

# rethink



**our voice: the Pakistani  
community's view of  
mental health and mental  
health services in Birmingham**  
report from the Aap Ki Awaaz project

## The CSIP/UCLAN Community Engagement Model

The research that is described in this report is a Community Engagement Project and was commissioned by CSIP (Care Services Improvement Partnership) and UCLAN (University of Central Lancashire) in 2006 as part of the Delivering Race Equality in Mental Health Care (DRE) strategy. DRE is an action plan for achieving equality and tackling discrimination in mental health services and draws on three key publications:

- National Institute of Mental Health England (2004a) Inside-Outside: Improving mental health services for black and minority ethnic communities in England. National Institute for Mental Health England.
- Blofeld J (2003) Independent inquiry into the death of David 'Rocky' Bennett. HSG (94) 27.
- Department of Health (2003) Delivering Race Equality: A Framework for Action. London: HMSO.

The UCLAN Centre for Ethnicity and Health model describes how a Community Engagement project must have the community at its very heart. There are three principle features:

- It is essential to work through a host community organisation (in our case Rethink)
- The host organisation must have good links to the target community (in our case the Pakistani community in one locality in Birmingham)
- The research project should involve members of the local community in carrying out the research project (in our case this was eleven members of the Pakistani community who became Aap Ki Awaaz Project Community Researchers).



## The Aap Ki Awaaz Project (Your Voice)

“Birmingham and Solihull Mental Health Trust are delighted to have had the opportunity to support Ajaib and the community researchers in undertaking the research associated with the Aap Ki Awaaz project. It is imperative that we listen to what communities have to say not only about mental health but also about the services they receive and this report goes a long way in getting the voice of our local community heard. The whole team have demonstrated a high degree of sensitivity and professionalism in their approach and are to be congratulated on the way that they have engaged the local community on this very important issue. I am confident that while this particular piece of work has been concluded the partnerships and collaboration it has brought together will continue to thrive”.

### **Lakhvir Rellon**

**Director of Diversity, Birmingham and Solihull Mental Health Trust**

“Aap Ki Awaaz Project is a true reflection and demonstration of the strength of the DRE building block around engaging communities. It is a demonstration of real life engagement, where it is the community talking to the community; in their own language, breaking down the big barriers and engaging with people who are our brothers, sisters, aunts, uncles; our community and family.

On behalf of CSIP/ NIMHE West Midlands I am honored to say a few words to support the crucial voices and journeys that Ajaib Khan has made, both personally and professionally and how well he has lead and encouraged a fantastic and dynamic team of community researchers. This report and project is just the beginning of the journey where under the guidance of Rethink, we can continue to work to improve mental health care and services for our Pakistani Muslim brothers and sisters now and in the future”.

### **Ranjit Senghera**

**Race Equality Regional Lead, CSIP West Midlands**

## Foreword

We are delighted to have been able to play a part in the community engagement project that has led to the publication of this report. The Aap Ki Awaaz Project shows the difference that research grounded in the real-life, day-to-day experiences of people can make.

There are important findings throughout the report, which deserve careful thought and reflection – backed up by concerted action from all of us who are concerned with improving our personal, community and society-wide mental health and well-being.

We may not be surprised by some of the findings, for instance, that the stigma of mental illness is a barrier to better mental health in the Pakistani community – as it is everywhere, or that more culturally sensitive services are needed to engage with the community. These are important confirmations of evidence amassed from across mental health and all our communities. They are part of the reason why the Department of Health's Delivering Race Equality work is so important.

But many of the findings are new, thought-provoking, worrying at times, but also full of opportunity for us all to engage meaningfully with the breadth of issues that affect the mental health experiences of people from the Pakistani community.

We must be concerned that so many people told researchers that negative portrayals of the Muslim faith impacted on their sense of mental health. Almost two-thirds of Aap Ki Awaaz Project respondents said that mental illness was not culturally accepted in their community, while many reported a sense of fear and shame and a desire to keep mental illness secret.

These appear serious barriers to better mental health, but other findings suggest they are surmountable. Respondents expressed positive personal views toward people who have experienced mental illness and the hope that people could recover with the right support. These are strong foundations.

People who speak out about their mental health experiences are powerful agents of change and there are strong indications that they will find support within their community.

As a membership charity that provides services across England and Northern Ireland, we are committed to ending stigma and discrimination through the work we do every day. This report will help us to achieve our commitment.



**Paul Jenkins**  
Chief Executive, Rethink

## Summary

The research in this report was carried out by a group of community researchers in the West Midlands who were supported by the CSIP/UCLAN 'Community Engagement' programme. The research topic was chosen to support the work of a Rethink community development programme seeking to raise awareness of mental health issues and assist mainstream services to better engage with the Pakistani community. The project became known as the Aap Ki Awaaz Project (Your Voice) and was one of 40 community projects who took part in the CSIP/UCLAN programme 2006/07.

## Background

The aim of this research was to explore the Pakistani community's view of mental health issues, and understand how individuals would like their mental health needs supported by service providers. This topic was chosen by the research team as one that could contribute in practical terms to better engagement and improvements in the mental well-being of the Pakistani community.

## Methods

Through the community engagement programme, the group of eleven community researchers carried out face to face interviews among the Pakistani community, ran focus groups with service users and carers, and distributed a postal survey to mental health service providers locally connected to the project based in Birmingham.

It is important to highlight that the study sample does not claim to be representative of the Pakistani community's view of mental health (dimaghi sehat) and mental illness (zehni bemari). However, the study provides a clear reflection of important issues in the community, which compliment findings from other research studies, and highlights action points for both the community and service providers to build upon.

## Results

We carried out 152 interviews with members of the Muslim community.

Individuals provided positive personal views of mental illness:

- 88% felt people can recover from mental illness
- 82% would try to understand the person and their illness
- 77% would sympathise with the person
- 67% would talk to the person
- 61% would respect the person

*"Mental health is key health. If it's good you can implement your religious and social activities effectively, with positive outcomes"*

*"Good mental health is everything. If it deteriorates it not only affects one person but all those linked to you become upset"*

These views however are contradicted by respondents views of the Pakistani community view of mental illness (zehni bemari):

- 83% believe the Community want to keep it secret
- 78% believe the Community are ignorant of it
- 76% believe the Community are ashamed of it
- 69% believe the Community think it is magic and possession
- 58% believe the Community fear it

*“Our community is not aware of even better health, so mental health is far away from their thinking”*

*“A taboo issue. We don’t like to talk about it, we never mention it when someone in the family is suffering”*

We asked about perceptions and influences on mental wellbeing.

- 74% felt culture and family traditions within the Pakistani community impact upon perceptions of mental health
- 64% felt mental illness is not culturally accepted in the Pakistani community
- 61% felt current perceptions and media publicity of Muslims is affecting their mental health and well-being

We also asked about views of mental health services: 52% were not aware of any local mental health service provision. Of those that had contact with services, 1 in 3 rate current mental health services as good, 1 in 3 as average and 1 in 3 as poor. Many people felt language barriers, stigma and ignorance of any mental health provision explained why relatively

## Background

Britain is a multicultural society with over 6 million people making up our black and minority ethnic (BME) communities. This figure represents about 1 in 8 of England’s population. These communities share an experience of disadvantage and discrimination, particularly in relation to health care.

few people accessed them from the Pakistani community rather than poor quality of provision or lack of cultural sensitivity. However when asked what services people would like it was locally based, culturally sensitive, multi-linguistic provision.

## Conclusion

We found that there is fear, shame and secrecy surrounding mental health issues among the Pakistani community in Birmingham. We also found that the current perception and media publicity of Muslims in Britain is affecting mental health and well-being in the community. The research team make several recommendations. The challenge is for the Pakistani community to engage with efforts to promote mental health awareness and well-being within the community, and for service providers to step up efforts to provide more culturally sensitive mainstreamed services as well as outreach projects which enable community leaders and local Muslims to shape and own practical programmes leading to better health outcomes.

Successive studies have shown that people from BME groups experience relatively higher levels of mental illness than the white British population some of which may be attributed to socio-economic factors such as the experience of racism, unemployment, homelessness, social exclusion, poor physical health and living in deprived areas.

Inequalities in access have also been observed. BME service users, particularly Black African or African Caribbean, are more likely to come into contact with mental health services compulsorily (Davies et al 1996, Bhui et al 2003, Morgan et al 2005a, Commander et al 2003) and by more negative routes, such as those involving the police and other criminal justice agencies (Healthcare Commission 2007, Morgan et al 2005b). It has also been reported that some BME groups are less likely to seek help and

support if experiencing mental illness. *Celebrating Our Cultures* reported that BME communities have greater problems accessing health services than the white population (NIMHE 2004b). One of the main reasons for not accessing services is due to mistrust of healthcare professionals but also fear and stigma within communities (Keating and Robertson 2004). This can in turn lead to delays in accessing and seeking professional help (ODPM, 2004).

The report *Real Voices* identified that respondents from BME communities who do access mental health services felt that access was difficult and language difficulties were problematic, staff lacked cultural awareness and sensitivity, there were too few staff from BME backgrounds represented in mental health services, and that communities themselves lacked interest in mental health (Walls and Sashidharan, 2003). A Healthcare Commission report (2006) on the experiences of patients using NHS services found that BME communities did not feel involved in decisions over their mental health care.

Calls for local strategies and service delivery to reflect the needs of BME populations are being consistently made through research (SCMH, 1998; SCMh 2002) and public inquiries (Blofeld, 2003). The improvement and modernisation of mental health services is a key government objective (Department of Health, 1999) and part of this programme of work includes Delivering Race Equality in Mental Health Care (DRE).

Mental illness affects people in different ways. The way you perceive mental health and the way you deal with mental illness depends on the different influences in your life and your cultural background. A cross cultural study of mental health beliefs and attitudes towards seeking professional help between Asians and Westerners showed that culturally determined causal beliefs of mental distress contributed to attitudes towards seeking professional help for psychological problems for the British Asians and Pakistani group, but not for the Western group (Sheikh and Furnham (2000).

Kai and Hedges (1999) focused on BME participation in needs assessment and service development in primary care. This followed a community engagement model to look into the perceptions of Pakistani and Bangladeshi people on psychological distress. Results showed that a) racism and socio-economic disadvantage were the main source of their distress, b) the role of health care professionals were felt to be geared to dealing with physical rather than personal distress and c) characteristics of health care professionals (such as age, sex, ethnicity and social status) affected communication.

Locally some key issues emerging prior to the project in Birmingham, through Rethink community development work, were:

- Stigma about mental health within the community may be large and this needed to be overcome so that mental health as an issue can be accepted
- The community may be ignorant or unaware of the facts of mental illness
- The community may be unaware of which services are available to them or how to access these services once they themselves decide they need to 'face the problem'
- Culture and language barriers can hinder people from taking up services and there is a 'keep it to yourself' approach adopted across the community where mental health issues are concerned

The Rethink Community Development Service, based in Birmingham, is a Rethink initiative to work positively within BME communities and to work in partnership with people from Pakistani / Mirpuri and other local communities, offering an information and outreach service to those who experience mental health difficulties and to their carers.

It was the aim of our research to engage effectively with the local community to learn more about how they viewed mental health issues and identify a number of action points to take forward locally to improve service provision for the Pakistani community, and increase mental health awareness.

## Aims and methods

The overall aim of the Aap Ki Awaaz project was to engage with the Pakistani community in and around one locality in Birmingham on the subject of mental health. In particular the researchers were keen to:

- learn about perceptions of mental health and mental illness;
- explore the community's specific mental health needs;
- understand how mainstream mental health services were regarded by the community, and what changes were necessary to improve access

This research was a community engagement project. To break this down, 'community' means that members of the Pakistani community in one locality in Birmingham have designed, conducted and written up this piece of research supported by a steering group and research expertise within Rethink and UCLAN. 'Engagement' means that the researchers truly engaged with the local community by committing to listen to their views of mental illness, recording people's experiences and importantly putting the community's views and needs into this report.

The Aap Ki Awaaz project worked with a team of 11 Community Researchers. Rethink were keen to recruit a mix of people in terms of gender, age, spoken languages and dialects, background and interest in mental health which we achieved. There were seven men and four women, aged 20 to 53, in terms of experience three worked in mental health, one volunteered with service users and seven were interested to learn more about mental health. All of the community researchers engaged with the research because they saw the Aap Ki Awaaz project was a way to help their community in a meaningful way. The project also attracted support from Inzamam ul-Haq (touring with the Pakistan Cricket Team) who helped the team to promote the research and mental health issues in the local press.

*"It was important to recruit researchers from within the Pakistani community so that we could engage easily and more effectively with the target audience and relate to sensitive issues and needs in the process of this research."*

**Ajaib Khan, project co-ordinator**

All members of the project team were involved in the design of the research and all received training from UCLAN in basic research methods. Collectively the team decided to use three methods of data collection:

- Firstly a questionnaire was used to capture the views of members of the Pakistani community. The questionnaire was used by the Community Researchers to interview 152 participants face to face. Being able to communicate in various different languages helped participants to engage in open discussion with the community researchers. The interviews were recorded on the questionnaires in English but selected words were in Urdu and Mirpuri dialect. Participants were recruited via posters in the Mosque, health centres, local businesses, adverts in news papers and by 'word of mouth'
- Secondly two focus groups were conducted to supplement the information provided in the questionnaires. One was held with four carers and the other with eight mental health service users
- Thirdly a brief questionnaire was sent to 30 service providers for them to share their views, practices, experiences and concerns over supporting the mental health needs of the local Pakistani community. We received seven responses.

The data analysis process was supported by Rethink's research department, UCLAN and the Aap Ki Awaaz community researchers. The findings were then presented to the members of the steering group to discuss and make recommendations. This report is a summary with the findings presented in several themed sections, combining feedback from both the questionnaires and focus groups. The recommendations are those agreed by the steering group as being the most important priorities for the Pakistani community, in Birmingham.

# Results

## 1. Profile of interview participants

A total of 152 questionnaires were completed. Respondents were:

- 52% male and 48% female
- 20% under 25, 25% 25-29, 21% 30-39, 18% 40-49 and 16% over 50
- 100% Asian or Asian British – Pakistanis
- 97% muslims
- 53% born in the UK, 46% born outside the UK, 1% unknown

Of the 70 people born outside the UK, 83% have lived in UK over 11 years. The first languages spoken were Urdu (41%), English (40%), Punjabi (23%).

## 2. Understanding mental illness and mental health

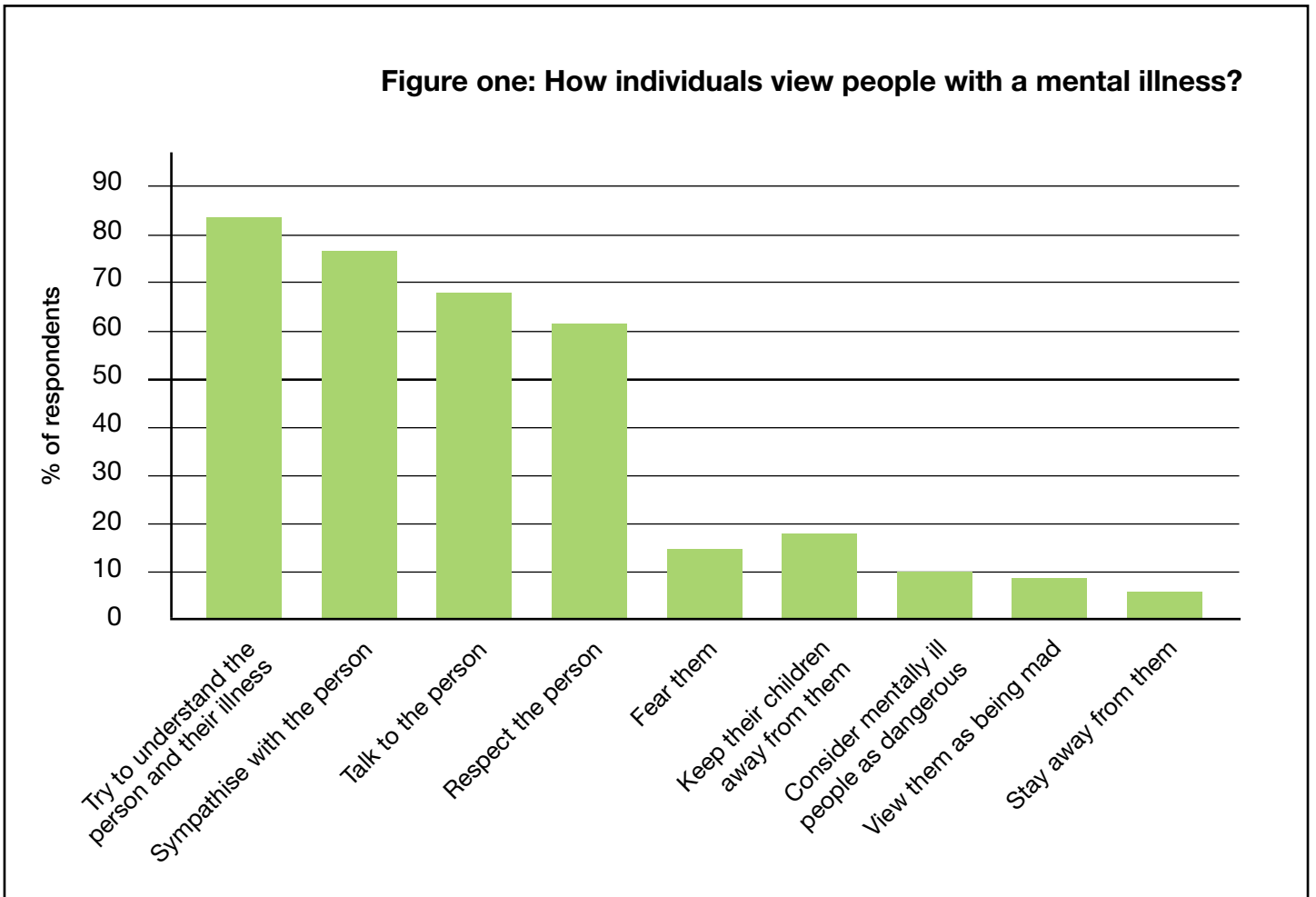
Many respondents to our questionnaire were well aware of the importance of good mental health. We asked: **What does the terms mental health mean to you?** Descriptions of well-being and the importance of mental well-being were provided by 43% of respondents.

*“Mental health is key health. If it’s good you can implement your religious and social activities effectively, with positive outcomes”*

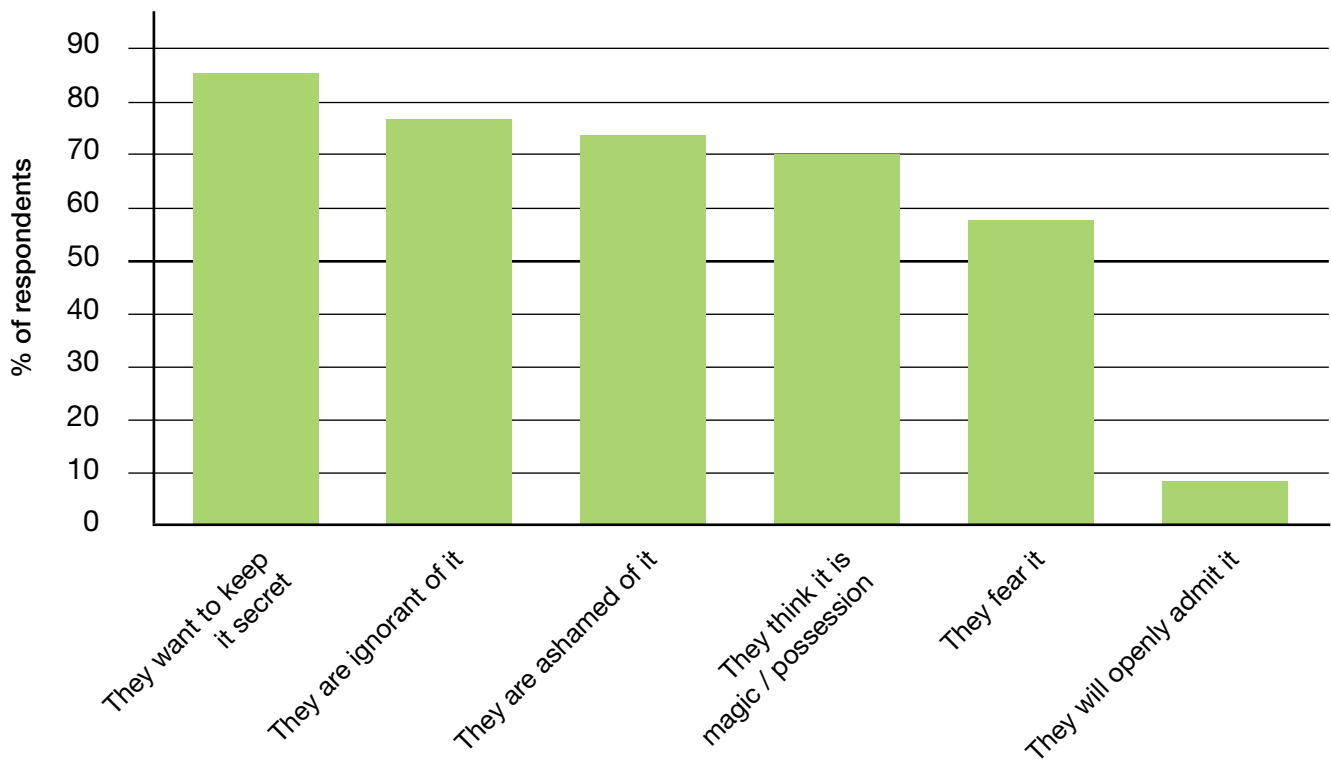
*“Good mental health is everything. If it deteriorates it not only affects one person but all those linked to you become upset”*

*“It is real health. For me a healthy mind leads to good physical health and vice-versa”*

**Figure one: How individuals view people with a mental illness?**



**Figure two: How does the Pakistani Community view mental health?**



Those respondents (57%) linking mental health (dimaghi sehat) to mental illness (zehni bemari) mostly provided sensitive or factual descriptions of mental illness although 14 people (16%) used stigmatised words such as: “You aren’t normal”, “you are ‘paagal’ (mad)”; “Crazy”; and “Someone who is cuckoo”.

**People were also asked how they would personally view a person with a mental illness** (see figure 1). Most people reported they would react with understanding, sympathy and respect. In addition 88% felt people with a mental illness can recover and live and work normally and only 3% felt they had no hope or should be locked away (8%). We also looked at variations in responses by age, gender, and birth country. Interestingly, the only variation is between male and female attitudes with men more likely to view people with mental health problems as mad and feeling children should be kept away. However, this broadly positive view is contradictory to how respondents felt the community as a whole perceived mental illness.

Respondents were asked: **How does the Pakistani community view mental health in general?**

*“Don’t fully understand it. Will use it against the person when they recover. Try to rationalise it by giving materialistic solutions i.e. you have everything and have no reason to be down. They may believe you are possessed or someone has done black magic, as they may be jealous of you”*

*“A taboo issue. We don’t like to talk about it. We never mention it when someone in the family is suffering”*

*“Pakistani community has very little awareness and view it as a weakness of the person. They think it is jinn possession or black magic, or nazar (evil eye) and feel medication and counselling cannot help them”*

*“They know it exists but they don’t see it as an illness. They think the person is making it up to get attention. They see it as shameful to expose”*

A far more negative community view of mental health was described, with most people acknowledging the Pakistani community collectively feel that mental health is 'a taboo subject', the community lacks education and awareness, they keep it hidden within families, it is seen as a spiritual thing – black magic or possession and some do not recognise it as an illness (see figure 2). A few provided more positive summaries:

*“Some people give it importance and others have no idea what it is. But now the situation of our community is better than before”*

*“They think it’s a sad thing and something can be done about it”*

*“They see them as normal people”*

These collective attitudes play a major role in not being able to recognise mental illness and therefore not attending to the immediate support needs of those in distress.

**“Culture and family tradition do have a role to play in our mental well-being. How you live and grow up has an impact on your thinking and mental state”**

### 3. Do religion and culture impact on views of mental illness?

The project team felt that religious beliefs and cultural background might affect how the community perceive mental illness and deal with mental health issues. Thus the interviews asked: **Do you think our religious belief affects the way we perceive mental health? Do you think our culture and family traditions affect the way we perceive mental health?** We found:

- 39% felt religious beliefs impact on perceptions of mental health, 59% disagreed and 2% were not sure
- 74% felt culture and family traditions within the Pakistani community impact upon perceptions of mental health, 24% disagreed and again 2% were not sure

Religious belief does affect the way some Muslims perceive mental health and mental illness. People we spoke to explained how:

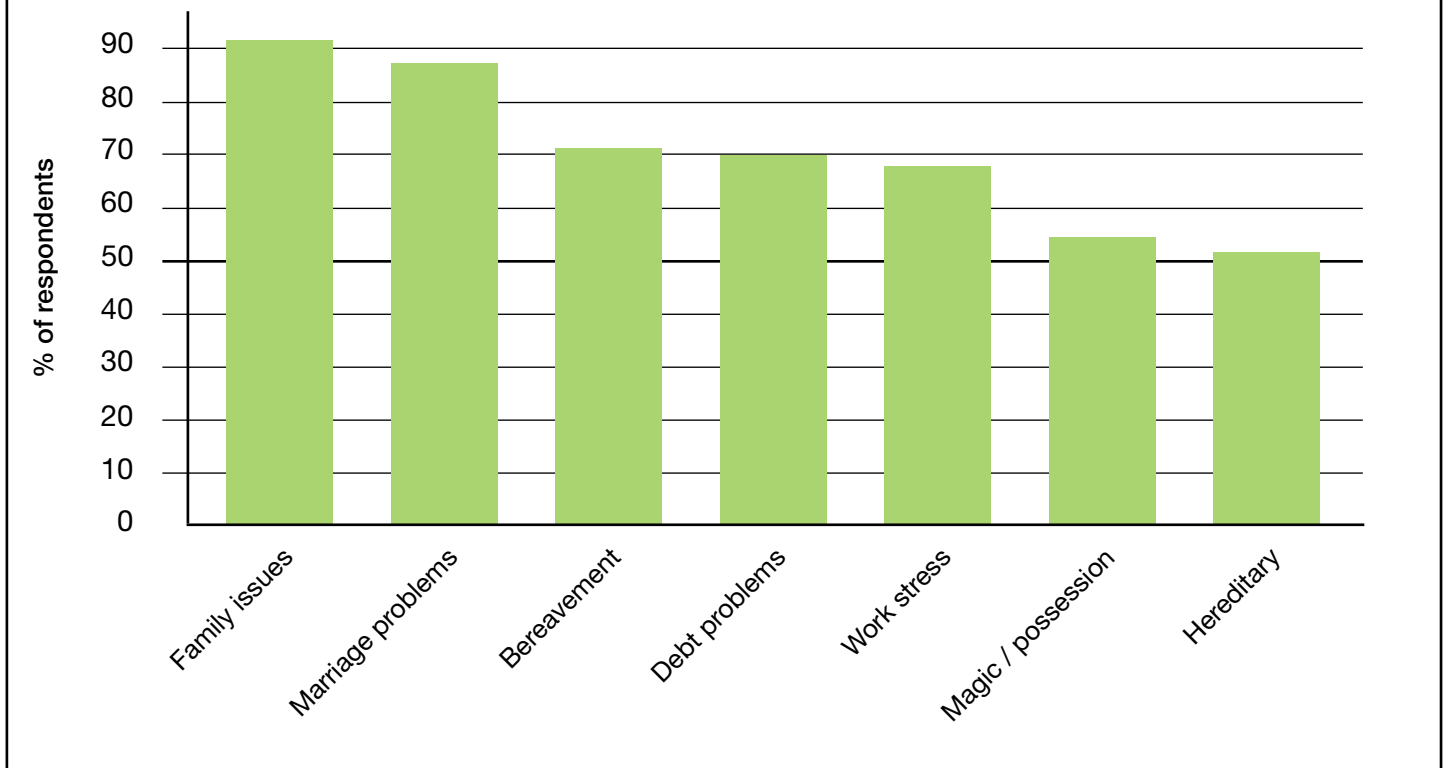
*“Only mentally healthy person can implement the religious teachings successfully and remain strong belief”*

*“Our beliefs have an effect on mental health. We know that Allah and the Prophet (peace be upon him) have mentioned about jinns and black magic. Our religion can help people overcome and deal with mental health and enable the person to become positive as having hope in Allah is the key and asking for his help is crucial”*

*“Different scholars have different thoughts, they don’t all recognise mental illness being an illness. They think its magic and confuse the carers”*

*“In some cases people believe they are hearing voices from god. Some people believe it is black magic. Some go to faith healers and believe they can cure the mentally ill and not the professionals. They view it as a spiritual problem”*

**Figure three: Why do people develop a mental illness?**



Culture is also clearly an important influence on perceptions of mental illness. People born in the UK were more likely to feel culture and tradition impacts on peoples' perceptions of mental health than those born abroad. We also asked if mental illness is culturally accepted in the Pakistani community: 64% said no, 14% yes and 24% were not sure. In addition we heard how culture impacts on positive well-being:

*“Culture and family tradition do have a role to play in our mental well-being. How you live and grow up has an impact on your thinking and mental state”*

*“Good culture and family traditions are helpful for our mental well-being”*

*“If we pursue it positively then it is good for our mental well-being, and if we abuse it then it's a tension and result will not be fruitful”*

#### 4. Mental health problems and pressures in the Pakistani community

In carrying out the project, the community researchers were keen to understand specific pressures of daily life faced by the community. The 152 respondents provided an overall 'stress' rating from 1 very stressful to 5 no stress at all. The average score was 3 with only 11% describing high levels of stress. There were many causes including: worry of children, marriage problems, financial difficulties, physical health problems, studying and employment. Of those interviewed, 40% had personally visited a GP about their mental health problem or knew someone who had.

**Why do people develop a mental illness?** The main reasons provided are given in figure three. Other reasons were: drugs and alcohol abuse, domestic violence, sexual abuse, racism, social deprivation, lack of religion and living with a physical disability.

The Pakistani community has in recent years been under intense scrutiny, particularly from the media. Public perceptions of Muslims have also changed. The research team were keen to learn: **Has the media portrayal of Muslims affected the mental health of the community?**

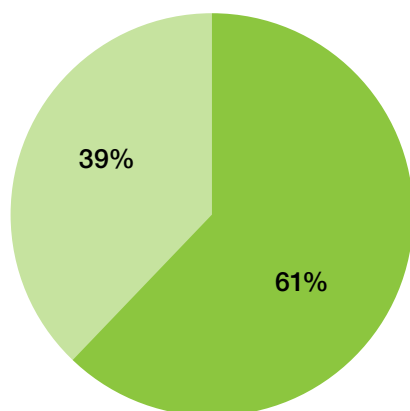
*“Causes stress, feel like victims and are labeled. We feel anger at media’s injustice against Muslims, feel frustrated and unequipped to make a difference. All this can affect our mental health”*

*“People with strong faith are not affected with these news and perceptions”*

*“It can put a lot of extra pressure on already vulnerable immigrants who are already under lots of stress”*

*“Muslims are struggling to overcome the negative stereotypes that media presents particularly in relation to terrorism. Muslims are more self conscious and worry about themselves in the future”*

**Figure four: Role of the media and mental health of Muslim community.**



39% DOES NOT affect our mental health and well-being

61% DOES affect our mental health and well-being

Some respondents held strong views that the media portrays Muslims in a very negative manner, referring to them as ‘terrorists’ and hence giving the community a bad name. This leads to mistrust within society and anger among the Muslim community who feel frustrated and ill-equipped to make a difference to these perceptions. Nearly two in three respondents said that this negative portrayal does have an affect on their mental health and overall well-being. They feel scared and disappointed, their self esteem becomes very low and this leads to stress and mental health issues.

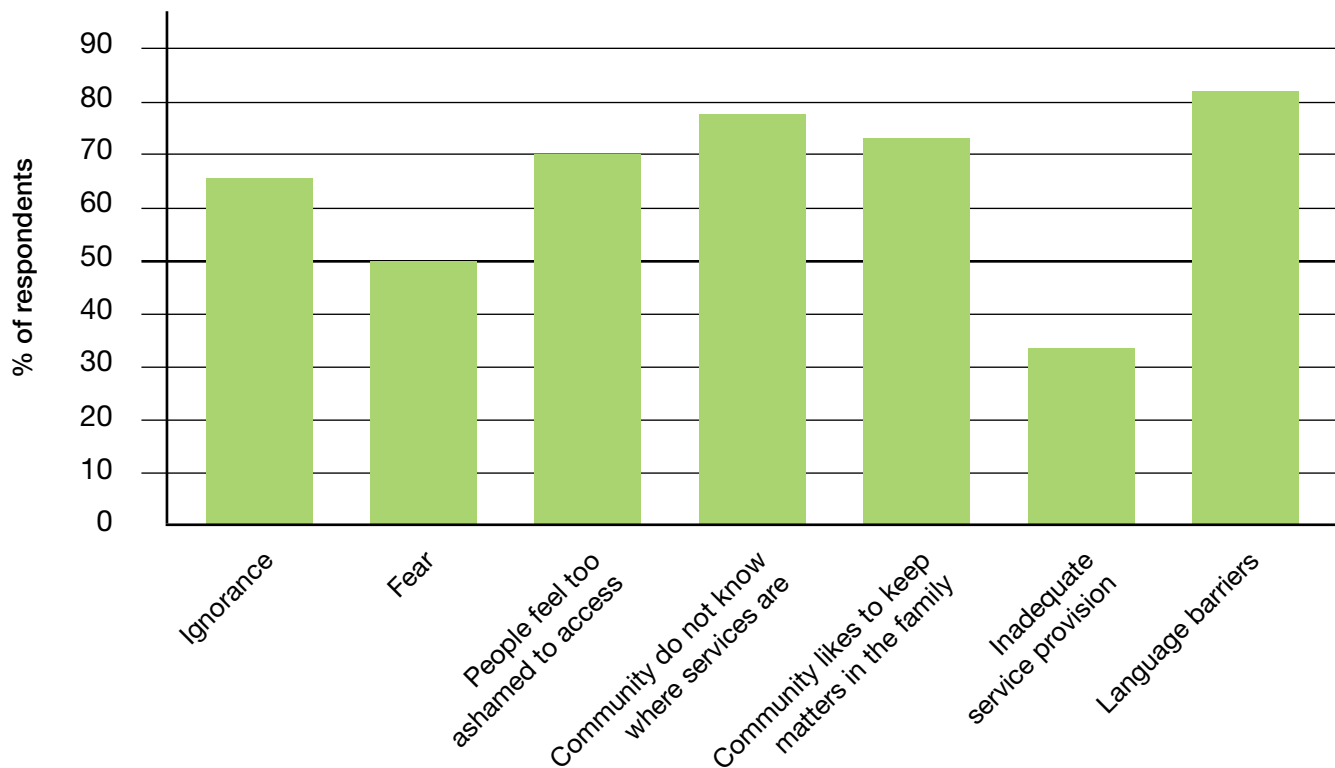
## 5. Help seeking pathways

The way we perceive mental illness and our level of concern determines who we would turn to for help if we or someone we knew developed a mental health problem. Most people (73%) would turn to a member of the family for support and a GP (70%) for professional advice and medication. Other people would first turn to a friend (45%) the mosque or local Iman (22%), a spirit / faith healer (11%) or a homeopath (7%). These preferences are consistent with the community view that mental illness is kept as much as possible within the family.

**What help would people like?** Respondents listed their preferred treatment methods as:

- Medication (62%)
- Whatever the GP recommends (60%)
- Religious worship (59%)
- Local mental health support service (58%)
- Talking therapy (47%)
- Homeopathic medication (13%)
- Faith healing (11%)

**Figure five: Why is there a low uptake of mental health services from the Pakistani community?**



However, we know from local statistics that very few Pakistani community members attend local mental health services. It was crucial that the research learnt from the experiences and concerns of the community to understand why there is low uptake of current provisions (see figure 5). There is generally a stigma attached to mental health among all communities, particularly BME communities, and likewise the Pakistani community has fears the stigma attached to mental health which can lead to the low uptake of statutory support services.

*“The person feels uncomfortable when no focus on cultural needs”*

*“Staff is not well guided or aware about community’s own needs and priorities, culturally and religiously”*

*“We need a separate centre for Muslim women as they can’t participate openly when there are unknown men around”*

A high proportion of people felt that the low uptake of services was due to people not knowing where services were (76%) rather than inadequate service provision (34%). Furthermore, many people cited personal barriers, including fear and shame, as being responsible for the low uptake of services rather than the external barriers. In order to reduce stigma and encourage uptake of services, we asked what type of services people would like to see in their local area to support those with mental illness. The most commonly cited recommendations were for:

- Services with staff from the community
- For more community based services particularly day centres
- Improve current provision particularly addressing access issues, providing more talking therapies, women only services, more time for appointments
- Raise awareness in community of mental illness and service provision
- Employ professionals who understand the issues affecting the Pakistani community

*“More islamic services, counselling with people who are experienced in the Pakistani community in mental health”*

*“One-to-one home visits. More day centres. More centres linked to local mosques”*

It is clear the community feels services need to be improved to meet the cultural needs of the Pakistani community. They also need to communicate more with the community and encourage access through awareness raising out-reach work. **How important is the provision of Pakistani only services?** Interestingly, equal numbers of people agreed and disagreed (36% wanted Pakistani only services, 36% want mixed services, 28% not sure). The solution would be to provide a range of effective provision.

## 6. Feedback from current service users

**What do the people using mental health services think of them?** Responses were provided by 52 people (34%).

- 33% rated them as good or very good
- 30% rated them as poor or very poor
- 37% rated them as average

People liked personal care and attention, provision of interpreter services, supportive attitude of staff and professionals, effective advice, counselling, home treatment and art therapy. The services provided were rated as culturally appropriate for 40% of users. People disliked poor communication,

long waiting periods, short consultations, not enough information provided and no understanding of cultural needs.

*“Felt safe, home treatment very convenient, so I didn’t have to go to hospital”*

*“Psychiatrist attitude and staff, lack of understanding and support. Never was empowered or made to feel my mental health would improve”*

*“Medication – side effects, mental health workers not understanding and culturally aware. Not person centred. Seeing other unwell patients didn’t help”*

More people expressed that the service they experienced did not meet the cultural needs of the Pakistani community and would like to see improvements such as more awareness and appropriate staff.

*“I like to see the services educating people regarding mental health issues and making people aware of the services, giving reassurance that they are there to help people with mental health problems”*

*“Services which fulfill community needs because mental illness is not like other diseases, privacy and confidentiality are important to make people more confident to attract towards it”*

*“They should have anonymous centres where you could go without shame, perhaps hold it in mosque will make it accessible. More Muslim women in profession”*

**“I like to see the services educating people regarding mental health issues and making people aware of the services, giving reassurance that they are there to help people with mental health problems”**

**What did current service users think influenced access to services?** Respondents felt that there were several reasons that accounted for low uptake of mental health services in the Pakistani community. The most common reasons were:

- social and religious values
- language barriers
- support from family members
- lack of awareness of local services
- more attraction towards faith healers and spiritual leaders who are recognised as experts in these matters in comparison to medical professionals
- fear and feeling of shame
- not openly admitting the illness and keeping it within the family

The reasons for not accessing services were more to do with the characteristics of the community itself, how the community perceived and dealt with mental illness, whereas factors that increased uptake were more about delivery of services.

More people from the Pakistani community would access mental health services if service providers made improvements in terms of community engagement, but there was also recognition that improvements also required greater involvement of the Pakistani community within mainstream mental health provision.

## 7. The view of service providers

Service providers recognised a range of general issues that affect the uptake of services from the Pakistani community, mainly:

- fear and stigma
- lack of awareness of services
- cultural and religious issues
- belief that it is jinn possession and black magic rather than an illness
- services are not culturally sensitive and therefore unable to meet the individual needs of the community

*“There are language issues and a stigma attached to attending mental health service buildings”*

Some issues were about the interpretation of ‘mental health’ within the Pakistani community, others were related to service delivery. Service providers felt that several areas needed addressing to best meet the needs of the Pakistani community:

- Communication needs to be addressed on two levels. Firstly language difficulties are a barrier to accessing services and although some staff speak various Asian languages on the whole there was a recognised need for more multi-lingual staff. Secondly service providers recognise greater promotion work is required to ensure that information sharing with the community is effective.
- Improve staff cultural knowledge and awareness. Providers felt they need to have greater knowledge about cultural and religious issues within the Pakistani community and to learn about their needs and expectations, such as the importance of gender specific services, providing Halal food or having access to translators.
- Service improvement: Providers realised that they needed to engage more with the community but they also felt their services were generally adequate in areas such as facilities and access. Staff were becoming more culturally aware and having staff to speak various Asian languages and understand the Muslim religion was considered a positive step towards appropriate service provision.

## Conclusion

The process of completing a community engagement project, with in-put from a steering group of key local stakeholders from the Pakistani community and local mental health services and the recruitment and training of local community researchers is as important as the findings from the research project.

This project has brought together 11 community members to learn more about mental health within a community that feels mental health (*dimaghi sehat*) and mental illness (*zehni bemari*) is taboo. An interview survey asked Pakistani men and women from across the community in Birmingham to talk freely about their mental well-being and views on mental health issues. Completing the study is progress in itself both on a personal level for the individuals involved who have worked and learnt together and for the mental health community. Much of the DRE framework is about building partnerships, engagement, information sharing which is what Aap Ki Awaaz Project sought to achieve.

The findings from the project, as detailed in the results section, lead us to reflect on three key points.

Firstly, on an individual level members of the Pakistani community are aware of mental health issues, sensitive to the distress mental illness can bring, respectful of individuals living with mental health problems and hopeful about recovery. However, collective community views of mental illness are reported very differently. Collectively the community fears mental illness, is ashamed of it, doesn't understand and keeps mental illness a secret. This tells us that mental health promotion work is important at the community level. We need to tap into the understanding that individuals have about mental health and well-being, and use this to influence and change collective assumptions, fears and taboos.

Secondly, the general public and mental health providers need to be aware and sensitive to the pressures faced by the Pakistani community in Britain. The media in particular is putting intense pressure on the Pakistani community, and the identity of the community, which may impact on well-being and people's willingness to engage with service providers.

Thirdly, service providers need to reflect on explanations for low take up of current services: language barriers, stigma, ignorance, lack of information. Only 1 in 3 thought poor quality of services explained unwillingness to engage. People who use services also have mixed views. The Pakistani community request that more services are provided locally while recognising progress being made to improve mainstream facilities.

We would like to build on the findings of this report to drive forward actions leading to change.

### **Our long term goals are to:**

- Remove stigma and taboo of mental illness within the Pakistani community, building on individual understanding to produce collective support and understanding instead of shame, secrecy and fear
- Provide more services within the community to support the mental health needs of the Pakistani community
- Increase engagement with the community at every level brokered through community development projects
- Increase the diversity of staff working in mental health

## Acknowledgements

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In particular, the Aap Ki Awaaz project team would like to extend their sincere thanks to all the participants from the Pakistani community who have provided us with invaluable information for this research and shared some of their personal experiences with us.

### The Aap Ki Awaaz project team

**Project Co-ordinator:** Ajaib Khan.

#### Community Researchers:

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#### Personal reflections from the research team:

*“My concern was that I did not have any previous experience so did not know what to expect. I had never presented to an audience before or conducted an interview. This project allowed me to do all this and much more. It took lots of determination and time from my busy lifestyle, and I have now realised how big a problem it is in the Pakistani community and the scale of the task to rectify these issues. I would like to involve myself in the mental health sector and engage with community work.”*

*“Dividing time between my work, family and this project was an obstacle for me and my knowledge about mental health was limited. Some of the fears I initially had were not being able to deal with the community and hence not completing my given tasks. However, as the project progressed, it built my confidence and support from the team helped me overcome my fears. I am now more aware of mental health issues and would like to explore further.”*

#### We recommend:

- On-going awareness raising and education programmes within the Pakistani community
- Working with mental health champions in the community to share their personal experiences
- Development of a one stop health shop in the community, including a significant mental health component
- Encouraging Muslim service users and carers to get more involved in campaigns and local forums to influence the shape of local mental health services for the Pakistani community
- Continuing to fund community development workers to network, communicate and build understanding and awareness in both Pakistani community and mental health services
- Working more closely with religious leaders – Imams – to bring about improvements in mental well-being for the community
- Mental health commissioners investing in a range of recovery focussed mental health services, including complementary therapies, all of which should be more sensitive to traditional and cultural values whether delivered through mainstream teams and services or specialist projects.
- Mental health services should introduce comprehensive staff training programmes to ensure that everyone working in mental health has appropriate values and skills to work with diverse client groups.

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We thank all our partner agencies who support and fund our work.

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