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## **British Asian families and the use of child and adolescent mental health services: a qualitative study of a hard to reach group**

### **Abstract**

We explored attitudes to and experiences of Child and Adolescent Mental Health Services (CAMHS) among families of South Asian origin who are under-represented as service-users in an area of a Scottish city with a high concentration of people of South Asian origin. Six community focus groups were conducted followed by semi-structured interviews with families who had used CAMHS and with CAMHS professionals involved in those families' cases. Lastly, parents of children who had problems usually referred to CAMHS but who had not used the service were interviewed. Qualitative analysis of transcripts and notes was undertaken using thematic and logical methods.

Participants consisted of: thirty-five adults who identified as Asian and had children; 7 parents and/or the young service users him/herself; 7 health care professionals involved in the young person's care plus 5 carers of 6 young people who had not been referred to CAMHS, despite having suitable problems.

Focus groups identified the stigma of mental illness and the fear of gossip as strong disincentives to use CAMHS. Families who had been in contact with CAMHS sought to minimize the stigma they suffered by emphasizing that mental illness was not madness and could be cured. Families whose children had complex emotional and behavioural problems said that discrimination by health, education and social care professionals exacerbated their child's difficulties. Families of children with severe and enduring mental illness described tolerating culturally inappropriate services. Fear of gossip about children's 'madness' constituted a major barrier to service use for Asian families in this city. Given the widespread nature of the concern over the stigma of children's mental illness, it should be considered in designing culturally competent services for children's mental health.

## **British Asian families and their use of child and adolescent mental health services: a qualitative study of a hard-to-reach group**

### **Introduction**

Pathways to care and treatment for mental health problems vary according to ethnicity in adult populations (Morgan et al 2005). Higher rates of mental ill health among minority ethnic groups have been attributed to deprivation and disadvantage (Nazroo 1997), with a suggestion that social cohesion and support may underlie those groups with lower rates (Sproston and Nazroo 2002). While adults, children and adolescents may share risks and protection based on a shared minority ethnic culture, there are specific factors affecting young people in terms of stressors and the context of pathways to care.

According to national survey research, Pakistani, Bangladeshi and Indian young people have lower prevalence rates of mental health problems compared with white and black 5 to 15 year olds (Meltzer et al 2000: 27). A secondary school-based survey in east London which showed that Bangladeshi children had a lower risk of psychological distress, despite their greater disadvantage, compared with other groups suggested that 'cultural protective factors' might be responsible (Stansfeld et al 2004). A survey of adolescents admitted to psychiatric inpatient units found that, of the Asian teenagers, none was admitted with affective disorders (Tolmac and Hodes 2004) and young people of South Asian origin (tracing their descent to India, Pakistan or Bangladesh) have been under-represented in child and adolescent mental health services (CAMHS) in general (Messent and Murrell 2003; Minnis et al 2003). Despite recent contributions, the epidemiology of mental health problems in children and adolescents from minority ethnic groups is poor and difficult to interpret (Ramchandani 2004: 77). Our previous research suggests that a lack of common language and disagreement on the appropriate interpretation of children's behaviour can limit the treatment options offered to some minority families (Minnis et al 2003). Given the poor research evidence base, the possibility that the under-use of CAMHS by some ethnic groups indicates unmet need cannot be dismissed. Institutional racism and cultural competency is a concern in the NHS as a whole and mental health services in particular (Department of Health 2003).

This qualitative study explores the dimensions of service provision, and of other aspects of South Asian patients' lives which promote or hinder the use of CAMHS. The questions addressed are:

What are Asian families' attitudes to children and adolescents' mental health problems and to help-seeking for such problems?

For Asian families whose children have mental health problems, what is their experience of help-seeking?

## **Methods**

The study had the approval of the University of Glasgow, Yorkhill NHS Trust and relevant Primary Care Trust ethics committees. All participants gave informed and signed consent in English, Punjabi, Hindi or Urdu.

### *Phase 1 – Community focus groups*

Six focus groups were convened between September and December 2003 with a total of 35 participants (see table). The groups were all conducted by MV who is multi-lingual (Hindi, English, Punjabi), with HB assisting at one group. Participants identified themselves as Asian, had child-care responsibilities and had had no previous contact with CAMHS. The groups were recruited using a mixed strategy to ensure that no single network was over-represented and were convened by a Community Education worker, a member of the Hindu Temple and a bilingual NHS worker. The themes which recurred in discussions informed the membership of groups so, for instance, when 'grannies and aunties' were consistently discussed as influential figures, we convened a group of older women. We contacted neighbours and friends of friends to purposively sample groups that included Sikhs, Muslims and Hindus, men and women, older and younger adults.

Three vignettes were presented to each group describing the kind of problem that would commonly be referred to CAMHS: a 12 year old depressed girl; an 8 year old boy with behavioural problems; and a 14 year old boy with psychotic symptoms. [Reference to a web-based appendix.] Participants were asked what advice they would offer such children's parents and whether health and social services would be helpful to those with similar problems. Focus groups are a good method for establishing group norms and cultural values (Kitzinger 1995). These norms, values and expectations were then explored further in one-to-one interviews in phase 2.

### *Phase 2 - Family and professional interviews*

Seven families who had a child currently using services or who had recently used services were recruited through a community CAMHS team in the study location and we called them 'service users'. The locality included wards where 48% of the population were from a minority ethnic group according to the 2001 census, compared with 5% for the whole city. The CAMHS team put us in contact with all Asian families with whom they had professional contact. Five families who had 6 children with difficulties considered appropriate for treatment by CAMHS, but who had not been referred to CAMHS, were recruited via a range of community professionals including general practitioners, health visitors, school and general practice based nurses and a classroom support worker. We called these people 'potential service users'. The community professionals were asked to put us in contact with any Asian family with children or adolescents who were experiencing emotional or behavioural problems and/or learning difficulties that might benefit from CAMHS. The problems that these families experienced, as shown on the table, included behavioural problems (highly withdrawn and highly disruptive), autism, learning difficulties and speech problems. The division between 'users' and 'potential users' was not always clear; one parent described her child having used CAMHS, and we classified her as such, although she felt that the family's relationship with the service was over. Another family had not been seen by CAMHS, but the child had seen a psychologist at school, however, since no further referral resulted from this contact they were classified as potential users for our purposes.

Interviews, conducted between March 2004 and March 2005, were semi-structured, following a topic guide devised in the light of the issues raised by our previous research (Minnis et al 2003) and by the focus groups. In interviews with service-users we asked about meeting with the child or adolescent mental health team, in terms of what had happened, whether it had met with the family's expectations, whether the right people were in attendance, how it could have been more helpful and whether people were satisfied. Interviews with potential service users followed the same pattern, but started from asking about meeting with the community professional from whom we had received the contact, or in the single case of a family that one of us knew personally, we simply asked about the children. The problem was initially named by the young person (for the older service users) or the carer in their own terms, rather than the interviewer introducing it into the conversation using the professionals' terminology. Once the problem had been described, we asked about

the services that had been received, how helpful they were, whether health, social and education services could have been better and whether they could imagine more effective or more convenient services.

In interviewing the CAMHS professionals we were seeking background information to contextualise the interview with the service user. We asked the professional to give us a summary of the individual's case which, if they had little contact with the young person, involved consulting clinical notes. Where interviews with service users had been difficult to interpret, we sought clarification; for instance, in a case where parents spoke about a 'school doctor' we confirmed with the CAMHS professional that this referred to an educational psychologist.

All of the CAMHS professionals were interviewed by HM over the telephone, and all of the family interviews were conducted by MV in families' own homes, with the exception of one service user, interviewed by IW in a community setting and the aunt of two potential service users was interviewed by HB, in a private setting.

#### *Phase 1 and 2 - Convening interviews*

Focus groups were relatively easy to convene and participants were willing to discuss the hypothetical situations presented in the vignettes. These groups agreed that people of Asian origin would be very unwilling to speak about mental health problems with anyone except close and trusted family members. Of the small number of Asian families who were in CAMHS at the time of the study, all agreed to be interviewed; however one family was not interviewed because they missed 3 home appointments and subsequently did not respond to 3 follow-up phone calls. We had an almost total population of service users of this CAMHS team between March 2004 and March 2005 and the small number reflected the under-use of services (Minnis et al 2003). Family members who had used the service preferred to be interviewed together therefore interviews involved the parent(s) with the young person. For each service-user an interview was also conducted with a CAMHS professional. Interviews with potential users were with a carer or parent(s) only.

For potential service users, the rate of refusal to participate was more difficult to ascertain. In addition to the five families with whom we spoke, we were given the names of 2 families with whom we failed to arrange an interview, and we know that 2 further families declined to have their details passed on to us. Although we had

agreement from a number of voluntary and religious organisations that they would identify potential users, no names were forthcoming.

Potential users were strikingly difficult to access. We had initially planned to identify potential users via members of the focus groups and our own informal networks, but in the end only one case was identified in this way. Instead we followed the alternative strategy of getting contacts via community professionals, as described above and even when identified, families were reluctant to be interviewed. One of our community contacts turned out to be the mother of a service user, and while she expressed relief at telling her story to a health professional, she refused to be contacted again and refused to be audio-recorded. This woman suggested that her reticence to discuss her child's problems was the norm among people of South Asian origin, and she claimed to know many families who had similar problems and who avoided statutory services.

*Data management and analysis:* Focus groups and interviews with families and professionals were audio-taped, except in two cases when detailed contemporaneous notes were taken. Interviews were transcribed and, where necessary, translated with checks on the quality of translation made as soon after the interview as possible. Transcripts and notes were coded for themes that emerged from respondents' own concerns and those defined by the research questions. The group interviews were summarised as themed maps. This allowed discussions about services, about family and about God or fate to be separated out, but also cross-referenced. The individual interviews were summarised as a narrative and the themes cross-referenced. In making sense of the individual interviews, the contrasts between child and adolescent cases and between different types of problems were considered. People of South Asian origin in this city are a small and visible minority and, and given the small numbers of interviewees and the very distinctive stories, these cases are potentially highly identifiable. In order to present narratives to show the development of problems, the contact with service providers, and the contrast between types of problem, but not identify individuals, we constructed case studies amalgamating details from different interviews. Periodic discussions between members of the research team and presentation of research findings to the clinical team have meant that interpretation has been shared, despite our different professional and disciplinary backgrounds. Our focus has been on how these cases were understood by the family and, where possible, the young person.

## **Findings**

### *Findings from the community focus groups (phase 1)*

Participants identified a range of people from whom help could be solicited, including family, friends, voluntary and religious organisations and statutory services. While CAMHS was never named there was a clear account of the General Practitioner as the route to specialist services: as one woman said 'everything goes through the doctor here.' Referral routes via education and social services were also described, although more tentatively.

Although routes to access specialist health services were discussed in principle, compelling reasons why services would not actually be sought were also identified. The most important reason was the need to prevent gossip about the difficulties described in the vignettes which were defined as 'family problems' which should be kept private, since sharing these 'with outside people' would be shameful. Mental illness or madness was described as shameful, as were the associated services: 'psychiatry is a bad word it means wrong in the brain' said a Sikh woman. To be labelled 'mental' or 'pagal' (mad) was said to be stigmatising and so should be avoided at all costs, to the extent that, according to a Muslim woman, even if a child went mad and died 'we will never share with outside people.'

Concern about gossip was urgent: 'the least people know the better' explained a Punjabi-speaking Muslim woman, so 'everyone keeps quiet, no-one speaks outside' and 'we stay behind the curtain' added another. 'The fear of what people will say' prevented the uptake of services because even if 'you tell one friend, she will just tell a couple more' and if you 'talk to neighbours then gossip will spread', so 'we cannot trust anyone'. This lack of trust extended to health professionals since, according to the group of Sikh women, there were 'Asian girls who work in the health services' who 'cannot keep a secret', so although ethics should, in theory, prevent gossip, 'not everyone sticks to the ethics.' Gossip could be passed on without actually naming those involved, but nonetheless making their identity clear. The Sikh and Hindu group of women said 'we are a small community so word spreads fast' which meant that, in the words of an English-speaking Muslim woman 'Asians don't use outside services. [We're] scared of the talking.' The Hindu women's group agreed that 'our people will do nothing, only gossip' in the face of mental illness. The agreement that gossip about mental illness was a problem, across the discussion groups was striking.

The shame of and blame for children's mental health problems was associated with the mother of the child. The stigma of mental illness was a powerful reason for confining discussions and help-seeking to close and trusted family, which implied avoiding services. An additional reason was an expectation that services could be discriminatory. Concern that teachers 'did not appreciate our black children' was expressed in a Muslim women's group and that social services failed to recognise both men's rights and the value of compromise in resolving family disputes, was voiced by men. Men's concern that social workers 'will listen more to women' was illustrated by stories of custody battles after the separation of spouses, and the problem was seen as systemic and generalised to any statutory service, including health services. Children's troubles were described as family matters that should not involve 'outside' professionals, particularly if there was a risk of discrimination.

Muslim and Sikh focus groups noted the ethnic majority's openness in discussing madness, and while some women expressed approval, others viewed it as an unfortunate 'lack of pride' or 'honour', which contrasted with what Muslim women described as 'keeping our parents' izzat' and Sikh women referred to as the 'honour' or 'pride' which was 'part of our culture.'

The agreement over the stigma of mental illness contrasted with the range of opinions offered on related matters and the willingness of discussants to contradict one another. For instance, a Muslim woman suggested that a troubled boy should be taken to the mosque, only to be challenged by another woman as follows: 'No! Why send him to strangers?' Speculation among the Hindu and Sikh women that too much freedom in Britain exacerbated children's problems was contradicted by a woman saying that 'back home' things were 'more accepted' such that, compared with Britain, 'India is becoming more modern.' There was no evidence of a systematic contrast between people's opinions according to religion, gender, class or generation in these groups. People of South Asian origin in this Scottish city are, compared to other British cities, a more homogenous group (Bradby 2002). Compared with English cities, migration to Scotland was more recent and in this particular city was overwhelmingly Punjabi, so Sikhs, Muslims and the much smaller numbers of Hindus have a common language and to some extent culture. Self-employment in family-run business has been the norm for South Asians, with few manual workers and a small (although growing) professional class.

### *Findings from family and professional interviews (phase 2)*

Interviews were examined for details of the patient's experience and for consensus or disagreement between professionals, families and patients in diagnosis and treatment. Unsurprisingly the professionals tended to use more medical language than users, so, for instance a boy recalled he 'used to become cheeky' when he 'went hyper' whereas his psychiatrist described 'psychotic symptoms' and 'hypomanic mood swings'. Similarly a mother said her daughter was 'slow' at school whereas her psychiatrist described 'moderate learning difficulties'. In most cases the clinicians' assessment broadly concurred with that of the service user (or the user's family), although the latter's language was (again unsurprisingly), more optimistic and more clear-cut. For instance a boy was described by his doctor as having a condition that was 'well-managed' and 'stable' whereas his mother said 'Bacha thik kar dita hei' (They made my child better), implying a stable recovery rather than a stable condition. Occasionally a parent was significantly more optimistic than the professional, as with the mother of a 14 year old who said 'my daughter has recovered' whereas a health visitor suggested that she was 'not fully well.'

We could not find a consistent contrast according to the religion or generation of the service users or potential users. One mother of a service user said perhaps the 'old generation ... whose mum have come from Pakistan or India' might not know about mental health services but 'my generation, like, they know about it.' However, this woman, like other British-born parents in the study, said that she herself had been unaware of the availability of mental health services prior to the onset of her child's problems. Judging by the partial evidence we had regarding parents' employment and our impressionistic assessment of people's homes, the families we interviewed were typical of the South Asian population in this city, being self-employed and neither very poor, nor very wealthy.

The problems being treated by CAMHS and those identified as potentially suitable for CAMHS can be divided into three categories: 1) severe and enduring mental illness; 2) complex emotional and behavioural problems; and 3) learning difficulties. First, 'severe and enduring mental illness', includes diagnoses of bipolar disorder and psychotic episodes, which manifest themselves in adolescence, but not in childhood. These symptoms are very disruptive to daily life and the three service users with psychosis or bipolar disorder in this study had all arrived in CAMHS via the emergency services, rather than referral from community services. None of the potential users had a severe or enduring mental illness. The second category of

'complex emotional and behavioural problems' applied to all 6 of the potential users and 3 of the CAMHS users. Young people with a specific diagnosis such as ADHD or autism spectrum disorder also had behavioural problems that made school and/or family life very difficult. The only child who had neither severe and enduring mental illness, nor complex emotional and behavioural problems was the young daughter of parents with learning difficulties. This family was well supported by the extended family and the girl's needs were being addressed at school. This case was an example of the third category, 'learning difficulties' without the added complexity of emotional and/or behavioural problems.

The remainder of the paper concentrates on understanding how severe and enduring mental illness contrasts with complex emotional and behavioural problems and on difference between service users and potential service users. We amalgamated evidence from a number of cases in order to protect the identity of the families in the following case studies.

#### Case study 1 – severe and enduring mental illness

**Rifat** was 13 when first admitted to hospital hearing voices. At that time she 'did not want any help' and felt that 'everybody was against me', worrying that the hospital was 'going to keep me over there for ever.' During the first couple of years Rifat felt very suspicious of her medication, and, particularly when she felt well, she would stop taking it and subsequently symptoms would recur. Rifat says in the past she 'went hyper', got very withdrawn or 'could not think'. She attempted suicide on at least two occasions, has been admitted to hospital as an emergency twice, once against her will, (under section) when legal powers were invoked to impose treatment. Rifat's mother points out that Rifat is not mad, but does have an illness. Since the family had not met this type of illness before, they were extremely worried and sought help from the Molvi (holy man) at the mosque. Stories of possession by ghosts or djinns (which they now regard as foolish) frightened the family and they put prayers written on fragments of paper (taveez) around Rifat's neck.

Now aged 18 and attending college, Rifat says she understands the importance of her medicine. Her clinicians describe her condition as stable and appropriately medicated. Rifat's mother says her daughter is 'fully recovered now'. Rifat's mother makes no criticism of medical staff and their understanding of Rifat's medical needs,

but insists that hospital arrangements were deeply unsuitable for her daughter: Rifat was in a mixed psychiatric ward sleeping next to a young man. No special provision was made for food requirements, toilet and hygiene habits or her prayer routine, which, as an observant Muslim, were important elements of daily life.

#### Severe and enduring mental illness

Parents described the difficulty of being confronted with their child's suffering which they did not initially recognise as illness. A migrant mother who spoke only Punjabi said 'we did not know about this type of illness' ('sanu pata ii nahin si ki is tarah di beemari bhi koi hei') and she relied on her English-speaking sister-in-law to locate and read information on her child's mental illness. Parents who were British-born and English-speaking described similar bewilderment with the onset of psychotic symptoms. All 3 of the young people with severe and enduring mental health problems had remained in contact with CAMHS (albeit intermittently) and said they derived benefit from medical treatment and, despite serious inadequacies in the inpatient facilities, declared themselves entirely satisfied with the service they had received.

#### Complex emotional and behavioural problems

The expression of a clear-cut satisfaction, despite various problems was not the case for families coping with complex emotional and behavioural problems. The difficulties of coping with a child's complex problems were evident in the isolation described by the child's mother (or in one case, aunt). Compared with the cases of severe and enduring mental illness, parents were more likely to describe conflicts with clinicians, as explored below.

For complex emotional and behavioural problems we found no contrast between the families who were in contact with CAMHS and those who were not: both groups faced challenging, complicated problems and felt unsupported or unhappy in some measure. These families gave confusing and sometimes confused accounts of their route through and receipt of services: individuals' names, clinic locations, agencies and occasionally professions were named as providers, but why people had progressed from one service provider to another was not clear. We asked people about whether they were satisfied with the services that they had received, and both users and potential users expressed dissatisfaction. The mother of a service user with behavioural problems said 'I haven't had any help apart from writing down

prescription' and went on to explain that she felt a lack of 'any emotional support' from her child's psychiatrist who was 'cold'. While the mother said that the doctor would not attend to her exhaustion and stress, the doctor reported that the mother would not comply with the prescribed medication regimen and did not attend a parenting group. Another mother who was a potential user of CAMHS but had contact with health visiting and social work said she 'was not satisfied [with] the way institutions have handled [my case].'

Despite expressing dissatisfaction, the mothers quoted above were actively seeking help from service providers, even when naming some of those services as inappropriate. In this respect, these mothers were similar to the parents whose children had severe and enduring mental illness. However, another group of parents of children with complex emotional and behavioural problems were actively trying to disengage from the services because they felt that the service was poor and that their child was discriminated against. This group included families who had contact with CAMHS and those who did not. This process is illustrated by the following composite case study.

#### Case study 2 – complex emotional and behavioural problems

**Muni** was eight years old when an educational psychologist referred him to CAMHS, describing his classroom behaviour as extremely disruptive. Muni speaks Punjabi at home, which, together with extended periods spent in the Punjab, may have contributed to his delayed speech in English. Muni's parents were annoyed by the referral, with its implication that their son was abnormal. They maintained that Muni was an ordinary boy who was sometimes naughty. His teachers disagreed and referred to shouting, fighting and double-incontinence, which made it very difficult to contain Muni in a mainstream classroom, while his poor speech, motor-skills and social skills suggested special educational needs. Missed appointments, together with the difficulty of working through an interpretation service, compounded existing communication problems, making assessments from psychology, occupational and speech therapy difficult and an agreed diagnosis impossible. The school excluded Muni on several occasions while health and social care professionals attempted to stay in contact with his parents.

It had been hoped that the transfer to secondary school would allow Muni to leave behind a bad reputation and start afresh. However, Muni, now 13, has been excluded permanently from two secondary schools. The first exclusion was because he fought and spat, although his parents say that he was simply defending himself against bullies. The most recent exclusion was due to an attempted arson attack on the school in which Muni was implicated. His parents say that although he has behaved irresponsibly with matches in the past, on this occasion he was a victim of mistaken identity and did not start the fire. They feel Muni is being subject to racist victimisation by pupils, teachers and is being punished for being immature. His father says 'every child does some stupid things' and that he is learning bad ways from school, since at home he is a 'kind, helpful, intelligent child.'

It is not clear what distinguished the families who felt dissatisfied but remained engaged with services from those who felt dissatisfied and aggrieved about discrimination and sought to disengage. From our evidence the families that felt discriminated against had experienced a similar service compared with other families, and had not experienced greater language barriers.

Two children experiencing complex emotional and behavioural problems due to family separation and loss were unusual in being cared for by an aunt and in having no contact at all with services, such that discrimination by and engagement with services could not be gauged. Despite the children's serious problems, there was no contact with social or health services other than the family doctor. The children were reported to have been on the 'at risk' register in the city where they previously lived, but when they moved, contact with social services ceased. They lived in a largely white suburb, away from the neighbourhoods more densely populated with South Asians, had adequate economic resources, enjoyed good close family relations, and had a wider network of family and friends. These children had been accepted into their aunt's home to keep them out of local authority care although she had no experience of behavioural or emotional problems with her birth children. The aunt spoke fluent English and had worked in caring services all of her adult life. This family avoided the possibility of unsatisfactory or discriminatory services for the complex problems which the children experienced by avoiding services altogether. This was a means of controlling the damaging gossip about the children's difficulties which was unique among the people we were able to identify. Nonetheless, the

management of the stigma of mental illness played an important role in understanding the various responses to that we found.

#### Avoiding stigma

The stigma of mental illness was a consideration for all of the carers interviewed except for the two parents who had learning difficulties and whose child had similar problems. Parents of service users and of potential users said that any mental illness was likely to be seen as madness: a service user's mother said people would be described as 'pagal hai' (he's mad) or as having a 'brain problem' if the illness became public knowledge. A British-born mother of a service user said 'There is stigma attached ... to say ... that 'my son has suicidal thoughts'' and consequently she could not allow these things to be spoken about in her family.

This stigma was connected to the assumed heritability of madness because, as the Sikh mother of a service user with complex problems explained, 'it becomes hereditary and comes in the blood.' She expressed concern that she would be seen as bringing madness into her husband's family and was at pains to explain that mental illness did not run in her family, and, although she had not known it when she married, it did run in her husband's family. This woman explained that her husband and parents-in-law had kept her husband's sister's severe problems a secret from everyone and she had only learned about it through third party gossip. The fact that the in-laws continued to maintain the secret, even after the woman's own son's problems became apparent, was worrying because of the aspersion it cast on her own family's reputation and therefore the potential damage to the marriage prospects of her children. The Muslim mother of a service user explained that no-one would mention a relative's mental illness, even if it persisted for years because in 'our Asian society ... you don't say these things'. Likewise, in the words of another service user's mother:

You don't really go round announcing [a child's problems] and it is very difficult for our Asian families. They can't understand...[in] my Asian society.

The use of mental health services was taken to imply madness in one's family and this implication was something that mothers in particular wished to avoid. The reason for this avoidance was spelled out by a Muslim mother who explained that 'our people are closely related in [name of city] and families observe other families' health' with a view to evaluating potential marriage partners. The importance of

marriages contracted by family members cannot be under-estimated for both Muslim and non-Muslim Punjabis in Scotland (Bradby 1999).

### Resisting the stigma of madness

We have identified three distinct ways in which parents resisted the potential stigma of their child being talked about as mad. First, where children had complex emotional and behavioural problems without a specific diagnosis, parents termed their child's problems 'naughtiness', 'immaturity' and above all else 'not mental illness.' To maintain this position parents gave weight to professionals who agreed that their child was 'normal' and who defined the problem as 'behaviour not illness'. Muni's case illustrates the way that parents suggested that minor flaws in their child's behaviour had been exacerbated by discriminatory treatment in school. These parents emphasised the external causes of their child's problems reducing the need to find fault with the child or with their own parenting. Anti-Asian prejudice from white professionals was mentioned with regard to schools, but this was not the only form of discrimination discussed: a Sikh couple felt that a Muslim professional was unjustly labelling their child as having special needs; another couple said that Asians were jealous of their child's 'fair skin' because he had one Asian and one white parent and non-Asians treated him differently because he was 'a half-in-half.'

Second, for families where a serious and enduring illness with florid symptoms, or those with conspicuous behavioural and emotional problems such as soiling at school or repeated suicide attempts, it was difficult to deny a mental illness. Nonetheless steps were taken to minimise gossip. For young people with a specific diagnosis, parents insisted that this was not madness but rather a particular and limited deficit. Children with severe and enduring mental illness were described as fixable or as already fixed by medical intervention and parents consigned the illness to the past as 'cured now.' A child who had experienced a number of psychotic episodes requiring inpatient emergency care was described as 'recovered' by her parent, although the underlying condition was probably ongoing. One mother said her daughter 'had [a] bit [of] learning difficulty, but she is OK now.' A child who presented a risk to himself and to others through his reckless behaviour with knives and matches was described by his mother as having 'a chemical imbalance ... something lacking in his brain' which she hoped would be fixed by appropriate medication. She explained that 'my son is naughty because of ADHD disorder.'

A mother described how her daughter's episodes of inpatient care had taken place at a hospital on the far side of the city from her home and, while the long distance was inconvenient in some ways, 'the location provides us with some confidentiality from our community.' That follow up care had been provided in a community setting which was 'not a hospital which deals with mental illness' was good because 'the word mental in our community is very unacceptable.' The preference for distant services was not expressed by anyone else in this study. Despite the widespread concerns that mental illness in the family would be gossiped about and attempts to avoid gossip being an important consideration for users of services, stigma was never mentioned by professionals when explaining how people had been treated.

The third strategy was to remain beyond the reach of service provision and to contain the problem within the family. We identified one family in which this had taken place.

## **Discussion**

Focus groups identified the GP as the main referral route to specialist services, but did not mention CAMHS. Evidence from phase 1 and 2 suggested that mental illness was closely associated with madness and therefore highly stigmatised and parents were concerned about associated gossip which would broadcast the stigma. The stigma of mental illness described by these people relates to Goffman's (1963) notion of 'spoiled identity'. However, for the families in this study it was the identity of the whole family and not just the individual that risked being spoiled. Stigma arose from the heritability of madness, with the mother's standing in her husband's family as a potential carrier of madness and children's marriage prospects jeopardised. Gossip about madness was a strong disincentive to any help-seeking beyond very close, trusted family. Some parents described fears about their children being discriminated against by professionals.

Several strategies for minimising stigma were identified. Parents were reluctant to ascribe children's problems to illness, preferring to describe them as naughtiness or immaturity, exacerbated by racism. When children's problems were undeniable and obvious, mental illness was differentiated from madness, and the discrete and curable nature of the episode was underlined.

During acute episodes of severe and enduring mental illness inpatient services were welcomed: parents expressed their trust in medical professionals, despite the

hospital services being arranged without apparent consideration of minority religious needs or sensitivities around gender. Families with complex emotional and behavioural problems did not welcome service providers, but despite their dissatisfaction, some remained engaged with professionals. The parents who felt that discrimination played a role in their children's complex ongoing troubles resisted interference from professionals they distrusted. One family, living in a well-off suburb, had avoided health and social services, despite the severity of their children's problems, despite the considerable strain on family relationships. This case may illustrate the strong motivation to avoid potentially stigmatising services.

The strength of this study lies in the triangulation of three sources of information on families' attitudes to CAMHS: community focus groups; family interviews where children or adolescents were experiencing problems; and interviews with professionals involved in CAMHS. Furthermore the study contacted families who had experienced CAMHS as well as those who had not been service-users. Interviews were conducted in the language that the family preferred. While ethnic minority users of CAMHS are hard to contact, those who do not access the service and who are not fluent or confident users of English are even more difficult to reach. Our previous audit of clinical notes suggested that people of Asian origin were less likely than other patients to reach a consensus diagnosis with professionals (Minnis et al 2003); anecdotal evidence from professionals suggests that Asian families' problems were more longstanding and entrenched by the time they encountered services and therefore more difficult to address. One family, who avoided services altogether and, perhaps because of their good familial and economic resources, seemed no worse off than the families in contact with services and, in some ways, seemed better off, raises the question of the utility of CAMHS, as currently configured, for Asian families with complex emotional and behavioural problems.

This study did not seek to recruit a matched sample from another ethnic group and therefore the extent to which gossip and stigma affect the experience of CAMHS users generally remains an unanswered question. Evidence from our focus group discussions noted that the ethnic majority was willing to discuss these matters openly and without shame.

#### Policy implications

This study describes the disincentives identified by Asian families for involvement with CAMHS. For severe and enduring mental illness, service users and their parents

were pleased that their symptoms had been overcome, but where problems were complex, there was little satisfaction expressed. From our evidence, it is difficult to discern any specific advantage to using CAMHS for these children with complex emotional and behavioural problems.

Overcoming cultural and linguistic barriers remains a major challenge for the health service (Hunt and Bhopal 2003). Increasing the proportion of minority ethnic staff among health professionals is an important equality issue and may raise awareness among ethnic majority staff of the sensitivities around mental illness. However, it does not necessarily solve the problem of access to and uptake of specialist services because it may sharpen patients' fear of gossip. Minority ethnic children are hard to reach with generic services so local solutions for working with specific ethnic groups may be preferable (Ramchandani 2004: 78).

Given the nature of children's mental health problems and the associated value judgements, there is a particularly acute need for interpreters who are not only linguistically and culturally competent, but who also have an understanding of CAMHS and its associated services and can help to join them up. One means of addressing the concern about gossip would be for CAMHS to maintain its specialist status, at some distance from community services, thereby facilitating confidentiality. However, this would need to be accompanied by the simultaneous provision of good support for frontline services such as school nurses to encourage use of a range of services.

In the current study's locality, there is a relatively stable ethnic minority group with origins in the Indian and Pakistani Punjab and the linguistic needs of this group are largely met by Punjabi, Hindi and Urdu interpretation. In such circumstances we would recommend the employment of a health promotion worker whose post would not be closely identified with clinical CAMHS, but whose role would be to build bridges between the community and CAMHS and to develop cultural competence across the range of services with which children interface.

Severe and enduring mental illness, particularly when first manifesting itself, may create such an urgent need for support that cultural insensitivity will be tolerated, at least for a time. Nonetheless a profession is judged by the routine performance of all members rather than the best practice of the most competent members (Gerrish et al 1996). Since health care is routinely provided by a multi-disciplinary team, a

profession is equally likely to be judged by the routine performance of another profession. Furthermore, the onus is on the professionals to demonstrate appropriate cultural knowledge and empathy where a group has learned to expect ignorance and hostility (Gerrish et al 1996), as is the case for racialised minorities in Britain. If, as this study suggests, service-users do not distinguish between health, social care and education professionals, cultural (and linguistic) competency must be demonstrated across the board in order to overcome low expectations.

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**Table – study participants**

<i>Phase 1</i>				
<i>Focus groups</i>				
Group (number of participants)	age range	Gender	Religion	Language(s) used in focus group
1 (10)	20-60	Women	Muslim	Urdu, Punjabi, English
2 (6)	40-60	Women	Sikh	Hindi, Punjabi, English
3 (4)	20-40	Women	Muslim	English, Urdu
4 (5)	20-60	Women	Hindu & Sikh	English
5 (6)	50-60+	Women	Hindu	Hindi
6 (5)	30-60+	Men	Muslim	Urdu
(Total 35)				
<i>Phase 2</i>				
<i>Users of CAMHS services</i>				
Participant	Child's gender, age at onset, problem	Language	Carer(s) interviewed	Community professional interviewed
User 1	Girl, 13, bipolar disorder	English	None	CAMHS nurse therapist
User 2	Boy, 12, psychosis	English and Punjabi	Mother	CAMHS psychiatrist
User 3	Boy, 8, learning difficulties and behaviour problems	Punjabi and English	Both parents	CAMHS social worker
User 4	Boy, 11, behaviour problems	Urdu	Mother	CAMHS psychiatrist
User 5	Girl, 6, learning difficulties	English	Both parents	CAMHS psychiatrist
User 6	Boy, 6, ADHD	English	Mother	CAMHS psychiatrist
User 7	Girl, 14, psychosis	English	Mother	Multicultural health advisor
<i>Potential users</i>				
Potential user 1	Girl, 7, autism spectrum disorder	Urdu	Mother	
Potential user 2	Boy, 10, behaviour problems	English	Mother	
Potential user 3	Boy, 5, speech and behaviour problems	English and Punjabi	Mother and Aunt	
Potential user 4	Boy, 6, behaviour problems, learning difficulties	English	Aunt	
Potential user 5	Girl, 5, withdrawn behaviour, learning difficulties	English	Aunt	
Potential user 6	Boy, 13, disruptive antisocial behaviour	English	Both parents	

