The mental health needs of black and minority ethnic communities in Chapeltown and Harehills

Report to Leeds Adult Social Care

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Foreword

This research was originally commissioned by Leeds Social Services (now called Adult Social Care) on behalf of the Black and Minority Ethnic Advisory Group to the Mental Health Modernization Team (BMEAG). The intention was to provide a basis for commissioning mental health services in Chapeltown and Harehills, using the £120,000 made available by the closure of the Black Mental Health Resource Centre (BMHRC) in Chapeltown.

In 2005, a research specification was drawn up, and tenders invited - but eighteen months and two consultants later, the work had not begun. In February 2007, Touchstone’s Community Development Service (Community Development Service) were approached, and asked if they would assist with this research. The CDS had no experience of conducting research of this kind, so it was with a mixture of excitement and trepidation that we agreed to assist.

The CDS were concerned that the process by which the data was collected should be valued as highly as the findings themselves, and that value of participatory methods of research and community involvement were recognised and respected. For the CDS, the research was a valuable opportunity to engage ordinary people in discussions around how to take control of their own mental health, to share effective strategies, and to learn the challenges of commissioning. We wanted to include the knowledge, opinions and experiences of all people living in Chapeltown and Harehills, which meant we did not want to make mental health service use, or carer status a requirement for the focus group participants. The approach would be based on the University of Central Lancashire’s Community Engagement Model (http://www.uclan.ac.uk/facs/health/ethnicity/communityengagement/index.htm). However, unlike the UCLAN model, there would be no academic input or oversight.

The final CDS research proposal outlined their preferred method – a process which would combine community engagement with the training, development and employment of mental health service users from the communities themselves. Of the £10,000 available to pay for the research, £8,500 would end up in the pockets of the local community, either through employment opportunities, or as payments for participation in the focus groups and one to one interviews. This was agreed by the Social Services lead, on behalf of the BMEAG.

From the outset, the CDS were clear that they would not willing or able to deliver on some aspects of the original research brief - such as preparing a detailed service specification, or prioritising the needs of one community over another. What they proposed was a 16 week research programme (Appendix 1), that would present the initial findings of the Desktop research to the BMEAG, who would in turn set the priorities for the research team by choosing which particular communities the next stage of the research should focus on. The CDS felt different communities might want very different things and they were unwilling to decide in favour of one community preference over another - as this could potentially undermine the position of trust the CDS had worked hard to establish. Instead, the CDS would
explore what a suitable service would look like for each of the communities, and present these findings to the BMEAG and ASC, via the research.

The process of data collection for the desktop research was difficult, within the agreed timescales (Appendix 1). Not all organisations approached were able to participate, and this left some significant gaps in the data that were reported back to the BMEAG in July 2007.

The final draft report was submitted to ASC in December 2007. Amendments to this report were suggested in January 2008, and additional interviews were conducted to augment the desktop research. CDS also offered to conduct additional focus groups to address the under-representation of the Black Caribbean communities in the focus groups. These were completed in March 2008, and findings have been incorporated.

The delays caused by the unrealistic timescales of the research team set the process back 12 weeks. The additional work to tidy up the first final draft have added another 12. The CDS and the research team are keen that the conclusions and recommendations of this research are offered back to the participants as soon as possible.

This research is offered with one final caveat – that its findings are squarely based upon the experiences of people living and working in Chapeltown and Harehills. Many of the conclusions found here echo the findings of larger national pieces of research into the experiences of BME people. But they remain the conclusions about Chapeltown and Harehills. It would be unsound to draw more general conclusions about “the BME communities of Leeds” from this research.

The research team are keen that the findings contained within this report are used to inform the development of services that enhance and consolidate the mental well-being of people living in Chapeltown and Harehills. This report demonstrates that by trusting and respecting the gifts and skills of those living and working within the area, credible solutions can emerge. The aspirations and talents of the communities should be used as the building block for successful change – we don’t always need to find “experts” to tell us how things can get better.

March 2008
1. INTRODUCTION

Background to the research

This research was initiated by the BME Advisory Group to the Mental Health Modernisation Team (BMEAG), and paid for by Leeds Adult Social Care (formerly, Leeds Social Services). It was commissioned to inform decisions on how to spend the monies that were freed up by the closure of the Black Mental Health Resource Centre in 2004.

Aims and objectives

The brief provided by Adult Social Care (ASC) was:

- To produce a brief needs-analysis of the mental health support needs of the BME community in Chapeltown and Harehills mapped against existing services available to this group.
- To identify models of service delivery that is likely to be most effective in meeting the prioritised needs. To make recommendations about the best use of the ring-fenced resources allocated.
- To work on behalf of the commissioners and in partnership with the BME Advisory Group of the Leeds Mental Health Modernisation Team.
- To produce a service specification for provision of new services and use this to inform a tendering process to award contracts to the successful provider/s.

Touchstone Community Development Service for BME Communities (CDS) reluctantly agreed to undertake this research using an adapted version of the University of Central Lancashire’s Community Engagement Model.

Terminology

Black and Minority Ethnic (BME) – This term is used to refer to people of minority ethnic status as who are not white British including Irish people and other white minorities. The ethnicity categories used by the researchers are those of the National Office of Statistics 2001 Census. Where other descriptors are used (e.g. “African-Caribbean”), these are the descriptors used by the people we spoke to, and we have not altered them.

Mental Health/Mental Illness – We have chosen to use an inclusive definition of mental ill health and mental distress throughout this research. We have taken particular care to refer to mental health when we mean mental health, and mental ill health or distress when describing the contrary. The research methods actively encouraged participants to explore these concepts for themselves, and to explain these ideas in terms of symptoms, effects or behaviours. Some of the people we spoke to used very specific organisational definitions of mental health and mental illness to explain the reason why they worked with some people rather than others. We have tried to let people use the words they feel are most appropriate when describing patterns of thought, emotion and feelings that distress them or those
around them, and we have tried not imposed any normative descriptions of mental ill health or disease.

**Chapeltown and Harehills** – are areas found within the two electoral wards of Chapel Allerton and Harehills and Gipton and usually carry LS7 and LS8 postal codes. Population data was not available at sub-ward level.

**Methodology**

The first stage of desktop research involved collating demographic and epidemiological data for the area, as well as mapping current service use/uptake. This was then written up in an interim report delivered to the BMEAG in July 2007.

The second stage (July 07 – September 07) involved the recruitment and training of 4 additional community researchers; agreeing the way in which the second stage of research would be completed; how we would to establish the preferred models of mental health provision; and to produce recommendations for a service specification, with reference to budgetary considerations.

This information was collated and written up during October and November 2007 for presentation to ASC in December 2007.

Revisions to this final draft were suggested by ASC in February 2008, and the work was completed in March 2008. Further focus groups within the Black Caribbean communities are due to take place in March 2008 and will be included as an appendix in later versions of this report.

A full outline of the research stages and timescales can be found in Appendix 1.

**Methods Used**

**Reference Group** - the research was advised and guided by a Reference Group made up of mental health workers from local statutory, voluntary and community services, non-mental health workers and a local person (see Appendix 2). Their role was to oversee the decisions made about whom to include in the research, and to use their contacts to ensure participation.

**Literature Review** - this began with a review of national and local reports, publications and strategy documents (see Appendix 5) to assist with data collection, and identify national and local issues that relate to BME communities.

**Community Mapping** – this took place with the assistance of Community Development Workers (CDWs) from the CDS, and Information for Mental Health and helped to identify the key contacts and interest groups who would be contacted in the course of the research (see Appendix 4).

**Interviews, and discussions with service providers** - A set of key questions were devised that formed the basic structure of the interviews and discussions (see
Appendix 3). The questions helped guide the interview, and notes were taken. Some interviews were conducted face-to-face – others via telephone or email. Participants were also encouraged to add any additional information they felt relevant.

**Informal visits and contacts** - These took place as a way of publicising the research, as well as scoping potential for the recruitment of Community Researchers, one to one interviewees, and focus group participants. These were selected from the lead researcher’s own contacts, knowledge of the area, community mapping by the CDS and recommendations by Reference Group members (see Appendix 4).

**Staffing**

The research project was hosted by the CDS, but was not conducted by the CDWs. The co-ordinator provided supervision and guidance to the research team, and the CDWs supported the research team with advice, information and practical assistance with the focus groups.

**The Lead Researcher** was appointed by Touchstone, drawing on her considerable experience of working within the area, with a particular focus on the mental health of BME communities.

**Six Community Researchers** were recruited during the period of desktop research to work alongside the lead researcher and CDWs during the second stage of the research. All of them came from the Chapeltown and Harehills areas of Leeds, were of BME origin and had some personal experience of mental health - either by direct experience, through caring for someone, or through their previous work/life experiences (see Appendix 6). Unfortunately, one of these six researchers dropped out during the training period for personal reasons.

The Community Researchers undertook training that would equip them to carry out focus groups and individual interviews (the latter dependent on having a current Criminal Record Bureau check). The training included confidentiality, boundaries, lone working, equal opportunities and diversity, planning and organising groups, and interview skills. Researchers were given mobile phones, familiarised with the relevant Touchstone policies and procedures around risk assessment and health and safety.

They were paid an hourly rate of £9.56 an hour - the standard rate paid to Touchstone Support Workers. Welfare rights advice was offered to those people on benefits to ensure their income levels were not adversely affected by their work. Community Researchers were allowed to work up to 9.75 hours a week, to ensure their income levels remained within those permitted by the benefits system. Feedback from some of the community researchers about their experiences is contained in Appendix 6.
STAGE 1 – THE DESKTOP RESEARCH

The aim of the first stage of this work was to research the current mental health service use/uptake by BME communities in Chapeltown and Harehills.

The objectives at this stage were to:
• Collate demographic and epidemiological data for the Chapeltown and Harehills area
• Recruit partners for the Reference Group to advise, support and give focus and accountability to the research
• Write up key findings and make recommendations regarding provision of mental health services and support for BME communities in Chapeltown and Harehills and
• Provide an interim report to BMEAG, to enable them to advice on which communities’ needs should be prioritised in the next stage of research

The Local Picture

Chapeltown and Harehills are areas within the city which have diverse Black and Minority Ethnic (BME) communities: from traditionally established groups from the Caribbean, Africa, South East Asia and Ireland, to newer migrants from Eastern Europe and asylum seekers and refugee communities. There is a vibrancy and energy in the area that marks it out from other parts of Leeds, but there are still disparities in access to health and health provision, employment, education and housing between the different BME communities.

The BME population of the city is 10.8% compared to the average for England and Wales (12.5%, 2001 Census). The Chapeltown and Harehills areas have high concentrations of established ethnic communities - Black Caribbean, Indian and Pakistani - and who have recently been joined by Zimbabweans, Somalis, Polish, and Iraqi-Kurdish. The largest communities are those of the Pakistani and Black Caribbean communities (see graph, p11).

Chapeltown and Harehills suffer high levels of deprivation in areas of income, health, education, housing, crime and living environment in comparison to the national average (Office of National Statistics). There are high levels of worklessness in Chapeltown and Harehills with 50% of the working age population on Jobseekers Allowance, Incapacity Benefit or Income Support (Neighbourhood Improvement Plan 2007).

Harehills has been identified under the Neighbourhood Renewal Strategy of the Leeds Initiative for funding from the Neighbourhood Renewal Fund (NRF) which aims to regenerate the area as well as improving people’s health, community safety, training, employment and education (Leeds Initiative Guide 2005). The areas are also included in the Safer, Stronger Communities funding streams to address issues that lead to deprivation (Neighbourhood Improvement Plan 2007).
The provision of mental health care, services and support in the area varies across the different BME communities. The Count Me In Census 2006 (Leeds analysis) reveals that some BME groups - in particular, African, African Caribbean, Pakistani, mixed parentage and Irish - experience high rates of detention under the Mental Health Act. However, Chinese and Indian People are significantly less likely to end up on a psychiatric ward than a white British person of either sex.

This research is timely due to local and national strategies and developments in mental health services and health provision:

- i3 modernisation of mental health day services in the city
- Count Me In Census 2006 results – which are a key element of the Delivering Race and Equality Action Plan
- Community Development Service based at Touchstone – national initiative in engaging BME communities in mental health/wellbeing (Delivering Race Equality)
- The recent restructure of Adult Social Care (Leeds Social Services)
- The recent restructure of Leeds Primary Care Trust
Examples of mental health services and support for BME communities in Chapeltown and Harehills

What follows are three samples of feedback gained from interviews and discussions held with some of the services and agencies included in Appendix 4. These have been chosen to give a snapshot of the depth and diversity of services being offered from the community, voluntary and statutory sectors.

Community Sector

Leeds Black Elders Association (LBEA) – is a community based organisation in Chapeltown that is partly funded by ASC and various small funding bodies (e.g. Awards For All, Age Concern, Joseph Rowntree Trust).

The organisation works with older people from the African-Caribbean community to provide various services:

- Advocacy
- Befriending
- Community Transport
- Decorating
- Dementia Café
- Gardening
- Home Security/Improvements
- Meals on Wheels (provides culturally sensitive meals in LS6, 7, 8 and 9)
- Stroke Club
- Volunteering Project

The Dementia Café or ‘Forgetfulness Club’ is a monthly get together for those who experience memory loss aimed at older Black Caribbean people. Audrey Johnson, a project worker at LBEA, feels the club provides a valuable service for elders in the community and like many organisations, short-term funding is always a threat to maintaining activities for marginalized BME communities.

Voluntary Sector

Advocacy Support – is an independent voluntary organisation based in Harehills that runs an advice service for BME communities, including refugees and asylum seekers. The service is funded by Leeds Primary Care Trust and ASC. The people who have accessed the service are represented in the following table:
<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number of clients seen April 2006- March 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pakistani</td>
<td>698</td>
</tr>
<tr>
<td>Indian</td>
<td>32</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>48</td>
</tr>
<tr>
<td>Chinese</td>
<td>353</td>
</tr>
<tr>
<td>Asian Other</td>
<td>54</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>3</td>
</tr>
<tr>
<td>Black African</td>
<td>49</td>
</tr>
<tr>
<td>Black Other</td>
<td>3</td>
</tr>
<tr>
<td>Roma</td>
<td>190</td>
</tr>
<tr>
<td>Other</td>
<td>46</td>
</tr>
<tr>
<td>Unknown</td>
<td>17</td>
</tr>
<tr>
<td>Total</td>
<td>1493</td>
</tr>
</tbody>
</table>

- Female clients 775
- Male clients 813
- Total number of client sessions: 1588

Services provided:
- Drop-in advice sessions
- Home visits for disabled and elderly users
- Assisting and supporting users to set up interest groups
- Outreach work to hard to reach groups
- Advice on benefits, housing, health, racial harassment, immigration and citizenship, employment, education and debt

Derek Sankar and Henry Lau at Advocacy Support suggested their ability to reach large numbers of people from BME communities was due to their providing staff and volunteers who share similar cultural identities and backgrounds with their clients. In addition, Staff with community languages are particularly important when trying to attract non-English speaking clients who may have difficulty expressing themselves, even via interpreters. Agencies that provide quality services in languages other than English frequently build a positive word-of-mouth reputation amongst non-English speaking communities, which leads to further success. Clients can chose a male or female worker and the perceived advantage of approaching a non-Statutory agency with strict confidentiality is of particular importance to communities who have negative experiences of State services (e.g. Home Office, Immigration Services, Police etc.)

A specialist advice surgery in Harehills and Beeston for newer migrants from Roma communities, Poland, Slovakia and the Czech Republic has been running twice a week for a year. It is also due to run out of funding. Partnership working with services like RETAS-Leeds (who work with asylum seekers and refugees) has helped keep the advice surgery going by using RETAS-Leeds workers to assist with interpreting and translation.
The lead researcher asked Derek and Henry what they thought about a community based mental health support service in the area. They did not feel there had to be a new service but could build on services and models of working that were already operating. These included:

- Developing partnerships with various BME agencies
- Training volunteers from specific BME communities to utilise their skills and experience
- Working within the community and utilising offices and services and working from those local buildings and centres

**Statutory Sector**

**Example 1: Community Mental Health Team (Leeds Partnership Foundation Trust) – Sector 3, St Mary’s House, Chapeltown**

The community mental health team supports people with a diagnosis of severe and enduring mental illness. Referrals usually from a GP or consultant psychiatrist. They do not accept self referrals. The team consists of a clinical manager, outreach worker (working with black males), Social Workers and Community Psychiatric Nurses (CPNs). It is a mixed team of women and men and ethnicities (African, African-Caribbean and white).

The team receive a high number of referrals for clients from BME backgrounds (South Asian, Muslim and Sikh, African-Caribbean, Eastern Europeans – Kosovans, African refugees – mainly women). The lead researcher spoke to Dave MacFadyen, a CPN in the team, who said it was rare to get referrals for Chinese people.

The lead researcher also spoke to Robin Ellis, outreach worker, about his work which is predominantly with black males (caseload of 20) who usually have a diagnosis of schizophrenia. He said a lot of his work is about managing risks to both the service user and the public at large but feels there is more emphasis on the managing the risk the client poses to the public.

Many of the clients he works with view going into a psychiatric hospital as the same as going to prison. About 40% have little or no family support and only two people on his caseload are in employment. Robin expressed how many of the men are stuck in a “bored bubble” and not engaged in employment, education, training or other activities. He felt one way to better engage people in day-time activities might be to organise groups around shared interests, rather than focusing directly on their shared experience of poor mental health. 25% of his caseload are asylum seekers e.g. from the Ivory Coast and Zimbabwe.

Robin’s preferred features of a community based BME mental health resource included:
• Access to talking therapies and psychological services
• More black counsellors
• A One-Stop Shop with different strands e.g. drugs advice, benefits, getting back into employment
• Health Bus – taking health staff into the community, rather than waiting for people to come to them

However, he was undecided about the provision of a culturally specific service and wondered whether it would be more beneficial to make improve the cultural awareness and capability of generic services, in order to make them more accessible and better able to meet the mental health needs of BME communities.

Example 2: Child and Adolescent Mental Health Service (CAMHS) East and North East Leeds, Osmondthorpe One Stop Centre

The lead researcher spoke to Janet Shepherd, senior practitioner, who covers the Harehills area. Feedback also came from other colleagues answering the service questionnaire (see Appendix 3).

CAMHS is a statutory service that works with children 0-17 years and families. Their work primarily centres on therapeutic and preventative work. If a young person needs more in-depth therapeutic work they are referred on to the Child and Family Unit at St James's Hospital. CAMHS provide consultation and training for Tier 1 staff (health visitors, nurses) and can offer topic-based meetings to places like Children in Vulnerable Accommodation (CHIVA) and Aspire, the Leeds Early Intervention in Psychosis (EIP) service.

Most children and young people with mental health problems will be seen at Tiers 1 and 2 (0-16 years teams) and CAMHS can cover services that straddle Tiers 2, 3 (e.g. specialist clinics) and 4 (Day units and in-patient services like Little Woodhouse Hall).

One colleague fed back that the majority of cases are from BME backgrounds. For example, out of the last seven cases, five were BME (African-Caribbean, mixed parentage, South East Asian) backgrounds. Janet has worked with some asylum seekers from CHIVA. She feels the CAMHS is accessible because they go into the community e.g. Chapeltown Children’s Centre, Leopold Street and Children’s Centre on Compton Road, Harehills, and all of them offer interpreting and translation services.

The team consists of people from diverse work backgrounds including social work, nursing, occupational therapy, youth work, counselling and play therapy. Janet felt the team had a good gender mix, and although their ethnicity did not always reflect the communities they served, they have an “equal opportunities outlook.”

There have been some ideas generated around how CAMHS uptake can be improved - for example providing outreach with services for BME groups, employing
more staff from BME backgrounds, and having a flexible approach to BME people who may be mistrustful of services.

CAMHS feel there should be more parenting groups in the local areas, with mentoring/buddying schemes supplementing individual support work.

They report the main concerns expressed by users of the service are around waiting times, and that people are generally positive about the service and workers.

**Example 3: Adult Social Care (North East Leeds), Roundhay Road Area Office**

Discussions took place with Ros Cheetham, Children’s Service Delivery Manager and Sue Naidu, Social Worker. Of particular concern were the effects of the changed structure of ASC and the impact the modernisation of mental health day services was having. This will often mean signposting service users away from traditional mental health day centres and settings (e.g. Roundhay Road Day Centre that also housed the Community Alternatives Team), as day services would no longer be focused around particular buildings.

Ros suggested funding things that have an impact on the every day life of mental health service users - like the Supporting Parents Fund, funded by Leeds Partnerships NHS Foundation Trust (formerly Leeds Mental Health Trust). This assists parents who use mental health services to meet childcare costs and other related activities.

Sue valued the importance of the Primary Care Trust supported Leeds North East Mental Health Forum (recently ended due to lack of funding) in bringing together ASC, Leeds Partnerships NHS Foundation Trust, voluntary sector and service users.

Unfortunately, the service were unable to provide monitoring data on ethnicity or the type of mental health issues faced by their client group, within the required time frame.
The Mental Health needs of BME communities in Chapeltown and Harehills

Mental Health Service Users (Adults)

There is a pattern of increasing long-term illness (including mental health conditions) in Leeds which has risen from 14.2% in 1991 to 18% in 2001. The national average recorded is 17.9% (2001 Census). In Chapeltown and Harehills these figures are 20.8% and 15.2% respectively (ONS, 2007).

The local Count Me In Survey – a one day snapshot of in-patient service users, conducted by mental health services suggests that the BME communities in these areas experience different and often harsher treatment, when accessing mental health services. For example, black African and Caribbean people are:
- More likely to be referred through the criminal justice routes
- More likely to be admitted to psychiatric hospital (5% Leeds Partnership Foundation Trust (LPFT); 9% nationally)
- More likely to be detained under the Mental Health Act (67% LPFT; nationally 44%)

By contrast, Chinese people do not feature as a discrete group within the local Count Me In Data, and so similar research into local routes, admission, and detention levels cannot be drawn – although national data suggests significant under-use of services.

We cite these two examples, as a way of highlighting the very different health inequalities experiences by BME communities, and to warn against simplistic over-generalisations. It if for this reason that we have

Needs and Issues

Irish

- People from the Irish community are still suffering high levels of alcohol dependency and other health issues related to their social and economic status and aging (e.g. dementia) (Gan Didean, Homeless Irish People, 2006)

- Irish people are still experiencing high rates of admission to psychiatric hospital and seclusion (Count Me In Census 2006). They also experience high rates of suicide and Irish women are more likely to be hospitalised for mental distress (Gan Didean 2006). Some links are being made with older Irish people and older African-Caribbean people from the Roscoe Methodist in Chapeltown, through luncheon clubs (Leeds Irish Health and Homes).

Chinese and Vietnamese

- It is difficult to know about these communities’ mental health needs as the small, dispersed nature of the communities means that they are sometimes
invisible in statistics and research. Some health issues have been identified in research by Ian Law including, stress and anxiety (Chinese Action Research Project, 2004). In addition, the under-reporting of the high levels of hate crimes perpetrated against Chinese people working within the catering industry can further erode confidence, and sense of safety, and whose after effects are worsened by isolation, long working hours and statistically low uptake of support from health services.

- Some Chinese people are accessing mental health support through the Chinese Satellite Project at Touchstone Support Centre. The community development worker for the Chinese community is taking up issues of access to GPs and other health services. Additional work is being undertaken to include mental health promotion work, and outreach to the ‘hidden’ Chinese and Vietnamese community.
- Chinese people are accessing Advocacy Support, a BME advice service in Harehills (353 Chinese clients seen between April 2006 - March 2007). According to Henry Lau, specialist case worker, this was attributed to having access to workers who are from the same cultural background, speak the main Chinese languages, Mandarin and Cantonese and are from the same cultural background.

**Black Caribbean, African, Mixed Parentage**

- Locally, there is still a focus on the risk management of people (particularly males) from these communities. This is compounded by the lack of access to psychological and talking therapies, disparity in family support, the stigma associated with poor mental health and mental distress communities that experience high levels of deprivation, crime and worklessness. Outreach worker, Robin Ellis reports many of the men on his caseload are often linked to forensic services and do not usually access GPs. **There needs to be more in-depth research into the mental health needs of women from these communities as there is little local information regarding their mental health needs.**
- There are some initiatives that are based in the locality that address some of the issues around worklessness, like the STEP Project (Support Towards Employment Project) delivered by Leeds Mental Health Employment Consortium, about supporting mental health service users into employment, education, training and volunteering opportunities. Of the 61 service users engaged in the STEP project, 20% identified as Black, Asian or Chinese British, 8% from the Middle East, Africa and European Union countries (Independent Evaluation, STEP 2007).

**Pakistani, Bangladeshi, Indian and Kashmiri**

- Although these communities are in many ways very different, we have grouped them together to avoid unnecessary repetition.
- Discussions with the Community Development Workers for these communities suggested stigma, cultural and language issues, and the terminology surrounding biomedical understandings of mental health and
treatment were particular barriers to seeking assistance – especially for older people.

- Those services providing a service responsive to gender and linguistic needs find they have the largest uptake of South Asian people.
- Many South Asian people undergoing mental distress find themselves isolated (especially women), with few people to speak with. That said, services which address health are more likely to attract audiences of women and older people, and projects focusing on South Asian men’s health are few and far between.
- Understandings of mental ill health vary within these communities, with traditional or religious understandings of mental distress still common. The stigma and taboo attached to such understanding makes it harder to ask for help or assistance, as it can sometimes bring about moral or religious censure.
- The South Asian experience of mental ill health or well being is not homogenous: Pakistani people are significantly over-represented in mental health services; Indian people are significantly under-represented.
- Poverty and racism are still major factors affecting the mental health of South Asian people (especially Pakistani and Bangladeshi people).
- Negative portrayal of particular cultural and religious practices in the media produces a circle of fear and suspicion, as well as a general atmosphere of Islamophobia.
- Kashmiri People - All attempts to research or engage people who identified as Kashmiri and lived in Chapeltown and Harehills were unsuccessful. No demographic data was available as Kashmiri is not a category used by National Office of Statistics (census Data), and has only been adopted by Leeds City Council in recent years. No health services we spoke to offered information on the needs of Kashmiri people, beyond the fact that they are frequently “hidden” within other Asian ethnicities. Particular effort was made to recruit researchers from Kashmiri backgrounds, and to ensure focus groups were open to all communities – including Kashmiri people. It is with regret that the research team note the absence of a distinctive Kashmiri voice from Chapeltown and Harehills in this research. Leeds Social Services’ Kashmiri Older People’s Research (October 2005) makes only one reference to mental health needs, pointing to a need for Pahari speaking mental health support staff (p12).
- The lead researcher was aware of only one organisation working in the city with people from Kashmiri backgrounds, Leeds Kashmiri Elders Association (LKEA) based in Burley.

Older People from BME communities

The Older Better Strategy, Healthy Leeds (Leeds Initiative and Older People’s Modernisation Team) is a five-year plan to improve the lives of older people in the city. It recognises the general health needs of older people from BME groups, but says little about their mental health needs (Older Better Strategy, p26, 2006).
In Leeds the population of older people from BME communities is rising and an estimated 9,167 people over 60 come from around 12 different communities, with the majority coming from Indian, Pakistani, Irish and Caribbean communities. Through consultations with BME elders specific barriers were highlighted that affected their quality of life. These included language, inadequate access to culturally specific services, financial difficulties and a lack of training for staff on specific needs and racism (Older Better Strategy, p26-27, 2006).

Statistics collected as part of the Index of Multiple Deprivation show that the Chapel Allerton ward (including Chapeltown) and the Gipton and Harehills ward are areas where older people face particularly low levels of income (Older Better Strategy, p11). This does not give a breakdown by ethnicity but shows the difficult economic conditions some older people from BME communities are living in.

**Needs and Issues for older BME people**

From interviews with services and agencies (See Appendix 4), discussions with the Community Development Workers, and consulting previous research into the needs of older people from BME communities the following needs were identified:

- Improved support for trips and physical exercise and day care provision beyond luncheon club activities
- Improved access to cheaper transport
- There is not enough culturally appropriate domestic support like homecare or a sitting service for those who live alone
- Access to GPs is a problem experienced by many older people from the local BME communities – e.g. not being able to make advanced appointments, having to stand a queue for an appointment, as well as treatment by some receptionists which is not always culturally sensitive or respectful
- Dementia is an issue for many of the BME communities (Home Support Service for Older People, Leeds Black Elders, Irish Health and Homes). This has been identified in the Older Better Strategy which reports approximately 6,000 older people suffer from this condition in Leeds, although, there is no recording of ethnicity (Older Better Strategy, p29-30, 2006). Some older people do not relate to terms like ‘mental illness’ and ‘mental health’. Some have little understanding about conditions like Dementia and Alzheimer’s (African-Caribbean worker, Home Support Service for Older People). This raises issues about better information and education about mental health issues and conditions for carers to enable them to understand

**Young People**

Young people account for a greater proportion of the BME population of Leeds than the white British population. 16.6% of the BME population are aged 10-19,
compared to 13.5% of the white British population (Improving Housing, Empowering Communities, Leeds Housing Partnership, 2005).

Several agencies and services are working with BME teenagers and young people in Chapeltown and Harehills. Some of these are activity based or offer a variety of services like supported housing, counselling, health and sporting activities and training.

- 10-2 Club, 13-25 year olds.
- Archway, 16-25 year olds
- Getaway Girls, girls and young women
- Leeds Cyber Café, Chapeltown Road.
- Shantona Women’s Centre, children and young people.
- Youth Service (Leeds City Council) 13-19 year olds

The lead researcher found it difficult to locate mental health services for teenagers and young people in the area.

An exception is Aspire – an Early Intervention in Psychosis Service for 14-35 year olds, based in Harehills. They have BME workers for African-Caribbean and South Asian communities. Sholebroke Hostel (Touchstone) in Chapeltown for homeless young people aged 16-25, provides support to young people experiencing mental health crisis and distress, and Ku Sikia counselling service (Black Health initiative) provides counselling for young people.

**Needs and issues for young people from BME Backgrounds**

The lead researcher spoke to Adrian Lee, from the Youth Service, who covers the Chapel Allerton Ward (includes Chapeltown, Scott Hall and parts of Harehills near Spencer Place). He explained that the young people he works with do not usually talk about mental health or mental illness, although he did identify that some young people may experience various stress and/or crises in their lives (e.g. school exams, peer pressure, family problems and contact with the police). If there is a mental health issue, the young person is usually signposted to other services – often outside the area e.g. the Market Place for counselling. Adrian emphasised partnership working with local BME specific agencies like, Black Health Initiative (e.g. Mayisha Project – which works with young people under 25 that have substance and/or alcohol misuse issues) as young people from BME backgrounds were more likely to access services that are local and culturally specific.

The service has workers from BME backgrounds, which Adrian suggests helps young people from BME backgrounds access the service as this is usually by “word of mouth”. The young people are mainly African-Caribbean and South Asian (they run joint initiatives with Sikh and Muslim girls as well as separate groups). Of the 750 contacts the service has with young people in a year, 50% come from BME communities.
Children and Families

Limited participation in the research by Children and Family Services, and an overall focus on the needs of working age adults meant that little comment can be offered on the mental health experiences of BME children and families in this report. Opinions came anecdotally, often as an aside to a larger discussion. The experiences of BME children who care for their parents/guardians are often isolated. Children caring for lone parents are often doubly afraid to seek help, for fear of unwanted contact with Social Services. The mental health of Refugee and Asylum Seeking children who arrive unaccompanied is a current cause for concern at Solace. Of particular note was the desire for services with crèche facilities, where parents can attend without worrying about their children.

BME Carers

The Older Better Strategy of the Healthy Leeds Partnership mentions the needs of older carers, but does not say anything about BME carers. General issues and concerns for carers mean that they are more likely to be on low incomes, be women, socially isolated, have poor access to transport and may have their own health needs besides the family member they are caring for (Older Better Strategy, p27-28). Some of these issues are experienced by BME carers following feedback from interviews with workers from Home Support Service for Older People, Advocacy Support and the Community Mental Health Team at St Mary’s House. There are additional issues that BME carers also experience as identified below:

Needs and Issues for BME Carers

- Information, education and awareness of mental health care pathways so that BME carers have a contact and not left to cope with a family member becoming unwell on their own (see personal story).
- There is evidence from some of the agencies interviewed (Home Support for Older People, Community Mental Health Team) that black families may need additional support to access the help they need before a family member is experiencing a mental health crisis, distress or becoming unwell. This raises issues about going to the GP and educating and informing carers about mental health issues and conditions. This can be difficult in some BME communities.
- African-Caribbean carers often hear about services “word of mouth” and may struggle caring for a family member who has multiple support needs and be unaware of the services that are in the area (Sandra Herbert, African-Caribbean worker, Home Support Service for Older People).
- People from BME communities may not identify with the label of “carer”. Providing care to a family member or friend is often seen as part of life and not an identity in itself. This poses a particular challenge to Carers Services who must use different ways of explaining their role, before they can reach their intended audience (Touchstone CDWs)
• Culturally appropriate forms of respite care are hard to find (Touchstone CDWs) – making it harder for carers to take a break. Greater use of Direct Payments to fund respite care is an obvious solution, and ASC have already noted this option is especially popular with BME Carers.

A Personal Story

A carer’s experience of supporting her teenage son through the mental health system.

Ms X is of African-Caribbean origin and lives with her two sons in the Chapeltown area of Leeds. She works locally and is involved in a community group. Two years ago her son ‘S’, who was aged 15 at the time experienced “a psychotic episode”, as diagnosed by a psychiatrist. Ms X had been to her GP because of concerns over the change in her son’s behaviour. He was withdrawn, would not come out of his room and was not sleeping or eating. She felt she was not taken seriously when the GP told her it was because her son was “just a bit down”.

Ms X spoke to a friend who worked with young people. After talking to ‘S’ he suggested referring him to Aspire (Early Intervention in Psychosis service for Young People). ‘S’ was assessed by the psychiatrist from the service and diagnosed with clinical depression. Ms X said he suggested her son did not need medication and should partake in exercise and activities.

Ms X was still concerned as her son became more withdrawn, lost weight and was not taking care of his appearance. She took her son back to see the GP who prescribed anti-depressants. After a week, ‘S’ became delusional, hyperactive and displaying bizarre behaviour. Ms X went back to the GP who then referred ‘S’ to the Child and Adolescent Unit at St James’ Hospital and would get a place at Little Woodhouse Hall (near the Dental Institute in the city centre) early the following week. ‘S’s condition deteriorated over the weekend and he was sectioned (Section 2 – 28 Day Assessment) and admitted to the Becklin Centre. He was to be transferred after the weekend to Little Woodhouse Hall. Ms X was concerned that he had to stay on a ward with adults for about a week and did not think this was appropriate.

‘S’ eventually went to Little Woodhouse Lane, but because he had been acting aggressively Ms X said the staff could not cope and he would not be able to stay there. Ms X expressed that she would not be able to manage, but reluctantly she had to take him home. She experienced difficulties in managing her son and ensuring he was taking his medication. She also had a younger son at home. ‘S’ was eventually discharged from Little Woodhouse Lane.

During this time Ms X felt she had no support if there was a crisis and there was not a safe space for her son to go to if his condition deteriorated. There was an occasion when she needed crisis support but had difficulties trying to contact the Crisis Resolution Team through NHS Direct.
The future
Ms X’s son will be attending college in the autumn and has a part time job which has helped improve his communication. The family are supported by a worker from Aspire (Community Links) who works specifically with African-Caribbean service users, which Ms X feels has helped engage and motivate her son. Although she feels that her son’s personality has changed and he is not as outgoing and sociable as he was, Ms X is more confident for his future and emphasised the importance of the practical and emotional support she received from her family. Ms X’s son is still under a consultant psychiatrist at the Child and Adolescent Unit and attending outpatient appointments. He is still taking medication, which his mum feels has helped stabilise his mental health. If there is a crisis Ms X can contact Aspire.

Reflecting on the family’s experience of the mental health services, Ms X says:

“I faced a lot of barriers and didn’t know where to get support, especially because I didn’t know the mental health services. I didn’t feel the services were supportive at first and I didn’t feel I was taken seriously. I still struggle with understanding what my son’s illness is and when he’s being a teenager.”

This story highlights the following:

- The lack of mental health services and support, such as acute in-patient facilities for teenagers
- The difficulty in accessing out of hours crisis support and services.
- Better information and support for parents and carers of teenagers experiencing mental distress
- The importance of family support in assisting recovery

Asylum seekers and Refugees

It is extremely difficult to get accurate, up to date, ward level data on the number of asylum seekers and refugees for the Chapeltown and Harehills area. The services and organisations interviewed suggested the largest migrant communities came from Somalia, Congo, Zimbabwe, Eritrea, Uganda, Iran, Iraq (Kurdish). Some of these services and others contacted (see Appendix 4) work with Eastern European migrant communities like Kosovans and more recent migrants like, Polish, Czech Republic, Slovakia and Roma communities who are often minorities within the countries stated (Roma in Leeds, 2006).

The statistics on this group are limited and this is recognised in the Older Better Strategy. Although it focuses on older people, it does include numbers of asylum seekers in Leeds. In November 2004, of the 2703 asylum seekers in Leeds 8 (Harehills), only eight people were over the age of 65 (Older Better Strategy, p28). Positive Action For Refugees and Asylum Seekers (PAFRAS), a support organisation in Harehills offer legal advice and give out clothes and food. They had an average of over 270 visits a month to their twice weekly drop-in at St Aidan’s
Church Hall this year. There are approximately 3,000 people in Leeds who are destitute and seeking asylum (e.g. often homeless, left without food, lack of access to public services like medical care) *(PAFRAS Newsletter, Spring 2007)*.

There are a hidden group of Chinese refugees and asylum seekers, numbering approximately 1000-2000 people *(Chinese Action Research Project, 2004)*. The Community Development Worker leading on the Chinese Community reports these people are frequently not aware of the health services available to them (e.g. Health Access Team) and often leave medical problems untreated.

Solace is the only organisation providing mental health care exclusively to asylum seekers and refugees, and is based in Harehills. It offers counselling and psychotherapy. They have a senior therapist and qualified and experienced volunteer counsellors. From June 2006 - May 2007, Solace had 145 referrals (three referrals a week on average), 80 of whom were from GP surgeries and health centres in Leeds (55% of the total number of referrals). After being assessed clients are offered a course of counselling (12 weeks on average) or, where appropriate, referred on to other agencies (e.g. if the client requires psychiatric assistance). They have also trained thirty freelance interpreters to work in a counselling setting.

Andrew Hawkins, Manager at Solace is critical about how the categories of ‘asylum seeker and refugee’ are included with other BME groups. He said:

“…we feel that the circumstances of asylum seekers (not so much refugees) are very different from other BME groups – not only because they have been subjected to extreme situations in the past (multiple traumas are very common - members of a family murdered, imprisonment, torture and rape can be the experience of just one person), but also because asylum seekers are deliberately socially excluded by the State.”

**Needs and Issues for Asylum Seekers and Refugees**

- Anecdotally there seems to be increasing levels of self-injury and attempted suicide. In one month PAFRAS had seen eight destitute asylum seekers who had recently attempted suicide. When the lead researcher visited in June this year, Christine Majjid, project manager stated that three people she had contact with had attempted suicide in a week
- The Health Access Team (HAT) raised concerns about the costs being charged for secondary care. Unsuccessful asylum seekers have to pay for secondary care, and this provides a significant disincentive to them approaching any health service for fear of having to pay *(Destitute in Leeds, p32-35, 2007)*
- Some African refugees are accessing statutory services like CMHT in the area – but these are mainly women (CPN, St. Mary’s House)
- Some asylum seekers and refugees are not being referred to some services and not showing up in monitoring data. This may be because some do not
have access to public funds because of their immigration status e.g. there are very few accessing the Housing Support Service at Community Links even though they may be homeless and destitute (*Destitute in Leeds, 2007*)

- Chinese asylum seekers are experiencing difficulties in accessing GPs and hospital services due to not having adequate language skills. Previous research has identified the need to develop contact and provide English language classes, information, advice and support (*Chinese Action Research Project 2004*)
- There is some practical and emotional support for asylum seekers and refugees in the Chapeltown and Harehills area, but many rely on donations and support from agencies like, PAFRAS, Leeds Asylum Seekers Support Network and others (see Appendix 4). Black Health Initiative in Chapeltown have a website to help this client group understand what health services there are in the country and agencies and staff can download information to give to clients. It is also in 15 languages – [www.bcathealthinitiative.co.uk](http://www.bcathealthinitiative.co.uk).
- Sure-Start in Chapeltown has a weekly drop-in for pregnant asylum seekers and refugees which is run by a nurse from the Health Access Team

Summary of needs and issues

The mental health needs of these groups must be seen in relation to wider social and economic factors in the Chapeltown and Harehills area (e.g. low income, worklessness, discrimination, housing, crime and ill-health) and how some BME communities are overrepresented in in-patient and forensic mental health services (e.g. black Caribbean, African, mixed parentage, Pakistani and Irish).

Older people from BME communities need better support to access primary care professionals, particularly GPs. Conditions like Dementia and Alzheimer’s are experienced by older people, but are not often understood by carers.

There are little or no mental health specific services for teenagers and young people. Locally agencies like Black Health Initiative and the Youth Service are supporting young people with issues that impact on their mental health, others like Aspire are making earlier interventions with young BME people experiencing psychosis.

The little work that has been included about the needs of BME carers needs show that they need clarity and support around pathways to services when a family member is experiencing mental health distress or crisis. Many women are carers and they may have additional support needs.

Supporting the mental health of asylum seekers and refugees falls to too few over-subscribed and under-funded services. The stress on migrants whose future is far from assured is significant and is borne out by the anecdotal evidence (e.g. PAFRAS) of self-harm and parasuicidal behaviour amongst the destitute. Solace is
the only local agency offering psychological support (counselling and psychotherapy).

More in-depth research needs to be done about the mental health needs of specific groups like women, children and families and people with disabilities from BME communities. For the purposes of this report, only teenagers, young people and adults have been included.
3. STAGE TWO – THE COMMUNITY RESEARCH AND CONSULTATION

Introduction
Stage Two of the research was the process by which the research team was widened to include additional community researchers, a methodology agreed, before a series of consultation exercises took place. These groups explored perceptions of mental health and well-being; experiences of mental health services; and how community members would most like to see their mental health safeguarded and maintained. These consultations took the form of focus/discussion groups in a variety of community settings and one to one interviews at participants’ homes.

Focus Groups
162 people took part in 14 focus groups, held over six weeks. The focus groups were held in a variety of community-based locations and at a variety of times – to maximise attendance. On several occasions, CDW suggested hosting these within groups they knew, as they had an interest in mental health, and would be willing to discuss sensitive matters.

The way in which these focus groups were held also influenced the nature of the sample. The nature and focus of the groups were publicised well in advance. It was clear from this information that only residents of Chapeltown and Harehills should attend, and that they should be of BME origin. However, participants were not asked for monitoring data until the end of each session. This has led to a number of anomalies (e.g. post code, ethnicities, and religion/belief) which are discussed at greater length below.

The groups were attended by people with mental health problems, carers, and other interested individuals. In the course of discussions it became clear that some of these participants were or had been health/social care professionals (one group contained one current and one former Social Worker). The majority of participants had experienced mental distress themselves at some point in their lives, with some receiving ongoing treatment from secondary services in the UK and overseas.

Although three of the 14 focus groups were arranged to specifically canvas the opinions of black Caribbean people, these were poorly attended. The two focus groups for black Caribbean adults included local people who were not found through services and agencies. In addition to these ethnically specific focus groups, black Caribbean people participated in a number of other activities (e.g. the focus group aimed at carers and for Touchstone’s Support Centre Service Users). Although additional focus groups were planned to rectify the comparatively small numbers of black Caribbean people questioned (7% of focus group participants, compared to 19% of the BME population of Chapeltown and Harehills), it was not possible to complete these within the available time frame/budget. Although the quality of the
information gained within these sessions was very high, and chimed with the broader themes emerging from other aspects of the research, this remains a serious shortcoming of the research.

**The Focus Group Summaries**

**Group 1: Irish Adults – held at Leeds Irish Health and Homes (6 participants)**
Participants within this group felt they get a raw deal from GPs (appointment systems, attitude towards mental health and treatments offered) and some people’s current and past experiences of prescribed medication has made them fearful of coming off medication. There was a strong sense of feeling stigmatised if you have mental health and alcohol issues.

Some people would like organised activities in Day Centres whilst others prefer more holistic and complimentary medicine (massage, aromatherapy), general health activities and a move towards self-management of their health issues:

“What you want to know what I’d spend money on. Going for a swim or Jacuzzi at the Light. Or the steam room. Hand out vouchers, and get people looking after themselves. Free passes for complementary medicine – aromatherapy. Physical stuff can really clear your head for half an hour.”

“I’d rather sit in Millennium Square than in a Day Centre.”

Popular choices included “Employing the right people from own community” and this was expressed in some peoples’ appreciation for the support they get from Irish workers whom they can identify with:

“You’re going to feel more comfortable and they’ll have more insight.”

**Group 2: Black Caribbean Adults 1 - held at Touchstone Support Centre (5 participants who were not found through mental health services)**
Racism and prejudice were strong factors in peoples’ experiences of the mental health system and life in general. One participant expressed concern that discrimination can occur from behaviours which are misunderstood by staff with different norms and expectations:

“... Mental Health Act can be used wrongly. If we wave our hands to communicate it’s seen the wrong way. If you don’t interact the way they think you should, they think you’re going off.”

There was a feeling that support with mental health issues can come from different people who may be friends, family members, or mental health services, but that usually one looked to those close to you first.
For one participant a reliance on faith has helped with their ‘recovery’:

“I had reached a point, I’d gone so far. I needed to pull it together. The damage… had already occurred. I’m still clearing up the mess now. The answers were only within me. No one was no help. Went down the GP and took medical help - but that wasn’t the thing that helped. I thought it was making me worse. I had my faith. I could get on and pray in the middle of the night.”

Some commonalities with the other black Caribbean focus group in looking at creative ways of coping e.g. alternative therapies, talking more - community radio, sharing experiences, arts and music to build confidence and self-esteem. In relation to what should be provided in the area, the group wanted to see things that help people avoid mental health, something new, something for younger people and counselling.

**Group 3: Black Caribbean Adults 2 - held at Touchstone Support Centre (3 participants who were not found through mental health services)**

Prevention of mental distress was a strong theme from the group. A need for more opportunities to talk and get support earlier was expressed. There were different views about seeing the GP to avoid mental health issues escalating, as well as people reporting a fear of seeing GPs about their mental health.

As with young black people, concern was raised about:
- The use of illicit drugs and that involvement from an early age can lead to mental illness in later life
- The need to raise awareness and education around mental health
- A strong sense of using the community and creative options as a preventative measure e.g. drama, media, creative training packs, Community Mental Health Educators, local radio

**Group 4: Young black people from Aspire (3 participants)**

Participants expressed strongly that there is a stigma around anything to do with mental health, particularly from their peers. They also expressed concerns around the helpfulness of mental health terminology (mental illness) to describe their experiences, although all of the participants have a diagnosis, and aware of others in the community who are experiencing poor mental health.

Mental health awareness and the need for good mental health promotion were important to the group as well as taking steps to avoid poor mental health. More alternatives to medication needs to be publicised and made available…
“There needs to be other things besides medication, people need to learn and understand it. Sit down and talk to you about things, explain, breathing techniques, maybe look at a herbal route (less side effects).”

The effect illicit drugs are having in the community and on young peoples’ mental health and well-being is a concern (also see responses from young Bangladeshi men). They expressed reluctance in going to see their GP even when drugs were not a factor:

“Not everyone’s keen. I have a mental health issue and this would prevent me. GPs can use technical terms and they don’t always have time to explain things to you. They don’t listen to you”.

Like the Irish participants these young black people appreciate the support they get:

“A service is better than going to the GP. It’s more relaxed and informal. It gets you out the house, they are more supportive”.

Group 5: Pakistani Women – held at Montague Burton (25 participants – two groups attended)

The main theme running through the group was the importance of having the opportunity to meet other people and make friends in order to combat isolation and bring people together. The setting was important (also see Leeds Irish Health and Homes, Apna Centre and Milun Women’s Centre) in the style of a Community Café that is non-stigmatising and visited by peripatetic workers (e.g. nurse).

There was a strong expressed need to share ideas, prayers and support with other women in Leeds and Bradford. There remains a significant stigma around discussing mental health conditions such as depression within the community, particularly for women. Many women feel they do not get any support from family on such matters. The women were keen to ensure their concerns for older people (transport, homecare, assistance to attend healthcare appointments, and adaptations in the home) were highlighted.

There are links with other focus groups (young black people, black adults) things that help people avoid poor mental health and promotion, but this needs to take account of language and literacy issues (employing bi-lingual staff), and the ability to understand medication (side effects, dosage). Again, as in other groups, access to primary care professionals like GPs (appointment systems, length of time with GP).

Group 6: Pakistani Men – held at Montague Burton (15 participants)

Unlike some of the other focus groups, Pakistani men from the Montague Burton men’s group did not place great emphasis on employing people from their own community. They felt it was more important to employ those people who are committed and supportive towards themselves and their community.
Participants thought that any new or existing service should help people to recover when things have gone wrong and offer support to those who may need urgent help.

Similarly to the Pakistani women’s group, they valued befriending opportunities for people to meet each other, as well as easier access to GPs:

“….problems in getting appointments.”

“Every two weeks there is a different GP.”

The men also identified that any new service should take account of women’s mental health and well being as:

“…they need someone to discuss their problems”.

Group 7: Asylum seekers of different ethnicities, held at Solace (9 participants)

The overwhelming factor that participants said affected their mental health was uncertainty about their immigration status, and waiting for a decision about their asylum status. Although people with refugee status were invited, the participants were all awaiting asylum decisions. Participants felt this second-class status impacted on every aspect of their lives including housing, education and access to healthcare. The provision of vouchers to purchase food rather than cash was particularly stigmatising.

For this group, it mattered little who provided help and support, so long as it came.

Like Pakistani men from the Montague Burton men’s group who rated highly access to their GP, participants from the Solace Focus Group felt access to see a GP was easier if you spoke English:

“GPs don’t know how to treat asylum seekers…..receptionists are difficult to deal with if you don’t speak good English when registering.”

Group 8: South Asian Women - held at Khushi Group (15 participants).

The main issues to come from the Khushi Group included better understanding and promotion of mental health as well as a focus on issues for older people, those who are housebound and those with mobility issues as they can become isolated and lack confidence to go out. Bereavement and dealing with feelings of loss were a concern:

“Support is required when partners pass away, who do we turn to? Children do not want to be responsible.”
There was a shared feeling that one can get more support within community groups as concerns expressed around attitudes of GPs and their ability to take mental health issues seriously:

“When we talk to the GP he does not want to know us. We can’t even explain things properly and express our feelings. Support worker is required in our community as language is a big barrier.”

A Community Café and mobile health bus were popular choices from the Khushi Group (mainly Indian women) and other South East Asian groups (Apna Centre, Milun Women’s Centre and Bangladeshi Men’s Group). As a participant from the Khushi Group expressed:

“We want our own centre in North Leeds where all the community members can come and meet. This is where a community nurse, GPs, counsellors can be present.”

Group 9: South Asian Women - held at Milun Women’s Centre (16 participants)

There is a real need for safe spaces for women to come to where their voice can be heard. Some identified a Community Café as somewhere to do this as well as somewhere to work, read, and meet other women. Some of the women are experiencing mental health issues (depression, post-natal depression). They have identified the need for counselling and someone to talk to:

“….should be of our culture who understands our background, this is the only way. Understanding the culture ….only then you can understand the root of illness. English counsellor will not be able to understand cultural background.”

Although another participant expressed the difficulties in seeing professionals who are from the same ethnicity:

“Apart from the GP who can you speak to about your problems in private and who can give you advice, guidance on your health issues. Any Indian GP knows all my family. I don’t like telling GP all my problems.”

Helping religious groups get more involved in mental health was recognised as a way to raise awareness and remove the stigma that is often attached to mental health. This was also identified in the LIHH focus group.
Group 10: Touchstone Carer’s Group– held at Touchstone Support Centre (7 participants)

The carers that attended were from various ethnicities including black Caribbean, Chinese and Indian, have a variety of issues from using GPs, medication and concerns about the family member they are caring for. Some participants felt that overall, peoples’ mental health is getting worse in the community. Some reasons for this include illicit drug use and changes in circumstances like losing a job or bereavement (the latter was also a concern in the Khushi women’s group):

“Death has a lot to do with it – lost best friend, can’t get over it. Takes a long time to get better when you lose somebody, especially black people.”

“Big gap that needs filling. When you look after someone that dies nobody wants to know. You need somebody just for contact when someone dies.”

“Opportunities that help people meet each other and make friends” was a popular choice of this group, in common with several of the South Asian men’s groups (e.g. Montague Burton Pakistani Men and Bangladeshi Young People).

Group 11: Apna Centre, Pakistani men – held at the centre (15 participants)

Within the group there was a strong sense of providing opportunities to promote mental health awareness:

“People suffering from mental health should be given extra help at our centre – weekly sessions for older and younger members of our community.”

“…..require workshops which help to understand depression better – it will make people discuss their problems which they cannot discuss with the GP.”

As with other Focus Groups included in the research participants considered having easier access to their GP was important along with related concerns about prescribed medication, side effects that are not adequately explained, and that the GP should be someone from their own community who speaks their language.

The provision of a Community Café was also important to participants as identified with other groups (Apna Day Centre, Milun Women’s Centre, Khushi Group).
Group 12: Bangladeshi Men's Group – held at Bangladeshi Centre (15 participants)

Participants from the group wanted to have a space to relax in that was safe and comfortable and provided for their community in particular e.g. Community Café. This has been a common theme in some of the other groups like Apna Centre, Milun Women’s Centre and the Khushi Group). This would be a place that is “buzzing”, visited by GPs and nurses and offered various classes, like English. Easier access to GPs was another priority.

Participants expressed their concerns for younger people about bullying, school achievement, after school classes and training opportunities and apprenticeships to improve job skills.

Popular choices included, “mental health awareness sessions” and “how to deal with mental health issues”; leaflets in Bengali promoting positive mental health; helping avoid poor mental health by promoting a healthy lifestyle and single sex sporting activities like swimming and badminton.

Group 13: Bangladeshi Youth Group (13-19) – held at Bangladeshi Centre (15 participants)

Young people in the group expressed social concerns that impacted on their mental health and well being such as drugs, living in a high crime area, exclusion from school, failing exams, poverty and family problems.

Like young black people there is a fear, lack of trust and stigma in approaching their GP if they had concerns about their mental health:

“I wouldn’t speak to a GP, why? Because they would just put me on medication and probably send me to an institute.”

Participants in the group wanted a greater focus on the provision of local sporting activities (boys only), outings, residential trips and an internet café for health issues and easily available information. It was important that these were provided in the evenings and weekends. Other main choices for the provision of any new service should take account of opportunities to meet other people and make friends and provision for women.

Group 14: Various Ethnicities - held at Touchstone Support Centre (11 participants)

The group that participated were a mixed BME group (African, Black Caribbean, Bangladeshi, Indian and Chinese) that use the Support Centre and access various services and activities (e.g. Women’s Group, Drop-In). Therefore, a lot of discussion was around their experiences of the mental health system and professionals within
them. This varied from accessing day services at St Mary’s House to in-patient services.

There was an overall feeling that psychiatrists, in particular did not listen to them or seem to focus on their views and feelings. People also felt it was important to get support before things reached a crisis point.

Although everyone in the group attends the Support Centre, one of the male participants (black Caribbean) did not feel that a worker’s ethnicity was important and that he felt strongly that a person’s approach was more beneficial. In his experience black people had not always been the best to work with him.

In common with Leeds Irish Heath and Homes and Milun Women’s Centre, helping religious groups get more involved in mental health was a popular choice. Equally important was providing something for the whole community and things that help people recover when things have gone wrong.

Group 15: Black Caribbean Adults – held at the Mandela Centre (14 participants)

The group comprised of men and women aged between 23 and 52 who predominantly identified as African Caribbean.

The participants felt that mental health was connected to a sense of understanding why you feel as you do, with clear, rational, thoughts and a feeling of achievement and “moving forward.” Discussions centred on the importance of balancing physical and spiritual aspects of life, as these promoted the ability to cope with “Normal Society” and other people, as well as a broader sense of well being that comes from feeling positive about oneself.

One woman reported seeking counselling from her GP:

“when I experienced it, I hoped I would be able to access [an] African Caribbean councillor but my GP didn’t know any in our community.”

even though there were and are several operating in the local area.

Most people in the group felt that the ethnic origins of mental health staff were not as important as staff having understanding of different cultures and treating service users as individuals with individual needs:

“It’s not about colour or culture, but how they interact with you.”

Sharing information regarding loved ones who were unwell or becoming unwell came up time and time again. Carers understood the complexities of data protection and confidentiality but felt at times crises could have been prevented if important
information had been shared with them. Such eventualities could have been anticipated if they had been more involved in the care process:

“Appointments are a biggie, they send out appointments to family member who is sick, they don’t respond or open mail so don’t attend appointments. Carer’s don’t know until after the event or when crisis occurs.”

Group 16: Older Black Caribbean - held at Roscoe Luncheon Club (10 participants)

The group was held at a Luncheon Club, hosted by Roscoe Methodist Church and was comprised of men and women between 55 and 85 years of age.

Good mental health - to them - meant feeling good about themselves; waking in the morning and feeling like anything is achievable. Poor mental health was feeling depressed and wanting to stay indoors; not wanting to see anyone and feeling very low.

They felt the mental health of the wider community was affected by racism, financial worries, loneliness, and family difficulties. Environmental factors also had a negative impact, with poor physical surroundings (including rubbish) mentioned.

The majority of people in this group felt that the church, their faith and the power of prayer were positive coping mechanisms for good mental health; their strong belief in God enabled them to get through difficult times.

The group’s preferred method of maintaining good mental health was to turn to family, or to physical activity (e.g. taking walks, swimming, or going to the gym) – although participants felt the availability of such activities were limited, as facilities did not cater for their needs (echoing the findings of LCC research into BME use of Leisure Services, 2007). Healthy eating and a balanced diet were important factors.

They also emphasized that attending the luncheon club provided them with the opportunity to improve and enhance both their physical and mental health, by retaining social interaction, participating in physical exercises and getting out of their homes; reducing their isolation.

The group contained another person who had unsuccessfully sought counseling from her GP, following a bereavement:

“No advice or signposting was given - The GP had no idea where to refer [me] to ...[saying] no alternative non-medicinal services were available in the area.”

Finally, they expressed a strong preference for an easily accessible drop-in centre, where they might obtain information, advice and services, and where several
complementary “extras” could be sited under one roof (e.g. hairdresser, make-over salon, aromatherapy room).

Focus Group Preferences

By the time the focus groups were being planned, it was already clear that an attempt to produce a “one size fits all” service specification would not do justice to the diverse needs and aspirations of the varied communities. As such, the research team felt a better approach would be to identify the key priorities of each group, to enable commissioners to target resources more effectively.

With this in mind, each focus group was asked to prioritise a number of statements about how investment should be made in Chapeltown and Harehills. Participants were asked to vote for a range of service options based upon the findings of the initial (desktop) phase of the research. These were largely descriptive features of a particular service. In addition, members of the group could add their own suggestions or ideas at the end.

Although this ability to “add” options to the list was more properly representative, and suited the participatory style of the research methods used, this led to a wide variety of options with very few votes. Significantly, the votes cast at the end of focus groups did not always reflect the apparent priorities of the groups in the preceding discussions. For example, in one of the black Caribbean focus groups, significant importance was attached to the power of community radio in promoting mental health and the opportunities it presented. But despite an apparent consensus within the group, it received very few “votes” at the end.

The Non-adjusted Focus Group Data

The raw data is presented on the following page. Voting patterns were quite evenly spread across the available options, with the highest number of votes for a Community Café. This option emerged repeatedly although there were different interpretations of what this might be. In general, the idea of a community café incorporated ideas of an ethnically mixed community base, serving food and drinks, operating as a non-stigmatised social space, where healthy eating and lifestyles could be promoted and advertised.

The preferences which got the highest number of votes were:

7.8% - A community café
6.7% - Things that help people to avoid poor mental health.
6.5% - Helping me to see my GP easier
6.4% - Promoting good mental health
6.4% - A mobile health bus
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The Adjusted Focus Group Preferences

Adjusting the Data
The research team were concerned that with limited funds, commissioners will want to ensure whatever services are provided will meet the needs of as many communities as possible. It is with some reluctance that the research team propose a “one size fits all” solution. To do so requires the raw data be adjusted to ensure the priorities of numerically smaller focus groups are not lost in the final analysis.

A number of ways of doing this were attempted before settling on the “3-2-1” system, which was thought to be the fairest. However, this compromise is offered with the caveat that any attempt to balance statistically unequal points of view will always be open to question and debate.

The option(s) with the highest numbers of votes in each group were coloured red and received three points each; the second highest were coloured orange and received two points; and the third highest scoring options coloured yellow and received one point each. Where there was more than one first, second or third choices, all of them were coloured and scored.

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Analysis of the Focus Group Preferences

Overall conclusions are hard to draw from this data. There is no overall consensus – needs vary from community to community and group to group.

- **Black Caribbean** respondents prioritized comments on Services – with most saying they wanted to see an improvement in existing services, and a minority asking for new services.

- Activities which combat isolation (meeting new people, community café, mobile health bus) scored highest for **Carers, Pakistani, and Bangladeshi** groups in particular.

- Counselling or talking therapies scored consistently highly among **black Caribbean** respondents.

- Evening or weekend activities are most popular with **Younger people** and **Carers**.

- **Older people**, especially **older Pakistani** and **Bangladeshi people** favoured the idea of a community café.

- Promoting good mental health was particularly important for people from **black Caribbean** groups.

- Preventative work scored highly across all communities, especially with **black Caribbean** participants, **Irish** people, and **Pakistani Women**.

- The ethnicity of staff was more important to people from **Irish** and **black Caribbean** backgrounds than any other group.

- The ethnicity of staff mattered least to **Refugees and Asylum seekers**.

- Culturally specific work was valued most highly by **Bangladeshi Men** and **black Caribbean people**.

- **Pakistani men** and **women** voted consistently for things that involved the whole community.

- Work with younger people scored highly amongst the **black Caribbean** participants.

- Easier access to GPs was an issue for everyone but especially significant for **Bangladeshi men, Pakistani men, young black men** and **Refugees and Asylum seekers**.

- The idea of a health bus seems particularly popular with **Asian Women**.

- Increased involvement of religious groups in mental health scored consistently across most of the groups, but was especially marked where focus groups were held in venues with connections to religious activity (one of the **Asian Women**’s group and **Older black Caribbean** group).
One to one interviews

11 people took part in one to one interviews. These interviews took place after the focus groups, and participants were selected to enhance the general findings of the focus groups themselves, and to help shape the overall findings and recommendations. The participants have not been “double counted” in the statistical data. Four summaries have been included to give a flavour of these interviews.

Interview 1

Ms X is a 38 year old woman living in Harehills with her two daughters and is seeking asylum from Uganda. She has received a diagnosis of post traumatic stress disorder and depression and has regular counselling with Solace. Like other asylum seekers involved in the Solace focus group, waiting for a decision about her immigration status is unsettling:

“Uncertainty about my immigration status has made my mental health worse…. I have been detained twice (causing stress, isolation, and trauma).”

Good mental health means getting a decision:

“I know that I will be safe. Safe from my past in Uganda.”

In common with some of the focus group participants, Ms X would like an opportunity to meet other people in a similar situation to herself and to talk about things.

Interview 2

Mr S, 58, Chinese attends Touchstone Support Centre in Harehills and is a carer for his father who has dementia. He feels it is important to invest in and provide for older people (e.g. provide Social Workers for the elderly) which is an issue in his community:

“…..lack of help from society because children are too busy to care for their elderly parents. For me most important mental health issue is dealing with the sudden problems that come with age.”

Like other interviewees (see Mr J) how care and services are provided are more important than a person’s identity:

“What is important in people providing help with feelings is that they are caring and loving. Nothing else matters – it doesn’t matter what religion, race or gender they are. Doctors should understand. Social services should have a good relationship with the elderly.”
Interview 3

Mr J is 32, Pakistani, resides in Harehills and has experience of using mental health services (he has been hospitalised) and wants to offer support to others:

“I was a patient on Roundhay wing years ago. This was an awful experience. Since then I have started to volunteer for the Becklin Centre because I wanted to give something to people who are struggling like I did. I contacted the Mental Health NHS Trust volunteer co-ordinator about this and she told me about the Becklin Centre.”

Mr J highlighted how important his Muslim identity and religion (attending the local mosque) had been for support and aiding recovery. However, he was of the opinion that in his experience many people from his background did not like not talking about problems with how they were feeling.

Echoing Mr S’s comments, he went on to say that a worker’s identity was not as important as how they act:

“What is important is that a person listens to you and hears your ideas. It doesn’t matter who they are – what religion or anything. Although some Muslim men would prefer to talk to men, not women, because we are often separated in our religion.”

He would like to see:

“...more information for patients, they need definitions of what is happening to them. An advocate or therapist should explain what is happening during their time in hospital. Ward staff could do this, or even volunteers. So there needs to be enough of these staff.”

Interview 4

Miss M, is 55, Irish Catholic and lives in Chapeltown. Echoing other interviewees (Mr S, Mr J), Miss M stated that the identity of staff is less important than their attitude and experiences:

“The identity is not important in terms of gender, ethnicity, religion etc. What matters is that they have also experienced mental health problems – this way they really understand. People who have an understanding of the problems, but have not experienced them can still help, but the most valuable help comes from people who experienced the problems themselves.”

What should be provided (links with feedback from some of the South Asian focus groups):
“I think a Community Health Centre should be built. This would include support workers, doctors, nurses and care workers. They would provide food and a place for people to talk together and do activities. What is important is to get people off the streets. Older people (possibly ex-army people) really need support – some of them are on the streets and they should be helped.”
The Profile of Participants

Overview
The participants of the research were the people who attended focus groups, and agreed to one to one interviews. Although we attempted to target our focus groups to mirror broader demographic data, the monitoring data was not taken until the end of each session. This led to some unusual and unexpected data, for example at least 15% of participants were found to live outside of the LS7 and LS8 areas.

The percentages given are mostly rounded up to single digits, for the sake of simplicity.

Monitoring forms
These were designed to get around some of the difficulties experienced by CDWs when working within BME communities. The forms (Appendix 8) were designed to be accessible and clear (large font, use of symbols where possible) to allow participants with limited English to complete with minimal assistance. Each field was written on a separate slip, which could be torn off the main form and placed in an envelope. Guidance on completion was offered by the researchers. This design allowed the research team to collect data in a way which did not link fields to a particular respondent, and so guaranteed complete anonymity. Although this design was very popular with respondents, the “open” design of the forms (i.e. not stating categories for ethnicity, sexuality, etc) meant that some responses were hard to interpret. In these cases, the responses have been accounted for under “not known”.

2001 Census Data
This data was of surprisingly limited value to the research team. Aside from being six years out of date, the raw data available was difficult to interrogate, or manipulate. This research focused on the BME population of two electoral wards in North East Leeds. Extrapolating ethnicity data from the available Ward level data was quite straightforward. However, when looking for patterns within this population (e.g. religious observance and long term health difficulties etc) things became less clear. As a consequence, comparative statistics have only been presented for ethnicity, and even then with some caveats (see below).
Overall, the researchers were pleased with the gender mix of the participants, although surprised by the over representation of men. The size of the transgender population reflects the presence of a single transgender person in the research. With such a small sample size, and a limited number of focus groups, it was difficult to ensure an even gender balance within communities. There was particular difficulty in canvassing the opinions of “smaller” populations such as the Bangladeshi and Irish communities. Only one Irish woman was consulted, and no Bangladeshi women, despite attempts to encourage them to take part in single sex groups.
The age of participants was spread quite evenly, with a slight bias towards the older population. The only focus groups which specifically targeted particular age groups were for Bangladeshi and black Caribbean young people, and older black Caribbean people. These were held comparatively late in the process, to ensure the voices of teenage people were not excluded from this research. Otherwise, it was common for groups to contain people in their twenties through to people in their sixties. The bias in favour of older people perhaps reflects their greater willingness to participate in exercises of this type.
We have shown the ethnic make-up of participants against the combined populations of Chapeltown and Harehills.

The focus groups were arranged to target particular ethnicities, or experiences. However, despite the researchers’ efforts, several of these groups were particularly under-attended – in particular those arranged for people of black Caribbean and Irish origin (see above). As the Black Caribbean community are the second largest single community of Chapeltown and Harehills (p11), two additional focus groups were held in March 2008 to ensure better representation. Had all those invited to the original Irish focus group attended, the numbers would have matched the demographic profile of the area.

Participants were encouraged to define their own ethnicities, which meant not everyone used categories used in the 2001 census. These included Iranian, Italian, Kurdish and Palestinian, and are covered by the “Other categories”. Of the total participants, at least 7% had sought asylum in this country (based on the number of attendees at the Refugee & Asylum Seeker focus group).
Sexuality of Participants

The majority of respondents did not choose to share their sexuality. Of those who did, the evidence suggests that many people confused this category with gender and vice versa – despite guidance offered by the research team. The category “LGB” was used by one the respondents to describe their sexuality, and so was included.

The fact that so many respondents chose not to respond to this question, further demonstrates that sexual identity is still taboo across many BME communities, or “does not require explanation”.
In the 2001 Census 69% of Leeds residents reported themselves to be Christian, 3% Muslim, and 1% Sikh. However, ward level data on religious belief was not available by percentage, nor could it be interrogated by ethnicity.

As a consequence, we have not attempted any comparison with the wider Leeds data – other than to say – of the people we spoke with, there was a much higher incidence of religious belief than in the broader population. 17% of people in Leeds classify themselves as having “no religion”, in our survey, only 5% of people described themselves in such terms.

Respondents were allowed to define their own religious beliefs – again leading to anomalies such as “Chinese” which lay outside the usual framework. 4% of participants described their religious belief in ways that the census would class as “other Religion.” The 2001 census reported this figure as 0.2 across the general population of Leeds.

The way in which the focus groups were organised also makes it impossible to draw out any particular “Sikh” or “Hindu” perspectives. The groups were not organised by religious belief (or by ethnicity) and so it is impossible to draw conclusions along these lines.
Although great efforts were made by the team to poll the opinions solely of Chapeltown and Harehills residents, more than 17% of participants were from outside this area.

This reflects the mixed composition of the groups from which many of our focus groups were drawn and the fact that significant numbers of BME people travel from LS17 and LS9 to attend groups held in Chapeltown and Harehills.

The research team found this fact of particular interest in light of current changes and trends within day activities to become less building based, and more “generic.” The groups we spoke to evidently identified strongly with people of similar ethnicity and experience as them, and are willing to travel to meet people with whom they shared a sense of commonality. This is of particular interest when looked at against the outcomes of the focus groups which identify transport and location as being key factors in suggested mental health provision.
Disability and the Participants

Despite discussions which indicated a great awareness of mental health, mental ill-health and disability, surprisingly few participants described themselves as having a disability.

The 2001 census data does not specifically discuss the issue of disability, preferring to talk of “limiting long-term illness.” 18% of the general population described themselves as having one of these. The ward based data is again difficult to interrogate by BME population and so specific comparisons are very difficult to make. Looking nationally, BME groups report higher levels of disability and long term health conditions than their white British counterparts (Fourth National Survey of Ethnic Minorities, Nasroo 1997) and higher rates of mental distress (Inside/Outside, DH 2003).

So, at first glance it may appear that the participants were unusually “able.” However, the experiences and difficulties described within the groups suggests participants did not connect these experiences with the concept of disability. This may also be down to the fact that a sign indicating physical disability was used on the monitoring form. This is an area for much greater investigation.
Participants were asked to report all the languages they either speak and/or write. They were not asked to grade their level of proficiency in these languages, so this data may be of limited use. However, most participants spoke several languages (some as many as four), with English, Punjabi, Urdu and Bengali the most common.

The level of illiteracy within the sample was 7%, but may reflect the limited educational opportunities available to some older participants. However, this further underlines the importance given in the focus groups to oral communication within BME communities, and the way in which information and knowledge is spread through word of mouth.

It may be possible to extrapolate broader conclusions from this information. Our data suggests that both Punjabi and Bengali are primarily spoken languages, and so the usefulness of written materials in these languages may be limited.
GP registration

GP registration of participants was very high – running at 91%. We did not have any local data against which to benchmark this figure, but feel this reflects the health-focused nature of many of the organisations that hosted the focus groups, and their influence over their members.

Such a level of GP registration adds weight to the issues raised around access to primary care.

It is more concerning then, that although GP services are crucial to most mental health care pathways, many participants seemed unaware of this, beyond the prescription of medication, or referral to in-patient services; and where talking therapies were requested by participant, GPs either did not know of these, or did not refer to them.
5 - KEY FINDINGS

We have grouped these findings thematically, with each key finding matched to one or more recommendations:

- Appropriate and responsive services
- Effective communication
- Building Capacity
- Children, families and young people
- Older People
- Carers
- Other findings and recommendations

Appropriate and responsive services

Key finding 1: The importance of BME specific support services

The loss of BME specific resources (e.g. Black Mental Health Resource Centre) was felt by many we consulted to indicate a “disinvestment” in BME community mental health services, especially without a concurrent investment ensuring mainstream services become more diverse. Withdrawal of funding for BME projects without an alternative that is demonstrably suitable for BME clients will exacerbate feelings of unhappiness and resentment towards commissioners.

- **Recommendation 1 - Until mainstream services are able to prove their ability to engage with BME communities, BME specific initiatives are needed. Where disinvestment is planned, special effort will be needed to “prove” the alternatives have a track record of delivering culturally competent services, and service use reflects local demographics**

Key finding 2: The unique importance of building based services to BME communities

BME specific services provide a safe space where race, ethnicity, and difference can be discussed openly, and where the negative effects of discrimination and prejudice are given value and importance. They are also places where community stigma is felt less acutely. Their existence allows significant mutual support to take place. The move away from building based services is important, but fails to address the lack of safe spaces for BME people experiencing mental distress. It also erodes the informal network of support which comes from BME practitioners being based in the same place.

- **Recommendation 2 - There remains a role for BME specific services, which frequently double as places of psychological safety for BME people. Some of these will need to remain building based**
Key finding 3: The importance of non-specialist mental health support
The services, agencies and groups in the area that provide greatest support to the mental health of the different BME communities are not always “mental health providers”. Even so, these “non-specialists” (e.g. Leeds Black Elders, Advocacy Support, Leeds Racial Harassment Project, and Black Health Initiative amongst many others) are frequently cited as crucial to the wellbeing and recovery of the BME communities.

- **Recommendation 3 - The role of non-specialist organisations should be recognised as crucial to the psychological survival of the BME communities, and funded accordingly**

Key finding 4: The importance of a representative BME workforce for some communities
The staffing of such projects was of particular importance to those young Black Caribbean and Irish people we spoke to. However, services with workers drawn from BME communities (and who also speak community languages) are perceived as more accessible and relevant, and such employment is frequently interpreted as an investment in the communities themselves.

- **Recommendation 4 - More BME people should be employed within services which promote and support the mental health of BME people**

Effective communication

Key finding 5: GPs need to know the resources available to them
People are increasingly aware of alternatives to medication. However, the focus groups suggest that because some GPs are not aware of the range of services in their areas, they are unable to refer or to advise their patients of them. Anecdotally, GPs report being overwhelmed by information, and that they cannot keep up with the different resources available to them.

- **Recommendation 5a: GPs need to be consulted about how best to meet their information needs regarding the support available to BME people in particular, and**

- **Recommendation 5b: These findings should be used to inform a strategic approach to informing GPs of the resources available to them, which promote the well-being and recovery of their patients**

Key finding 6: The importance of non-medical language
Many of the services consulted (Appendices 3 and 4) stated that the BME people they worked with preferred not to use the language of medicine, illness or diagnosis to express their distress due to stigma, and their negative experiences or perceptions of the mental health system. In particular, some did not always associate terms like Dementia or Alzheimer’s with mental health conditions (Home Support for Older People, Community Links).
• **Recommendation 6** - Services should attempt to engage with the language used by BME people to describe their own distress, and not rush to their own formulation of the problems. Mental health promotion aimed at BME groups should consider the benefits of a non-medical approach, in its descriptions, and advice

**Key finding 7: The power of word of mouth reputations**
All focus groups were asked to discuss how they had found out about mental services. Usually this came in the form of a personal recommendation from someone they trusted. This word of mouth reputation was also felt to be the cause of much fear and mistrust of services, where one person’s experience became generalised as the norm.

• **Recommendation 7a:** Serious consideration needs to be given to this finding. For narratives of mental health to be changed at street level, much work needs to be done to promote good experiences and outcomes for BME people, and positive images of how to deal with mental health

• **Recommendation 7b:** Greater importance should be given to meaningful community engagement activities, and funding made available to self-help organisations, in order to increase the profile of BME service users with positive stories to tell

• **Recommendation 7c:** Services need to make active links with the communities in which they are based through outreach, rather than waiting for BME people to spontaneously approach them

### Building Capacity

**Key finding 8: Improving generic services**
Many participants (both service providers and service users) felt that more new BME specific services were not as important as the improvement of generic services - to ensure they are accessible, culturally aware and sensitive, and resourced to support the diverse needs of multi-faith and multi-nationality communities. However, many participants inside and outside services felt that there were no real consequences for services that did not change, and so had little incentive to do so.

• **Recommendation 8** - Commissioners should ensure the ongoing improvement of mainstream services in dealing with BME communities. A whole systems approach should be adopted, using equality impact assessments throughout the commissioning and re-commissioning process. All services should be expected to show positive action to ensure equity in staffing and service use, which accurately reflects the communities they service. Failure to improve should incur financial penalties
Key finding 9: Capacity Building and Community Development Approaches work
The BME communities contain a wealth of untapped enthusiasm and expertise around improving mental health, which can be mobilised to great effect. Positive Action for Refugees and Asylum Seekers (PAFRAS) and RETAS-Leeds focus on developing the skills of users which lead on to volunteering options and sometimes to paid work. Capacity building initiatives such as Minority Ethnic Mental Health Opportunities (MEMHO) Healthy Living Centre have involved BME communities in the design and delivery of small-scale health projects, which have had a lasting impact on even the “hardest to reach” communities. Small amounts of money, with simple application procedures have made a big difference.

• **Recommendation 9** - Further capacity building initiatives need to be funded, which ensure the gifts and skills of the communities to heal themselves are recognised and rewarded financially. Such funding needs to reward evidence based work as well as “new initiatives.”

Key finding 10: Short term funding and the drive for “innovation” reduces capacity
Short-term and uncertain funding for projects supporting BME people erodes the confidence, capacity and resilience of the BME communities at large. The “stop-start” nature of BME projects makes real development and improvement hard to attain. The pressure is always to do something new, rather than to mainstream success.

• **Recommendation 10:** Core funding should be identified to fund projects which promote positive health and engagement with mainstream health services for BME people. The amount of funding should be linked to the performance of mainstream services in engaging BME people and uptake of services

Children, families and young people

Key finding 11: More research needed into the needs of children and families
There was limited participation with this research from children and families services, resulting in a significant limitation of the research. Young BME carers are doubly ignored, and frequently do not receive the statutory support that is their right.

• **Recommendation 11:** A thorough and systematic review of mental health services for families and children of BME origin should take place, with a particular emphasis on the needs of young BME people with caring responsibilities to ensure these needs are not overlooked
Key finding 12: There is no consistent approach to addressing the mental health of young BME people
Focus groups and service providers both expressed concern that young people from BME backgrounds are not receiving adequate support with their mental health. Although services such as Aspire and BHI provide excellent care and support, these services are not sufficient in themselves to meet this need. The inappropriate use of adult services by teenagers leads to lasting damage, and perpetuates fear and mistrust of services amongst the BME communities.

- **Recommendation 12:** Focused work around emotional wellbeing and mental health of young [BME] people should be a priority for schools, youth groups, and sporting activities. Access to non-stigmatising, culturally capable advice and support for this age-group is particularly important, as is mental health promotion

Older People

Key finding 13: Older people and GPs
Older people from BME groups, notably African-Caribbean and Chinese people are experiencing difficulties in accessing some GP practices in the area. There are a variety of issues that include appointment systems, waiting times, attitudes of receptionists, medication and language support.

- **Recommendation 13a:** The Primary Care Trust should ensure all GP practices conduct equality impact assessments on their services, to ensure older people are able to access timely and appropriate care

- **Recommendation 13b:** Advocacy services should be developed to assist BME people to access primary mental health care, with a particular focus on older people. This could be achieved by making advocacy services more readily accessible to older BME people in such places as luncheon clubs and day centres

- **Recommendation 13c:** The CDWs should make achieving access to primary care for (older) BME people a priority

Key finding 14: Culturally appropriate services for older people
There remains a lack of culturally appropriate home-care services for older people, and funding worries remain high on the agenda of existing day services/luncheon clubs working with older people. Although some services exist, many BME elders do not access them because of lack of transport.

- **Recommendation 14a:** There should be better home-care provision for older people from BME communities that takes account of their cultural needs, particularly those who are house bound. Although the Direct Payments Scheme can offer an opportunity to ‘buy in’ culturally sensitive home care services, those working with and supporting older
people from BME communities (including carers) need better information on how to access the scheme, the assessment procedure, and the management of finances

- **Recommendation 14b:** Continued funding and support for work with older people with Dementia across a wide range of BME communities - to encourage socialising with other BME groups

- **Recommendation 14c:** To provide a minibus that can be shared across the locality

**Carers**

**Key finding 15:** Support for people who voluntarily look after others (carers)

Many participants who provide care to people undergoing mental distress do not identify with the label “carer” and were not aware of potential avenues of support available.

- **Recommendation 15a:** Services who provide support to carers need to promote their services in a way which makes better sense to BME carers. (This may entail the use of words other than ‘carer’ to describe the role). BME Carers need better information and support and greater awareness of their right to support themselves

- **Recommendation 15b:** Mental Health Service pathways need to be clearer and better understood by both service users and carers. A carer’s experience featured in Section 3 illustrates how worker support from young people’s services like Aspire is making some difference to carers

**Other findings and recommendations**

**Key finding 16:** Refugees, Asylum Seekers and deliberate self-injury

There is anecdotal evidence of significant levels of deliberate self-injury and attempted suicide by refugees and asylum seekers.

- **Recommendation 16:** Urgent research needs to take place into this, to better understand the anecdotal evidence. In particular, the needs of refugees, asylum seekers and other BME groups need to be considered and incorporated into the local Suicide Prevention Programme

**Key finding 17:** Lack of psychological services for BME people

There is a lack of BME referrals to mainstream psychological services, even though Community Psychiatric Nurses and Outreach Worker caseloads contain high numbers of BME people. There are few counsellors from BME backgrounds,
and few bilingual practitioners. The funding of such services is high on the agenda of black Caribbean people and Asian women, in particular.

- **Recommendation 17**: An action plan to improve access to psychological services for BME people is needed urgently. Psychological services should undertake equality impact assessments to analyse these difficulties, and produce measurable targets for the improvement in recruitment, training, advertising of services, available training and workforce development

**Key finding 18: Support for a One Stop Shop/Community café**

There is significant support for a non-stigmatising, safe space, in which social activities can take place, alongside the delivery of more general health services e.g. peripatetic clinics with GPs and other professionals; drugs services, benefits advice and getting back to employment.

- **Recommendation 18**: Partnerships should be encouraged between existing community centres/building based services, to widen their use, and encourage health services to use them as a base. Models such as Technorth in Chapel Allerton provide an interesting template of a multicultural community centre housing many projects of different types
## Appendix 1

### Original Research Timetable

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<tr>
<th>Week Number</th>
<th>Week Commencing (2007)</th>
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<tr>
<td><strong>Initial</strong></td>
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<td>Advertise Lead Community Researcher</td>
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<td>Shortlist</td>
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<th>Reference group and Method</th>
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<tr>
<td></td>
<td>Research possible partners for reference group</td>
<td>1-2</td>
<td>14/5 – 21/5</td>
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<td></td>
<td>Recruit reference group</td>
<td>2-4</td>
<td>21/5 – 4/6</td>
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<td></td>
<td>Meeting to agree TOR and discuss interim findings</td>
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<td>14/5-11/6</td>
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<td>Count me in and LMHT ethnicity data</td>
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<td>Service Audit/Audit of service use in Chapeltown and Harehills</td>
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<td>11/6 – 25/6</td>
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<td>Use of GP surgeries in Chapeltown and Harehills</td>
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<td>Presenting needs of population</td>
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<td>Models of service delivery</td>
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<td>Interim report to Chapeltown and Harehills reference group</td>
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<td>14/5 – 11/6</td>
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<td>Write up findings and present to BME subgroup</td>
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<td>18/6</td>
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<td>BME Advisory group provide focus of research – inc which communities/needs will be targeted</td>
<td>5-7</td>
<td>11/6 – 25/6</td>
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<td>Identify and Train peer researchers (x4)</td>
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Appendix 2

Reference Group Members

- Sharon Williams, Researcher – Touchstone.
- Kimberley Saggu, Community Development Worker – Touchstone.
- Eddie Mulligan, Community Development Worker – Leeds Irish Health and Homes.
- Councillor Jane Dowson (Chapel Allerton Ward).
- Marcia Hylton, Chair of Hibiscus Carers’ Management Committee.
- Robin Ellis, Outreach Worker – Community Mental Health Team, St. Mary’s House.

Reference Group Aims

- Establish membership of the group.
- Provide support to the researcher.
- Provide a focus to the research.
- Provide advice and guidance on interest groups, visits, contacts, community mapping.
- To ensure representation of the Reference Group from different sectors: voluntary, community and faith sector (VCF), statutory sector, non-mental health service, local person, and carer. Also where possible, from different BME groups.
Appendix 3 –

Desktop Review Questions

1. WHAT TYPE OF SERVICE DO YOU PROVIDE? E.g. work with young people, families, and older people.

2. WHO USES YOUR SERVICE? E.g. BME communities.

3. IS YOUR SERVICE ACCESSIBLE TO BME INDIVIDUALS/GROUPS? Can include numbers here.

4. IF YOUR SERVICE IS ACCESSIBLE, WHAT REASONS CAN YOU GIVE FOR THIS? E.g. employ BME workers, encourage BME individuals to self refer.

5. IF YOUR SERVICE IS NOT ACCESSIBLE, WHAT REASONS CAN YOU GIVE FOR THIS?

6. WHAT DO YOU THINK WOULD IMPROVE OR INCREASE SERVICE UPTAKE BY PEOPLE FROM BME GROUPS? E.g. reviewing referral process, going into communities.

7. WHAT TYPE(S) OF ‘MENTAL HEALTH’ SERVICE(S) OR SUPPORT SHOULD BE PROVIDED IN CHAPELTOWN AND HAREHILLS?

8. DO YOU MONITOR ACCESS AND UPTAKE OF YOUR SERVICE BY BME GROUPS/INDIVIDUALS? IF SO, HOW ARE YOU DOING THIS?

9. WHAT DO SERVICE USERS SAY OF THEIR EXPERIENCE(S) OF USING YOUR SERVICE? E.g. you can give an overall comment or give individual service user example.
Appendix 4

Agencies and services interviewed.

A set of key questions were devised that formed the basic structure of the interviews and discussions. The questions helped guide the interview and discussion, with appropriate notes taken. Some were conducted in person or information given over the telephone or emailed. Participants also gave additional information and responses that were not restricted to the set questions. This was encouraged as it added to the discussion and raised other issues relating to BME communities that was not just about mental health.

Interviews carried out with the following:

**Adult Social Care (Social Services, North East Leeds)** - 79 Roundhay Road, LS7 4AA. Tel: 0113 249 5787

**Advocacy Support** - Contact: Derek Sankar, 267 Roundhay Rd, LS8 4HS. Tel: 0113 235 1877

**Child and Adolescent Mental Health Service (CAMHS) – East and North East Leeds** - Contact: Janet Shepherd, Osmondthorpe One Stop Centre, 81a Wykebeck Mount, LS9 0HN

**Community Links Housing Support Service** - Two teams covering the city, providing re-housing, mental support in person’s home. Also run Markham Avenue drop-in for BME clients (weekly). Service provides BME workers and South Asian family worker. Contact: Catherine Donnelly, Manager, Suite 3, Harrogate Rd. Tel: 0113 307 3900.

**Community Links Home Support Service for Older People** – covers LS7, 8 and 9. Contact: Sandra Herbert (worker for African-Caribbean people). Also has workers for South Asian and Polish communities. Suite 4, Bank House, 150 Roundhay Rd, LS8 5LJ. Tel: 0113 200 9180.

**Community Mental Health Team** - Leeds Partnerships NHS Foundation Trust. A community mental health team for people suffering from more severe and enduring mental health problems. Access is usually via a GP or Consultant Psychiatrist. Contact: Dave MacFadyen, CPN, Richard Hattersley, Clinical Manager, Robin Ellis, Outreach Worker. St. Mary’s House, St Mary’s Road, LS7 3JX. Tel: 0113 295 2313

**Leeds Black Elders Association** - Contact: Simeon Sobers, Manager 180 Chapeltown Road, LS7 4HP. Tel: 0113 237 4332

**Leeds Involvement Project** - Contact: Tanveer Ahmed, BME Disabled People Involvement Worker. Ground Floor, Unit 8 Sheepscar Way, Leeds LS7 3JB. Tel: 0113 237 4508; Minicom 0113 2374512. www.leedsinvolvement.org.uk
Leeds Racial Harassment Project (now Stop Hate UK) - Unity Business Centre, 26 Roundhay Road, LS7 1AB. Tel: 0113 298 5100. www.lrhp.org.uk

Positive Action For Refugees and Asylum Seekers (PAFRAS) - Contact: Project Manager, Christine Majid and Chris Manning, 269 Roundhay Road, LS8 4HS. Tel: 0113 248 4147. email: pafrasemail@yahoo.co.uk

Youth Service - Leeds City Council. Contact: Adrian Lee, 180 Chapeltown Road, LS7 4HP. Tel: 0113 214 5846.
Appendix 5

Other Relevant Services and Groups

Community and Voluntary sector

10-2 Club - Chapeltown’s Young People’s 10-2 Club (CYP10-2) is a progressive Club for Young People aged 13-25, living in the Chapeltown Area of Leeds/or living in the Leeds 6, 7 and 8 areas. Contact Felina Hulmes: Unit 15 Chapeltown Enterprise Centre, 231 Chapeltown Road, LS7 3DX. Tel: 0113 307 0303/262 6333. email: f.hughes@cyp-10-2club.org.uk.

Archway – Various services for 16-25 yr olds, supported housing, Resource Centre, counselling, welfare rights, crèche, sporting activities, ESOL support. 95 Roundhay Road, Leeds, LS8 5AQ. Tel: 0113 383 3900. www.archway-leeds.co.uk

Black Health Initiative (BHI) – voluntary organisation based in Chapeltown that promotes and supports the health and well being of African and African Caribbean communities in Leeds. Contact Stephen Derrick: Unit 10, Chapeltown Enterprise Centre, 231-235 Chapeltown Rd, LS7 3DX. Tel: 0113 307 0300. www.bcathealthinitiative.co.uk

- Ku Sikia Counselling Service (means ‘to listen; in Swahili).- for 7-11 yr olds attending Bracken Edge Primary School, Bankside Primary School and Holy Rosary and St Anne’s Catholic Primary School. Tel: 0113 307 0300. sderrick@bcathbhi.org.uk
- The Mayisha Project - provides drug prevention and harm reduction interventions to young people under the age of 25 who are affected by issues of substance and alcohol misuse. Tel: 0113 307 0301. email: admin@bcathbhi.org.uk

CHIVA (Children in vulnerable Accommodation) – Free service for refugee and asylum seeking children 0-19 yrs. Provide play, access to services, educational support, someone to talk to and therapeutic support. Funded by Leeds Children’s Fund, Education Leeds, LCC Early Years, LCC Housing Dept, ASC and CAMHS. Carr Gomm, 2nd Floor, Oak tree House, LS8 3LG. Tel: 0113 225 8915. email: chiva@carr-gomm.org.uk

Community Links (Northern) Ltd. Provides a variety of mental health services in the Chapeltown and Harehills area and city-wide. Head Office: Regents Court, 39a Harrogate Rd, LS7 3PD. Tel: 0113 307 0800.

- Aspire – Early intervention in psychosis service for 14-35 yr olds. The service also has a South Asian worker. Contact: Joan Higgins (African-Caribbean worker) Suite 1, Bank House, 150 Roundhay Rd, LS8 5LJ. Tel: 0113 200 9170. email: joan.higgins@commlinks.co.uk
- Home Support Service for Adults - 16-64 with both African-Caribbean and South Asian workers. Jamaica House, Chapeltown Road.
Feel Good Factor (FGF) - A Healthy Living Centre that aims to improve the health of people in North East Leeds. Contact: Corrina Lawrence, Director. C/o Unity Housing, 113-117 Chapeltown Rd, LS7 3HY. Tel: 0113 200 7736 or 200 7744

Getaway Girls – works with girls and young women, offering various projects - Asian Girls’ group, PPP Project, Choices Project, Inspiration Project, Users’ Group, volunteering opportunities, Summer Project and work with local schools. Contact: Georgia Cooper, 67 Bayswater Grove, LS8 5LN. Tel: 0113 240 5894.. email: georgia.cooper@getawaygirls.co.uk.

Information for Mental Health – Contact: Chris Lusardi, 26 St Michael’s Rd, LS6 3AW. Tel: 0113 275 2417. www.leedsmind.org.uk

LATCH (Leeds Action To Create Homes) – Self-help housing charity and collective that runs projects working with homeless people and volunteers in Leeds. Offers supported housing to homeless people, rehabilitate/renovate houses, provides training and skills. SHP (Supported Housing Project), SHIFT Project (Self-Help Improvement Project for Tenants). Contact: 176 Chapeltown Road, LS7 4HP. Tel: 0113 237 4482. email: latch@latch.org.uk.

Leeds Asylum Seekers Support Network (LASSN) –supports asylum seekers, has a hardship fund (weekly payments between £25-40), acts as hosts to those people who have arrived in the country and have nowhere to stay (e.g. for a few days). Contact: 233-237 Roundhay Road, LS8 4HS. Tel: 0113 380 5690 email: lassn@lassn.or.uk . Contact: Archana Choksi. email: archana@lassn.org.uk.

Leeds CAB Mental Health Outreach Advice Service – Roundhay Road Day Centre, 79 Roundhay Rd, LS7 4AA (alternate Wed 2-4); Becklin Centre, St James’s Hospital, Beckett Street, LS9 7TF.

Leeds Health Focus - South East Asian groups, offering various activities, healthy living and healthy eating courses. 228-230 Roundhay Road, LS8 5AA. Tel: 0113 248 8866/ 8262.

Leeds Irish Health and Homes - Voluntary sector organisation that provides culturally sensitive support for Irish people. Services include outreach, supported housing, activities (luncheon club, Rambling group, Let’s Knit group), newsletter, partnership working with other Irish services and groups in Leeds e.g. Irish Arts Foundation, Irish Centre, Touchstone Community Development Service. Contact: Eddie Mulligan, Community Development Worker, Unit 5, Gemini Park, Sheppscar Way, LS7 3JB. Tel: 0113 262 5614, www. info@lihh.org

Leeds Mind
- Leeds Mental Health Employment Consortium – Contact: Caroline Bamford, Convenor, 26 St. Michael’s Road, LS6 3AW. Tel: 0113 275 5307. email: consortium@employmentleeds.org.uk.
- STEP Project – Step Towards Employment – citywide project to support people who use mental health services into education, training, voluntary
work and employment. Contact: Kate Balmforth. Tel: 0113 224 3559. email: kate.balmforth@leeds.gov.uk

- **Working Minds Project** – funded through Access To Employment Funding, under the Worklessness strand of the Leeds Local Area Agreement and a contribution from Leeds Partnerships NHS Foundations Trust. They support mental health service users from Chapeltown, Harehills and Hyde Park to access work placements (within voluntary sector) and work focused mentoring opportunities. Contact: Caroline Bamford (contact details above).

**Leeds Refugee Forum** – umbrella organisation for Refugee Community Organisations in Leeds. Contact: Archana Choski, One Community Centre, Cromwell Street, Lincoln Green, LS9 7SG. Tel: 0113 380 5695. email: infor@leedsrefugeeforum.co.uk

**PATH (Yorkshire) Ltd** – Works with various voluntary sector agencies, Housing agencies, Arts, Media, Education, Criminal Justice and various others (NHS Trust, Leeds City Credit Union, Yorkshire Forward, West Yorkshire Fire Service). Place BME trainees in these agencies and deliver Positive Action Training to develop skills in employment. 29 Harrogate Rd, Chapel Allerton, LS7 3PD. Tel: 0113 262 4600. www.pathyorkshire.org.uk

**People In Action (PIA)** – work with people with learning disabilities. Multi-cultural centre. Contact: Chand Rani Singh (Group Co-ordinator). Technorth Family Learning Centre, 9 Harrogate Road, LS7 3PD. Head office: Oxford Chambers, Oxford Place, LS1 3AX. Tel: 0113 247 0411. www.peopleinaction.org.uk

**Polish Centre, Chapeltown Road** – Day Centre (open Wed morning). Luncheon Club for Older Polish people, School for 20 children at the centre, for those new migrants who are working.

**Refugee Action** – Contact: Mani Thama, Community Development Worker; email: manit@refugee-action.org.uk; Fidelis Chebe, Refugee Action, Suite 7, Floor C, Joseph’s Well, Hanover Walk, LS3 1AB. email: ficheb@yahoo.co.uk

**Refugee Job Placement Project** – The Gatehouse, Mansion Gate, Chapel Allerton, LS7 4RF. Tel: 0113 307 0567. email: mail@thebacktoworkcompany.com.

**Resourcing the Community** - Contact: Fathema Khatun, 233-237 Roundhay Road, LS8 4HS. Tel: 0113 380 5624

**RETAS-Leeds** – division of Education Action International. Offers information, advice and guidance on education, training and employment. Have a drop-in and appointments advice service, staffed by volunteers (Ukrainian, Russian, Congolese, Ugandan and Eritrean. Contact: Duncan Wells, Regional Director, 335 Roundhay Rd, LS8 4HT. Tel: 0113 240 7320. email: Duncan.wells@education-action.org.

- **Welcome to Leeds** – Befriending service is based in same office as RETAS-Leeds
Roscoe Methodist Church - Chapeltown Road.

Shantona Women's Centre - Activities for Bangladeshi women, children and young people. Contact Nahid Rahsool, c/o Bangladesh Community Centre, Roundhay Road, LS8 5AN. Tel: 0113 249 7120.

Solace - Counselling and psychotherapy service for refugees and asylum seekers. Contact: Andrew Hawkins, Suites 1 and 2, Bank House, 150 Roundhay Rd, Harehills, Leeds LS8 5LJ. Tel: 0113 249 1437 email: info@solace-uk.org.uk

Together, Working For Wellbeing (formerly MACA) - A service that supports carers of people with mental health needs or dementia living in Leeds. Also offers crisis counselling and complementary therapies. Contact: Julie Hemsley or Diana Robinson, North Leeds Respite and CSS, Unit 26 Unity Business Centre, 26 Roundhay Rd, LS7 1AB. Tel: 0113 242 7707. www.together-uk.org

Touchstone - Leeds – Voluntary sector mental health organisation providing support city wide, including services that cover Chapeltown and Harehills. Head Office: 2-4 Middleton Crescent, Beeston, LS11 6JU. Tel: 0113 271 8277. www.touchstone-leeds.co.uk

- Chinese Satellite Project
- Community Development Service
- Community Support Team
- Flexifund
- Minority Ethnic Mental Health Opportunities
- Sholebroke Housing
- Sikh Elders Neighbourhood Network
- Support Centre
- Supported Housing

Statutory sector

Primary Care Mental Health Team – Focus Learning and Self Help (FLASH). Open access clinic. Runs from Chapeltown Health Centre, Spencer Place every Thursday 1-4pm and Friday 1-3pm. Offers a resource library, one-to-one support to use self-help materials. Open to those 16 plus in the area, no need for professional referral. Tel: 0113 295 1795.

Community Alternatives Team (CAT) address as previous – offers mental health service users opportunities to get involved in training, employment, education, volunteering and sports and leisure. Workers include an Asian women's worker.

Leeds Thomas Danby College – provides personal counselling and welfare services. Guidance and Welfare Services, Roundhay Rd. Tel: 0113 284 6305, www.thomasdanby.co.uk
Health Access Team – HAT aims to support asylum seekers and refugees in accessing health care and services that promote health and wellbeing. The Team will work with any asylum seeker or refugee and will offer support on a short to medium term basis depending on the complexity of need. Leeds PCT, 0113 295 2740.

Neighbourhood Learning Project (Adult and Community Learning Service) Chapeltown and Harehills area. Leeds City Council. Tel: 07891270634.

Other Useful contacts

ACCESS (African-Caribbean Children’s Educational Success Service) – Barnado’s. Contact: Naomi Colhoun, widening Participation Project Support Officer. Tel: 0113 208 6752/209 6796, open 4-5.30pm, Leopold St next door to Chapeltown Children’s Centre.

Leeds Cyber Café – Yes Cyber – offers computer courses, job search, and basic skills. 131 Chapeltown Rd, LS7 3DU. Tel: 0113 262 0794.

Sure Start Chapeltown Children’s Centre Partnership comprises of 3 centres offering services to local families and young children. 62 Leopold St, Chapeltown, LS7 4AW.

• Sure Start, Chapeltown - drop-in service for pregnant asylum seekers and refugees);
• Chapeltown Children’s Centre - nursery, free counselling service for parents and carers of a child under 11;
• The Mosiac Centre
Appendix 6

References - reports, publications and newsletters


Count Me In Census 2006 (Leeds Analysis) Leeds Partnership Foundation Trust.

Count Me In Census 2006, Healthcare Commission, CSIP, NIMHE and Mental Health Act Commission.


Gan Didean/Without a Place to Stay – Homeless Irish People, Eddie Mulligan, Leeds Irish Health and Homes, 2006.


Roma in Leeds – An Audit of their situation, needs and services. Draft copy Commissioned by the Travellers Health Working Group, December 2006.

Two Heads Are Better Than One – Leeds Social Services, 2005

Community and Service Newsletters

Community Cascade E-News - Issue 60, 1 June 2007 – Contact: Jean Wilson. Tel: 0789 127 063. email: jwilsonldwnorth@hotmail.com

Community Highlights newsletter, www.communityhighlights.co.uk

Feel Good Factor Newsletter.

Leeds Irish Health and Homes, contact: Eddie Mulligan eddie@lihh.org

LIPpy - Service Users and Carers Newsletter, Leeds Involvement Project.

North East Mental Health Forum Newsletter.

Positive Action For Refugees Newsletter.

Space2 News – Contact: Emma Tregidden and Dawn Fuller, Bracken Edge Primary School, Newton Rd, LS7 4HE. Tel: 0113 214 5862. email: admin@space2.org.uk

Unity News – Winter 2006/7 – Unity Housing Association, 113-117 Chapeltown Rd, LS7 3HY. Tel: 0113 200 7700.
Appendix 7

Materials relating to the Community Researchers

The Advertisement for Community Researchers

Community Researchers BME (Genuine Occupational Requirement)
Touchstone are looking for 4 enthusiastic people to assist them with a piece of research into the mental health (MH) needs of people from Black and Minority Ethnic (BME) backgrounds, who live in the Chapeltown and Harehills areas of Leeds.

These 4 people will:
- Be from a BME community
- Have direct experience of using or caring for someone using MH services
- Be enthusiastic and committed to finding out what other users and carers think of MH services
- Assist with one to one interviews, and group discussions about how things can be improved
- Not need any previous experience of research
- Be available to work 10 hours a week, from 9th July until 31st August (7 weeks, or 70 hours in total)
- Have an existing Criminal Records Bureau Check, or be willing to have one completed
- Come with a recommendation/reference from an existing MH service provider

In exchange for this commitment Touchstone will offer:
- Training and support
- £9.56 per hour
- An opportunity to build your confidence and learn new skills
- An insight into how services are developed and commissioned

Purpose of the Work:
- To discover what the BME people of Chapeltown and Harehills want from MH services, on behalf of Leeds ASC
- To help identify gaps in service provision
- To provide a suggestion of how these gaps can be filled
- To enable people with direct experience of MH difficulties to shape the way in which MH services are designed and run

Duties:
- To assist with community research project
- To undergo basic training (confidentiality, equal opps, MH awareness, basic research methods/skills)
- To contribute to the development of research techniques and practice in this field
- To conduct 1-2-1 interviews
- To assist with running of focus groups.
- To keep simple records of what has been done
- To contribute to the completion of the Final report

Touchstone is an Equal Opportunities Employer. If you are interested, or know someone who is interested in this work please contact jonb@touchstone-leeds.co.uk or call 07760 173496 by 13th July 2007.

Reflections on the use of community researchers – notes from discussions between research team September 2007

<table>
<thead>
<tr>
<th>What worked</th>
<th>What could be improved</th>
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<tbody>
<tr>
<td><strong>Recruiting</strong> people from the same ethnicities and similar backgrounds of the people and communities we wanted involved in the research. We were able to recruit people on benefits, in paid work and/or studying or doing voluntary work.</td>
<td>Better preparation, information and advice on benefits, especially over how much they can earn without stopping benefits. Advice given through MEMHO/Leeds CAB advice sessions for BME clients.</td>
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<td><strong>Different ages</strong> e.g. having a young person helped bring a young person’s perspective to the research.</td>
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<td><strong>Different skills and experience</strong> – Written and verbal communication (e.g. community language skills); research skills; ability to engage with different people and communities (e.g. with people who are not with services).</td>
<td><strong>Involving the Community Researchers in more of the administration tasks</strong> e.g. collecting data, monitoring information from the Focus Groups and individual interviews.</td>
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<tr>
<td><strong>Pairing Community Researchers</strong> together and working with Community Development Workers giving support and helped compliment different knowledge, skills and experience.</td>
<td>Pairing was not always successful meaning some Community Researchers worked in isolation, or were delayed by lack of contact with their fellow researcher.</td>
</tr>
<tr>
<td><strong>Service User background</strong></td>
<td>Recruitment of more Community Researchers with a mental health diagnosis.</td>
</tr>
<tr>
<td><strong>Knowledge of Chapeltown and Hare hills</strong> (one or both).</td>
<td></td>
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<tr>
<td><strong>Training and preparation sessions</strong> – Confidentiality, Boundaries, Equal Opportunities and Diversity, Risk Assessment, Lone Working; Research skills.</td>
<td><strong>Availability</strong> – some of the Community Researchers were not always able to make the sessions (studying, work commitments) so more time needed to keep them up to date.</td>
</tr>
<tr>
<td>Forward planning and preparation by Community Researchers in getting</td>
<td><strong>Availability</strong> – some Community Researchers had other commitments</td>
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groups and communities together, use of venues and centres. which reduced the amount of time they could give to the project.

| Use of Touchstone facilities and resources e.g. work mobiles, computers, phones, workspace, meeting room. | More administrative support to relieve pressure on Lead Researcher and CDS Co-ordinator. |
| Regular contact, guidance and support with Lead Researcher (p/t) and Community Development Service Co-ordinator. |

**Lessons for the Future**

- **Time** – We tried to do too much, too quickly. This affected everything: recruitment, training, preparation, arranging and carrying out the Focus groups and one to one interviews, collating data, monitoring information, people’s views and the final write up.
- **Strategic** – The researchers felt they would have benefited from greater guidance on how to target the communities we wanted to research.
- **Monitoring** – More guidance and support could have been given around the process of collecting monitoring data (e.g. explanations in Focus groups and interviews of its value and better briefings on categories such as ‘Sexuality’).

**TOUCHSTONE COMMUNITY RESEARCHER FEEDBACK**

It would be good to get feedback about your experience of being a Community Researcher with Touchstone during the carrying out of the research into the mental health needs of Black and minority ethnic (BME) communities in Chapeltown and Harehills. Community researchers can use this feedback form or feedback verbally.

**About Me: Rukhsana Khawaja**

Born and educated in Karachi, Pakistan and took up further studies in the UK. I have been actively involved in community work since the past 20 years. Set up a number of projects in the community, especially for women. Education issues are very much close to my heart, especially in the community. I have been working for a High School for the past 15 years. Many parents look up to me for guidance and advice for their children. I also support many charities here and abroad, especially in the health and education field.

Married and proud mother of four sons, I have been living in Leeds, Yorkshire for the past 30 years. I equally, thank my husband who has always helped and guided me in various projects, his support is invaluable.
WHY DID I APPLY TO BE A COMMUNITY RESEARCHER?

I applied to carry out the above mentioned community research as I have the necessary skills to do this job. I also have extensive links in the BME community and have carried out a number of research projects. These projects were carried out on the behalf of Leeds University, Leeds Metropolitan University, Lifeline Youth Project and Health Focus.

My fulltime job itself involves me with the community. I am very passionate about the community and the issues affecting them. I feel very strongly that someone should up and take a lead to deliver them. I know it is a hard job, but then it is a hard job to start any project.

This explains why I got involved in this project. This project has been an eye opener as I heard a number of case studies of participants. It is sad that this project was short term and therefore I feel that I could not do much in this area. I am sure that in the future if any opportunities came my way I would surely respond to take part.

TRAINING AND PREPARATION

I think it was sufficient training and preparation given, especially to the new applicants. It was a lot of hard work on the part of Touchstone and well prepared which made people feel confident enough to deliver.

Please comment on the areas of work you were involved with, including planning, organising and carrying out the Focus Groups and/or Interviews

FOCUS GROUPS

Sindy and I sat down and prepared how to deliver each session according to the needs of the Focus Groups and individuals. Prior to the actual meeting taking place, I personally went to introduce myself to the group members so that they got familiar with me and at the same time I informed them that if they have friends who like to take part, to bring them along. Likewise, Sindy did with her groups.

We made the members aware of the ground rules as to how they can participate in this discussion. We felt the members made us feel very much at home. They thought that we can resolve all their concerns and pass all the issues mentioned to the appropriate bodies concerned.

All the Focus Group work was completed successfully, in fact a lot of other groups inquired if we could interview them as well but due to limited funding we could not do it.
INTERVIEWS

I carried out six interviews. Most of them were working in the mental health field. GP’s need more training with mental health issues. This came out more clearly in some discussions, rather than just giving medication.

All interviews took place in the individual’s home.

HOW WILL THIS EXPERIENCE HELP ME IN THE FUTURE

It was an eye opening experience. I think in future if any further opportunities come up, I would very much like to take part. In a way, the community was relying on us to take on these issues. Being an Asian person and from the same background it did help.

Any further comments…………………..

I thoroughly enjoyed myself, it’s been very rewarding when we completed each session. We had a very positive response from the community. In future we require more timescale to organise and plan our meetings with all workers involved. We would like to see the outcome of this research work.

TOUCHSTONE COMMUNITY RESEARCHER FEEDBACK

It would be good to get feedback about your experience of being a Community Researcher with Touchstone during the carrying out of the research into the mental health needs of Black and minority ethnic (BME) communities in Chapeltown and Harehills. Community researchers can use this feedback form or feedback verbally.

About Me: Surinder Chana

I came to the UK as a refugee from Uganda in 1972 with my parents and four brothers. I was a carer for my mother at the age of 17 for three and a half years and at the time looked after my brothers and my father. At the age of 20 when sadly I lost my mother, I took up a position as a junior in an Underwriting Department with an insurance firm. From then on my career went from strength to strength, moved to London working in the city as a corporate broker. Got my registration as Lloyds broker. In 2000, I relocated to Leeds and got involved with community and charity work.

Many parents look up to me as a role model for their children and I offer valuable advice as and when required. This could be a school issue, further education or University. Most of the time it is assisting with the language problems, as I speak Punjabi, Urdu, Gujarati and Hindi. Not to mention resolving legal issues which at times I end up going to court. Mind you I have yet to lose.
My time is spent in the public domain very much. I also carry out duties at Temples around Leeds and Bradford. I am unmarried and live in Chapel Allerton with my dog, Rosie.

WHY DID I APPLY TO BE A COMMUNITY RESEARCHER?

I applied to carry out the above mentioned community research as it was something that appealed to me. It gave me an insight to the community as a whole which I wanted to carry out for some time to put things into focus. As I have been working for the BME community for sometime, it was always problems relating to mental health, mental illness and mental well being that surfaced to the top. Wide experience and as a service user I wanted very much to get involved in this project.

I am unemployed but a day doesn’t go by when I don’t receive a telephone call to resolve some sort of issue – may it be legal, school, but mainly relating to health/hospital/GP (I don’t get paid for these duties performed, I do this purely from the goodness of my heart as I care for the community). I am very passionate about the community and the issues affecting them. I know it is a hard job but then it is a hard job to start any project. My main object to participate in this project was to confirm my thoughts and feelings and this was exactly what the outcome was that there is a lack of resources in the community especially in the BME community.

TRAINING AND PREPARATION

Sufficient training and preparation was given. Additional attention was provided to the new applicants. Thanks should go to Touchstone – Jon Beech and Sharon Williams who put the team together to deliver the well prepared agenda which made people feel confident enough to participate.

Please comment on the areas of work you were involved with, including planning, organising and carrying out the Focus Groups and/or Interviews

FOCUS GROUPS

Rukhsana and I sat down and prepared as to how we were going to deliver each session according to the needs of the Focus Groups and individuals. Prior to the actual meeting taking place each group was informed beforehand and the agenda discussed so that they got familiar with us. They were also informed that if they had friends who would like to take part, to please bring them along as well. If they are disabled, transport can be arranged for them.

We made all the members aware of the ground rules as to how they can participate in this discussion. In all the centres we were made to feel welcome. They thought that we can resolve all their concerns and pass all the issues mentioned to the appropriate bodies concerned.
We felt each Focus Group was successful and a lot of groups asked if we could interview them but this was limited due to limited funding. I think such gatherings should take place on a regular basis. This is the only way to weed out the underlying problems, make people talk.

**HOW WILL THIS EXPERIENCE HELP ME IN THE FUTURE**

If any further opportunities come up in the future, I would like to take part. The Focus groups were relying on us to take their issues further. Being an Asian person and from the same background it did help. Being a service user and the help that I have received for my well being, I would like to thank all those people. I would like to spend time developing and delivering the concerns that arose. This project has provided me with a better understanding of the issues concerned and mental health was the main issue in this project.

**Any further comments..........................

I thoroughly enjoyed myself and it has been rewarding. We had a very positive response from the community. In future we require more time for organising and planning our meetings with workers. There should be more networking amongst the centres.

I have taken up the matter of the Community Health Bus up with local councillors and the affect of drugs on young people in the area I have liaised with local police. It is important that local people take part in looking after their areas.

These issues came out of some of the Focus Groups, that is why I think it is also important that medication is explained and the side effects by the GP. There were also concerns about drugs prescribed for depression and the appointments system at surgeries.

I would like to see the outcome of this research and receive a copy of the final report.
Appendix 8

Materials relating to the Focus Groups

Written Guidance for Focus Group Participants

The Research Project
The research has been commissioned by Adult Social Care into the mental health needs of the Black and Minority Ethnic communities of Chapeltown and Harehills.

They want to find out what kind of mental services people in Chapeltown and Harehills want, and use. They also want some advice about how they could best spend £120,000 a year to make the mental health of people in Chapeltown and Harehills better.

Touchstone
Touchstone is a Mental Health charity, who have agreed to find out the views and opinions of the different communities. Touchstone has employed people with direct experience of MH to do the research, and help decide what needs to be asked. We will be interviewing groups of people and individuals over the next few weeks.

There will be around 8-10 focus groups with different groups within the communities. There will also be 10 or 12 in depth interviews with individuals. If you are interested in doing an in-depth interview, please speak to one of us at the break or at the end. We hope to speak to about 130 different people.

Confidentiality
We will be recording the discussions, making notes, and typing up a summary of what was discussed. Only members of the research team will have access to these recordings/transcripts. What you say will be treated as confidential. Although we might use your exact words – we won’t say who said it.

It is important you know that we have a duty to prevent people we know about from being harmed. If you say something that makes us think someone might be harmed, we will have to act to try to stop it.

If you want to know how your opinions were used, please leave your name and address so we can send you a copy of the report. If you want a copy of the recording we can let you have one.

Monitoring
ASC are keen we speak to a good range of people. At the end of today’s session we will ask you to share some information with us about how old you are, the languages you speak etc. We do this to help us prove that we have spoken with a good range of people. We will make sure the information you give us cannot be traced back to you as an individual.
Looking After Yourself
Mental health is a hard topic to discuss. If what we talk about makes you upset or worried, you can leave at any time. You can also speak to a member of staff at the end. But please make sure you speak to someone if you need to.

Payment
Everyone who takes part in the research will receive a fee of £15 in cash to cover their expenses. You will be asked to sign a receipt for this money. If you are on benefits you need to tell the benefits agency about this payment, but it should not affect your claim.
The Focus Group Questions (and prompts)

1. What does good mental health/well being mean to you?
   - How do you know when things are okay?
   - How do you know when things aren’t okay?
   - (Where do you get your ideas about good mental health from?)

2. What are the main MH issues within your community?
   - Examples of these: Depression, Drug use, Trauma, Anxiety
   - Are these the same as other people in C&H?
     - If so why? If not why?
   - Are there particular causes/reasons for this?

3. Where would you go if you needed help with how you feel?
   - Health Services, Charities, Family/friends, Places of worship
   - Are there particular reasons for choosing one over another:
     - Is it important to have staff you can identify with?
       - Ethnicity, experience, understanding, language
     - Is it important formal/informal
     - Does the seriousness or type of problem make a difference?
     - Is location or transport a factor?
   - When would you think about speaking to a GP?
     - What would prevent you from speaking to a GP?

4. What can you do to avoid MH probs from developing in the first place?
   - Physical activity, Family relationships, Education/work, Harm minimisation
   - Who are the best people to promote this sort of thing?
     - Who knows about these things?
     - Who do you trust?
   - What works?
     - Local examples
     - How can we do more of these things?

5. What would you like to see more of, to enhance/protect the MH of people in C&H?
   - Activity
Focus Group Question 5 - Activity

I think the money should be spent on...

Helping people meet each other and make new friends
Helping people avoid poor mental health
Helping people to recover when things have gone wrong
Employing the right people from my community
Employing the right people from any community
Something new
Helping existing services get better
Something for my community in particular
Something for the whole community

Older People
Young People
Men
Women
Counselling or someone to talk to
Things that happen during the day
Things that happen at evenings and weekends
Helping me to see my GP easier
Promoting good mental health
Helping religious groups get more involved in mental health
A Community Cafe
A mobile health bus
Something else (please say what)
Additional choices (“something else”) selected by participants from Focus Groups

Leeds Irish Health and Homes
- none

Black Caribbean Adults 1
- Use of community radio

Black Caribbean Adults 2
- Creative training packs

Young Black People
- None

Montague Burton (Women)
- Home visits
- Meals on wheels
- Employ people who are bi-lingual
- Help for families with disabled children
- Transport
- Help for families with disabled children
- Bath seats to sit in the bath

Montague Burton (Men)
- Something for blind and disabled people
- A centre open seven days a week
- More newspapers and reading materials
- Young people off the street and Asian children jobs
- Activities – outings, parks, exercise and keeping fit
- GP and dentist to see groups at the centre
- Chemist
- Meals on wheels
- Social Service phone link

Solace
- Transport
- Crèche

Khushi Group
- Yoga
- English Class
- Support Worker in our community
- More getting together of the neighbourhood community
- Groups – they give more support
- Support required when partner passes away
- Transport – public bus for those who are housebound
- Someone who makes sure that when treatments given they are followed
- Ground floor venues
- Getting together with other centres e.g. Leeds and Bradford
- Meal on wheels
- Help with shopping
- Things that guide young people
- Activities – health related like, walking and swimming
- Own centre in North Leeds with a Community Nurse/GP, counsellor

**Milun Women’s Centre**
- Religious groups – raise awareness to remove the stigma of mental health
- Helpline to talk (24 hours)
- Bigger venues
- PCTs doing something more to raise awareness
- Yoga classes
- Aromatherapy
- Home help
- Transport
- People awareness of courses

**Touchstone Carer’s Group**
- None

**Apna Centre**
- Children- school support, drugs and counselling
- Improving centre – run out of money want to start women’s centre next door
- Homecare
- Health visitors, nurses
- Community policing because of drugs problem
- Activities at the sports centre
- Transport for outings, going to other centres in Leeds and Bradford

**Bangladeshi Men’s Group**
- All language leaflets to promote mental health
- Activities
- Training (ESOL)
- Outings
- Workshops
- Holidays

**Bangladeshi Youth Group**
- Internet café for health only
- Activities for boys only e.g. football, cricket, swimming, football tournament
- Activity money
- Trips – residencies to keep busy off the street
- Local facilities

**Touchstone Support Centre service users**
None
The monitoring form used throughout the research

Chapeltown & Harehills BME
MH research Monitoring

Please tear off the slips and put them in the cups provided

Thank you for your help
Appendix 9 –

The One to One Questions

The bullets are just prompts, in case someone does not understand the questions. They should not just be read out.

1. Which part of Chapeltown and Harehills do you live in?
   • Chapeltown/Harehills

2. Which community do you ID most strongly with?
   • Ethnicity
   • Locality
   • Religion/Belief
   • Gender
   • Age
   • Sexuality

3. What does good mental health/well being mean to you?
   • Feeling good
   • Meaningful relationships with Family/friends
   • Employment
   • Confidence
   • Financial Security
   • Debt Free
   • Daily chores
   • Socialising having an active life
   • Practising religion
   • Anything Else

4. What do you think are the main MH issues within your community?
   • Isolation
   • Depression
   • Drug use
   • Trauma
   • Anxiety

4b. What are the most important MH issues for you?

5. Where would you go if you needed extra help with your MH?
   • family/friends
   • place of worship
   • health services
   • charities
   • pub

6. What MH services do you know of in Chapeltown and Harehills?
7. **How do you find out about them?**
   - Word of mouth
   - Internet
   - Leaflets
   - GP surgeries
   - Media

8. **Have you ever used a MH service?**
   - Which
   - What was useful
   - What would you like to see improved

9. **If you were seeking help with your feelings, what sorts of people would you prefer to get this from?**
   - What factors are important to you in the identity of the person providing help / support to you?
   - Is their ethnicity / gender/ religion / belief important?

10. **What do you think social services should prioritise – helping to prevent MH problems from happening, or helping people recover?**
    - If both, what do you prefer?

11. **Is the answer something new or doing what we do better?**
    - New ideas?
    - Enhancing existing services
    - Small pots of money

12. **If you could do one thing to promote good MH in Chapeltown and Harehills, what would it be?**

13. **Would you like to add any further comments or raise any further questions?**
    - What has not been asked?
    - Did you understand the questions?
    - Feedback
    - What will happen with the information?