

time to change

let's end mental health discrimination

Family matters

**A report into attitudes towards
mental health problems in the
South Asian community in
Harrow, North West London**

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rethink



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Introduction

Mental illness is commonplace; one in four people will, at some point in their lives, be affected. Experiencing stigma and discrimination because of a mental health problem is also common, with 9 out of 10 people who have a mental health problem experiencing it in some form. But when it comes to understanding how and why stigma and discrimination occurs, attitudes and behaviours may vary widely across different communities and geographies.

To date, the Time to Change social marketing campaign has been a mass-market intervention, with our audience defined in terms of demographics and attitude. However, although the campaign has reflected the different ethnic groups that make up the English population, it has not been developed from an understanding of the attitudes of specific ethnic groups.

Evaluation from the summer 2009 campaign showed that knowledge, attitudes, and behaviour had not improved at the same rate in BME (black and minority ethnic) groups as in the national sample. 11.3% of the English population are from minority ethnic communities and 15.8% are from communities other than white British.¹ Being an England-wide campaign, it is extremely important for Time to Change that we reach these groups.

Aims of the pilot are to:

- Improve knowledge, attitudes and behaviour towards people with mental health problems within one BME group, reaching 3,000 people
- Get measurable results so we can learn more about what works to change knowledge, attitudes and behaviour within a specific BME population using a tailored social marketing intervention

The BME population in England is large and diverse, and while there are similarities in attitudes and behaviour towards mental illness across the whole population, for the pilot campaign to have most impact it needs to target the attitudes and behaviour of one group.

The first stage of the project was to identify which BME group to work with, and in which area. Following scoping of different BME groups, both seeking to understand attitudes and behaviour

and practical considerations that could impact upon the success of the pilot, we have decided to focus on the South Asian community in Harrow, North West London.

Having decided to target this audience, Time to Change commissioned the Rethink research team to carry out qualitative research with this community to:

- Understand experiences of stigma and discrimination among people with mental health problems and carers
- Define the best group to target to improve the lives of people with mental health problems and carers
- Understand the attitudes and behaviour of people who don't have mental health problems or care for people with mental health problems

This report covers the findings of this qualitative research.

There were six key findings from the research:

- Shame, fear and secrecy surround mental illness
- The causes of mental illness are often misunderstood
- The family can be both caring and isolating
- Social pressure to conform
- People with mental health problems are not valued
- Marriage prospects can be damaged by mental illness

These findings will be used to develop the social marketing campaign to tackle mental health discrimination in the South Asian community in Harrow.

1. Experimental statistics last updated in January 2009 from the Office for National Statistics.

Who took part?

There were two stages of the research involving different groups of participants from the Harrow community.

Stage one: Consultation groups

People with mental health problems and carers took part in consultation groups to understand where and how they experienced stigma and discrimination. There was one consultation group with carers, involving 13 people; there were four consultation groups with people with mental health problems, involving 46 people.

Of the carers, most of whom were aged between 55 and 74 years, half were women. All but two described their ethnicity as Indian. The others described themselves as Pakistani and “other Asian”.

All the participants had cared for someone with a mental health problem for between seven and 30 years; diagnoses included schizophrenia, anxiety disorder and depression.

Of the people with mental health problems, 76 per cent were women. Ages ranged from late 20s to over 75, although the majority were aged between 45 and 65. Asked about ethnicity, 85 per cent said they were Indian, four people Pakistani, two Sri Lankan and one “mixed Asian and white”. Just over half – 59 per cent – were Hindus.

Participants had experienced mental health problems that included depression (the most common), anxiety disorder and schizophrenia for between two and 42 years.

Stage two: Focus groups and interviews

The findings from stage one enabled us to identify who to target with the campaign – extended family who knew someone with a mental health problem, aged 30-50. The second stage of the research explored the attitudes and behaviour of this group around mental health problems.

The research was carried out through two focus groups and six face-to-face interviews in Harrow in May 2010. There was one focus group of men, with three participants, and one of women, with four participants.

There were several requirements that participants needed to meet to take part in the research. These were:

- They had to come from a South Asian background
- Be aged between 30 and 50 years
- Have a relative with a mental health problem in their family network
- Not be a carer
- Not live in the same house as someone with a mental health problem.

Of the 13 participants, seven were men. All were aged between 30 and 50, with the majority in their early 30s. Except for two participants, who described themselves as Pakistani, all were Indian and nearly half were Hindus. The majority said their relative's diagnosis was depression or bipolar disorder; three did not know the diagnosis.

Who should we target?

Participants in the stage one consultation groups discussed the advantages and disadvantages of various target audiences for the campaign.

In the first stage of the research the participants were asked to indicate the extent to which different groups of people caused stigma and discrimination. It was clear that family had the biggest effect on the life of someone with a mental health problem. While close family are generally caring, extended family could be a source of discrimination.

Although participants defined who should be included under the term 'extended family' slightly differently, it was clear that they played an important role in people's lives. The extended family are part of family and community networks, part of events and decision making; in turn they can be responsible for staring, gossiping and excluding people affected by mental health problems and their immediate family.

We wanted to understand which would be the best target audience for the campaign to make a difference to the lives of people affected by mental health problems.

Through the discussion groups three main groups were identified within the extended family as potential target audiences for the campaign:

Middle aged, male and female, 30-50 years old

This group was discussed by both people with mental health problems and carers. This was because they are often the gate keeper to family decisions and influential over what happens in families. They could also have a positive role in terms of being able to influence both the older and younger generations.

Young people, male and female, under 30

Participants felt that the younger generation generally have better attitudes to mental health problems than other age groups, and will speak about mental health problems more openly among themselves.

People with mental health problems and carers see this group as being able to change things for the future – although there was concern as to whether they have the social standing in the community to impact on what actually happens in families and in the community more widely.

Older people, male and female, 65 plus

Older people are powerful and respected in the community, and do have influence in the family. However, they are also seen as having some ingrained attitudes around mental health problems, and sometimes attribute mental health problems to laziness or people having a 'weak' character. It was felt that it may be difficult to shift long held attitudes, and that they may be less receptive than other groups to the campaign.

We decided that the best group to target to improve the lives of people affected by mental health problems and carers would be the middle aged group.

What we found

Across the research groups six key findings surfaced as possible explanations for the stigma and discrimination experienced by people with mental health problems.

Shame, or sharam, fear and secrecy surround mental illness

“They have a fixed psychology, [it’s] how they’ve been raised, how the community behaves. You do not discuss anything around mental illness because it’s a no-go area.”

Mental illness is a taboo subject, meaning there is little open discussion about mental health problems. People with mental health problems agreed that their diagnoses were something to be kept private and not openly discussed, even with immediate family – one participant said they had kept their illness secret from their spouse for more than 20 years.

Part of the reason for this is the need to preserve the family’s reputation and status at all costs – indeed, one group argued that all problems tended to be hidden, not just evidence of mental health problems. Preventing community gossip, which can go on to negatively affect the whole family is paramount. Community gossip was mentioned by many participants as the most damaging behaviour of all due to its high level of impact both on the person with the mental health problem and their close family.

“The close family try to keep it within closed doors; they don’t really want the wider community to know about it. I think they feel it’s something to be ashamed of.”

“People are afraid [of mental health problems], they are afraid they might become contaminated or tarnished with the same brush.”

Rarely is there a senior family member making a formal decision to keep their relative’s mental health problem secret. Instead it is simply taken as given that as few people as possible should be told.

This ingrained acceptance of secrecy was particularly evidenced in the focus groups and interviews with the extended family members – our target audience. Of the 13 participants, three did not know the actual diagnosis of their relative who had a mental health problem and a further two could only speculate, by either assessing the relative’s behaviour or listening to family gossip. One participant stated that, with the exception of health professionals, not one single person outside of the family had ever been told that their relative had a mental health problem.

The causes of mental health problems are often misunderstood

The culture of secrecy that surrounds mental illness can, in part, be attributed to misunderstandings and misconceptions that have grown up around all aspects of mental health problems over many years.

“They think there is no need to go to the doctor – the doctor won’t do anything.”

Caring for people with mental health problems is the family’s responsibility, largely because many in the community do not believe that a mental health problem is a medical condition that can be managed and treated professionally.

Instead, there is often misunderstanding about the causes of mental health problems. These include:

- Black magic – which can also be a possible cure
- The will of God
- Genetic
- Bad parenting

It is perhaps unsurprising, therefore, that treatment options can be severely restricted. Even those who do recognise mental health problems can be reluctant to seek the appropriate treatment, either because they fear the family reputation will be hurt,

or because they believe the cause is genetic and so cannot be cured. Once a label of mental health problem or madness is attached to someone, many believe it can never be removed.

This misunderstanding around the levels and types of mental illness also demonstrates a lack of knowledge of the hopeful, positive reality of recovery for many people with mental health problems.

The family can be both caring and isolating

In the South Asian community, caring for a person with a mental health problem is seen as a family responsibility.

“In our culture, we do not throw our children out.”

Family relationships have a strong and integral role. Yet in seeking to protect relatives with mental health problems from gossip and stigma – and also to protect the wider family’s reputation – there is a tendency for the close family to reduce the amount of contact the person might have with the extended family or wider community. Party and wedding invitations, for instance, may be declined.

While the intentions of such behaviour are usually good – to protect the relative experiencing the mental health problem – the end result can be highly damaging, leaving the relative increasingly isolated.

One participant spoke of how his relative was treated:

“He doesn’t go out so he doesn’t have the chance to do something irrational or look out of place. If he doesn’t go out, you’re not going to see what his behaviour’s like. So his brother, mum and dad don’t want him to go out because they don’t want to be talked about.”

In situations where the person with a mental health problem lives in the same household as the close family, some extended family members reduce contact; fewer visits are made to the family’s home, increasing their sense of isolation.

However, one participant in the extended families research explained that this was often seen within the community as a mark of respect, to avoid drawing attention to the unwell relative or embarrassing the family.

Lack of awareness and understanding in families can also result in families neither recognising symptoms nor supporting people in getting formal help early (from non-family). The role of family also has a particularly strong impact on women’s ability to get help. One group of mainly female participants highlighted the role that men play in either allowing or restricting access to formal support for women with mental health problems.

This dependence on male support can leave many women, already hindered by the social norms in the community around mental health problems, even more isolated and without the means to recover.

Social pressure to conform

Within the South Asian community, adhering to cultural and social norms is important; people acting outside of these are often considered abnormal. Participants in the extended family research were asked if they agreed or disagreed with the statement: “Many people within the South Asian community don’t want to socialise with someone with a mental health problem.” There was strong agreement across the group.

“To associate with someone with mental health problems might be an issue for the rest of the community. It wouldn’t actually look good.”

Adherence to social norms is the key to achieving and maintaining respect and standing within the community. These include doing well academically, being married, having children and being employed. Living outside of these norms, whether through poor academic achievements or having a mental health problem, can be considered abnormal and damage the reputation and standing of the person with a mental health problem and their immediate family, reinforcing feelings of shame and the need for secrecy.

‘Successful’ members of the community, for example people with high status professions such as medicine or law, are highly praised and respected. There is even more pressure on these people to conform, and showing that people from these highly respected groups can and do experience mental health problems would be a powerful way to challenge people’s attitudes and behaviour.

Social pressures also play a part in increasing the isolation of people with mental health problems. People with non-stigmatising attitudes to mental health problems may still be put off from making a stand or speaking to someone with a mental health problem for fear of being ‘tarred with the same brush’, and damaging their own social standing.

“It’s like a taboo, not really wanting to get their hands dirty or exposed... it’s a really selfish attitude and selfish view, that if I’m associated with that person then my immediate family are going to be subjected to isolation... the stigma that’s associated with the individual that’s suffering with this illness will affect me.”

“You are doing something which is not normal; you are doing something which is abnormal, because nobody else is helping them, so why are you helping them?”

People with mental health problems are not valued

People with mental health problems and carers reported that people within the South Asian community commonly consider mental health problems as synonymous with being ‘stupid’. Therefore, others within the community do not listen to them or value their point of view as they would someone with a higher social standing.

“If someone knows [about my illness], thinks I have an issue, I’ve noticed they say hello, but just walk away, they don’t look at my face – they go and talk to other friends and leave me out of it.”

When asked for their general attitudes and knowledge about mental health problems, participants in the extended family group commonly used the words ‘abnormal’, ‘not with it’ and, ‘people that need help’ to describe people with mental health problems:

“I think of it as some[one] who is there but not quite there, with it, as in physically they’re there but mentally they’re only there some of the time rather than a hundred percent of the time.”

Marriage prospects can be damaged

“The family name gets spoilt a little bit. They’re very conscious of that.”

With many believing that mental health problems are both incurable and passed on through the generations via the genes, it is little surprise that marriage and mental health problems are closely linked. Mental health problems can be a serious threat to marriage prospects in families where arranged marriages are common, either for the person experiencing mental health problems or for relatives who become “tarnished” by association.

Participants explained that prior to agreeing a marriage, it is common for the families of the bride and groom to look into each other’s backgrounds, to ensure their child is marrying into a “good” family. Along with genetic illness such as sickle cell anaemia, evidence of mental health problems would impact on the status of the family and its desirability. Put simply, people are less willing to marry into a family with a history of mental health problems.

“If someone is suffering from mental health, the whole family becomes tarnished.”

At best, marriage prospects are dramatically reduced, with some families seeking matches in India rather than England so they can keep the bride or groom’s mental health problem a secret.

Where next?

The research has helped us identify the target audience for our intervention, as well as key messages and techniques to change attitude and behaviour.

When it comes to dealing with mental health problems, the South Asian community has some advantages over the rest of the country. The immediate family, for instance, can play an important role in caring for and protecting someone with mental health problems.

Likewise faith can play a central role. One group of participants agreed that some families, ignorant of the causes of mental health problems, seek cures through faith healers. But they were keen to differentiate this from the role of faith more generally. A belief in God and an individual's faith are important sources of support for some people with a mental health problem, who also argued that religious places provide calm environments that they value highly.

Furthermore there is a much stronger sense of community and people's place as part of the community than in the population more widely. In the research, we heard some of the negative impacts of this, in terms of some people not wanting to be associated with people with mental health problems in order to maintain their own image in the community. However, the strong sense of community could also be a positive way to tackle discrimination and provide the context to address some of the misconceptions.

There is a deep-rooted misunderstanding of mental health problems passed through generations. People with mental health problems must battle to get the right professional support and treatment while also struggling with ingrained attitudes that promote stigma, discrimination, isolation and sharam.

It is therefore important that we develop a campaign that can address misconceptions about mental illnesses and people affected by them, bringing mental illness into the heart of the community.

Below are the key messages, how to reach people and next steps.

Key messages

Participants identified a number of key messages they felt would help challenge stigma and discrimination in the wider community. Broadly these fall into three areas:

Normalising mental illness

- Mental health problems can affect everyone, including your family
- 1 in 4 people will be affected by mental health problems at some point
- Mental health problems can affect people of any status

Positive messages about people with mental health problems

- People recover from mental illnesses
- With the right treatment and support people can recover
- People develop mental illnesses through no fault of their own

Challenging the taboo

- Mental health problems are not shameful
- Talk about mental illness – don't brush it under the carpet
- Don't ignore people with mental health problems

How to reach people

- **Information**

Posters or leaflets in community settings such as religious centres, doctors' surgeries, libraries, community centres and leisure centres can be effective ways to reach people in their day to day lives, and increase levels of knowledge about mental health problems.

- **Plays and dramas**

Drama is popular in this community as a family event. This could be an effective way to tackle the secrecy around mental health problems and allow people to engage with the issues in more depth.

- **Asian specific media**

Local Asian specific media channels such as talk radio and newspapers have direct access to the target audience and reach many people in the community.

- **Community events/activities**

Because of the secrecy surrounding mental illness, holding events at community centres and religious settings could provide the opportunity to reach people and start conversations about mental health problems. This type of forum can play an important role in facilitating discussions to challenge prevailing attitudes and behaviours.

Next steps

The findings from this report will be used to design the pilot campaign which will run in Harrow. Targeting the audience of 30-50 year old people who know someone with a mental health problem, the campaign will use messages developed and tested with that audience.

We will use the findings of this research to work with a project group in Harrow, including community leaders, people with mental health problems, and other local people and organisations to establish the best way to tackle mental health discrimination in Harrow.

We will work with our partners in the community to develop and deliver the campaign. The pilot will be evaluated by the Institute of Psychiatry, Kings College London.

If you would like more information on Time to Change, what's going on in your area and how you can get involved, please visit www.time-to-change.org.uk or contact us

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time to change

let's end mental health discrimination

Time to Change is England's most ambitious programme to end the discrimination faced by people with mental health problems, and improve the nation's wellbeing. The leading mental health charities Mind and Rethink are running the programme, funded with £16m from the Big Lottery Fund and £4.5m from Comic Relief, and evaluated by the Institute of Psychiatry at King's College, London.



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