

Minority ethnic communities and specialist learning disability services

Report of the Faculty of the Psychiatry
of Learning Disability Working Group



Faculty report FR/LD/2
Faculty of the Psychiatry of Learning Disability
of the Royal College of Psychiatrists
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Executive summary and recommendations

This faculty report summarises the knowledge that is available regarding the use of specialist learning disability services by people with learning disabilities and their carers from minority ethnic communities. It also provides guidance for improving access to services and, where available, good practice examples. The content of the report is drawn partly from the literature and partly from discussions within a focus group that involved well-established researchers in this area as well as other people with expertise in service delivery.

Minority ethnic community is an umbrella term that covers many groups with significant variations in needs based on factors such as differences between subcultures, whether they comprise new or first-, second- or third-generation immigrants, and migration pathways.

Although the prevalence of learning disability in minority ethnic communities is at least at the same level as their indigenous counterparts, service users from minority ethnic communities are underrepresented in UK mental health services. This points to a number of barriers that exist for these communities in the use of mental health and learning disability services. It is important for organisations to understand such barriers and to improve access. Organisations should seek ways of 'reaching the community', involving the community in the development and delivery of services, and creating an environment for staff to develop and maintain cultural competency. Such measures should be part of the core business allowing integration of these initiatives into the day-to-day delivery of services.

RECOMMENDATIONS

1. Health organisations should have a strategic approach to meaningful engagement of the community including those from minority ethnic communities.
2. Providing information on mental health problems in people with learning disabilities and the local availability of services to minority ethnic communities is vital in improving access. The information provided must be accessible and needs to convey an informed and genuine effort at engagement, rather than a merely tokenistic approach.

3. Healthcare organisations should try to understand the barriers that minority ethnic communities face in relation to the access of mental health services and make efforts to address these.
4. A culturally competent workforce is vital for the effective delivery of services to a multicultural community. With support, minority ethnic communities could play a vital role in the development of a culturally competent workforce.

Introduction

Minority ethnic community is an umbrella term that includes many groups with different cultural and ethnic backgrounds. Even within a single community, variations exist regarding attitudes and access to services based on factors such as the difference between subcultures, whether they comprise new or first-, second- or third-generation immigrants, and migration pathways. It is therefore very difficult to generalise findings of one ethnic minority group to the whole community. Most of the literature in this area is based on research on specific communities; regarding learning disability, the South Asian community has been a main focus of research and service developments.

Despite variations, there are some common themes that are relevant to people of all minority ethnic backgrounds, and in contrast to mainstream groups, these differences continue to be stark. There are significant differences between the White majority and minority ethnic groups in the UK in their experience of mental health services and the outcomes of interventions (Cochrane & Sashidharan, 1996). A report on learning disability and ethnicity (Mir *et al*, 2001) also highlights inequalities in health and social care received by ethnic minorities. The colour-blind approach of policies operating within health and social care organisations ('we treat everyone the same' approach) ignores the needs of this vulnerable group.

There are significant economic and social disadvantages that are common to most minority ethnic groups, although the degree of this can vary between different communities. The material disadvantage is reflected in housing (inner-city housing) and work patterns (semi-skilled/unskilled with long working hours/unsocial shift patterns). Additional communication barriers which are either language or culture related can contribute to this problem. Studies of Asian families in which a family member has a learning disability reveal a deprived, isolated group who suffer racial abuse, encounter language barriers and experience significant levels of stress, but have little knowledge or understanding of learning disability (Nadirshaw, 1997). A decade later, Raghavan & Waseem (2007) mapped service use among young people with mental health problems and learning disability from Pakistani and Bangladeshi communities in Bradford, UK, and found little change: many did not access statutory child or adult mental health services. Families reported key barriers such as lack of awareness of services, language difficulties and lack of culturally sensitive services that made them reluctant to use these services.

Prevalence of learning disability

The 2001 UK census showed that 13% of the population are from minority ethnic communities, of which 7.9% are from Black and minority ethnic origin. This proportion has been influenced by both migration and births in the UK within Black and minority ethnic families. Although ethnic minorities represent a significant proportion of the population, they face discrimination, disadvantage and inequality in areas of health and social care (Modood *et al*, 1997; Acheson, 1998).

Evidence on the prevalence of learning disability in minority ethnic communities is not consistent. Conceptual and practical difficulties with the definition of 'learning disability' make prevalence data across ethnic groups and from communities around the world difficult to establish (O'Hara & Bouras, 2007). However, there are an estimated 170 million people with learning disabilities worldwide. The World Health Organization (2006) estimates that 2% of the population of India have a learning disability, and this figure increases to 3% when considering those under the age of 18. This compares with 12% of primary school children in Sri Lanka and 7% of children between the ages of 2 and 9 with some form of disability in Bangladesh (severe learning disability estimated at 6 per 1000). Mild mental retardation is much more common than severe mental retardation, accounting for 65–75% of all individuals with mental retardation (World Health Organization, 2006). A Western Australian study shows a higher prevalence of learning disability among Aboriginal communities (Leonard *et al*, 2003).

In the UK, although one study showed that South Asian and White populations have a similar prevalence of learning disability (McGrother *et al*, 2002), other studies have shown an increased prevalence of severe levels of learning disability in South Asian populations (Azmi *et al* 1996; Emerson *et al*, 1997). Of South Asian families with a family member who has a learning disability, in 19% there was more than one individual with a learning disability in the household (Mir *et al*, 2001). Emerson & Hatton (2004) predicted that the population with learning disability from minority ethnic communities will increase substantially over the next 20 years. There is very little evidence from other minority ethnic communities on the prevalence of learning disability. Consensus is that there is no reason to expect large variations, and certainly it is extremely unlikely that there is a lower prevalence than in the general UK population.

Key issues

EXPERIENCE OF MIGRATION

Migration, whether voluntary or forced, is a traumatic life event with disruption of lifelong attachments and external stability (Falicov, 1995). Family disruption continues through separations and reunions; and parents who raise their children in a culture that differs from their own often feel disempowered. Migration is associated with culture shock, difficulties with adapting to the new culture and a risk of increase in physical and mental health morbidity. There is evidence that people from some minority ethnic communities are more likely to be diagnosed with a psychiatric illness, especially psychosis, than the White Caucasian population (Chaplin *et al*, 1996).

Forced or involuntary migration is growing in importance and involves people who are forced to flee their homes and seek refuge elsewhere. Asylum seekers are people who move across international borders in search of protection, but whose claims for refugee status have yet to be decided. Procedures and appeals can take many years during which time applicants live in 'limbo'. Although 90% of asylum applications made in the UK are rejected, the majority of people stay on often because they have no passport or their country of origin will not take them back (Castles, 2004). Even though refugees whose claims are accepted technically have the same rights as citizens, the experience of serious traumatic events coupled with problems related to acculturation may impede their uptake of services.

Today, there is a growing awareness that migrants may not simply assimilate into receiving societies but rather tend to form communities and retain their own languages, religions and cultures. There is public debate about this in the UK, with some voicing concern about the apparent lack of acculturation, adequate competencies in the English language and an understanding of British history and identity.

The ethnic minority reality is often one of racism or perceived racism, discrimination and poverty (Sue & Sue, 1999). This is exacerbated by poor housing, high levels of unemployment, low pay, minimum pension rights, reduced benefits because of residence status, inadequate education and poorer health. Psychological and emotional distress may go unrecognised as patients from ethnic minorities often present to their general practitioners (GPs) with somatic complaints. At the same time, immigration and the quality

of housing available, especially in inner-city areas, often militate against the supportive network traditionally offered by extended families (O'Hara, 2003). Understanding of, and respect for, different family structures and community organisations in migrant groups are vital to service delivery.

NEW MIGRANTS

There is very little research exploring mental health issues in new migrants with learning disabilities. Owing to the nature of disability, it is unlikely that people with learning disabilities will be economic migrants travelling on their own. They are more likely to be a dependent member of a migrating family or refugees and asylum seekers. It is reasonable to assume that the adversity of forced migration confers the same risks of morbidity, if not more, in this vulnerable population. Other than psychiatric morbidity, problems with language and communication, prejudices and stigma within society in general, and within their own community and subculture in particular could also have an impact. This could significantly influence health-seeking behaviour, engagement with services and uptake of available health, social and community services.

It is also important to understand that new migrants can be different to older generations of immigrants in their profile of needs and patterns of engagement. Their relative lack of awareness of existing services as well as their reluctance to explore these services may escape the attention of professionals. This difference must inform service approaches to this population. It is therefore important that community mechanisms which foster inclusion are strengthened by close working with the voluntary sector and other community organisations.

ELIGIBILITY ISSUES

As resources are limited, services often put great emphasis on whether or not an individual meets their eligibility criteria. Learning disability is a social construct, the presence of which may be difficult to determine in the absence of learning disability-associated syndromes, a significant history of developmental delay, or an educational history. Mild learning disability in particular is fraught with challenges of diagnosis. Among minority ethnic communities, the language barrier, lack of adequate educational and healthcare opportunities in their country of origin and incomplete and uncorroborated histories makes such assessments particularly complex. It is not uncommon for the person with learning disability to be lost to services during transition from child to adult services. This may reflect the current experience of many service users and their families, but anecdotally, this may also in part be due to the fact that young people from some communities return to their homeland, are married there and later return to the UK as 'new entrants' into adult services, missing the transition phase.

GENDER AND DISABILITY IN RELATION TO SOCIAL ROLES

Gender influences not only the rates of mental health problems in minority ethnic communities but also the caring role (O'Hara, 2008). More recently, attention has focused on consent and forced marriages (over one in five cases dealt with by the Foreign and Commonwealth Office's Forced Marriage Unit in 2007 involved a person with a learning disability), and the belief that families may be choosing this illegal option primarily because they see marriage as the only long-term care option for their offspring with learning disabilities (Lakhani, 2008). The consequences of these forced marriages may be dire: the expectation that the marriage will be consummated may lead to sexual assault and rape, domestic violence, abuse and abandonment (Ann Craft Trust, 2009).

A study carried out using the Leicestershire Learning Disability Register (Beber & Biswas, 2009) ascertained that 4.6% of the study sample had ever married, the rate in the White ethnic group being 4.4% and in the Asian group 9.4%. The difference, however, was not statistically significant even though individuals from the Asian group who had ever married were significantly younger, significantly more likely to have children living at home and had a significantly lower mean IQ than their White counterparts. This finding may appear to be paradoxical to their level of functioning and raises the question whether they have adequate understanding of their role in the marriage, and their abilities to manage this relationship.

The government's Forced Marriage Unit has recently commissioned a research project to explore the reasons for forced marriage, identify the warning signs and draw up best practice guidance for professionals in dealing with the situations related to forced marriage (Ann Craft Trust, 2009).

Social and gender roles and expectations differ across societies and generations. A study from east London found that it was questionable whether or not Bangladeshi parents with learning disabilities were able to give informed consent to marriage (O'Hara & Martin, 2003). It is also unclear whether the spouse-to-be was fully aware of the circumstances. Although clinicians may work with a few cases which cause such concerns, there are many examples where a facilitative wait-and-see approach is also necessary, for example where the individual with a learning disability is also a parent and is gradually able to take on a more fulfilling adult role within the family and community, with the support of his/her parents and extended family members. It is important to strike a balance between clinical judgement, ethical, consent, vulnerability and safeguarding adult issues and working with local ethnic communities to find a way forward in what is often a grey area. However, it is important to acknowledge the cultural and contextual nature of consent and consider its difference from coercion as a matter of degree and perception, with persuasion playing a key role (An-Na'im, 2000). The welfare of the child is paramount in this, and safeguarding children processes must be followed if there are concerns. However, there is some evidence to suggest that this may not be the case for fear of professionals being regarded as 'culturally insensitive'.

Women with learning disabilities face a 'triple jeopardy' because of ethnicity, disability/impairment and gender (Mir *et al*, 2001). Owing to

discrimination and the lack of expectations from the family, they may suffer from unmet needs. Furthermore, some Asian women may be perceived by the wider society as isolated, possibly owing to their underlying reluctance to embrace services, as these services may be seen by their community as being part of a Western lifestyle. In some minority ethnic communities, women play a vital role in the family. They are more likely to be primary carers, even though men may be the designated carers. As part of their caring role, women perform a large number of chores to support a family member with a disability. They are also likely to have other commitments, including work at home and, in some cases, paid employment outside the household. This puts them under an enormous burden of practical demands and the stress of one's own expectations and responsibilities. They may be less inclined to discuss this with their families, let alone healthcare services. Prolonged stress can cause mental health problems, which then upsets the equilibrium of the family due to de-compensation in the primary carer. Unrecognised and unmitigated stress may also result in sustained expressed emotions of hostility and anger, coupled with shame and guilt. It is known that GP consultation rates are significantly higher in the minority ethnic community compared with the White UK population. Psychological and emotional distress may be unrecognised or not accepted, resulting in presentations with somatic complaints. This may perpetuate adverse family environments, including abuse. Even though women tend to be the main caregiver, men will usually attend health and social care appointments with the person who has a learning disability and they may not be able to provide adequate/reliable information. In such instances, services often overlook the women, who themselves may need an assessment and support.

Although the main caring role is taken up by women, men are more likely to be nominated as carers as they are more likely to liaise with agencies, may be more competent in English or because of the family structure. Lack of understanding of this by professionals can lead to barriers in understanding the situation. For example, men may not be available at the time when professionals want to make a home visit to carry out an assessment, and, especially in Muslim families, women may not want to deal with male representatives of the service.

CULTURAL CONFLICTS

Understanding and respect for different family structures is vital; the involvement of the extended family including 'non-blood' relatives may be seen as a collective social responsibility in some communities, especially those from South Asia. The strengths of such a support network may be inappropriately taken for granted by services, or may be perceived by professionals as a source of stress for the individual. Second- and third-generation immigrants may have very different attitudes in relation to this, which can lead to tension and (cultural) conflict within the family. The choice of language used in the delivery of services to bilingual families may not appear neutral to them; it

can be perceived as collusion between the professional and the most fluent family member.

Such close community networks also mean that often staff from ethnic minority communities employed by statutory services as a means of providing a more culturally acceptable service are part of the service user's community – and there may be concerns about confidentiality, especially if a family is disclosing sensitive information, or trying to seek help without being made to feel that they have failed in their duties as a parent. One study in a South Asian population showed that societal attitudes towards disability and the fear of obligation prevented families from seeking help from wider social networks (Katbamna *et al*, 2004).

The stigma of disability may not be as great if the condition is physically obvious. It can stimulate a greater faith in one's own spiritual beliefs or result in complete loss of faith. Some would argue that South Asian cultures are more accommodating of people with learning disabilities (McGrother *et al*, 2002). However, when this is complicated by additional needs such as mental illness or epilepsy it can be more difficult for families to come to terms with (P. Ali Choudhury, personal communication, 1992).

An important misconception about learning disability held by Asian parents is the notion of curability. There are many examples of families spending or losing their life savings in search of a cure. The severity of disability or the socioeconomic status of the parents did not have any effect on this attitude but the knowledge gained through counselling had a positive impact (Davis & Rushton, 1991). The additional diagnosis of a mental illness may make the family more vulnerable to charlatans claiming to use black magic and exorcism to rid their family member of 'evil spirits'. Complementary treatments are often used, and it is important to ask about these during consultation.

In the UK, the burden of care, both socially and financially, is greater for carers from minority ethnic communities compared with their White peers (Butt & Mirza, 1996) owing to a number of contributory factors such as poverty, poor housing and perceived racism. Carers of people with learning disabilities from South Asian communities in the UK show a high level of stress and self-reported depression, and their failure to take up services provided by statutory bodies has been attributed to their lack of skills relating to Western lifestyles (Devapriam *et al*, 2008). The report by the National Black Carers and Carers Workers Network (Afiya Trust, 2008) provides a similar picture. It points out the barriers for carers from minority ethnic communities in accessing all types of carer support, including short breaks (respite care) and direct payment. Lack of awareness, lack of culturally appropriate service provision and lack of appropriate support are the important contributory factors.

Use of learning disability services by people from minority ethnic communities

Despite reports of higher prevalence rates of learning disability in minority ethnic communities, individuals with learning disabilities from these communities are largely underrepresented as users of specialist learning disability services. South Asians tend to make less use of specialist services (Modood *et al*, 1997), community health and social services. Although there is a high use of generic services such as GP service and welfare support, specialist learning disability services such as psychiatry and behavioural support are underused (Raghavan *et al*, 2009).

There are many factors contributing to the low use of specialist learning disability service by people with learning disabilities from minority ethnic communities. A study using the Leicestershire Learning Disability Register showed that people with learning disabilities from minority ethnic communities have similar levels of mental health and behavioural problems, and that carers experience significantly more stress and receive less support than their White European counterparts (Devapriam *et al*, 2008). In 1998, Hatton *et al* reported high levels of distress among South Asian carers with a high risk of developing psychiatric problems. Low household income and more than one person with a learning disability in the household have also been associated with high carer stress (Azmi *et al*, 1996). Bouras *et al* (2003) studied the referral pattern to a specialist learning disability service from 1983 to 2001 and found that over time the proportion of Black and minority ethnic patients (predominantly African-Caribbean origin) have increased over time. The 2009 national census of in-patients in mental health and learning disability services in England and Wales (Care Quality Commission, 2010) found significant differences in admission rates between minority ethnic communities. People with learning disabilities from Black communities were more likely to be admitted than those from other ethnic groups. There are significant variations in the pathways to care between the mainstream and the minority ethnic population.

BARRIERS TO THE ACCESS OF SERVICES

LACK OF INFORMATION REGARDING SERVICES

Available evidence as well as views of experts working in this area indicate that families from minority ethnic communities lack awareness of the services provided. A consultation that the Working Group of this report has undertaken in Leicester with support from Ansaar, a voluntary organisation, indicates that carers from minority ethnic communities are largely unaware of specialist learning disability services. The transition from child services to adult services is highlighted as a particular point where young adults with learning disabilities from minority ethnic communities are likely to lose contact with services.

For children with mental health needs, school takes a leading role in seeking out support, but in the absence of an effective transition arrangement, these individuals are likely to be lost between services during the period of transition, resulting in a significant care burden for the family.

LANGUAGE BARRIERS

Language barriers prevent families/carers from communicating the nature and extent of problems experienced to primary care professionals, resulting in inadequate identification or minimisation of the problems and reduced referrals. When associated with a general lack of awareness of services, language barriers make it difficult for families to voice the need for additional support. Often professionals rely on a family member who is bilingual for interpretation. Use of a family member as an interpreter can lead to lack of trust from other family members who may interpret this as collusion, and therefore be unwilling to disclose information. The family member who interprets may also select to disclose only information that they think is relevant. Language barriers and use of non-professional interpreters may perpetuate a cycle of bad experiences and outcomes (Butt & Mirza, 1996). Use of a professional interpreter and planning the session carefully by meeting with the interpreter before the appointment are likely to be helpful. However, clinicians need to be aware that in some small communities, use of an interpreter from the same community may lead to the family being hesitant to disclose sensitive information.

THE ROLE OF FAMILY DYNAMICS IN DETERMINING ENGAGEMENT WITH SERVICES

The family's interaction with its own subculture, the wider community and services is determined by experience and perception of stigma. Attitudes to services may be influenced by events, starting with the news that the child has a learning disability. This may result in negative attitudes that are maintained by culturally insensitive choices offered to these patients and families. Within some cultures, family structures and relationships can be hierarchical. Even

though many families function as independent autonomous units, a range of both routine and important decisions may be made in consultation with the extended family, which may comprise second cousins and 'non-blood' relatives. Individual interests may be sacrificed for the collective welfare (or reputation) of the family, and the interests of the family may take precedence. This may influence expression of choice in health and social care measures. Families are usually interdependent, especially in times of crisis. It is therefore not uncommon for decisions to be made 'on behalf of' patients by distant family members, who may be respected and ascend the hierarchy with the support of the family. Services and professionals must recognise that such decision-making may be based on principles similar to 'best interests', and is not necessarily suppression of the patient's right to consent. However, abuse is not unknown, and professionals must learn the skills to appropriately distinguish between well-meaning assent and unacceptable violation of rights. Arriving at such conclusions requires sensitivity from the professional to ensure that patients and their families do not experience suspicion and do not feel alienated. This should take a collaborative approach with the family without pre-judgement, exploring pros and cons of the decision with all the relevant family members. Both an outright rejection of the principles of these complex decision-making processes based on Western values or an overemphasis on cultural aspects to the detriment of the safety of the individual concerned are likely to lead to wrong decisions being made.

As the level of individual contact with people outside their own ethnic group can vary, there can be significant differences in the perceptions and lifestyles of different generations of the same family. When providing services to families that have a range of structures and priorities, professionals need skills/knowledge to avoid giving primacy to a particular cultural or ethnic approach. Equally important in these situations is the use of language to communicate, especially in bilingual families. The tendency to communicate using a particular language with a more fluent family member may be perceived as collusion.

Families' emphasis on self-reliance and wanting to look after the individual can at times come into conflict with professional advice for hospital admission or a short break (i.e. respite or holiday with a paid carer). If not sensitively dealt with, these situations may lead families to distance themselves from the service. Professionals on the other hand may perceive the family as being secretive or difficult, leading to more communication barriers. One study in a South Asian population showed that societal attitudes towards disability and the fear of obligation prevented families from seeking help from wider social networks (Katbamna *et al*, 2004). Social deprivation and the lengths families go to in an effort to make ends meet can mean that key family members, often the decision makers, are not at home when professionals call for assessments or for the delivery of interventions/care plans. Women who are within the household may not want the professional visit to take place. Even when professionals are able to visit, the absence of the key decision maker means that the decisions cannot be implemented until the decision maker is convinced of the need to do so.

INFLUENCE OF CULTURE AND BELIEF SYSTEMS

Culture and belief systems can have a powerful influence on how families respond to behavioural problems and on seeking out the right support for the management of problems (Chamba *et al* 1999; Mir *et al*, 2001; Raghavan *et al*, 2009).

ATTITUDES AND BELIEFS

Attitudes and beliefs form an integral part of people's perceptions of their ethnicity and identity. Understanding the cultural and religious attitudes and beliefs plays a crucial role in determining the process of care. Services need to develop an understanding of these to promote engagement as well as providing care.

It is suggested that the variations in attitudes between Asian and indigenous British families could be related to cultural and religious differences rather than to any descriptive characteristics of the parent or their child (Fatimilehin & Nadirshaw, 1994). Attribution of meaning and conceptualisation of learning disability vary significantly across different ethnic groups. Some South Asian cultures are perceived to be more accommodating of people with learning disabilities than others (McGrother *et al*, 2002). The Hindu belief in the concept of Karma – the cycle of reward and punishment for all deeds and thoughts as the immortal spirit is reborn into another body – may provide an understanding or at least alternative explanation for the cause of learning disability and lead to a sense of acceptance or resignation. Middle Eastern cultures regard disability as a punishment from heaven, emanating from the spirits or caused by an 'evil eye' (Aminidav & Weller, 1995). Many Chinese people believe in fate and use a coping strategy of forbearance, seeking supernatural powers and praying to ancestors (Cheng & Tang, 1995). Clinicians often cite fatalism and the search for a cure as reasons why families from some ethnic minority communities are not interested in educational or rehabilitative programmes for learning disability. It is also frequently assumed that Asian parents do not have a positive or encouraging attitude towards disability, because of their religious or superstitious beliefs (Shah, 1992).

Fatimilehin & Nadirshaw (1994) studied differences in attitudes and beliefs of Asian and White British families and found that Asian families:

- had more contact with a 'holy person'
- were less aware of what their child's problem was called
- believed in a spiritual explanation/cause and felt that their religion had something particular to say about learning disability
- 50% said they did not know the cause of their child's learning disability
- faith helped to cope but offered little social or practical support
- wanted care to be provided by a relative when they were no longer able to provide it themselves.

Some families explore availability of a 'cure' for the disability. On occasions, families can invest heavily in terms of resources, emotions and

expectations in the search for a cure. Any signs of scepticism from services towards this attitude are likely to be perceived unfavourably, further widening the gap between these families and services. Therefore, there is a need for services to focus on the dissemination of meaningful, culturally fair information, which could enable families to make informed decisions on such matters.

LACK OF APPROPRIATE SERVICE PROVISION

Services provided can be insensitive to the cultural needs of ethnic minority communities, alienating them completely. Carers have repeatedly reported issues of insensitivity regarding dietary requirements, lack of same-gender accommodation, provision of bilingual carers and culturally sensitive material. Addressing these issues could present services as welcoming and accepting.

Although carers from minority ethnic communities experience similar or higher levels of stress as their White counterparts, they are reluctant to access specialist services due to distrust or fear of services. Although some of the above issues are not specific to ethnic minority communities, users and carers from this background are more likely to react to this by staying away from services (as highlighted earlier) leading to a sizeable hidden population with complex needs.

The Department of Health document on learning disability and ethnicity (Mir *et al*, 2001) summarises the evidence from literature on minority ethnic communities and service use as follows:

- poor standards of communication
- delays in diagnosis and treatment
- isolation, lack of support and high levels of carer stress
- low take-up and poor access to services
- high levels of unmet need
- lower levels of access to benefits and/or receipt of lower amounts of benefits compared with White claimants with similar needs
- low levels of knowledge of services available for the person with a disability or carers.

Service developments: good practice principles

INVOLVING THE COMMUNITY AND CAPTURING ACCURATE INFORMATION ON NEED

It is important for services to take active measures to involve the community in a meaningful way. It would, however, need a considerable amount of flexibility from the service provider to meaningfully engage the community, and would involve the following.

- Identifying the partners that would include community organisations, carers and people with learning disabilities from minority ethnic communities.
- A consultation that focuses on regular contact with the community through various means. It is important to use effective methods of communication with groups who may not share language or other cultural norms with the majority. Use of focus groups has been found to be effective.
- Robust linking of the consultation findings to implement change. User-carer organisations feel that they are 'being used' by the statutory organisations carrying out consultations, who are only focused on meeting targets and not following through with changes in service delivery. Consultations should not be a 'one-off' but part of an ongoing relationship between the healthcare service and the community.
- Providing a framework that is ongoing to identify and support people from minority ethnic communities to actively contribute through participation. Communities need to see the consultation becoming fruitful through real changes within the organisation (e.g. NHS trusts) as well as in staff attitude.
- Persistent efforts to include marginalised groups continuously through partner organisations, community liaison workers and publicity through radio, television and advertisements at community events as well as in places of worship.

A detailed discussion of the involvement of people with learning disability and their carers can be found in the Department of Health document on learning disability and ethnicity (Mir *et al*, 2001), which provides some good practice examples. The key themes from this document are summarised on the following page.

- Partnership with minority ethnic community groups in service planning – a variety of activities and appropriate publicity are needed to increase awareness of service provision within minority ethnic communities.
- Effective advocacy services need to be developed for people with learning disabilities from minority ethnic communities. Involvement of family needs to be acknowledged by the advocates.
- The role of family and community networks needs to be taken into account when planning services for individuals.
- Support groups can provide emotional support, promote engagement and enable a greater say in service care delivery for people from minority ethnic backgrounds with learning difficulties and their carers. These groups can also act as gateways to a range of support services. Outreach is needed to include those who cannot attend groups. Most support groups are not at present 'culturally inclusive', and many community organisations lack expertise or experience in supporting people with learning disabilities and their families.
- More bilingual staff and interpreters are needed to improve communication and access to services. In addition to the recruitment of staff from minority ethnic backgrounds at all levels in service organisations, training for all staff is needed to improve competence in cultural awareness and prevent the marginalisation of ethnic minority groups' needs.
- Service providers need accurate and ongoing information about the needs of minority ethnic communities.

The Leicestershire Partnership NHS Trust started a Communities, Rights and Inclusion (CORIIN)¹ programme in 2008 to ensure community engagement, protect human rights and promote social inclusion. The programme will contribute to the strategic development of the Trust and a new Communities, Rights and Inclusion Committee will report directly to the Trust Board. CORIIN focuses on the inclusion of the community as a whole, with a strong emphasis on Leicester's multicultural background. Some of the initiatives that CORIIN has initiated include:

- establishment of a Somali mental health forum in which the Trust is taking a capacity building approach to help develop members of the forum;
- two part-time secondments have been arranged in local Black and minority ethnic community groups to enhance shared learning and development of practice;
- Panj Pani radio (a radio station aimed at the Punjabi population) is hosted within the Trust; the Trust has been working closely with Panj Pani and has helped develop a system whereby Trust jobs are being advertised routinely on the radio.

PROVISION OF INFORMATION

Information that promotes a positive approach with details of support and services available will help carers stop focusing on curing learning disability

1. For more information regarding CORIIN and its initiatives, please contact Jon Bashford (Jon.Bashford@leicspart.nhs.uk).

or passively accepting it as fate and help them use active coping strategies that will include collaborative approaches with specialist learning disability services (Mir & Tovey, 2003). There are many examples of families spending or losing their life savings in search of a cure for a learning disability, whereas no effort is made to effectively access the appropriate support for managing the behaviour or mental health problems. A consultation with a carer group in Leicester revealed that carers from minority ethnic communities do not understand the role of specialist learning disability services and therefore have not accessed the services even when the individuals with learning disabilities that they look after had mental health or behavioural problems.

Information provided in different languages is only the first step towards involving people from minority ethnic communities. It is important for services to explore more effective ways of getting information to the communities. There are good examples of enhanced service provision that include but are not limited to, the following:

- using visual media such as videos/DVDs with a social story approach;
- using radio/television stations popular in minority ethnic communities;
- using places of worship/cultural centres and engaging respected community leaders to disseminate information;
- working with voluntary organisations to organise carer/user events within and close to the communities – such regular events, which bring the service in contact with minority ethnic communities, will allow cascading of information down to the community as well as develop trust. However, although voluntary organisations are very keen to play an important role in supporting families to access services, they often struggle with the lack of resources.

DEVELOPING A WORKFORCE THAT IS CULTURALLY COMPETENT

Developing a culturally competent workforce should go beyond providing diversity training. Cultural competence is a dynamic concept that allows flexibility to adapt to the knowledge of communities and willingness to learn from them. Cultural competence needs to be integrated both at the organisational and individual practitioner level.

ORGANISATIONAL LEVEL

Cultural competence needs to be included in the organisation's business plan, integrated into the organisational activities (inclusion in committees, policies, audits, performance assessments, patient satisfaction measures, having a board-level champion, etc.). A culturally competent organisation will have regular events that bring staff into contact with the diverse community. Clinicians attending these events often find them very useful in understanding the community. Recruitment of bilingual staff should go hand in hand with ongoing training for all staff.

INDIVIDUAL LEVEL

Staff should have good knowledge of the diverse needs of the community. Staff should be able to treat people in a way that is sensitive to the needs of the individual. Staff should show a good understanding and respect for cultural diversity when assessing and treating individuals.

IMPROVING ACCESS TO SERVICES

IMPROVING AWARENESS OF MENTAL HEALTH PROBLEMS AND SERVICES

As part of community involvement, there have to be efforts to improve awareness of mental health problems among primary care professionals, voluntary organisations and community/religious leaders.

'ONE-STOP SHOP' MODEL

Literature indicates that minority ethnic communities are more likely to contact services if there is a 'one-stop shop', for example a liaison worker or a voluntary organisation. However, unless sufficient capacity is built in, this system is unlikely to be successful and would end up as a lip service. There are many examples of this model.

Raghavan *et al* (2009) carried out a randomised controlled trial of a specialist liaison worker model and found it to be effective in increasing the contact between services and users from minority ethnic communities. Liaison workers in this model visited or telephoned at least once every fortnight advising about the availability of services as well as helping young people with intellectual disabilities and challenging behaviour make the initial contact.

Ansaar, a voluntary organisation in Leicester, provides support to individuals from minority ethnic communities to access services. It is a community project set up specifically for people with learning disabilities (www.ansaar.org).

The Signposting service in Bradford (previously known as Project 119) has developed links with all the local community leisure and recreation centres, colleges and Bradford Community Broadcasting, the local radio station. The service works in partnership with Bradford libraries and therefore works out of a community base, rather than an NHS location. The service has developed and grown based on adapting and facilitating the service users' needs and choices.

INTERPRETER SERVICES

It is important not to rely on other family members or other people selected *ad hoc* for interpretation. If interpretation is required, clinicians should have good access to a professional interpretation service round the clock. Although it is important for organisations to make efforts in employing staff that is reflective

of the local population, this is unlikely to remove the need for an effective interpreter service.

Access to a good-quality interpretation service is an issue that organisations struggle to provide. A mixed approach (employing bilingual staff, engaging dedicated professional interpreter services and use of telephone interpretation) is useful in addressing the interpretation needs. It is important, however, that the organisation has a system in place to assess the efficacy of such services in meeting the needs, to continuously improve the service.

PERSON-CENTRED APPROACH

One can not assume an individual's choice based on their cultural background. Individuals' needs can vary considerably even within the same culture. However, a good knowledge of the cultural background is essential for undertaking the person-centred approach when planning for people with learning disabilities from minority ethnic communities.

There are several good practice examples of the person-centred approach. Leicester City Council produced a toolkit (www.lcen.org.uk/page6/page67/page71/page71.html) to enable professionals to undertake person-centred planning for people with learning disabilities from minority ethnic communities. They have training sessions in languages such as Gujarati and Hindi and work with the community to develop social history models relevant to the community.

The Apqar Haq project is another good practice example for culturally competent person-centred planning. It is run in Oldham, where a range of initiatives have been implemented to improve transition services. A review of this good practice can be found in Chapter 6 of *Bridging the Divide at Transition* (Heslop *et al*, 2002: p. 103). One of the features of the Apqar Haq project was to facilitate rapport and communication by recruiting bilingual link workers. Rather than relying on traditional assessment formats, efforts focused on active listening and learning, keeping the individual and their families at the centre of the care planning process.

The Bangladeshi Parent Adviser Service in Tower Hamlets Learning Disability Service offers emotional and practical support to parents of children/adults with learning disabilities, helping them to work out solutions to problems (Davis & Ali Choudhury, 1988). In addition, the service accompanies parents in attending review meetings as well as helping to liaise with services. Information about this service can be found at: www.lddirectory.org.uk/files/91021/FileName/MicrosoftWord-BangladeshiParentAdviser2010amended.pdf

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