spirit.
But I would also tell of how good souls rescued me and how God remade me.

If I was healed - I would face my tormentors.
And say in my soul, "Forgive them Father, for they know not what they do."
And I would know in my heart that it was not my fault,
And I would forgive myself.

If I was healed - I would be a burning light.
For all the lost, lonely, lifeless souls, who are locked in the labyrinth of their despair,
But are still striving to find their way out into the light of freedom.

But most of all, If I was healed - my heart would finally unfold.
And millions of petals of peace and love would float through the skies,
And touch everyone who was in pain and give them hope,
That they could be healed and live the life they were born to live.

If I was healed.
If I was healed.
If I was healed...

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EXECUTIVE SUMMARY

BACKGROUND/CONTEXT

The African Caribbean Community Initiative (ACCI) was established in 1987 in response to community concern about the disproportionate number of African Caribbean's within the mental health system, and lack of appropriate aftercare/day care facilities.

The organisation provides a range of culturally appropriate, holistic services to individuals and families experiencing or recovering from mental ill-health and has developed a strong and active presence within in the community it serves in Wolverhampton.

Twenty years on, there is still cause for concern as a wealth of current research evidence suggests that African Caribbean's are:-

- The most over-represented minority ethnic group within mental health services;
- Over-diagnosed with schizophrenia and under-diagnosed with depression;
- Often delay seeking help from mental health services until they are in crisis; and
- Reluctant to seek help from mainstream services due to fear and mistrust.

In support of this 'Breaking the Circles of Fear' a report produced by the Sainsbury Centre for Mental Health, highlights the over-representation of African Caribbean people in the mental health service and details alarming statistics regarding poorer outcomes compared to their white counterparts.

This picture is also reflected locally in Wolverhampton where a recent local Primary Care Trust (PCT) audit of service data found that *"although the African Caribbean community in the city constitute only 3.9% of the total population they account for 16% of all in-patient admissions and 23% of admissions to the psychiatric intensive care unit."*

Women and Mental Ill-Health The Government Strategy for Mainstreaming Women's Mental Health (2003) highlights the importance for mental health services to respond appropriately to the needs of women. However, despite evidence of inequality and discrimination in service provision there is still very little research into African and African Caribbean women's pathways into mental health services.

Unless service providers can identify the specific needs of female service users they will continue to be ill-prepared and unable to begin to address them. In support of this, ACCI has recorded a consistent increase in the number of African Caribbean women using our services. Results from our annual member surveys clearly indicate the importance our female members place on accessing culturally appropriate services, designed to meet a range of needs not just those that relate to their mental illness (e.g. housing advice, educational/social activities, job search etc). Since opening our supported housing unit for vulnerable women back in 2004, demand for the service has far exceeded supply.

ACCI adopts a holistic approach to addressing the range of issues affecting our members including physical, social, and emotional needs. This involves addressing various areas from housing to education, to debt management, low

confidence and self esteem. Through our experience and work in this area ACCI identified the need to explore the range of contributing factors that can affect women's mental health for instance forensic history, suicide, eating disorders, domestic violence, self-harm, family dynamics and relationships.

National Developments - Delivering Race Equality in Mental Health Care (DRE) 2005 is a five year action plan for achieving equality and tackling discrimination in mental health services in England. The Delivering Race Equality Action Plan is specifically designed to deliver improvements in mental health services across the following areas:-

- Better access and information;
- More appropriate and responsive services;
- Culturally competent workforce; and
- Community engagement and development

If successful the DRE action plan should result in:-

- Equality of access;
- Equality of experience; and
- Quality of outcomes

ACCI – NEYLA (Wolverhampton) – Research Project
ACCI has encouraged and supported a member led women's group and women's creative writing group for a number of years. Over the years the groups have shared their experiences of mental health and other services in a safe and supported environment. Given there is currently very little research about the care pathways and experiences of African/ African-Caribbean women in the mental health system. It was considered important to seize the opportunity presented through the Centre for Ethnicity and Health's Community Engagement Mental Health Research Programme and work with ACCI's women's group to take this study forward.

ACCI's -NEYLA community engagement mental health research is unique in that it is the first report led, managed and undertaken by African/Caribbean women in the mental health system in Wolverhampton, making recommendations on how to improve services and understand the barriers and issues they face.

Methodology
ACCI's - NYELA project researchers were entirely made up of African Caribbean women aged between 30-55 years, who are current and ex-service users of ACCI.

The team consisted of 4 service users supported by a project coordinator seconded from ACCI's Omari Project – (an intensively supported housing scheme for African Caribbean women) and a mentor from The University of Central Lancashire's Centre for Ethnicity and Health.

A mixed method approach was adopted which consisted of two stages:-

- Survey questionnaire; and
- Service user led focus group session

There are a number of women who participated in the research who do not use statutory services, but have had some encounter with statutory services because

they have experienced a serious episode of mental breakdown and were hospitalised under Section. The study also included consultation with women who do not use ACCI Services, but were identified through known carers/family members and gave their consent to participate.

The use of questionnaires as a self-completion exercise is useful for gathering qualitative and quantitative information and identifying general trends; the disadvantage is that they cannot provide feedback about why choices are selected or rejected.

A focus group session was facilitated by the research workers, themselves former users of mental health services. ACCI's Service Manager attended the focus group acting as a scribe. It was initially proposed that an audio recording be made of the focus group session. However the group facilitator was uncomfortable with the session being recorded and therefore agreed to take her own notes.

The session was held at ACCI in February 2006 with ACCI service users and non-service users and was attended by 10 women. The purpose of the focus group was to acquire more open-ended qualitative information and to encourage the group to share ideas, experiences and to suggest possible changes that could be introduced into mental health services.

As part of the research the researchers compiled accounts of how the women taking part in the research described their personal journeys and experiences.

Issues that affected the delivery of this project included unforeseen losses to the research team and participants state of well-being.

Recommendations

There is evidence to suggest that there is a lack of research into areas surrounding black women and mental illness. Given the findings and conclusions from this research, the group wish to make the following recommendations:-

1. Further research into women with mental health issues who also experience domestic violence, sexual and financial abuse;
2. Further research into the reasons for women becoming mentally unwell;
3. Further research into the effects of mental ill health on children and their families;
4. Forums to be established to raise awareness of mental health issues in the African and African Caribbean communities;
5. Forums to be established for social workers and teachers to raise awareness of the support children and families need during times of crisis;
6. The role of the GP in supporting and diagnosing mental ill health is crucial, therefore GPs should be invited to play a more active role in organisations such as ACCI;
7. GP's together with general hospital services should develop ways for women to access general health services and not just to focus on mental ill-health;
8. The Shaw Trust and similar organisations should be involved with ACCI in order to promote their employment or return to work services and to

enable service users to explore pathways into employment under the ‘permitted to work’ rule;

9. The development of culturally competent counselling services and holistic services; and
10. More consultation with service users around care planning and legal rights whilst in hospital.

Conclusion

In undertaking this research we have been able to identify some of the key issues affecting the mental health of African/African Caribbean women. The Government’s ‘Delivering Race Equality’ Mental Health Care Action Plan – (DRE) 2005, will only be meaningful to the African Caribbean community when services are more appropriate and responsive.

The ability to engage BME communities will only be achieved when there is greater confidence and trust in statutory agencies. The African Caribbean community must also engage in a proactive mental health promotion programme beginning with churches, community groups etc. This is essential to de-stigmatise mental illness, only then will the appropriate support be forthcoming and ‘healing begin’. The role of the Black-led churches cannot be overstated.

Primary care agents such as GP’s must begin to link into the Black Voluntary Sector. Employment and training opportunities are areas that must be explored so that women experiencing/recovering from mental ill-health are able to rebuild and enjoy improved quality of life.

The limitations of this project are that it is a random piece of research (random, in that it only accounts for a small section of African Caribbean women with mental ill-health in Wolverhampton) and is therefore limited and subjective. The missed opportunity to make comparisons using the information collected on women’s mental health globally is a great loss, which would have given an objective analysis and provided the report with its literature review and reference material. These issues are explained in more detail in the body of the report. It is our firm belief that more extensive research is required to back up this initial user-led piece of work.

We therefore conclude ‘back at our starting point’ that there needs to be more research into the skills, strategies and techniques for engaging black women in research around the identification of their needs and appropriate services to meet those needs. Services need funding and monitoring for quality assurance, the elimination of racist practises, continued customer satisfaction and relevance.

1. BACKGROUND AND INTRODUCTION

1.1 The Centre for Ethnicity and Health's Model of community engagement

Background to the community engagement model

In November 2000, 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 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 a 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.

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.

1.2 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 provides 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 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

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[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.

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

1.3 The community engagement team

The community engagement team comprises of senior support workers, support workers, teaching and learning staff, administration team and a communications 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><td>Northern Team</td><td>Midlands Team</td><td>Southern Team</td><td rowspan="2">Senior Programme Advisors</td></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>
</table>

1.4 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

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[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.

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 this 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.

1.5 Wolverhampton – Background & Demographics

Once an industrial town Wolverhampton's multicultural population now reflects its city status. Most of its non white population originate from the Indian sub-continent or the Caribbean. This City also has an increasing number of refugees and asylum seekers. Members of Wolverhampton's black and minority ethnic communities can all be identified separately because of their culture, religion beliefs, way of life and language.

In Wolverhampton 22% of the population and 30% of the school cohort are from BME communities. Wolverhampton is home to large Black and Asian communities, which make up almost 5% and 14% of the population respectively. The city's Black Caribbean population is large (3.9%) especially in comparison with other cities and large towns in the area. There are more than 9,000 Black Caribbeans living in Wolverhampton, who form the second-largest ethnic minority group within the city behind Indians.

Wolverhampton's unemployment rate is 14.2%, however for BME communities the figure is 22.2%. Statistics show that 28% of all African Caribbean's and 19% of all Asians of working age are unemployed. The wards with the highest level of unemployment are St. Peter's (15.5%), Heath Town (13.0) and Blakenhall (11.6%), these are also the wards with the highest concentration of BME communities. Similarly 30% of people with disabilities are unemployed, compared with 5.6 of those without disabilities.

Approximately 5% of Wolverhampton's residents are likely to have English as a second language – a figure that is increasing as a result of growing numbers of refugees and asylum seekers. According to Wolverhampton's Asylum Seekers support team, there are approximately 51 different nationalities of asylum seekers currently living in the City of Wolverhampton in addition to the existing and established African Caribbean and Asian communities. Consequently, there are approximately 60-70 different languages spoken in the city, including a range of dialects.

Wolverhampton's Asylum Seekers team estimate that there are approximately 1200 Asylum seekers and 1000 Refugees living in Wolverhampton at any given time. However these figures do not include an unknown number of refugees and Asylum seekers and their extended families, which are moving around within the West Midlands..

Wolverhampton has been ranked as the 27th most derived Local Authority in England according to the Government's 1998 Index of Multiple Deprivation. Those who experience multiple deprivation have often been excluded from the labour market. As with most inner city areas, those who have the most difficulty returning to work are the long-term unemployed, lone parents, those with low basic skills, those with long term illness and disabilities (including mental illness) and BME communities who are often over represented in all these groups. There is a proven correlation between concentrations of BME communities and high

levels of social exclusion and disadvantage across a range of derivation indicators, especially unemployment.

Approximately 25% of Wolverhampton's population have, no or low levels, of formal qualification. Basic skills are also a particular concern almost the working age group, with 32% of the population with low levels of numeracy and 29% with poor levels of literacy. Both well above the national average.

Wolverhampton has the second highest level of lone parents in the West Midlands and one of the highest rates of teenage pregnancy in the Country. Whilst lone parent constitute 3% of Wolverhampton's working population, almost half of these are unemployed or economically inactive and two- thirds have no or low levels of qualifications.

A wealth of current research evidence suggests that African Caribbean's are:-

- The most over-represented minority ethnic group within mental health services;
- Over-diagnosed with schizophrenia and under-diagnosed with depression;
- Often delay seeking help from mental health services until they are in crisis; and
- Reluctant to seek help from mainstream services due to fear and mistrust.

In support of this a report produced by the Sainsbury Centre for Mental Health (2002) highlights the over-representation of African Caribbean people in the mental health service and details alarming statistics regarding poorer outcomes compared to their white counterparts.

This picture is reflected locally in Wolverhampton where a recent local Primary Care Trust (PCT) audit of service data found that *"although the African Caribbean community in the city constitute only 3.9% of the total population they account for 16% of all in-patient admissions and 23% of admissions to the psychiatric intensive care unit."*

2. THE FOCUS OF THIS REPORT

Since 2000 over 200 community groups have taken part in the National Institute for Mental Health in England's Community Engagement Programme.

ACCI NYELA (Wolverhampton) – An all female user led African and African Caribbean Women's Group were one of 40 community groups taking part in the National Institute for Mental Health in England's Community Engagement Programme during in 2005/6.

The Neyla Community Engagement Project was undertaken in Wolverhampton in conjunction with a range of partners. The research and project design was strongly influenced by the Department of Health Delivering Race Equality Action Plan's vision of improving services for African/African-Caribbean women.

This project was achieved by engaging with African/African-Caribbean service users and their respective communities to assess their experiences of mental health services.

Project Aim
To explore the wider contributing factors that can affect African and African Caribbean women's mental health e.g. forensic history, suicide, eating disorders, domestic violence, self-harm, family dynamics and relationships.

Project Objectives
The key objectives of this research report are to:-

- Explore the care pathway and experiences of African/African-Caribbean women within the mental health service;
- Highlight existing good practice and identify areas for improvement in services and approaches; and
- Make recommendations to improve equality, experiences and outcomes within mental health services for African and African Caribbean women service users in Wolverhampton.

Project Outcomes
In undertaking this research it is intended that findings and recommendations should assist in identifying and understanding the issues and lived experiences of those concerned. The evidence can then be used to address the disparities and make services more appropriate, responsive, relevant and equitable.

What will success look like?
Success is dependent on a number of issues such as raising awareness and understanding of mental health issues within the African-Caribbean community among churches, community groups and community leaders etc; thereby empowering them to feel confident in engaging, participating and influencing local service design and delivery.

Success will involve statutory services increasing their understanding of the innovative and holistic delivery of services within the voluntary sector.

Mental health services will only be truly effective when key stakeholders are able to trust, respect and value each others contributions, skills and expertise.

The Need for ACCI's NEYLA Project

The Government strategy for 'Women's Mental health into the Mainstream' (2003), recognises the need for mental health services to respond appropriately to the needs of women. However there is limited specific data about African and African Caribbean women in the system using structured or therapeutic services.

ACCI's Day Centre maintains a daily client attendance log and monitors outreach visits. Analysis of this data shows a consistent increase in the numbers of women accessing the centre's services and receiving outreach support from ACCI staff. The number of female service users is now almost equal to the number of males using the service.

ACCI opened an intensively supported unit for vulnerable women back in 2004. Demand for places is such that we could fill more than double the spaces available. The organisation often receives enquiries from statutory agencies and other services wanting to make referrals for supported accommodation for vulnerable women. ACCI also need to ensure that the range of services we provide meet the needs of our female clients.

Through our work in this area ACCI identified the need to explore the wider contributing factors that can affect women's mental health for instance forensic history, suicide, eating disorders, domestic violence, self-harm, family dynamics and relationships.

The ACCI NYELA research project was needed because there is evidence of inequality and discrimination for African and African Caribbean people within mental health services. There are many different factors that can contribute to mental ill-health, but information about African and African Caribbean women is limited, particularly data on care and their pathways into mental health.

There is an unmet need for research to obtain accurate data. In ACCI's experience the best way to address the gap in knowledge is to engage the women, support them to tell their stories and ask them to help identify solutions and ideas for improvements.

3. METHODOLOGY

3.1 The Project Team

The Project Team was made up initially of 7 people - ACCI's Service Manager, a Project Coordinator and 4 Research Workers. The initial project coordinator was a final year social work student who was selected because of the quality of skills shown during her 120 days placement with ACCI and her expressed interest in the proposed work. However, soon after drawing up the work plan and sourcing the literature review she left the project to take up a full-time job offer. Some two months later, a new project coordinator was seconded to the project from ACCI's intensively supported unit for African Caribbean Women with mental health problems, where she is employed as a Project Support Worker.

The Research Workers were entirely made up of African-Caribbean women between the ages of 30 – 55 who were current and ex-ACCI service users. ACCI's Service Manager and Administration and Finance Officer where charged with the day-to-day management and guidance of the team with some assistance provided when required by other ACCI staff.

ACCI often takes advantage of opportunities to empower our members (service users) who use our services and participate in activities at the day centre. For this purpose the organisation consulted with women who attend the day centre, those who live in ACCI's supported accommodation and women who access ACCI's Imani Outreach Service. This helped to gain their support to become involved directly in the devolvement of the project through contributing to all the information gathering stages.

Promotion and Engagement

The project was promoted through the quarterly community newspaper 'Community Whitmore Reans News'. Other means of promoting the project were also used to access African-Caribbean women in contact with statutory services.

ACCI Women's Group meets each week to participate in learning, skills building and pleasurable leisure activities. The group meetings are very well attended, a facilitator is provided from the local Adult College and the organisation ensures that their meeting area is available to them without question. The women organise and prepare for themselves with little input required from staff before each meeting.

On alternate Friday's the Women's Creative Writing Group meets. This is a well established group made up of women who only attend the centre for this activity and some who already attend the aforementioned group. This group has seen a significant growth in numbers attending, and has produced some stunning creative poetry, verse and life stories. The group's facilitator is a published writer, actor and lecturer of English Literature at a well renowned College. It is from within these groups that the survivors of mental health illness were approached and volunteered for the Research team.

Reasons for Getting Involved

The women were in no doubt about their ability to recount their life experiences; listen to and interpret the information received from others about their perceptions of the care pathways into mental health services within the

Wolverhampton area and to ascertain whether their experiences are a positive reflection of the care they receive. The women firmly believed that they have a vested interest in providing ideas for shaping changes in mental health services for African/African-Caribbean women and needed reassurance that they would be appropriately guided and supported in this.

Project Challenges
One Research Worker although very keen at the start decided that she would not be able to cope, but agreed to participate. Another member who featured very strongly in the initial stages and made an important contribution to information gathering and in shaping the questionnaires had to leave due to competing academic pursuits. However this member returned to the team when available to produce and deliver presentations at regional meetings when required by the research funders.

The reduction in the research team did have an impact and resulted in setbacks in terms of management of administration, meetings, delegation of tasks and the original timescale. The biggest concern for ACCI was the fear that the remaining researchers would start to feel the pressures of sharing more of the workload than was initially agreed.

Contributors
A mixed method approach was adopted which consisted of two stages:

There are a number of women who participated in the research who do not use statutory services, but all will have had some encounter with statutory services and in all cases this will have come about because they have experienced a serious episode of mental breakdown and are hospitalised under Section. There was also consultation with women who do not use ACCI Services but were accessed through known carers/family members, and where willing participation was agreed by the cared-for person.

3.2 Research Methods

The initial gathering of information into women's mental health globally was carried out by the first project co-ordinator together with the research team. When the project coordinator left it became the responsibility of the research team to collate and utilise the literature review. However this did not happen; and then another research team member left after finding it difficult and stressful even though she had helped to collect a wealth of information. Unfortunately, by the time the new project officer was in place a number of other tasks took precedence. There was no one in the project able to contextualise this information in time to meet the submission deadline of this report, thereby making the research more subjective than objective. If the opportunity was granted it would be helpful to revisit this research in the future and utilise the literature review. data gathered primarily consists of information about Asian and white women's experiences in the USA where information is more widely available. The bigger picture definitely needs to be explored in more detail for a more objective piece of research to be achieved.

3.3 Survey Questionnaire

At the commencement of the project it was agreed that 50 participants would be identified to receive questionnaires, of which 42 were completed. However, when examining the responses it was agreed that 38 of the questionnaires should be carried forward for data analysis.
The questionnaires were completed in one-to-one sessions due to time constraints, as it was intended to carry out one-to-one semi-structured interviews which would have gathered much more in-depth qualitative background information to the responses being given.

The use of questionnaires as a self-completion exercise is useful for gathering qualitative and quantitative information and identifying general trends; the disadvantage is that they cannot provide feedback about why choices are selected or rejected. **[Appendix 3]**

3.4 Focus Group Session

We chose to hold a focus group because we acknowledged the value and the power of shared experience.

A focus group session was facilitated by the Research Workers themselves and included former users of mental health services with ACCI's Service Manager recording the session. The facilitator was uncomfortable with the session being recorded on audiotape, however did take her own notes. The session was held at ACCI in February 2006 with ACCI service users 10 women attended. The purpose was to acquire more open-ended qualitative information and to encourage the group to share ideas, experiences and to suggest possible changes which could be introduced into mental health services.

The use of focus groups in research is a relatively new phenomenon and contested as the discussion is often difficult to transcribe. Other problems identified in the literature relate to the variable participation rates and dangers of discussion being dominated by the more assertive and articulate participants. As researchers we had to be aware and sensitive to these problems and we worked in pairs to maintain a balance between control and a relaxed atmosphere, as well as attention to content and process issues. **[Appendix 5]**

The women who attended were relaxed and gave freely of their time and opinions. Few who attended appeared to be inhibited in the group after the initial settling in period.

3.5 Personal Journeys and Experiences

As part of the research we compiled some accounts of how the women who took part in the research described their personal journeys and experiences.

3.6 Data Analysis

In order to analyse the information contained in the questionnaires a database was created using the computer software programme Excel. This led to the collation of figures, which were further defined in the production of tables and charts taken from the analysed data. The themes used in categorising questions

were ranked and probed to delve deeper into personal and professional relationships such as family, doctors and carers.

3.6 Training & Support

In order to allay the concerns of the Research Workers about their capability to undertake work, the University of Central Lancashire prepared a skills building training programme. The training programme started in July 2005 and ran through to the beginning of August 2006, offering:-

- Mental Health Awareness Workshops, held over two days;
- Training Days for Methods of Research, held over two days;
- Training Days for Report Writing, held over two days;
- Additional support was found in reference material provided in a student handbook issued by the University;
- The support of the UCLAN mentor, and project co-ordinator
- Sharing research collated around mental health issues with participants; and
- The knowledge base within ACCI.

3.7 Training Awards

As part of the project the University provided the opportunity to acquire Certificates in Community Research and Mental Health which was also built-in as part of the training sessions. The course was completed by two of the Research Workers – (i) Shirley Williams (Survivor) and (ii) Lenomie Myrie (current ACCI Service User) who completed the course and achieved the following graded Certificates:-

(i) University Certificate in Achievement in Community Research EZC003 - Merit
(ii) University Certificate in Community Based Research EZ1007 - Pass

3.8 Steering Group

Additional support for the project came from the Steering Group made up of professional people from diverse ethnic backgrounds; and there was also a good gender mix. The UCLAN mentor and Research Workers were included on the Steering Group

The Steering Group was made up of professionals, ACCI staff and the Project Team, and was responsible for assisting the Team to focus on the tasks set, providing guidance and relevant information where required or requested, and practical help and advice where necessary; including the review and progress of any reports produced by the Team. **[Appendix 1]**

ACCI provided the day-to-day guidance to the Project Coordinator and Research Team where necessary and facilitated access to service users, the distribution of questionnaires, provision of the private areas for questionnaires to be completed and likewise for the focus group session as well as working space, meeting venues, administrative support and other practical resources.

Regular briefing meetings were held by the Project Team which included the UCLAN mentor, and the Research Workers arrange meetings themselves to check on each others progress and to record and take concerns back for discussion at the Project Team Meetings or if necessary the Steering Group meetings.

The Project team performed the following tasks:

- Researched for information
- Attended training sessions provided by the University
- Delivery of presentations when requested about the research project
- Attended weekly team meetings; or as often as required
- Discussed the direction of the project
- Forward planning
- Held brainstorming sessions
- Completed the questionnaire
- Arranged and facilitated one-to-one questionnaire completion sessions
- Arranged and facilitated the focus group session
- Arranged session to gathered personal statements
- Provided input to case studies
- Completed delegated sections of the research report.

4. RESULTS

4.1 Questionnaire Study

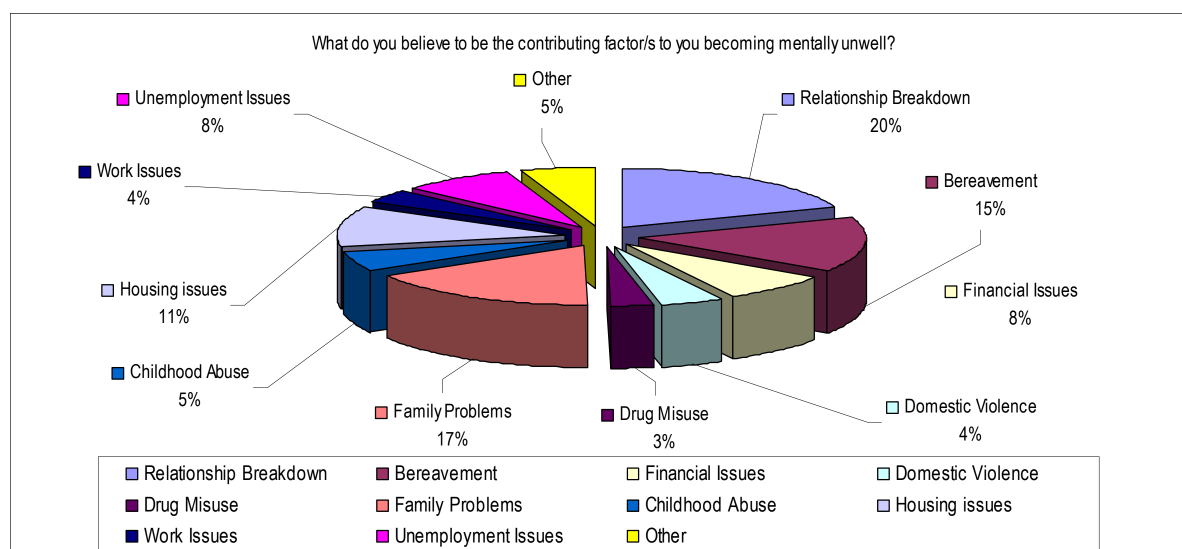
Total Number of participants: 42

Section 1: Personal Profile

Q1 What does the word "mental health" mean to you?

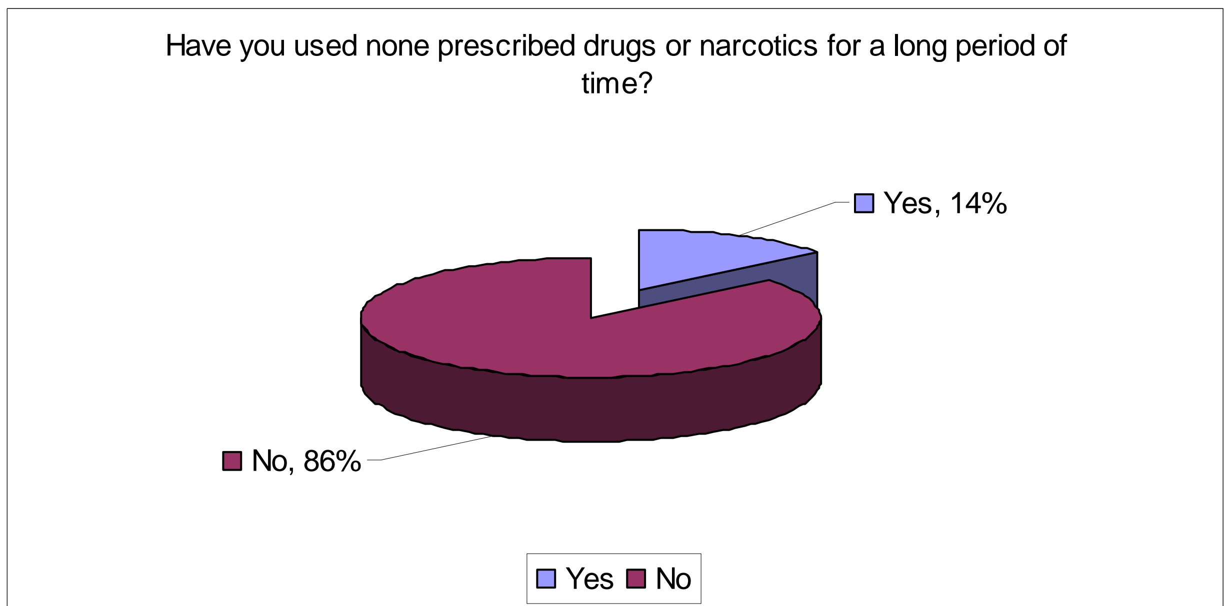
Mind Sickness	13
Lack of Coping Skills	6
Spiritual issues	9
Don't Know	8
No Comment	6

Q2 What do you believe to be the contributing factor/s to you becoming mentally unwell?



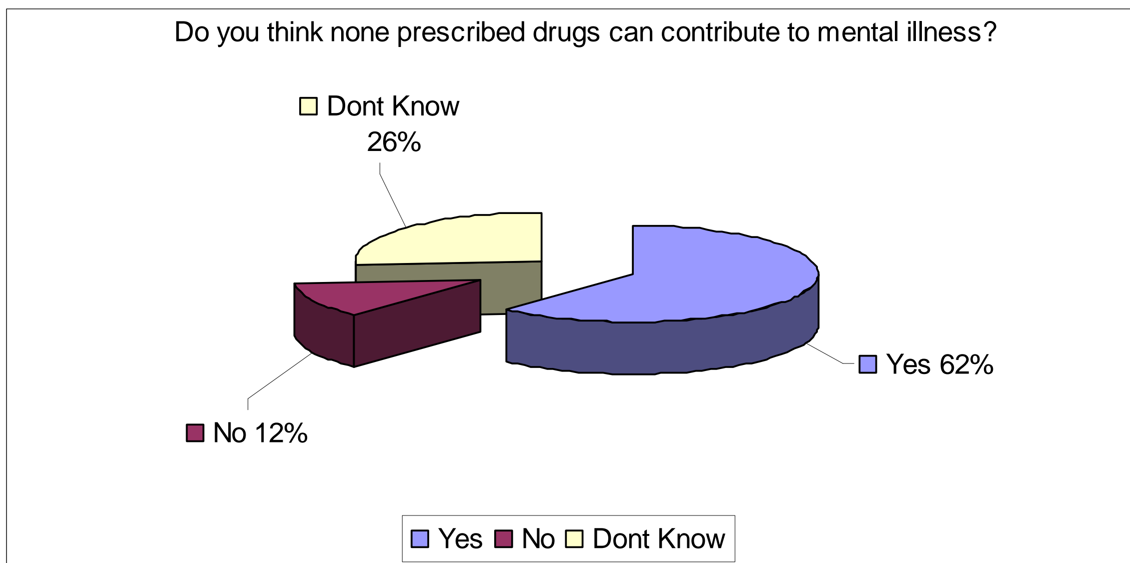
The respondents stated that the main contributing factor to their becoming mentally unwell was relationship breakdown. This was followed by family problems and bereavement. Other major contribution factors were housing issues, financial problems and unemployment issues. It would appear that some respondents had more than one contributing factor that contributed to them becoming mentally unwell. As apart from the major contributors a significant number had experienced domestic violence, drug abuse and childhood abuse and work issues.

Q3 Have you used none prescribed drugs or narcotics for a long period of time?



Here 36 respondents stated that they had not used prescribed drugs or narcotics for a long period of time. However, 6 respondents stated that they had taken non prescribed drugs or narcotics for a long period of time.

Q4 Do you think none prescribed drugs can contribute to mental illness?



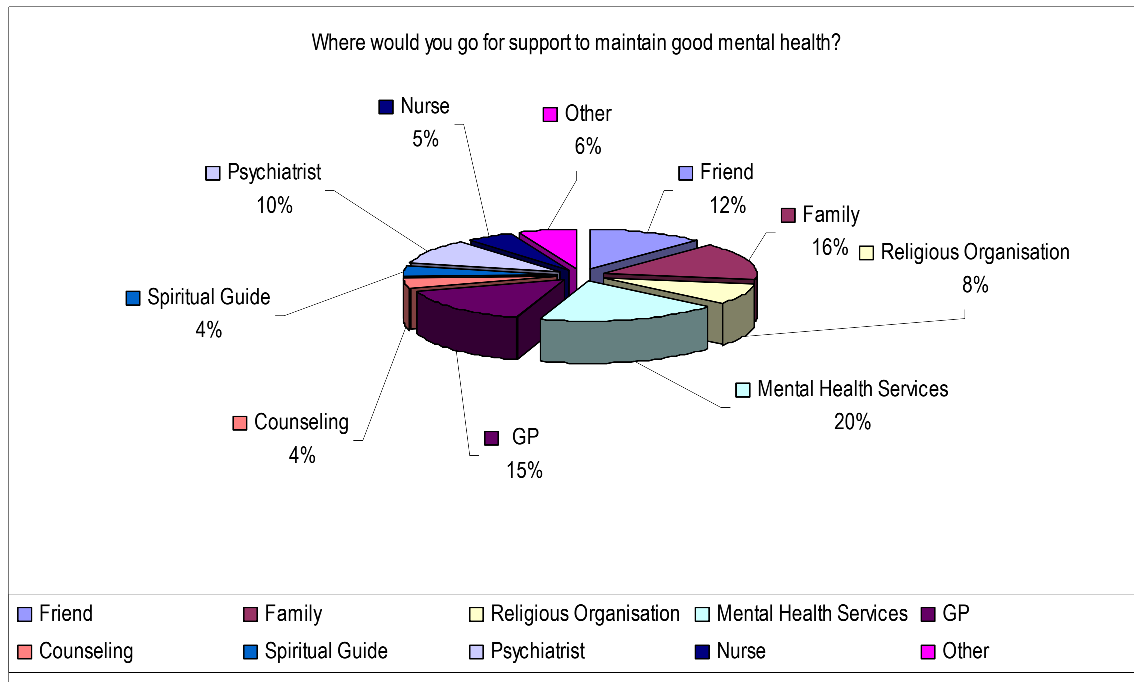
The majority of respondents 26 stated that non-prescribed drugs did contribute to mental illness. Of the remainder 5 stated that it did not and 11 indicated that they did not know.

Q5 If you have regularly used none prescribed drugs where you offered help from a professional anti drugs team?

Yes	1
No	5
No Comment	36

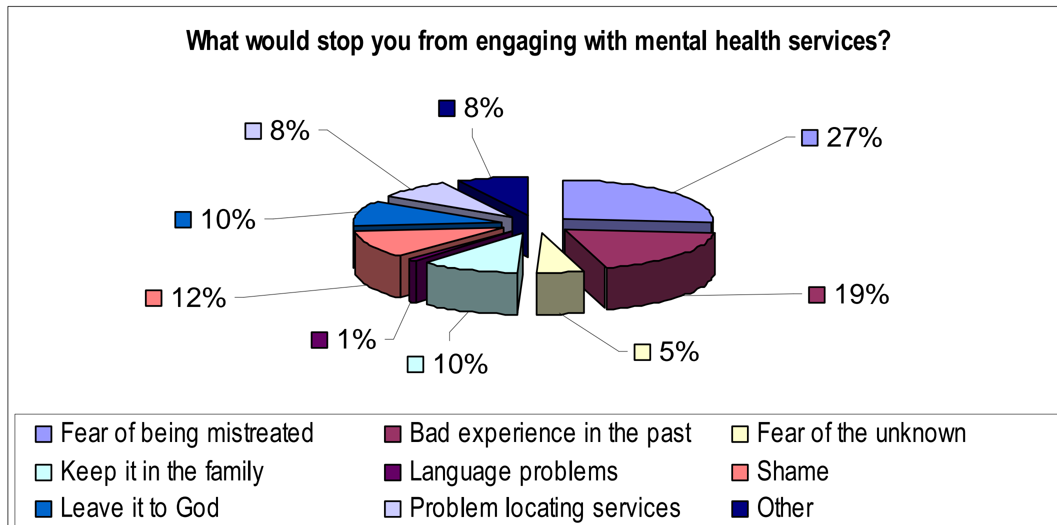
Here only one respondent indicated that they were offered help from a professional anti-drugs team member when using non prescribed drugs. Of the remaining respondents 5 indicated that they were not offered help and 36 stated that it was not applicable.

Q6 Where would you go for support to maintain good mental health?



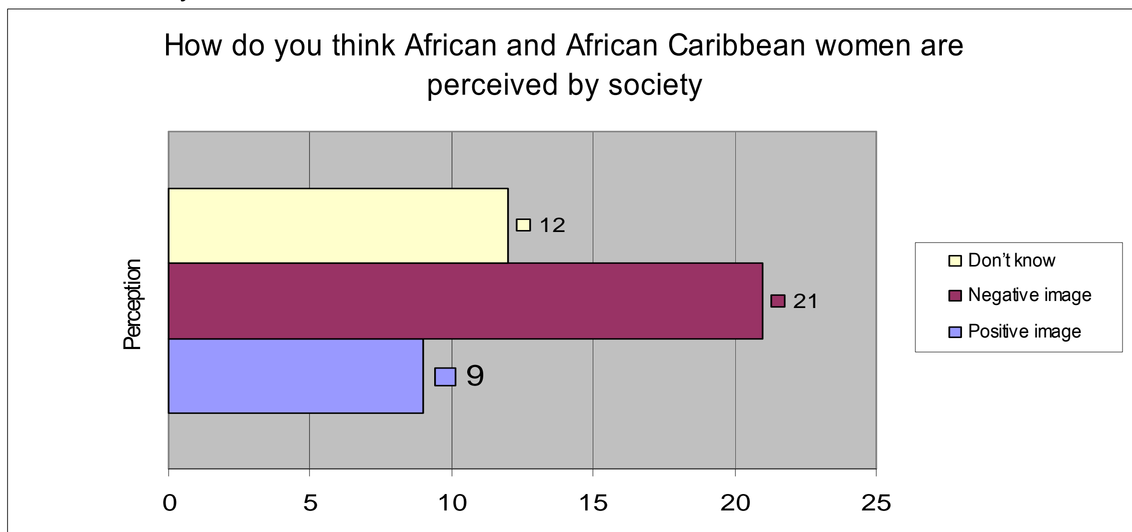
The findings indicate that the majority of respondents would go to Mental Health Services for support to maintain good mental health. Other preferred services were the respondents G.P, Family Members, Friends, Psychiatrist and Religious Organisation. As can be seen in the above table, Counselling was one of the least preferred options and had the same response rates, as respondents that chose to relate to spiritual guides for assistance. Only 5 respondents stated that they would go to a nurse for support to maintain good mental health.

Q7 What would stop you from engaging with mental health services?



The responses indicate quite clearly that it is the fear of being mistreated and bad experiences in the past, which would stop respondents engaging with mental health services. In addition respondents stated that shame was a big factor when it came to engaging with mental health services. There is also an indication that it was often kept within the family and as such engagement with external agencies was not a preferred option. The findings also indicate that a small number of respondents felt the situation was better left to God. In addition, fear of the unknown also contributed to a lack of engagement with mental health services.

Q8 How do you think African and African Caribbean women are perceived by society?



Here respondents stated that African and African Caribbean women were perceived with a negative image by society. Only 9 respondents felt that African and African Caribbean women held positive images within the society. The remaining 11 respondents stated they “didn't know”, only one respondent stated “other” which was one of the optional responses to the above question.

Q9 Do you think the way you are seen by society as an African or African Caribbean woman affects your mental health?

Yes	22
No	10
Don't know	10

As can be seen in the above table, 22 of the respondents felt that the way they were perceived by society, did impact on their mental health. Of the remaining 20 respondents, 10 felt it had no impact and 10 stated they did not know.

Q10 Do you think the public perception of African and African Caribbean women affects the services you receive?

Yes	35
No	2
Don't know	5

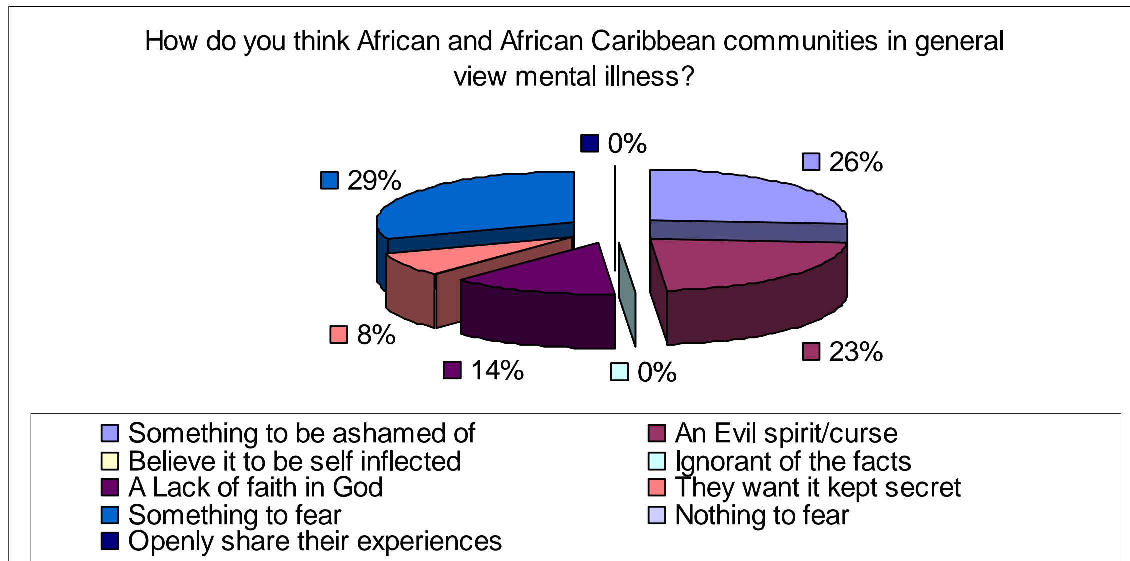
Thirty five respondents felt that public perception of African and African Caribbean women affects the services they received. Two respondents stated that it did not and five stated that they did not know.

Q11 Would you agree with the following statement; mental illness is common among women from the African and African Caribbean Community?

Yes	26
No	12
Don't know	4

The majority of respondents stated that they would agree that mental illness is common amongst women from the African and African a Caribbean community. Twelve respondents stated that is was not the case and four felt that they did not know.

Q12 How do you think African and African Caribbean communities in general view mental illness?



The findings indicate that the African and African Caribbean communities in general view mental illness as something to be feared and ultimately something to be ashamed of. A significant number of respondents that stated that mental illness are viewed as a curse or evil spirit. This is coupled with the findings that 9 respondents felt that some sections of the African and African Caribbean community believed that mental illness was due to a lack of faith in God. It is interesting to note that 5 respondents stated that mental illness was something to be kept a secret.

Q13 Have you been stigmatized or made to feel ashamed because of your mental illness?

Yes	37
No	5

As can be seen from the above table, 37 respondents indicated that during their mental illness they were made to feel ashamed and in some cases stigmatized. Only 5 respondents stated other wise.

Q14 Do you believe you are stigmatized more by your community because you are a woman with mental health issues?

Yes	16
No	22
Don't know	4

The response to this question is interesting, as only 16 respondents felt this was the case. On the other hand, the majority of respondents (22) did not agree with the above statement. The remaining 4 respondents stated they did not know. As such gender did not appear to be a factor in determining how their community viewed mental health issues.

Q15 Do you think culture and family traditions affect our mental well being? If so please explain.

Yes	21
No	18
Don’t know	3

As can be seen from the above table, 21 respondents stated that culture and family traditions did affect their mental well being. Of the remainder 18 stated that culture and family traditions did not impact on their mental well being and 3 stated they did not know. No explanation recorded.

Q16 Do you think religious beliefs affect the way we perceive mental illness? If yes, please explain.

Yes	17
No	17
Don’t know	8

The respondents were divided, with 17 stating that religious beliefs did affect the way we perceived mental illness and 17 respondents stating that it did not. Of the remainder 8 respondents stated they did not know whether religious belief affected the way we perceived mental illness.

Section 2: Diagnosis

Q17 Have you been to your G.P. about any mental health concerns?

Yes	39
No	3

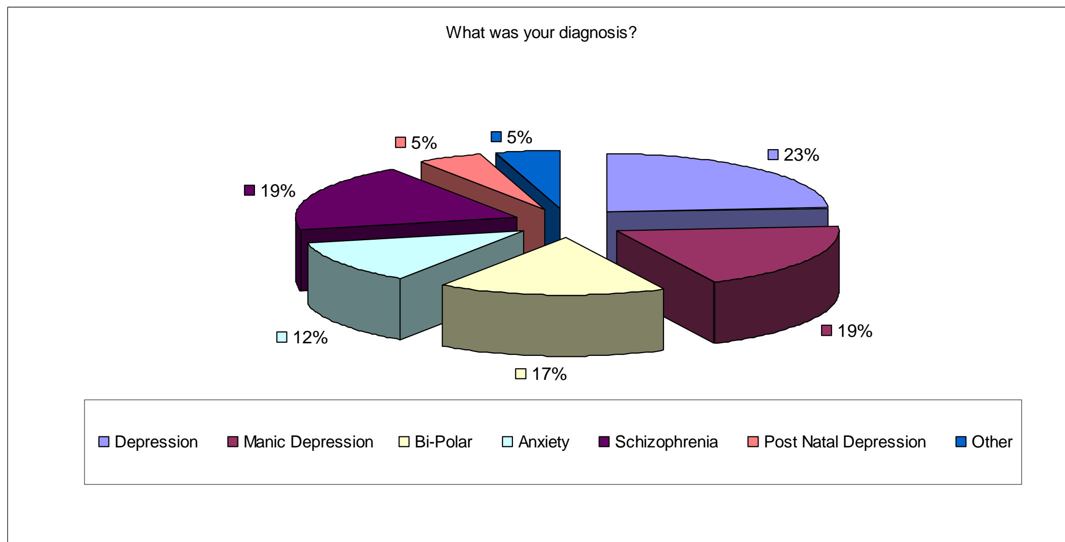
The majority of respondents stated that they had been to their G.P. about mental health concerns. Only 3 of the 42 respondents stated they had not been to their G.P about mental health concerns. As such it would appear that respondents were willing to share their concerns regarding mental health with their G.P.

Q18a Did you receive a diagnosis?

Yes	30
No	12

The majority of respondents (30) stated that they had received a diagnosis as a follow up to their concerns. Twelve respondents stated that they did not receive a diagnosis.

Q18b Were you diagnosed with more than one condition i.e. dual diagnosis?



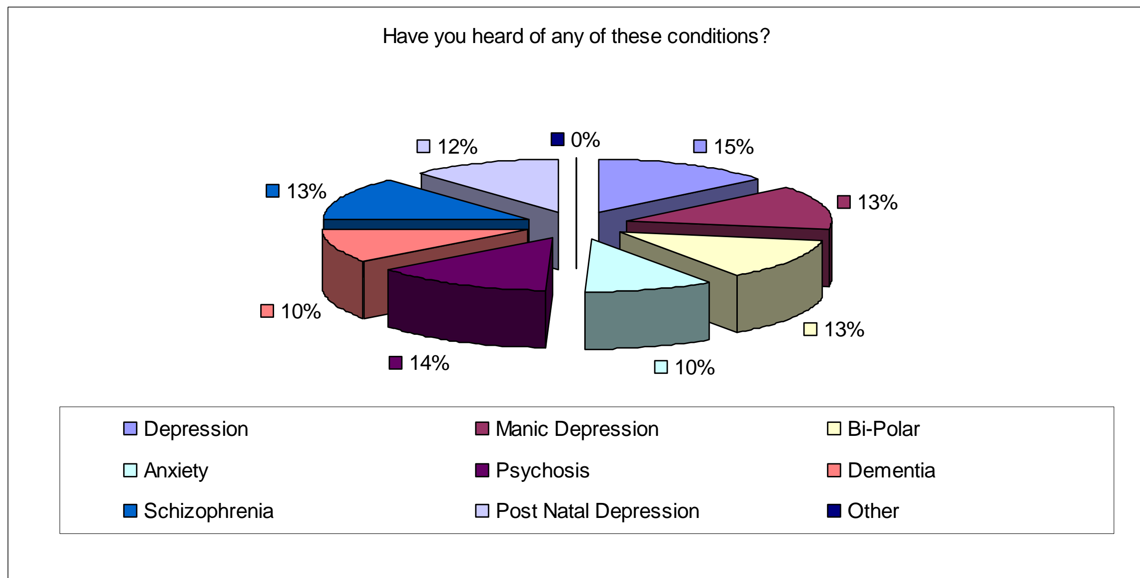
Here the overwhelming response from respondents was that they were not diagnosed with more than one condition i.e. dual diagnosis.

Q18c When you were first diagnosed how long did it take for Doctors/ Psychiatrists to diagnose you?

0-12 Months	20
1-2 years	15
2-5 years	6
5-10 years	0
15+	1

It would appear from the above table that a significant number of respondents were diagnosed within a period of 0 -12 months. However, it should also be noted that a slightly larger proportion of respondents were undiagnosed for 1-2 years. In addition, a smaller portion of respondents were undiagnosed for 2-5 years.

Q19 Have you heard of any of these conditions?



The above table indicates that the majority of the respondents are aware of, or had heard of the several of the conditions that are commonly diagnosed as, or contributed to ones mental ill health. The least common conditions appeared to be Dementia and anxiety.

Q20 Did you agree with your diagnosis?

Yes	18
No	24

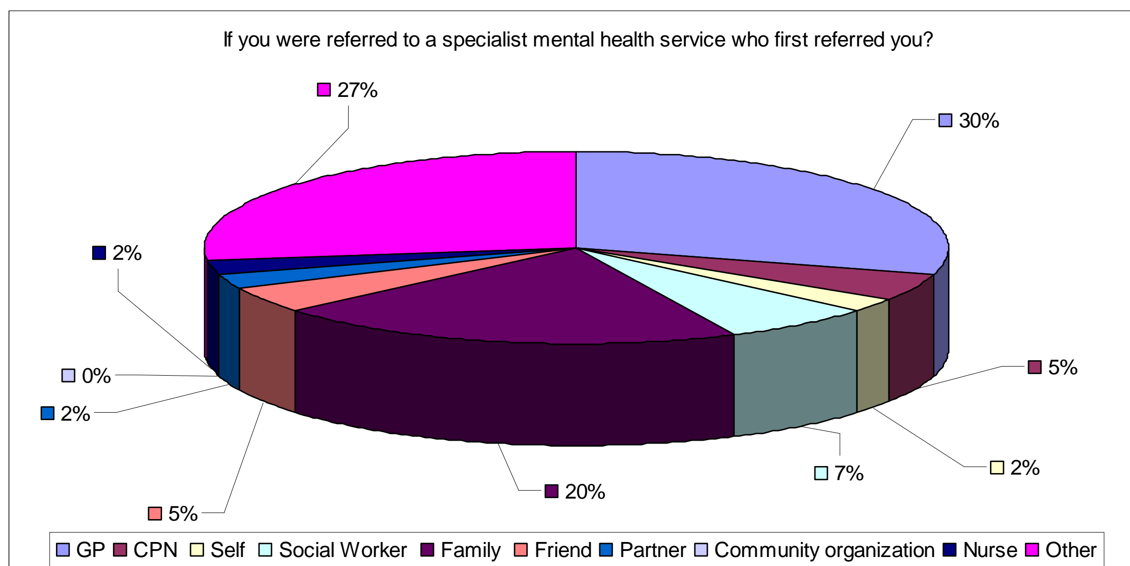
A significant finding here is that the majority of respondents (24) were found to disagree with their diagnosis. Less than half of the respondents that took part in this survey (18) stated that they agreed with the diagnosis made regarding their mental health.

Q20a Were you offered a second opinion?

Yes	0
No	42

The above table indicates that none of the 42 respondents were offered a second opinion regarding their mental health.

Q21 If you were referred to a specialist mental health service who first referred you?



The three top answers to this question were the respondents G.P, other and family. Please note that respondents were not asked to disclose what agencies were referred to as "other". It would be important to investigate this area, as over a third of respondents stated this as an alternative route to seek treatment for their condition. It is also important to note that only one respondent actually stated that they referred themselves to a specialist mental health service. The fact that Nurse, partner and friends also ranked amongst the lowest means of referral to a specialist mental health service is a significant factor.

Section 3: Care and Support in Hospital / Treatment

Q22 Have you spent time in hospital because of your mental illness?

Yes	32
No	10

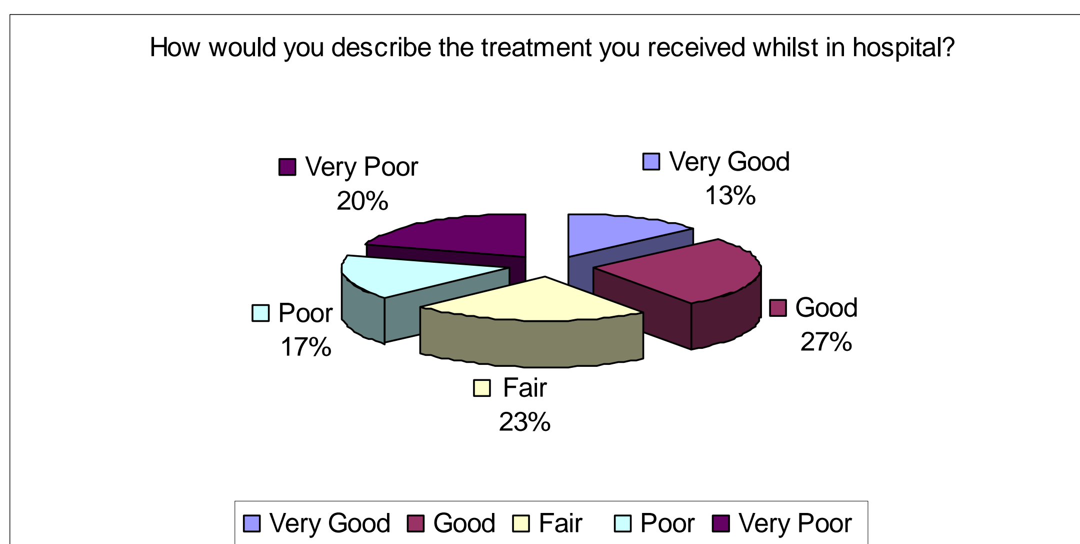
The findings reveal that the majority of respondents had spent time in hospital due to their mental illness. Of the 42 respondents only 10 stated that they had not spent time in hospital as a result of their condition, because of service intervention and finding alternative support. The following findings will be based on the responses of the 32 respondents that had experienced hospitalisation, as a result of their mental illness.

Q22a If you have spent time in hospital because of your mental health, how long did you spend in total?

0-12 Months	25
1-2 years	1
2-5 years	2
5-10 years	2
15+	0
Other	2

A significant proportion of respondents stated that they had spent between 0-12 months in hospital because of their mental health. One respondent had spent 1-2 years and the remainder had spent between 2 – 10 years. 10 respondents did not complete this question. However, what has emerged is that a large number of respondents had experienced hospitalisation as a result of their diagnosis.

Q23 How would you describe the treatment you received whilst in hospital? Please explain you're answer.



The majority of respondents rated the treatment they received in hospital as very good to good. However, a significant number of respondents stated that they felt the treatment was fair to very poor.

Q23a Were you treated with respect at all times?

Yes	19
No	11

Here 19 respondents stated that they were treated with respect at all times. The 11 remaining respondents stated that they were not treated with respect at all times. Two respondents failed to answer this question.

Q23b Were you consulted on the care plan you received?

Yes	20
No	7
Don't know	5

The majority of respondents stated that they were consulted on the care plan they received. However, researchers also noted that a significant number of respondents were not consulted regarding the treatment they received.

Q23c Was your treatment explained and administered in away that you could understand?

Yes	21
No	11

The majority of respondents stated that their treatment was administered in a way that they could understand. On the other hand 11 respondents stated that this was not the case in their experience and that treatment was not administered in away that they could understand.

Q23d Were you given a date when your care plan would be reviewed?

Yes	24
No	8

The above table indicates that the majority of respondents, 24 were given a date from which their care plan would be reviewed. However, a significant number of respondents, 8 stated that they were not given a date to review their care plan.

Q24 Were you made aware of your legal rights whilst in hospital?

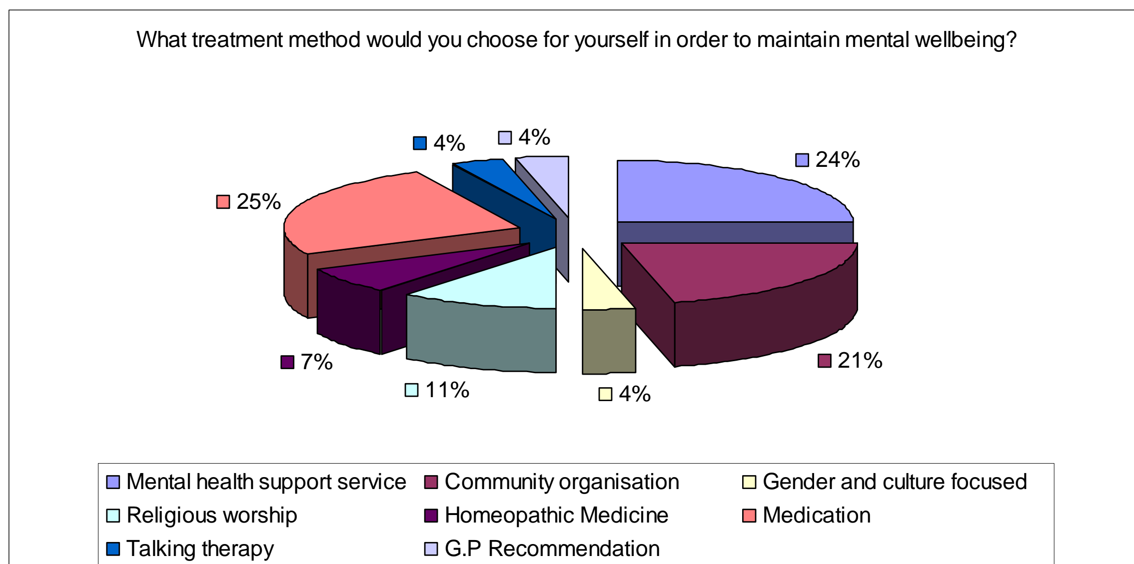
Yes	19
No	13
Don't know	

The findings indicate that 21 of the respondents were not made aware of their legal rights whilst in hospital. Nineteen respondents stated that they were made aware of their legal rights whilst in hospital.

Q25 Were you given an option of treatment?

Yes	0
No	32

Q26 What treatment method would you choose for yourself in order to maintain mental wellbeing?



From the options outlined in the above table, the respondents preferred choice of treatment was mental health support services and medication. This was followed by support from community organisations. The lesser choices regarding treatment methods for mental wellbeing were gender and culture focused interventions, along with religious worship, talking therapy and homeopathic medicine.

Section 4: Care and Support in the Community

Q27 Were you satisfied with the care and support you received after leaving hospital?

Yes	23
No	9

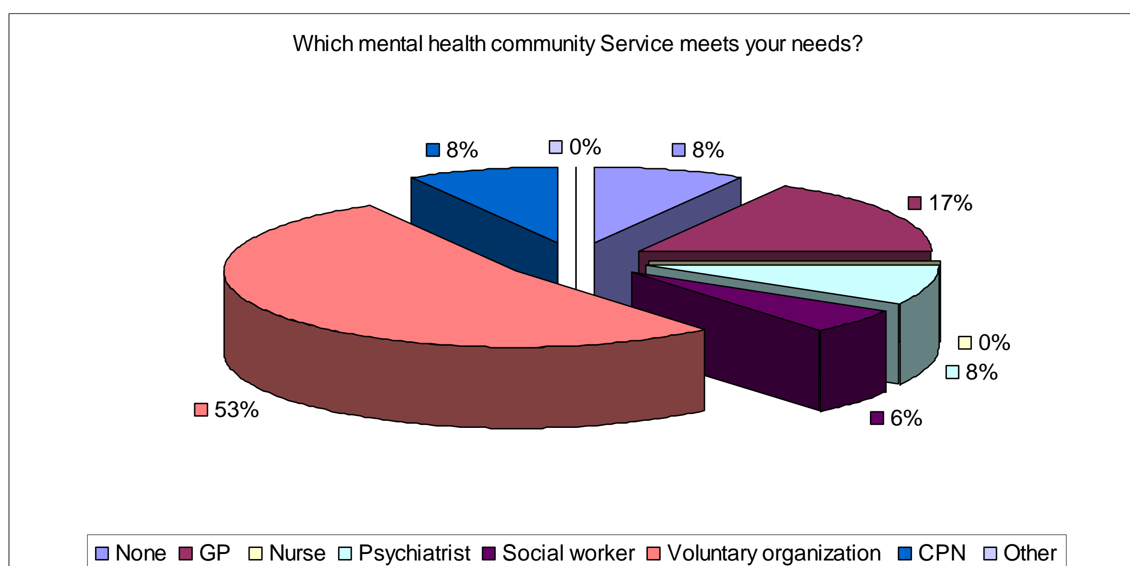
The findings from the above table indicate that 23 respondents felt satisfied with the care and support they received after leaving hospital. However, 9 stated that they were not satisfied with the care and support they received. It is important to note that this later finding indicates a serious lack in service provision and that further research may need to be carried out to ensure that everyone leaving hospital after treatment regarding mental illness, receive adequate care and support.

Q28 Were you made aware of what mental health community care service are available to you?

Yes	2
No	30

The above table reveals that the majority of respondents (30) stated that they were not made aware of what mental health community care services was available to them. Only 2 respondents stated that they were made of the community care services available to them.

Q29 Which mental health community Service meets your needs?



The findings of the above table record that 19 respondents felt that the mental health community service that best meet their needs, was that of a voluntary organisation. This was followed by GPs, a CPN, psychiatrist and finally social worker. 3 respondents stated that none of the above listed services meet their needs.

Q30 Does it make a difference if the support you receive is from a male or female mental health?

Yes	18
No	24

18 respondents felt that the gender of the mental health nurse did make a difference. Whilst the majority of respondents (24) stated that the gender of the mental health nurse made no difference at all.

Q31 How satisfied were you with the mental health community service you received? Marked 1 (Very satisfied) – 5 (Very Unsatisfied)

1	3
2	6
3	20
4	4
5	4
Don't Know	5

The findings show that respondents were only moderately satisfied with the mental health community service they received. Only 3 respondents were very satisfied and 2 were satisfied with the service. 20 respondents felt it was moderate and 4 respondents were very unsatisfied. 5 respondents stated they did not know.

Q32 Were you given support with finding out about any benefits you may have been entitled to?

Yes	26
No	11
No Comment	5

The above table indicates that an overwhelming majority of respondents were given support with finding out about any benefits that may have been entitled to. However, 11 respondents stated that they were not given the same levels of support and 5 respondents did not indicate a response to this question.

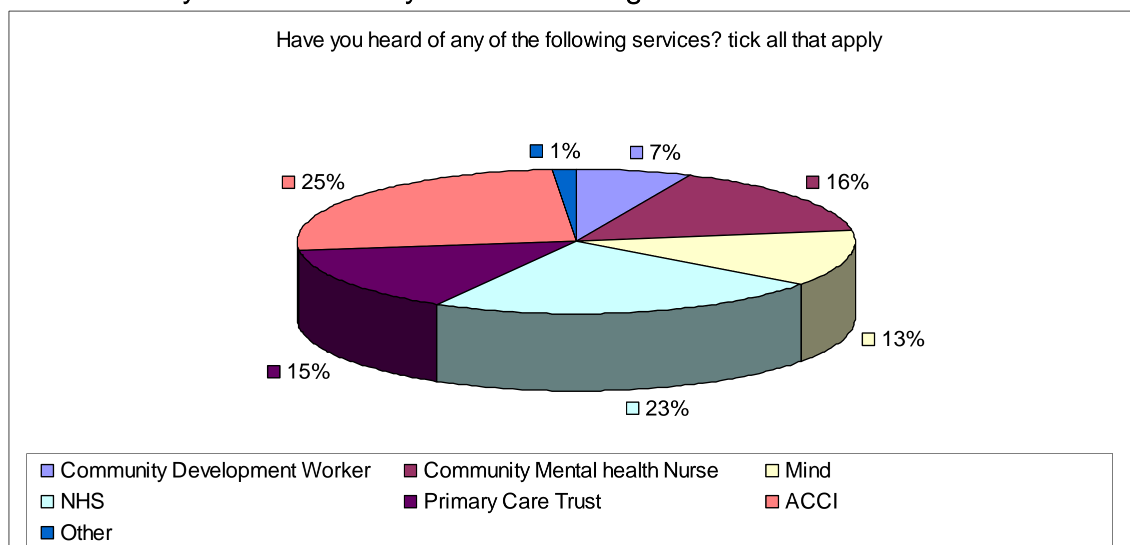
Q33 Were you supported in finding training and employment?

Yes	19
No	13
No Comment	0

The majority of respondents (24) felt that they were given very little support in finding training and employment opportunities available to them. 13 of the respondents stated positively that they did receive support in finding training and employment. The table also indicates that 5 respondents did not complete this question.

Section 5: Mental Health Service

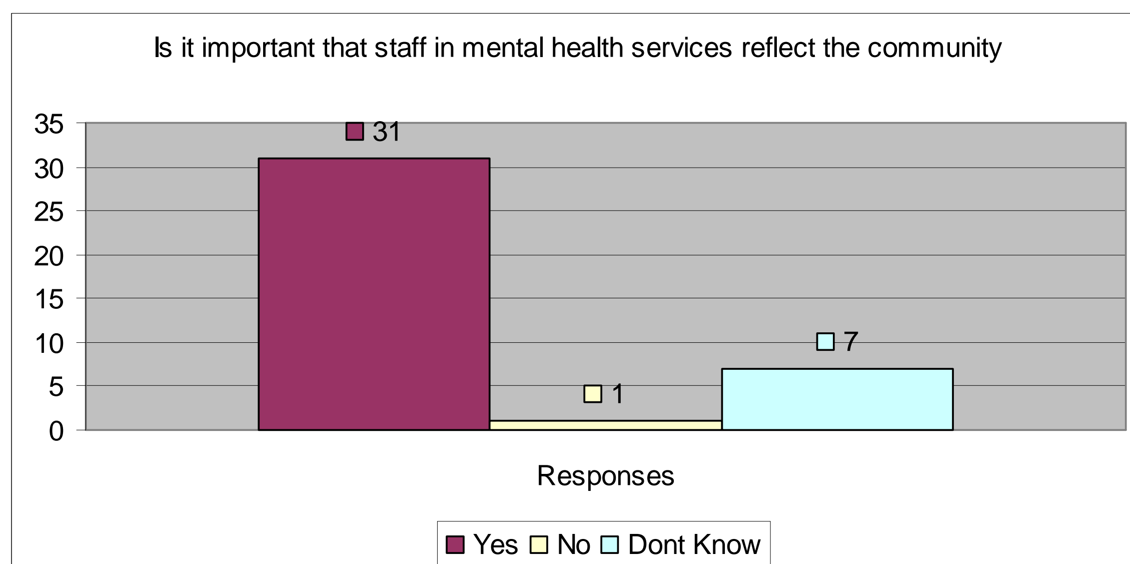
Q34 Have you heard of any of the following services?



Community Development Worker	20
Community Mental Health Nurse (CPN)	15
2	6
5-10 years	0
15+	1

The findings to this question indicate that the respondents are very aware of a number of services listed in the above table. In particular, ACCI, NHS, Community Mental Health Nurse, the Primary Care Trust. The least notable services were Community Development Workers and Mind.

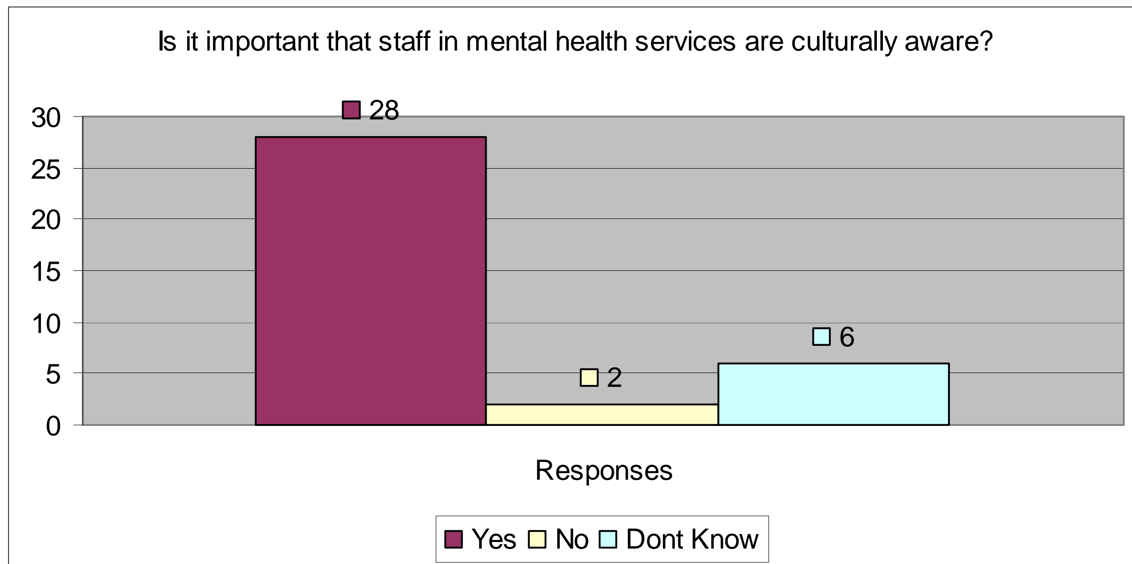
Q35 Is it important that staff working in mental health reflect the diverse community?



The majority of respondents (31) agreed that it was important that staff working in mental health should reflect the diverse community they serve.

Only one respondent stated it was not important and 7 felt they didn't know. 3 Respondents failed to indicate a response to this question.

Q36 Is it important that staff working in mental health are culturally aware of your needs as African or African Caribbean Women?



The majority of respondents felt that it was important that staff working in mental health services, are culturally aware of their needs as African and African Caribbean women. Only 2 respondents stated that it was not important and 6 respondents abstained from answering the question.

Q37 Would you prefer mental health services to be based within the African and African Caribbean Community?

Yes	26
No	8
Don't Know	3

The above table shows that respondents would much prefer mental health services to be based and delivered within the Caribbean Community. Here 26 respondents indicated that they would prefer this initiative and 8 respondents stated that they would not. 3 respondents felt they did not know and 5 respondents did not answer this question.

Q38 Would you prefer African and African Caribbean service providers?

Yes	20
No	6
No Comment	11

The respondents gave a mixed response to this question, with 20 respondents feeling that they would prefer African and African Caribbean service providers, to deliver mental health services within the community. Only 6 respondents stated that they would prefer alternative providers. However, what is interesting is that 11 respondents stated they did not know and 5 respondents failed to indicate their preference.

Section 6: Reformation of Local Services

Q39 Are there any changes in mental health or further developments you would like to see in the future?

Yes	21
No	16
No Comment	5

The majority of the respondents (21) felt that there were changes in mental health they would like to see in the future. 16 respondents stated that there were not any changes they would like to see. 5 respondents abstained from answering this question.

Q40 Do you think that more research into the mental health of African and African Caribbean?

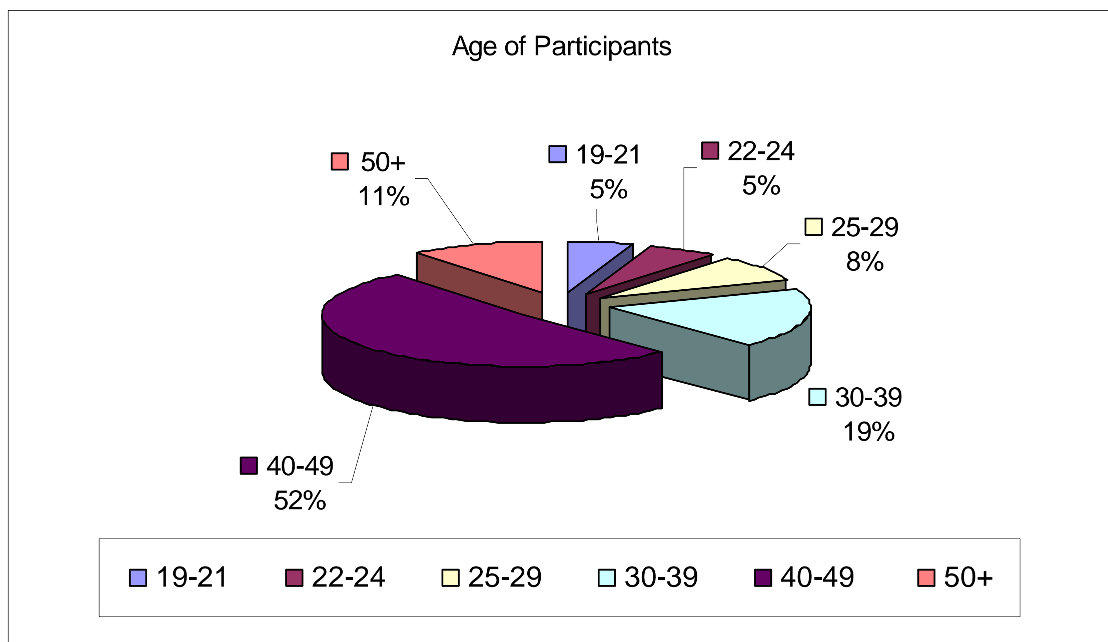
Yes	28
No	10
No Comment	4

The majority of respondents (28) felt that more research into the mental health of African and African Caribbean peoples could be undertaken.

10 respondents felt that that this was not necessary and 4 respondents abstained from completing this question.

4.2 CORE DATA: SAMPLE

Q1 Age of participants



Age of Participants	
19-21	2
22-24	2
25-29	5
30-39	6
40-49	23
50+	4

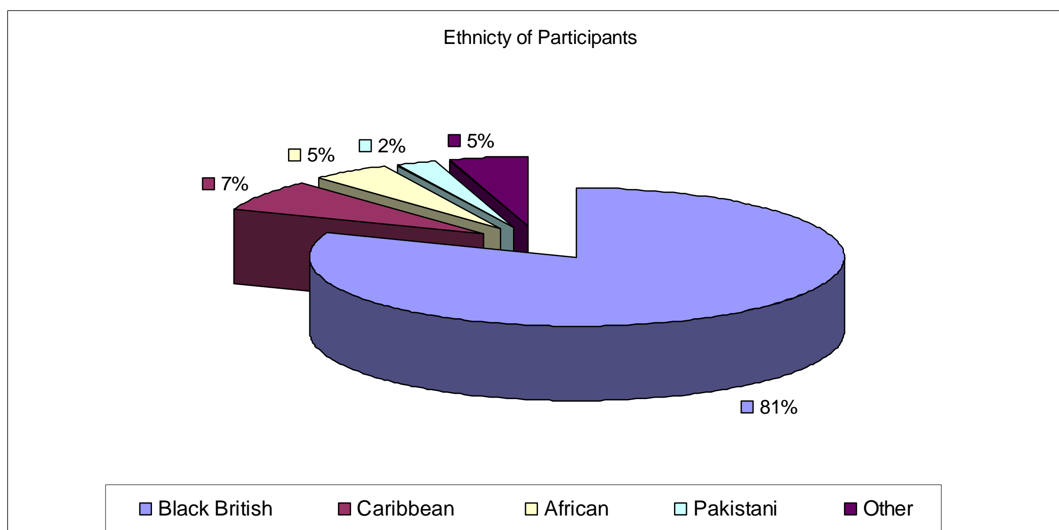
The highest age group was between 40-49 years

Q2 Gender

Female	42
Male	0
Transgender	0
Transsexual	0

The whole questionnaire was designed for women.

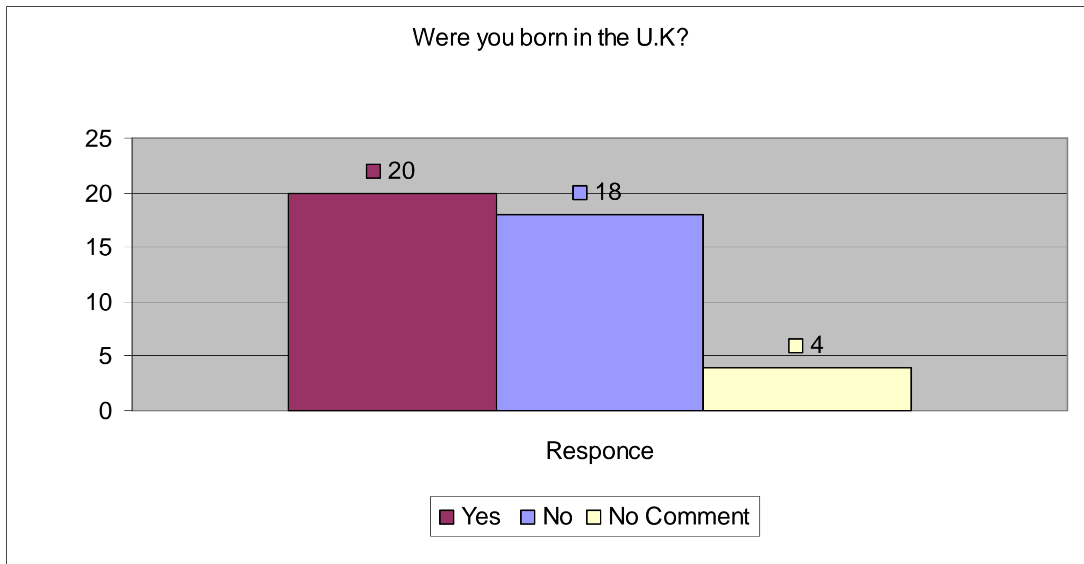
Q3 Ethnic Group



Black British	34
Caribbean	3
African	2
Pakistani	1
Other	2
White British	0
Irish	0
Scottish	0
Welsh	0

The main bulk of the participants are Black British, with a few from Africa, the Caribbean and one from Pakistan

Q4 Were you born in the UK?



Yes	20
No	18
No Comment	4

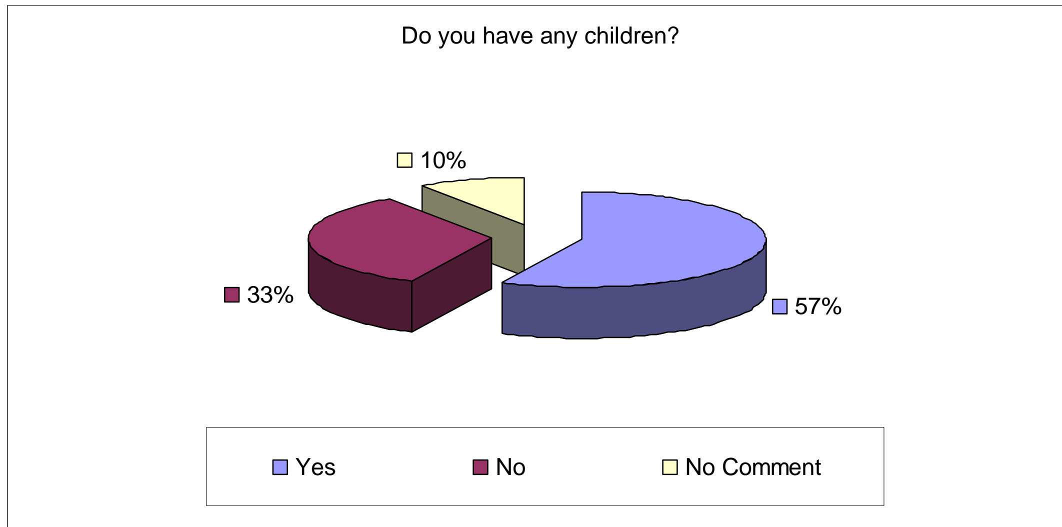
20 Participants were born in the UK but 4 made no comment

Q4a If no, how long have you lived here:

Less than 1 year	
1 – 5 Years	
6 – 10 years	
11 years or more	18

Out of 18 that were not born in UK they have been in the UK over 11 years.

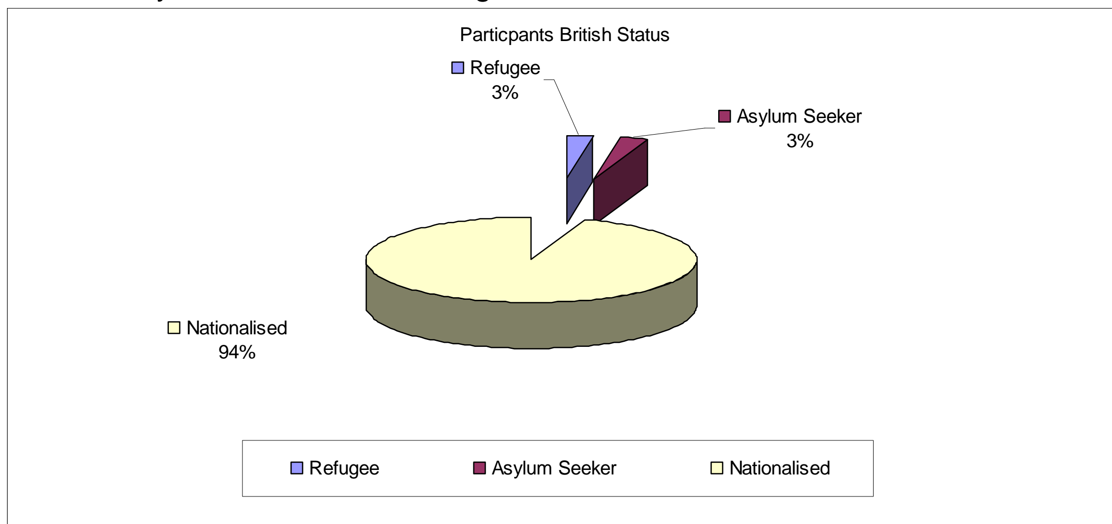
Q5 Do you have any Children?



Yes	24
No	14
No Comment	4

24 have children and 14 were not ready or did not have any.

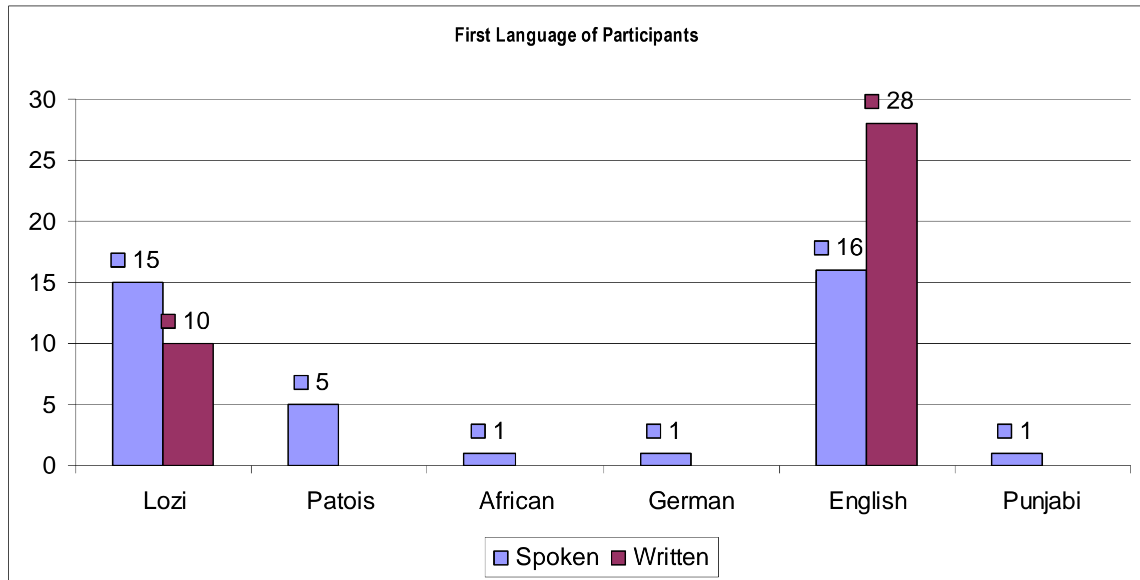
Q6 Are you one of the following?



Refugee	1
Asylum Seeker	1
Nationalised	16

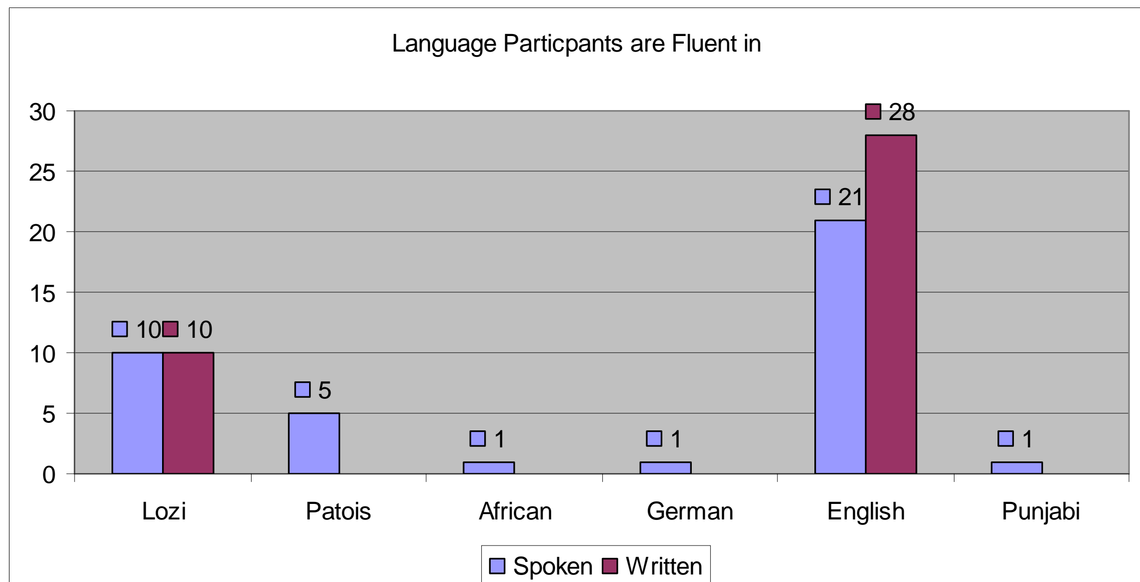
Out of the 18 not born in the UK 16 have received Nationalisation.

Q7 What is your first language?



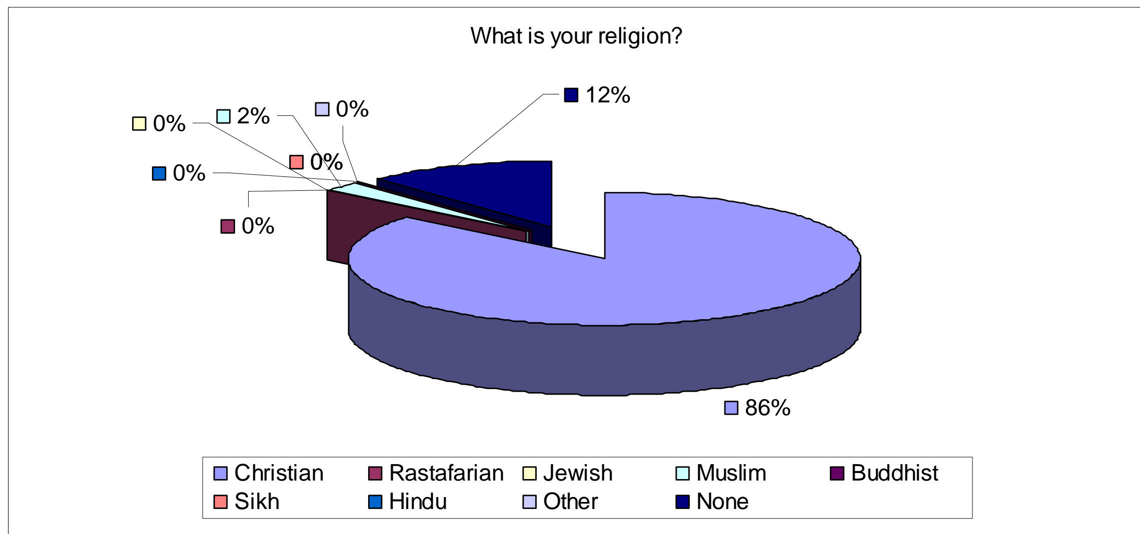
The first language of the participants was English both written and spoken, but Lozi was spoken as the second highest spoken language.

Q8 What language are you fluent in?



Again the most fluent language was English and as the previous chart Lozi again was the second highest spoken and written language.

Q9 What is your religion?

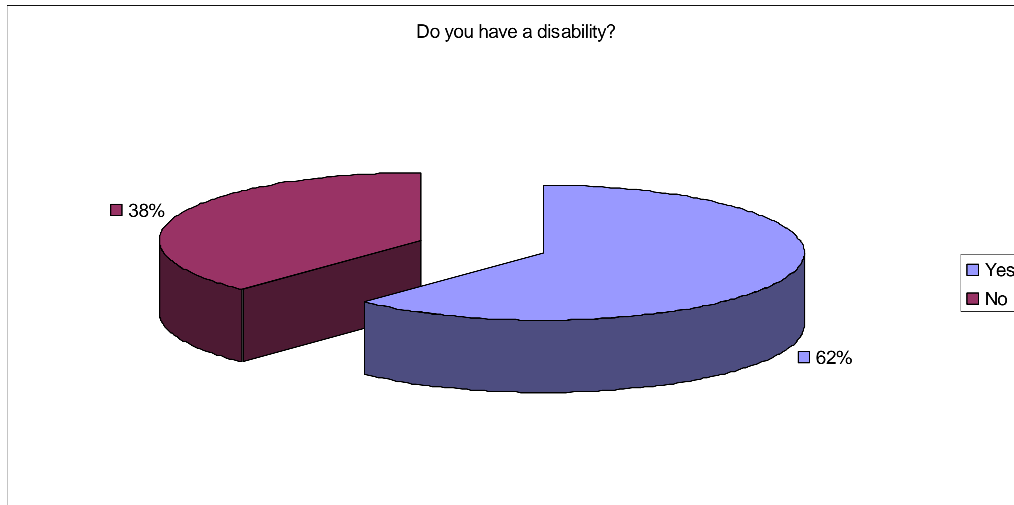


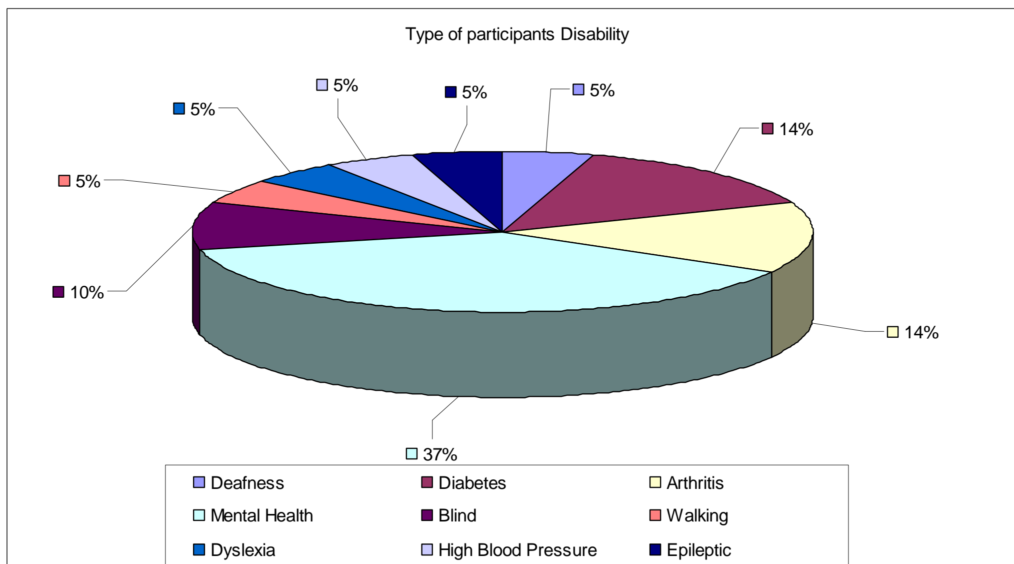
Christian	36
Rastafarian	0
Jewish	0
Muslim	1
Buddhist	0
Sikh	0
Hindu	0
Other	0
None	5

Q10 What is you sexuality?

Lesbian or gay woman	
Heterosexual or gay man	
Heterosexual or straight	42
Bisexual	
Other	

Q11 Do you have a disability?



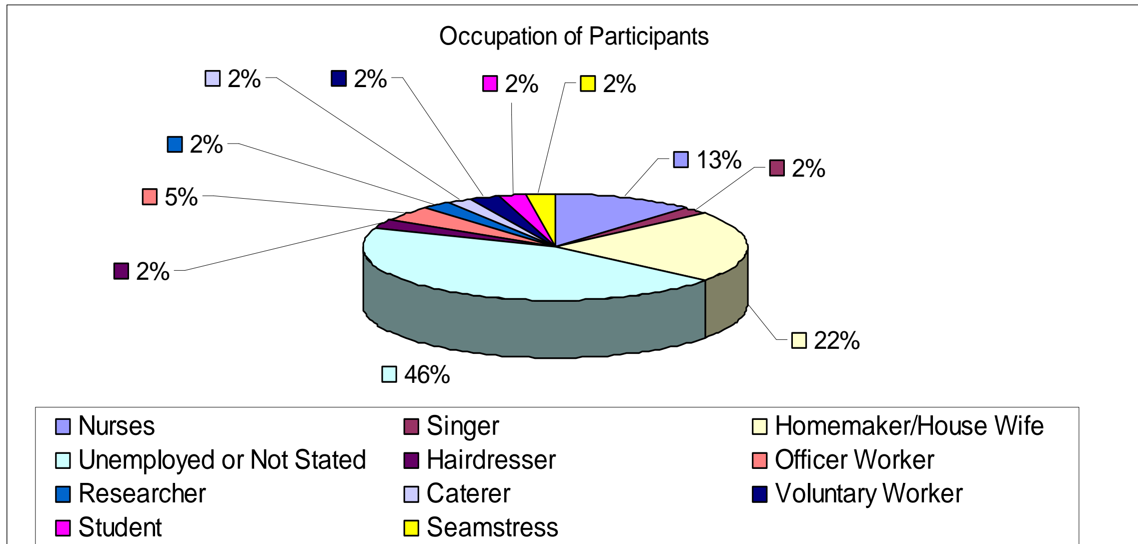


Yes	26
No	16
No Comment	5

Deafness	1
Diabetes	3
Arthritis	3
Mental Health	8
Blind	2
Walking	1
Hyper Tension	1
Epilepsy	1

The finding of the participants were that 62% had a disability and most of them had a mental health issue as their primary disability

Q12 Occupation of Participants



Nurse	5
Singer	1
Homemaker	9
Unemployed or Not Stated	19
Hairdresser	1
Office Worker	2
Researcher	1
Caterer	1
Voluntary Worker	1
Student	1
Seamstress	1

Over 19 were unemployed and 5 the second highest were nurses.

5 FOCUS GROUP FINDINGS

The focus group was held in February 2007. The group session was held in the ACCI building with 10 service users in attendance. The group was highly motivated and shared several ideas, experiences and suggestions about possible changes which could be introduced into mental health services.

5.1 The aims of the session were:

To gather information about service user's perceptions of the care pathways into mental health services within the Wolverhampton area and to ascertain whether their experiences are a positive reflection of the care they receive.

We also attempted to gain insight from service users/clients as to whether a holistic approach to mental health issues would be more appropriated to the way forward in the care approach.

What do the words "Mental health" means to you?

The respondents gave a mixture of working and personally experienced meanings to the word "Mental health". They are as follows:

- *"It's like one of your ribs"*
- *"Something to do with the mind"*
- *"Illness / disability*
- *"Whether I am sick or not I still have to visit my G.P."*
- *"It means you are sick in the mind"*
- *"Peoples imagination/depression"*
- *"It means you are violent, people look at you differently and you experience paranoia"*
- *"Someone who is not in the right frame of mind"*
- *"Discriminative expression, needs to be broken down by society due to the stigma attached to it"*

There was an overall negativity in response to this question. What emerged is that some of the group members identified the meaning of the word with a sickness of the mind, personal stigma and the lack of awareness held by society and its members, towards people with mental illness. The definitions of mental health, also gave an insight into how some participants may have experienced the effects of their own mental ill health.

How do you feel about long term incapacitation due to Mental illness?

The respondent's findings to this question are as follows:

- *"Not allowed to take full time employment"*
- *"Children are taken away"*
- *"People cannot take care of themselves and need to be helped"*
- *"You may look so well on the outside but feel differently on the inside"*
- *"The longer you remain unwell is the more mentally incapable you feel"*
- *"Need to get jobs to feel better, not necessarily a job to do everyday"*

- *"You feel better in a place like ACCI, a place where people communicate to feel better"*
- *"You can experience physical illness, as well as mental illness"*
- *"You have to keep on reliving upsetting things from your past which adds to long term mental health incapacitation"*
- *"Needs to keep occupied on a daily basis i.e. getting involved in activities"*

The group were in agreement that mental health automatically meant long term incapacitation. The findings reveal that often society and services isolated the participants and as such, they as service users/clients often failed to progress above and beyond the levels society and services, had placed their mental ill heath.

This isolation was found to also affect the respondent's physical well being which in turn would impact on their mental illness. As can be seen from the above quotes, the impact of their mental ill health, had far reaching implications which not only affected the respondents ability to find long term employment, improve their self confidence, but more importantly their ability to cope day to day life.

What would the availability of alternative therapies mean to you in your life?

The group's discussions regarding alternative therapies are as follows:

- *"Counselling"*
- *"I tried to hide it because I felt ashamed"*
- *"I would feel like I was doing something to myself to come back to the person I once was"*
- *"I feel happy with counselling but I don't feel totally safe with whom I am talking to, because my experience with the services is that things come back to bite you"*
- *"I would want to be offered an alternative to medication"*
- *"There would be fewer side effects in herbal treatments, so it would improve the quality of my life"*
- *"If alternative therapies could work we should be given the chance to use it"*
- *"A diet that has something to do with improving mental health"*

The findings indicate that several respondents held a positive regard towards the introduction of alternative therapies to compliment their current treatment. The respondents also felt that if there is something out there that could improve the quality of their lives they should be given the opportunity to try it, especially if it offered fewer side effects. This was in comparison to the medication they were prescribed.

Although the participants within the focus group had tried alternative therapies, in particular counselling, a number felt unsafe in disclosing too much to the mental health services. As they were unsure how this information was going to be used in the future. It was felt that certain agencies held the right to access this information and to ask for individual case notes at will. But what was most revealing, was how little participants knew about alternative therapies available to them.

When you are unwell who is the first personal person you contact to receive care?

The respondent's answers were as follows:

- *Partner*
- *Husband*
- *Son*
- *Daughter*
- *Mother*
- *I help myself through prayer*
- *I go to church*
- *Friends*

What has emerged from the above findings are that close family members and friends as well as religious leaders, were often the first point of contact, for participants when feeling unwell. The focus group members were asked to rate the importance they gave to the people they had chosen and why they had made that choice. They stated that their preferred choice was based on sound relationships. This was because, they felt safe with these individuals and that they in turn were respected and felt listened to, by those individuals.

When you are unwell who is the first professional person you contact to receive care?

- *"Prayer is very important to my well-being"*
- *"My husbands care is as important to me as food and water"*
- *"Partner helps me around the house and helps me to relax"*
- *"Prayer helps along with thanksgiving"*
- *"My son is very important to my well being, as he is my priority"*
- *"My mom encourages me to keep going and to do for myself"*
- *"My son, I have got to keep well so that he is not taken into care"*

Four of the participants stated that it was God that they turned to first. This was achieved via prayer and by reading the Bible. Other participants stated that they turned to medical professionals and voluntary sector groups for assistance. It was found that participants that were in regular contact with social workers or mental health professionals, stated that this relationship was often poor, as professionals failed to build sound relationships with them or take their concerns seriously.

On the other hand, when asked how important this professional contact was regarding their choice, it was stated very important. "It was a lifeline whilst enduring mental ill health", stated one participant of the group. However, the comment was made that the relationship with mental health professionals and social workers were often strained.

If you could make an alternative option to the first person to contact who would you choose?

Five participants of the focus group chose health care professionals, as an alternative option to the first person they would contact when feeling unwell. Here again it was due to a feeling of safety with regard to their health matters. The remainder of the group again chose people that were personally close to them.

How do you feel your relationship with this person is?

The findings reveal the following:

- *"I am glad for my children because the help take care of me"*
- *"My relationship with God is safe"*
- *"God baptised me and looks after me and loves me and I love God"*
- *"I can relate to my partner as he has been through a similar experience"*
- *"With a friend it's a relationship of trust and therapeutic"*
- *"It's good to have support of friends"*
- *"It's a good relationship to have a son"*

When you are unwell who is the first professional person you contact to receive care and how important is this persons care to you?

There was a variety of feedback given by participants.

The most popular response was that of visiting their local G.P.

Reasons:

- *"Very important as he gives me guidance with my illness"*
- *"She just gives me tablets"*
- *"I see my GP when I feel unwell"*

Relationship:

- *"Not very good"*
- *"I get on her nerves, because I rely on her too much when I am unwell"*
- *"She advises me to see the nurse"*

More similar responses were found in participants visiting alternative health professional and agencies.

Nurse: - First professional person to contact

Reasons:

- *"Gives me guidance on treatment and written information"*
- *"Nurses can push you aside from one person to another and you don't know why. It may be for my own good"*

CPN: - First professional person to contact

Reason:

- *"They can advocate as sometimes I can't speak for myself"*

Relationship:

- *"I have got to trust them because they treat me, but, I have been misdiagnosed and also given the correct treatment and wrong medication as well"*

Social Worker: - First professional person to contact

Reason:

- *"Trust"*

Relationship:

- *"I feel the relationship is good and trustworthy"*

Psychiatrist: - First professional person to contact

Reason:

- *"I don't know the best avenues to take when I am unwell"*

Relationship:

- *"Very important"*

God: - First professional person to contact

Reason:

- *"Trusts and believes in him in everything she does"*

If you could make alternative options to your first person to contact whom would you choose?

Why would this person be your first choice?

- *"Support worker because it is easier to talk to them rather than family because family can take it the wrong way".*
- *"ACCI staff would be my first choice because they would come to visit me".*
- *"My doctor is the person who knows about my illness and medication and I trust him".*
- *"My doctor because he would be my first point of contact".*
- *"My son because he cares for me and is around me more".*
- *"My sister because she's been a nurse and she can tell when I am unwell".*
- *"Support worker from CMHT because she comes out and talks to me".*
- *"Social Worker because I trust her".*
- *"ACCI and Christian leader because I have and need faith in them".*

6 PERSONAL JOURNEYS AND EXPERIENCES

This section contains the personal journeys and experiences in mental health of the African and African Caribbean participant who took part in the research. For reasons of confidentiality and anonymity of the participants, names have not been used and the initials contained are fictitious. However the personal journeys and experiences are very real.

AB - ACCI Service User

"I suffer with severe paranoia and can't travel into the town centre, I feel my meds are the cause of this and it is one of the unlisted side effects. I find I am very tired all the time and lethargic. I get very down and depressed because of tiredness. I cannot get to do all the things that I wanted to do".

CD - ACCI Service User

"I am progressing now because I can watch television now, I couldn't before for many years as I thought the TV was talking about me. I can go to college now and do exams. I have been to college and passed all my exams, which I couldn't do before. I can travel on the buses now which I couldn't do before".

EF - Ex ACCI Service User (Survivor)

"I had a breakdown many years ago and was put on and taken of medication too quickly which made me go very seriously ill and I was hospitalized because of that. It was a bad experience because I put my trust in doctors thinking they knew what they were doing and they let me down. It was almost like they were experimenting on whether I would be well or not after I came off medication, they did not really know. So I am now really scared to put my trust entirely with them."

GH - Ex ACCI service user supported by Imani Outreach services

"I feel that as a mixed race woman social services have been less tolerant with me in relation to my children. I know English mothers who have treated their children far worse than me, they have been given the chance of rehabilitation and not wanted it, where as I have been drug free for nearly 4 years and am still being denied the chance of being reunited with my children. I have known other Caribbean women who have suffered like me at the hands of social service because of their mental illness, and feel that what we have in common is the colour of our skin and the over he top situation with Wolverhampton social services. I feel that I should be given a chance like any other mother and prove that I can change."

IJ – ACCI Service User

"Since I have been coming to ACCI (African Caribbean community initiative) my mental health has improved alot. I am glad that ACCI have been there to support me even when I lived out of the area. I have improved a lot since seeing other African Caribbean people like myself. Staff are a good help if I need anyone to talk to."

KL – ACCI Service User

"My experience of mental health services has been poor, firstly I was physically assaulted, they call it restraint whilst in hospital, and then I was abandoned after leaving hospital and left up to six months later. Then after that I have been stigmatized and stereotyped by the services I have engaged with.

Up to this present day I have been discharged completely from mental health services and then admitted again, I am going to remain in the mental health service till death because I can't see much else changing. I am forty now and I have been in the system 18 years with the outlook for another 18. My physical health is overlooked constantly. I am constantly undermined, I have no children and the fertility services ignore me because of the mental health, I may as well be dead."

MN - ACCI Service User (relocated from outside of Wolverhampton)

"With the mental health condition that I have I can only take each day as it comes. Some days I may have 2 days good and the rest of the days up and down with both physical and mental health, the area that I live in doesn't help, before I came to Wolverhampton I wouldn't say everything was alright but life was as normal as can be but due to stress of moving and the area, my health has deteriorated and gotten worse. I would advise anyone who is moving to think twice if they have any health problems because the place you live can affect your mental health dramatically."

OP - ACCI Service User (when well will sometimes volunteer to do clerical work at ACCI)

"As a woman suffering with manic depression I personally find it difficult to manage or cope with the so called outside world. However, with the love and support from my family and ACCI and friends sometimes I wake up and think life is worth living again. However, I feel because you have a mental illness society tries to deter you from obtaining your goals."

QR - ACCI Ex-Service User

"It all happened from my childhood growing up, the experience I had with people. I had to look after myself as a child and my other siblings. It started when my family caused me to have an abortion and when I did have children it led to post natal depression. I was really worried after my pregnancy I had no support from my family only my husband. I was happy at the birth of my children but sad at the same time though the lack of support I received. I started going down hill and felling nervous. I didn't talk to anyone about how I was feeling. My husband spotted that I wasn't coping well and called the doctor.

The doctor came and he gave me a lot of medication Depixal and Haldol Decanote, for my depression. I've been on it from 1992. I've had 3 different kinds of medication, to me they were giving me too much medication, my ankles were swollen and my arms, it even effected my vision and I became overweight, but the doctors didn't want to hear my concerns. I was on 250mg and kept asking for it to be reduced. I'm now on 150mg and coping just the same. I'm OK now and quite stable but I was concerned for my health If I were to stay on a high dose of medication. I know my body but doctors wouldn't listen.

ST - ACCI Service User, supported by the Imani Outreach Service

"I had a brain tumour and the local hospital didn't believe that I was sick I couldn't walk, use the toilet and I could not see, If it wasn't for my foster carers I would have died, I have not got any trust in the health service at all. I am now on depression tablets for the rest of my life and now I am blind and struggle with the day to day living. "

UV - Ex ACCI Service User (Survivor)

> *"I came to use the service though my depression. I had to involve the family members as I wasn't sure what my illness was at first, but having attended the doctors the illness was then explained as I didn't understand it. I thought it was a midlife crisis, I just about understand what mental disorder is as a person and how it affects me as a person, and my body because I have short comings as well my physical health is not good at the moment. My doctor has been quite good and listened to me. I don't mind taking the medication they give. I am going though the process, it takes time, African Caribbean women need black support networks and the support of services, we are glad for it."*

6.1 CASE STUDIES

Case study - one

Participant 1: African Caribbean who is 40 years old

She was referred to ACCI by her local adult social services department. She has been involved with mental health services for over 17 years. On first contact with the mental health services after suffering severe symptoms of mental ill health, she was hospitalised with her best interests in hand. She had never experienced the overwhelming effects of mental instability before neither being away from familiar home life surrounding. She spent almost six months as an in-patient on a psychiatric ward and was diagnosed as a paranoid schizophrenic.

After holding down two long term employment posts the doctors unofficially re-diagnosed her as having a mild schizophrenic type illness. Although this re-diagnosis alleviated a lot strain from her life, she realised that the system in place can be damaging and not altogether infallible and was not sure if she could trust her life in the hands of the service providers.

She found trusting new people extremely hard and this way of life alienated her from her community. She knew she had to make changes. In her mid twenties she began attending the day service provided by A.C.C.I. just being around people of her own ethnicity colour and religious background both staff and members, brought on feelings of well-being, it was not long before these life barriers of distrust were broken down. As a result she has fulfilled a life of purpose, progress and achievements.

Case Study - two

Participant 2: African Caribbean who is 42 years old

She is 42 years old, and reports to having three breakdowns in 14 years. She was also bringing up two children as a lone parent and also assists in the looking after of her two grandparents. She explained that social service have been in her life for quite a long time as a result of her mental illness and bringing up children. Her mother who she says, offered little support and mainly by telephone. Her son had been taken into care twice, but now lives at home with her. She explained with her mental health in good condition she hoped to keep her son with her until he is ready to leave home.

She is currently on medication which is administered through depot injections. She reported her mental illness as being pretty steady throughout the fourteen years period. She stated that she believed that when you take depot injections you have less chance of a relapse. She also stated that her experience of having the illness as terrible and that once mental illness sets in you have no control of yourself and your actions.

She explained that she has had to learn coping methods to help her through what she describes as her struggle with mental illness. She also stated as part of coping she relied on family members although this was often only by phone. She reported having a support worker at ACCI (African Caribbean community imitative) who she said helped her over the years with gaining new skills doing

activities, social visits and training. She noted, having someone to talk to that understands you as a person and also your needs are very important. She also said that joining the church really helped her to find understanding and come to terms with her illness.

She explained that she had been let down by the hospital when they withdraw her medication completely, but feels now she has a say in her medication and doesn't depend solely on the Drs which is very important to her.

She explained she was now in part time work and said it is a great confidence builder. She has been able to meet new people and socialize, which she said was a great for her mental illness.

Case Study - three

Participant 3 - Mental Health Support Worker (no history of mental ill-health)

This case study was added because it is a factual account of a service user's treatment by statutory services, equally experienced and observed by the service user's support worker.

The service user is 48 years of age, single, has no children and lives independently in supported accommodation. Over a number of weeks the service user had been observed by staff and appeared to be experiencing physical pain. During this period of observation it was noticed that some of her daily habits had altered, and weight loss was rapid but when asked she claimed she was well, however she consented to visiting her GP; generally visiting her GP is something she is very reluctant to do. Her diagnosis was indigestion and she was prescribed an over the counter medication to treat the diagnosis. Following the first visit to her GP she returned to the surgery twice, and received the same diagnosis, but a blood test was taken during the last visit.

Within days of the last visit, she was found collapsed, disorientated and in excruciating pain, an ambulance was called and she was rushed to the local hospital's emergency unit accompanied by the support worker. She was taken straight to the examination cubicle and was attended by a Registrar. Her condition was worsening, as she was making the sounds of someone in a great deal of pain, she was writhing on the bed and almost fell off more than once.

The Registrar tried to ask her questions whilst making an examination, but she was unable to respond. The Registrar then asked the support worker who and why she was with the patient, and about the patient's background. The support worker observed that the Registrar's attitude change dramatically when he learned that the patient had a history of mental illness; his attitude towards the patient was less caring, and he left the cubicle for over 20 minutes. When he returned he looked at the patient, still in audible pain and writhing on the gurney, and said "*are you sure this is not acting out and this is a symptom of her mental health condition*?" The support worker's response to him was "*I want this woman treated in exactly the same way you would treat anyone that comes into a hospital with a physical illness, and I want you to find out what is wrong with her because we are not leaving until you do."* He left the cubicle and returned a short while after with some monitoring equipment. The moment he attached the equipment it was discovered that her blood pressure was seriously low and she

was immediately admitted. The Registrar apologised to the support worker, and said the patient was very seriously ill.

When she was admitted to the Medical Ward the nurse who was to prepare the patient's admission asked the support worker to questions relevant to the situation, but then began to ask questions around the patient's character, and behaviour and habits. The support worker asked the nurse to be more specific in her questions, if she wanted to know if the patient was a danger to others or herself, or if she presented a risk on the ward then she should ask the questions directly. The nurse apologised.

It was later learnt that she had suffered a ruptured ulcer and had to be given several blood transfusions. She was a hospital in-patient for 3 weeks and presented no threat to hospital staff or other patients. Had she returned home without treatment that day, she would not have lived.

7.0 DISCUSSION

Some difficulties were encountered early on in the team, when they expressed their concerns about the lack of skills, and practical knowledge of researching, fears about the abilities to tackle and produce the work required, their ability to remain mentally well and not become stressed and pressurised about the task.

The findings of this report will be completed under the following headings and this again will be replicated in the recommendations to ensure consistency of presentation, issues emerging and actions required. The discussions will incorporate the findings of both the questionnaire and focus group findings.

Better information

What has emerged from both the questionnaire and the focus group is a need for better information regarding mental health services, alternative treatments and employment opportunities. Several respondents had positive regard towards the introduction of alternative therapies, to compliment their current treatment. The respondents also felt that if there is something out there that could improve the quality of their lives they should be given the opportunity to try it.

When asked the majority of respondents stated that they were not made aware of what mental health community care services were available to them. Only 12 respondents stated that they were made of the community care services available to them from a total of 42 respondents.

The findings also indicate that the African and African Caribbean communities in general view mental illness as something to be feared and ultimately something to be ashamed of. A significant number of respondents stated that mental illness was viewed as a curse or evil spirit. This is coupled with the findings that 9 respondents felt that some sections of the African and African Caribbean community believed that mental illness was due to a lack of faith in God. It is interesting to note that 5 respondents stated that mental illness was something to be kept a secret.

What is required here is for forums to be established which allow the community to revisit these old held beliefs. Held from a time when there was little diagnosis of mental illness and indeed very little methods know about how to treat it. Instead some members of the community hide the problem or made a point that it was not to be discussed openly.

This would indicate that awareness raising needs to be done within the African and African Caribbean communities, the aim being to encourage increased knowledge of mental ill health and the support services available. But more importantly for service providers to re examine their policies practises and procedure to eliminate institutional racism and personal racism towards service users.

More appropriate and responsive services

The findings show that respondents were only moderately satisfied with the mental health community service they received. Only 3 respondents were very satisfied and 2 were satisfied with the service. 20 respondents felt it was

moderate and 4 respondents were very unsatisfied. 5 respondents stated they did not know.

The group felt that further focus group sessions should be held, where they could give feedback and comments about their experiences regarding their mental illness and the impact this has on the services they receive as a consequence.

In addition further help and advice could then be given regarding alternative therapies available, which may assist. What was interesting was how important sound relationships are to the participants of the focus group. This relationship could be with a family member, health professional, religious leader or social worker.

What is essential is that the relationship is consistent, sustained and is non-judgemental. It would appear that some health professional fail to establish the necessary rapport with their clients. This in turn could delay recovery in some patients.

As regards the community mental health service, the findings of this report indicate that 19 respondents felt that the community mental health service that best meet their needs was that of a voluntary organisation, ACCI. This was followed by G.Ps, CPNs, psychiatrist and finally social worker. 3 respondents stated that none of the above listed services meet their needs. One may ask why ACCI, but what must be realised here is that the service has been designed by African and African Caribbean's for African and African Caribbean service users in every respect. As such the service policies and procedures respect and reflect the needs and requirements of its clients.

Evidence for this point can be found in the following section.

Culturally competent workforce

The majority of respondents felt that it was important that staff working in mental health services, are culturally aware of their needs as African and African Caribbean women. Only 2 respondents from a possible total of 42 stated that it was not important and 6 respondents abstained from answering the question.

Several participants in the focus groups stated that they would like to engage in counselling activities, but felt unsafe in disclosing too much to the mental health services. As they were unsure how this information was going to be used in the future.

It was felt that certain agencies held the right to access this information and to ask for individual case notes at will. This indicates a lack of trust with some health professional and could mean that respondents would again rather attend a service that is geared to their needs and cultural requirements.

The majority of respondents (31) agreed that it was important that staff working in mental health should reflect the diverse community they serve. Only one respondent stated it was not important and 7 felt they didn't know. 3 Respondents failed to indicate a response to this question.

When asked if it is important that staff working in mental health are culturally aware of their needs as African or African Caribbean women, the majority of respondents felt that it was important that staff working in mental health services, are culturally aware of their needs as African and African Caribbean women. Only 2 respondents stated that it was not important and 6 respondents abstained from answering the question.

In addition, it should be noted that when respondents were asked did they prefer mental health services to be based within the African and African Caribbean Community. They stated that they would much prefer mental health services to be based and delivered within the Caribbean Community. Here 26 respondents indicated that they would prefer this initiative and 8 respondents stated that they would not. 3 respondents felt they did not know and 5 respondents did not answer this question. However, what should be noted is that the majority of respondents felt they would prefer the services to be based within their community. This was in addition to them requesting that the service providers be of African and or African Caribbean origin.

Community engagement and development

The report indicated that there appears to be a lack of community engagement, particularly, with the African and African Caribbean community.

What has emerged from the findings are that close family members and friends as well as religious leaders, were often the first point of contact, for participants when feeling unwell. The focus group members were asked to rate the importance they gave to the people they had chosen and why they had made that choice. They stated that their preferred choice was based on sound relationships. These relationships often tended to be based on close relationships with loved ones such as, sons, daughters, mothers and finally G.Ps and health professionals. This was because, they felt safe with family members who they felt respected them in return and listened to them.

As regards evidence of community involvement and development the questionnaire findings indicated that respondents were only moderately satisfied with the mental health community service they received. Only 3 respondents were very satisfied and 2 were satisfied with the service. 20 respondents felt it was Moderate and 4 respondents were very unsatisfied with the service. 5 respondents stated they did not know.

If we consider the case of employment, the findings show that respondents were only moderately satisfied with the mental health community service and support they received. Only 3 respondents were very satisfied and 2 were satisfied with the service. 20 respondents felt it was moderate and 4 respondents were very unsatisfied. 5 respondents stated they did not know. The findings indicate that more resources need to be placed into developing and sustaining community engagement. This in turn may reverse the data indicating that respondents from both surveys largely turn to the community, friends, religious leaders, partners and their children for assistance and support, when clearly this is should be the work of trained professionals.

8.0 RECOMMENDATIONS

This research was at times exciting especially in the embryonic stages but proved to be very challenging throughout. Challenging in that the proposed framework for community engagement embraced by us a radical and innovative way of involving service users and communities in research.

However, the practicalities of embarking on the research motivating and sustaining women who have experienced or are experiencing mental illness can throw the best laid plans out of the window.

Evidence suggests that there is a lack of research into the areas surrounding black women and mental illness, but we learned of the difficulties of trying to put theory into practice. Timing and planning was an issue as often we had to be led by the participants and their state of well being. In conclusion to this project we would make the following recommendations:-

1. Further research into women with mental health issues who also experience domestic violence and sexual and financial abuse
2. Further research into the reasons for women becoming mentally unwell
3. Further research of the effects of mental ill health on children and their families
4. Forums to be established to raise awareness of mental health issues in the African and African Caribbean communities
5. Forums to be established for social workers and teachers to raise awareness of the support children and families need during times of crisis
6. The role of the GP in supporting and diagnosing mental ill health is crucial. GPs should be invited to play a more active role in organisations such as ACCI
7. The GP together with general hospital services should develop ways for women to access general health services and not just to focus on mental ill-health
8. The Shaw Trust should be involved with ACCI in order to promote their employment or return to work services and to enable service users to explore pathways into employment under the permitted to work rule
9. The development of culturally competent counselling services and holistic services
10. More consultation with service users around care planning and legal rights whilst in hospital

9.0 Conclusion

In undertaking this research we have been able to identify some of the key issues affecting the mental health of African/African Caribbean women. The Government's 'Delivering Race Equality – DRE 2005, will only be meaningful to the African Caribbean community when services are indeed more appropriate and responsive.

The ability to engage the communities will be achieved when there is confidence and trust in statutory agencies. The African Caribbean community must also engage in a proactive mental health promotion programme building with churches, community groups etc, to de-stigmatise mental illness, only then will the support be forthcoming and healing will begin. The role of the Black-led churches cannot be overstated.

Primary care agents such as GP's must begin to link into the Black Voluntary Sector. Employment and training opportunities are areas that must be explored so that these women are able to rebuild and enjoy a better qualify of life.

The limitations of the report are that it is a random piece of research (random, in that it only accounts for a small section of African Caribbean women with mental ill-health in Wolverhampton), is therefore limited and subjective. The missed opportunity to make comparisons using the information collected on women's mental health globally is a great loss, which would have given an objective analysis and provided the report with its literature review and reference material, the reasons for which are explained in detail in the report. It is our firm belief that more extensive research is commissioned to back up this user-led piece of work.

We therefore conclude 'back at our starting point' that there needs to be more research into the skills, strategies and techniques for engaging black women into research around the identification of their needs and of the appropriate services to meet these needs. Services need funding and monitoring for quality assurance and the elimination of racist practises and continued customer satisfaction and relevance.

10.0 REFERENCES

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- Department of Health: Strategy Launched to Modernise Mental Health Services (1998)
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- Department of Health: Delivering Race Equality in Mental Health (2005): An Action Plan for Reform. Inside and Outside Services
- The National Service Framework Document for Mental Health (1999)
- Office of National Statistics: Wolverhampton Key Statistics (2001)
- University of Central Lancashire: The Centre for Ethnicity and Health's Model of Community Engagement (2005)
- Sainsbury Centre for Mental Health Breaking the Circles of Fear. A review of the relationship between mental health services and African and Caribbean Communities (2002)

Appendix 1

Make up of the Steering Group

The Steering Group was made up as follows:

- Service Manager - ACCI
- Race Equalities Lead - Wolverhampton City Council
- Director MH Services Hospitals - Primary Care Trust
- Health care researcher - ex PCT now CSIP, West Midlands
- Race Equality Lead - CSIP, West Midlands
- Project Coordinator - BME Health Care, Faith Groups
- Independent - Retired BME Strategic Commissioning : ex Wolverhampton City Council Social Services
- Joint Commissioning – Mental health Services, Adults & Communities - Social Services and Primary Care Trust Commissioner - Wolverhampton City Council
- Asian Women's Adhikar Association (AWAAZ) & Navjeevan project (Asian Women's mental health supported accommodation)
- Project Coordinator - NHS West Midlands Strategic Health Authority
- Senior Policy & Equality Officer, Race - Wolverhampton City Council
- Independent Senior Social Worker
- Mentor Support - University of Lancashire
- ACCI - Administration & Finance
- Project Coordinator – (Seconded from ACCI Women's Unit)
- 4 Service Users: comprising of current and ex-service users.

Appendix 2

African Caribbean Community Initiative
217 Waterloo Terrace, Newhampton Road East, Whitmore Reans, Wolverhampton. WV1 4BA
Tel: 01902 571230 - Fax: 01902 571233 - Email: support@acci.org.uk

Registered Charity No: 1081996 - Limited Company No: 4014153

Dear member,

Re: African Caribbean Women in Mental Health:
What are the pathways and experiences of African Caribbean women into mental Health services?

ACCI together with Care Service Improvement Partnership (CSIP) and the University of Central Lancashire (UCLAN) are now involved in a piece of research around African Caribbean Women and their pathways into mental health.

The aims of this project are:

- Raising the profile of issues African-Caribbean women face within the community.
- Gathering information from the community and using it intelligently.
- Utilizing the information to inform quality of service provision.

The research team is made up of service users/survivors of mental health and staff at ACCI. The team is supported by a Steering Group made up of community and health professionals who will meet on a monthly basis to coordinate the project, and provide guidance on strategy and policy development that will inform the research. The project will also receive support and guidance from a mentor from the University of Lancashire.

At the end of the project, the expectation is to produce a report based on the findings from the research. The report will be submitted to CSIP West Midlands to influence the creation of strategies and policies around African-Caribbean women accessing services in the West Midlands area.

Material gathered during this research will be treated as confidential and securely stored.

We would like you to confirm that you understand the terms of participation by completing the attached form.

If you decide to take part in this valuable research simply call or come into ACCI where staff will help you complete a simple questionnaire. We can also visit you at home if more convenient.

All participants will receive a £10.00 gift voucher.

Yours sincerely

Mary-Ann Collymore
Project Coordinator

CONSENT FORM

1. I confirm that I have read and understand the information detailed in this sheet. ☐

2. I confirm that I understand the terms of my involvement with regard to the Community Engagement Programme. ☐

3. I have been given the opportunity to ask questions about the study, and have received satisfactory responses. ☐

4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving an explanation. ☐

5. I have been made aware that any information that I volunteer will be treated in strict confidence, and I agree that the information I learn about other participants in this research must be treated as confidential. ☐

6. I agree to being identified in this interview and in any subsequent publications used ☐

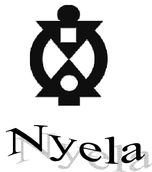
7. I do not agree to being identified in this interview and in any subsequent publications. Where used, my name must be removed and my comments made unattributable. ☐

Signed: ________________________________Date______________________________

West Midlands
Development Centre

Appendix 3

Survey Questionnaire



Care Services Improvement Partnership CSIP

Nyela Project - Community Engagement Programme **Women's Mental Health Research supported by ACCI**

Questionnaire

(To be conducted in person by authorized Community Research Workers)

Code No.

[ ] [ ] [ ] [ ]

Section 1: PERSONAL PROFILE

1. What does the word mental health mean to you? ....

…………………………………………………………………………………..

…………………………………………………………………………………

2. What do you believe to be the contributing factor/s to you becoming mentally unwell? (tick all that apply)

Relationship breakdown [ ] Bereavement [ ] Financial issues [ ]

Domestic violence [ ] Drug misuse [ ] Family problems [ ]

Housing issues [ ] Childhood abuse [ ] Work issues [ ]

Unemployment issues [ ] Other [ ]…………………………………………….

3. Have you used none prescribed drugs or narcotics for a long period of time?

Yes [ ]
No [ ]

4. Do you think none prescribed drugs can contribute to mental illness?

Yes [ ]
No [ ] Don’t know [ ]

5. If you have regularly used none prescribed drugs where you offered help from a professional anti drugs team?

Yes [ ]
No [ ] Not Applicable [ ]

6. Where would you go for support to maintain good mental health and why?

Friend [ ] ……………………………………………………………………..

Family [ ]……………………………………………………………………..

Religious organisation [ ]……………………………………………………….

Mental Health services [ ]………………………………………………………

GP [ ]……………………………………………………………………………

Counselling [ ]…………………………………………………………………..

Spiritual guide [ ]………………………………………………………………..

Psychiatrist [ ]……………………………………………………………………….

Nurse [ ]……………………………………………………………………………..

Other [ ]……………………………………………………………………………..

7. What would stop you from engaging with mental health services?

Fear of being mistreated [ ]   Fear of the unknown [ ]   Shame [ ]

Bad experience in the past [ ]   Problem locating services [ ]

Leave it to God [ ]   Language problems [ ]

Keep it in the family [ ]   Other [ ] …………………………………..

8. How do you think African and African Caribbean women are perceived by society?

Positive image [ ]   Negative image [ ]   Other [ ]   Don't know [ ]

9. Do you think the way you are seen by society as an African or African Caribbean woman affects your mental health?

Yes [ ]
No [ ]   Don't know [ ]

10. Do you think the public perception of African and African Caribbean women affects the services you receive?

Yes [ ]
No [ ]   Don't Know [ ]

11. Would you agree with the following statement; **mental illness is common among women from the African and African Caribbean Community?** If yes, please state why you think that is.

Yes [ ]………………………………………………………………………
No [ ]

12. How do you think African and African Caribbean communities in general view mental illness? (Tick all that apply)

Something to fear [ ]   Something to be ashamed of [ ]

They want it kept secret [ ]   Ignorant of the facts [ ]

Openly share their experiences [ ]   An Evil spirit/curse [ ]

A Lack of faith in God [ ]   Believe it to be self inflected [ ]

Nothing to fear [ ]   Other [ ]

13. Have you been stigmatized or made to feel ashamed because of your mental illness? If yes please explain.

Yes [ ]………………………………………………………………….
No [ ]

14. Do you believe you are stigmatized more by your community because you are a woman with mental health issues?

Yes [ ]
No [ ]

15. Do you think culture and family traditions affect our mental well being? If so please explain.

Yes [ ] …...……………………………………………………………………

……………………………………………………………………………………
.
……………………………………………………………………………………

No [ ]

16. Do you think religious beliefs affect the way we perceive mental illness? If yes, please explain.

Yes [ ] ………………………………………………………………………
No [ ]

Section 2: DIAGNOSIS

17. Have you been to your G.P. about any mental health concerns?

Yes [ ]
No [ ]

18a. Did you receive a diagnosis?

Yes [ ]
No [ ]

18b. Were you diagnosed with more than one condition i.e. dual diagnosis?

18c. When you were first diagnosed how long did it take for Doctors/Psychiatrists to diagnose you?

0-12months [ ] 1-2 years [ ] 2-5 years [ ]

5-10 years [ ] 15 + [ ] other [ ] please state

18d. What was your diagnosis? ....

………………………………………………………………………………………

19. Have you heard of any of these conditions?

Depression [ ] Manic Depression [ ] Schizophrenia [ ]

Bi-Polar [ ] Psychosis [ ] Post Natal Depression [ ]

Anxiety [ ] Dementia [ ] Other [ ]

20. Did you agree with your diagnosis?

Yes [ ]
No [ ] if no please explain why ……………………………………………….

………………………………………………………………………………………

……………………………………………………………………………………....
.

20a. Were you offered a second opinion?

Yes [ ] if yes please state the outcome……………………………………….

………………………………………………………………………………………

No [ ] if no please state why ………………………………………………….

………………………………………………………………………………………
.

21. If you were referred to a specialist mental health service who first referred you?

Self [ ] GP [ ] Family [ ] CPN [ ] Partner [ ]

Friend [ ] Social Worker [ ] Nurse [ ] Community organization [ ]

Other [ ]

Section 3: CARE AND SUPPORT IN HOSPITAL/TREATMENT

22. Have you spent time in hospital because of your mental illness?

Yes [ ]
No [ ]

22a. If you have spent time in hospital because of your mental health, how long did you spend in total?

0-12months [ ]   1-2 years [ ]   2-5 years [ ]

5-10 years [ ]   15 + [ ]   other [ ] please state ………….

……………………………………………………………………………………….

23. How would you describe the treatment you received whilst in hospital? Please explain you answer.

Very Good [ ]……………………………………………………………………

Good [ ]……………………….……………………………………………………

Fair [ ]…………………………..……………………………………………..

Poor [ ]…………………………………………………..…………….................

Very Poor [ ]……………………………………………………………………

23a. Were you treated with respect at all times?

Yes [ ]
No [ ] if no please state reason…………………………………………………

…………………………………………………………………………………………

…………………………………………………………………………………………

23b Were you consulted on the care plan you received?

Yes [ ]
No [ ] if no please state the reason…………………………………………….

…………………………………………………………………………………………

…………………………………………………………………………………………

23c. Was your treatment explained and administered in away that you could understand?

Yes [ ]
No [ ] if no please state the reason……………………………………………..

…………………………………………………………………………………………

…………………………………………………………………………………………

23d. Were you given a date when your care plan would be reviewed?

Yes [ ]
No [ ] if no please state the reason…………………………………………..

……………………………………………………………………………………

……………………………………………………………………………………

24. Were you made aware of your legal rights whilst in hospital?

Yes [ ]
No [ ]…………………………………………………………………………..

……………………………………………………………………………………

……………………………………………………………………………………

25. Were you given an option of treatment?

Yes [ ]
No [ ] if no please state the reason…………………………………...………...

……………………………………………………………………………………

……………………………………………………………………………………

26. What treatment method would you choose for yourself in order to maintain mental wellbeing?

Mental health support service [ ] Community organisation [ ]

G.P. recommendation's [ ] Religious worship [ ]

Gender and culture focused [ ] Homeopathic Medicine [ ]

Medication [ ] Talking therapy [ ] Other [ ]

Section 4: CARE AND SUPPORT IN THE COMMUNITY

27. Were you satisfied with the care and support you received after leaving hospital?

Yes [ ]
No [ ] If No please state the reason……………………………………………

…………………………………………………………………………………..

…………………………………………………………………………………..

28. Were you made aware of what mental health community care service are available to you?

Yes [ ]
No [ ]

29. Which mental health community Service meets your needs?

GP [ ] Nurse [ ] CPN [ ] Social Worker [ ]

Psychiatrist [ ] Voluntary organization [ ] None [ ] Other [ ]

30. Does it make a difference if the support you receive is from a male or female mental health worker?

Yes [ ]if yes please state why…………………………………………………
No [ ]

31. How satisfied were you with the mental health community service you received?

Very satisfied				very unsatisfied	Don't know
1	2	3	4	5	[ ]

31a. What if anything, did you like about the service you received? ....

…………………………………………………………………………………

…………………………………………………………………………………

31b. Could any thing have been changed to further improve the service you received?

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

…………………………………………………………………………………

32. Were you given support with finding out about any benefits you may have be entitled to?

Yes [ ]
No [ ] if no please state reason…………………………………………………

…………………………………………………………………………………

33. Were you supported in finding training and employment?

Yes [ ] if yes please state how..…………………………………………………

No [ ] if no please state reason…………………………………………………

Section 5: MENTAL HEALTH SERVICE

34. Have you heard of any of the following services? tick all that apply

NHS [ ] Mind [ ] ACCI [ ] Community Mental health Nurse [ ]

Primary Care Trust [ ] Community Development Worker [ ] Other [ ]

35. Is it important that staff working in mental health reflect the diverse community they live in?

Yes [ ] If yes, please explain why………………………………………………

No [ ] If no, please explain why……………………………………………….

36. Is it important that staff working in mental health are culturally aware of your needs as African or African Caribbean women?

Yes [ ] if yes please state why…………………………………………………
No [ ]

37. Would you prefer mental health services to be based within the African and African Caribbean community?

Yes [ ] if yes please explain…………………………………………………
No [ ]

38. Would you prefer African and African Caribbean service providers?

Yes [ ]
No [ ]
Don't know? [ ]

Section 6: REFERMATION OF LOCAL SERVICES

39. Are there any changes in mental health or further developments you would like to see in the future?

Yes [ ] if yes please explain……………………………………………………….

………………………………………………………………………………………

………………………………………………………………………………………

No [ ]

40. Do you think that more research into the mental health of African and African Caribbean women could benefit you?

Yes [ ] if yes please state reason……………………………………………..………
No [ ]

Appendix 4

Core Questions:

Please answer the following questions for the purpose of data monitoring. You do not have to answer any question if you wish not to, but we do encourage that you answer all the questions. All information will remain confidential.

1. Age last birthday:

16-18 [ ] 19-21 [ ] 22-24 [ ] 25-29 [ ]

30-39 [ ] 40-49 [ ] 50+ [ ]

2. Gender: Male [ ] Female [ ] Transgender or transsexual [ ]

3. Ethnicity:

White	British	[ ]
	Irish	[ ]
	Other (please explain)	[ ]
	……………………….................	
Asian or Asian British	Pakistani	[ ]
	Indian	[ ]
	Bangladeshi	[ ]
	Other (please explain)	[ ]
	…………………………………	
Black or Black British	Caribbean	[ ]
	African	[ ]
	Other (please explain)	[ ]
	…………………………………	
Chinese or Other	Chinese	[ ]
	Other (please explain)	[ ]
	…………………………………	

4. Were you born in the U.K: Yes [ ] No [ ]

If no, how long have you lived here:	Less than 1 year	[ ]
	1 – 5 years	[ ]
	6 -10 years	[ ]
	11 years or more	[ ]

5. Are you a:

British Citizen	[ ]
Refugee	[ ]
Asylum Seeker	[ ]

Other (please explain)……………

6. What is your first language? Spoken:………………………………….

Written:………………………………….

7. Which language are you fluent in? Spoken:………………………………….

Written:………………………………….

8. Do you have any children? Yes [ ] No [ ]

9. What is your occupation? ……………………………………………………

10. What is your religion?

None	[ ]
Christian	[ ]
Buddhist	[ ]
Hindu	[ ]
Jewish	[ ]
Muslim	[ ]
Sikh	[ ]
Rastafarian	[ ]
Other [ ]………………	

11. What is you sexuality?

Lesbian or gay woman	[ ]
Heterosexual or gay man	[ ]
Heterosexual or straight	[ ]
Bisexual	[ ]

Other (please explain)…………………………………………

12. Do you have a disability?

Yes [ ] (please explain)……………………………………………………….
No [ ]

THANK YOU FOR YOUR PARTICIPATION

Nyela Project - Community Engagement Programme
Women's Mental Health Research supported by ACCI

If you would like to share your personal journey and experiences in mental health services, please do so in the space below using both sides if necessary. **Please return by 26th January 2007**

Appendix 5

FOCUS GROUP SESSION

1. What do the words “Mental Health” mean to you?

2. How do you feel about long term incapacitation due to mental illness?

3. What would the availability of an alternative holistic therapy mean to you in your life?

4. When you are unwell who is the first personal person you contact to receive care?

   4a. How important is this persons care to your well being?

   4b. How do you feel your relationship with this person is?

5. When you are unwell who is the first professional person you contact to receive care?

   5a. How important is this persons care to you?

   5b. How do you feel your relationship is with this professional person?

6. If you could make alternative options to your first person to contact whom would you choose?

   6a. Why would this person be your first choice?

Appendix 6

FOCUS GROUP EVALUATION FORM

1 How did you find the content of the session?

Very poor
Poor
Average
Good
Very good

2 Did you find the information relevant?

Yes
No

3 Were you given enough time to ask questions?

Yes
No

4 Would you find other follow up sessions useful?

Yes
No

5 Do you think you would benefit from further sessions?

Yes
No

6 Can you think of ways the sessions could be improved?

7 Any comments