Reaching out

Working with black and minority ethnic communities
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All photographs shown in this report are for illustration purpose only.
A message from Mark Goldring, Mencap’s chief executive

This report follows a major piece of research looking at Mencap’s work with people from black and minority ethnic (BME) backgrounds. We wanted to find out how successful we are in reaching out to people from BME communities, and gather ideas about how we can meet their needs.

Diversity is an important part of all our work. Our vision is a world where everyone with a learning disability has choice, opportunity and respect, and we do mean everyone. We want to make sure that people from BME communities are using the services and support we can offer, and we will do all we can to work with them to make sure this happens. We also want our staff to reflect the communities they work with. Having a diverse workforce brings together different points of view and different skills and talents. This enriches us, making us a stronger organisation and more able to appeal to as wide a range of people as possible.

The inspiring success story of Midland Mencap has provided us with valuable information about best practice. We can transfer what they have learnt to all our work at the local level, and will work in partnership with other organisations and statutory providers to move this important work on to the next stage.

I hope you find this report useful. I am grateful to all those who participated in the research, and to the Lord Ezra Fund for providing the funding that made it possible.

Mark Goldring CBE
Chief executive, Mencap

Foreword by Dave Rogers
Chief executive, Midland Mencap

Midland Mencap is proud to be associated with this research, and I would like to thank everyone who contributed to the work and helped make this report possible.

The future holds many challenges for us and we are in a good position to tackle them successfully. What we have found out during this research will be invaluable as we continue to develop services that are accessible and relevant to the city’s BME communities.

We join Mencap in encouraging all partners and stakeholders to work with us to deliver the support that individuals and families affected by learning disability are asking for.

David Rogers
Chief executive, Midland Mencap
Introduction

This report, written in 2006, is based on research commissioned by Royal Mencap Society and Midland Mencap. Royal Mencap Society is a national organisation, which provides a variety of support to people with a learning disability, their families and carers. Midland Mencap is an independent organisation. It works at a local level in the Birmingham area, and is affiliated to the national organisation. There are approximately 600 affiliated groups working locally to make up the Mencap community.

Midland Mencap is one of the first groups to recognise and target the unmet needs of people with a learning disability in black and minority ethnic (BME) communities. The research was carried out to gather information about the experiences of families affected by learning disability among BME communities in Birmingham. We particularly wanted to find out about difficulties in accessing services, especially among elderly carers. And we wanted to find out about levels of awareness and perceptions of Mencap. Finally, we wanted to evaluate the work that Midland Mencap did in these communities during the two years 2004 to 2006, following their appointment of a BME development worker.

The research involved interviews with 40 family carers from BME communities and 20 organisations that work with BME communities in the Midlands. This included statutory organisations, BME voluntary agencies and voluntary agencies focusing on carers, disability, family services and education. A full list of participants is included in appendix 1.

Background

Mencap’s vision is a world where everyone with a learning disability has an equal right to choice, opportunity and respect. This vision drives all we do in our work with people with a learning disability, their families and carers. We have found, however, that some groups of people have been under-represented in our work. One such group is people from BME communities, which make up about 8% of the UK population. Therefore, one of Mencap’s priorities is a commitment to increasing the work we do with people from these communities.

Valuing People highlighted that special attention should be given to the needs of this group of people – who are often overlooked when it comes to service provision. It is estimated that less than a quarter of the people with a learning disability in BME communities are even known to their local statutory service providers1. In light of this, it is important that campaigning organisations and service providers like Mencap examine whether they are meeting everyone’s needs and genuinely offering them equal chances.

This research project is one of Mencap’s initial steps towards becoming a more diverse organisation. The project was carried out in conjunction with Midland Mencap, which is one of the first groups to recognise and target the unmet needs of people with a learning disability in BME communities.

Black and minority ethnic families’ experiences

Barriers to receiving appropriate services
People from BME communities are almost always under-represented in the client base of both voluntary and statutory service providers. Carers and those who work with them report the following difficulties when trying to access services:

- Lack of accessible information

Among the key findings of this research is evidence to show just how little carers from BME communities know about the services they could be using. They lack basic knowledge about the services that are available, and they have no understanding of how those services operate and consequently what their rights are. But worst of all, they often have no idea what learning disability is, how it affects the person they care for and what they can do to help.

Carers told us that the lack of accessible information was the greatest problem they faced in caring for their loved ones. They want more information about the particular conditions that they are dealing with, and about the financial support available and how they can get it. Older carers need information about what is available for the person they care for, including daytime activities like employment, volunteering or leisure pursuits.

Although this information is sometimes available, it is often not in a format or language that carers can understand. They told us that agencies use a lot of jargon and complex medical terms that they do not understand. And very few services make information available in community languages. Even when translated written material is available, it is often hard to understand – terms like ‘learning disability’ do not have equivalents in some languages.

Organisations find it difficult to explain things to carers face to face if they do not have someone who speaks their language. Sometimes services have a worker who speaks Urdu or Punjabi, but provision for people who speak Bengali, Somali or Arabic is much less frequent. Some carers feel that this represents a lack of effort on behalf of services to reach them. Other carers say that organisations are so short of resources that they do not advertise because they would not be able to cope with the resulting demand. In either case, without access to essential information, carers are unable to do all they can to care for their family members. This has negative consequences for the wellbeing of both the carer and the people they care for.
“...parents’ lack of understanding and lack of confidence to speak up affects the child’s diagnosis and can delay the correct input.”

Professionals

“Nobody can tell me what I can do to help (my son) with his reading and writing. He is slow and needs me to do more for him, but there’s nobody to tell me... When you ask me what I need to help, I don’t know what to say. I don’t know enough about learning disability to know what it is I need to know.”

Soubia, who cares for her husband and two children, all of whom have a learning disability

“I’m a single parent and as well as my daughter, who’s got Smith McGuinness Syndrome, I have two other children. When I was told about her condition at the hospital, they just gave me negative information like, we don’t know how long she will live or whether she will be able to walk. They didn’t really explain what the condition was or what I could do to help her. I’ve never met anyone else with a child with this syndrome so I still don’t know whether what I’m doing is the right thing for her.”

Rebecca, who cares for her daughter

Culturally inappropriate services

People with a learning disability and their carers from BME communities told us of the frustration they feel because of the insufficient and ‘patchy’ availability of services – such frustration is common across the board, regardless of ethnic background. However, some people from BME communities find it especially hard to find appropriate services. This is because the services that are available are inaccessible to them because of language barriers, or they are unsuitable because they do not meet their cultural needs.

Carers highlighted information services and advocacy as areas of need, especially in terms of finding a route to other services. However, they are useless if language barriers prevent communication with staff. In addition, many BME carers lack knowledge and confidence in their dealings with professionals, and this is a further barrier to the good-quality services they are seeking. Other practical aspects of the design of services make them inappropriate for people from certain cultural backgrounds. For example, some Asian carers are uncomfortable with the idea of using overnight respite services for their children. So in areas where an overnight service is all that is available, they may not get any respite at all.

“Day respite is essential, some Asian carers will not let their child go to overnight respite. If they won’t allow their child to stay overnight they are denied respite altogether.”

Professionals

Some Asian families are also hesitant to let their daughters participate in mixed gender activities, or to let them travel very far. This means that they have very few opportunities.

“More culturally appropriate services are needed for females with a learning disability, for example day care with female workers with appropriate language skills. Parents often won’t send daughters on trips with male teachers/drivers, etc.”

Professionals

The failure of some services to accommodate religious requirements, such as eating only halal food, also prevents certain groups of people participating. Effectively, this means that people from BME communities often face double discrimination – on the basis of their disability and their ethnicity or religion – and certainly do not have equal access to services. This has serious implications, both for the affected families and also for the organisations involved because it has an impact on their compliance with race relations legislation.

Lack of understanding and stereotypes

A variety of inaccurate stereotypes and misperceptions about BME communities also contribute to the difficulty people face in obtaining appropriate services. For example, services often try to justify the low number of BME people they work with by saying that BME communities ‘look after their own’ and do not like to use state support services. In many cases, this is far from true – but this sort of argument serves to reduce the sense of responsibility that services have to reach out to the families in these communities.

There is also a tendency to think of BME communities as a homogeneous group, and to overlook the many differences between and within communities. For example, organisations say that African Caribbean communities are more aware of services generally and more aware of their rights and entitlements to services. The groups that appear to have the greatest need are the Pakistani and Bangladeshi groups, which also have the highest incidence of people with profound and multiple learning disability. However, across these groups, engagement with services and knowledge of entitlements varies considerably according to socio-economic class and education level. Without understanding these variations, organisations may make invalid assumptions about individual families’ needs and circumstances.
“Generally there is no single need for BME carers. Some need translation, some can’t read in first language or English, some are well-educated and some are very poorly educated. Some are too meek to get help and some are very pushy. You need to be pushy to get services.”

Professional

• Lack of social contact

Many BME carers told us that they feel extremely isolated and powerless. Another common misperception is that people in BME communities get a lot of support from extended families, and that they therefore need fewer services like respite. This is far from the general case. In fact, the taboo around learning disability in some Asian communities means that parents receive very little support from within their communities.

Without access to mainstream information or support, they do not know how to get the best for their child or who to turn to for help. This often has a negative impact on the mental health of carers, which can affect the level of care they are able to provide for their children. Often, women may become lone parents, receiving little or no support from their family. People in this position told us that they feel a sense of guilt because of their child’s condition and their inability to meet the child’s needs. Bangladeshi participants suggested that unless the taboo that leads to such guilt is addressed, the situation for carers is unlikely to improve.

“The shame and taboo surrounding learning disability makes it difficult for mothers to get help and support. They get little practical support from their families and no emotional support either. The situation is so bad that mothers are more likely to seek help from agencies that are outside their community rather than from Bangladeshi specialist agencies.”

Professional

“I don’t know anyone else who has a child with this condition. I feel that I’m not doing enough for her... I’m not doing things properly. I’m worried that I’m letting her down and I don’t know where to turn for help.”

Carer
Reaching out

Knowledge about services often comes through social contact with people who are in a similar situation. Carers told us that their main source of support is school. This is followed closely by community health services. They also told us about getting support from Midland Mencap and social services. Only one person gets support from her church. A small percentage say they get no support at all – 10% of those we interviewed. When carers have contact with each other through school, they tend to be able to access more services. They often find out about entitlements through either their home liaison worker or through conversations with other parents.

As the child gets older, family carers find that they are entitled to less and less support. If the transition process is not dealt with effectively, carers and their children often become increasingly isolated. Some older carers become extremely isolated. They experience less and less social contact, and so lose opportunities to get information about appropriate services. The effect of this is felt more strongly among people who come from a community that sees disability as taboo.

For some African Caribbean users, the church provides a point of contact and some practical and emotional support. But other ethnic groups, such as the Bangladeshi community, did not report receiving support from their places of worship.

Accessing Mencap services
Our research also highlighted perceptions of Mencap, and the difficulties that professionals and people from BME communities face in using our support services. Such perceptions mainly refer to our community support services, which provide advice and support to people with a learning disability in local communities and their families and carers.

This is done both directly and through our network of Mencap affiliated groups. However, some of the comments also apply to the rest of the organisation, including our housing, education and employment services, and our campaigning activities.

POONAM’S STORY
My daughter is 42 years old she has epilepsy. She hasn’t talked since she was 13 years old and she has complicated health needs. She has a psychiatrist, a health worker and goes to a day centre provided by social services. She loves going there, she does sewing and crafts.

I am not totally on my own because we live with my other daughter who takes care of us. She used to live in America but came back here to help when my husband died. I have never really known what is wrong with my daughter. She was born in Hong Kong and had meningitis. We think that her brain was damaged at that time. She was just a baby so we didn’t notice at the time. It was later when we lived in Japan that we noticed that she was different from my other children; she just didn’t develop and things have slowly got worse over the years.

Because we’ve travelled so much we’ve never really had an overview of her health condition. She is split up into her body parts, a psychiatrist for her brain and the GP for her aches and pains. We have another specialist to help with her stomach problems.

I am 77 years old and have my own health problems lately and I worry that I am leaving all the caring to my other daughter when I’m not healthy enough to keep on.

I would like to make contact with other carers like me, just so we can talk about our experiences and maybe support each other. I would also like to go somewhere locally to learn to use a computer. The teacher would need to speak Hindi, so I could understand. There used to be classes round here but they just stopped. I really enjoyed them!
Lack of awareness of Mencap and its services

Awareness of Mencap and its services is very low, not only among carers from BME communities, but also among the organisations we interviewed. Only just over a quarter (6 out of 20) of the organisations interviewed reported being aware of Mencap and its services, and several of these were not aware of the distinction between the national organisation and the local group – Midland Mencap.

“I have heard of Mencap but to be honest I’m not sure what they do. I know it’s about children with a learning disability… I think that they run youth clubs.”

Professional

Only one of the carers interviewed had heard of national Mencap. He reported becoming aware of Mencap through his own research on the internet. Others were either aware of Midland Mencap or had a general awareness of an organisation called Mencap that deals with learning disability, but were unable to say what services Mencap provides.

Of those who had heard of Midland Mencap, 66% were also aware of some services. The most well-known services are the Saturday playscheme and the holiday playscheme. We also found some awareness of the youth club, respite care and the BME project. Again, a significant number of people who are aware of their local Mencap are not clear about the services it provides.

Anticipation that Mencap cannot provide for language and cultural needs

Even when people have an understanding of Mencap and a desire to use our services, the lack of appropriate language provision is a barrier. As one agency worker describes:

“A user may pick up a leaflet in Urdu and think, ‘I’ll contact this organisation’. When they call up, they are answered in English and there is no language provision, so they hang up. Some can get by in English if it’s face-to-face, but there is still too much room for misunderstandings”

Professional

One professional reported that she could not recommend the information and advice helpline to her BME clients because she felt that the service would not be able to offer appropriate language provision. In fact, a translation service is available, but the people who may want to use it are clearly not aware of this. Only two of the organisations we interviewed reported using Mencap services such as the website, information and advice, research, fundraising and campaigning.

Need for local service provision

BME service users often prefer to access services locally. Many have multiple needs, due to poverty, problems with literacy and isolation. They are much more likely to go to a local agency than they are to travel to an area they are unfamiliar with. Also, some women’s families do not allow them to travel outside their immediate home area. This all means that many people are more likely to turn to their local groups rather than attempting to access the national organisation. In Birmingham, the local group is well placed to meet the needs of carers from BME communities. However, in many other areas no such provision is offered by a Mencap affiliated group yet.

Problems experienced with statutory services

Carers and professionals also described some of the problems they encounter when using statutory services. Again, some of these problems are common to families from all communities. In this section, however, we highlight the additional, specific difficulties faced by members of BME communities:

Difficulty understanding the system

Many people from BME communities who live in the UK have come from societies in which health and social service provision operate very differently. The lack of information in their languages makes it very difficult for them to understand how things work in this country. They struggle to find out what services they are entitled to and what they need to do to have their needs met. For example, a number of carers told us that they would like to have a social worker, but they don’t know about the procedure they need to follow to make this happen.

“I don’t know what the rules are and I don’t know who can tell me the rules.”

Narjis, mother of four children, two of whom have a learning disability

“Respite needs introduction and facilitation in parents’ language. Issues about future care for adults needs to be in carer’s language and face-to-face.”

Professional
Inadequate or inconsistent support from social services

When we asked carers how they normally find out about services the most common answer was through their child’s school, followed closely by through their GP. Other sources of information include health workers, friends and family, the library, leaflets, TV, newspapers or newsletters and other voluntary sector agencies. Nobody told us that their social worker provides them with information – in fact, carers reported receiving a poor-quality service from social services and those who do have a social worker reported experiencing a lack of consistency in that relationship.

“We are going to sell our house and move to an area where you can get a social worker. We have two boys with severe autism and we have been told that we don’t qualify for a social worker. We get no support from anyone. If we didn’t have help from Midland Mencap I would be as ill as my wife – then who would look after the children?”

Family, who have five children in total

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People who do have a social worker say that the service they receive is badly lacking, with little or no consistency. They report that the ‘rules’ associated with accessing services seem to change as their social worker does. Some have had their social worker removed and have not been told why, while others report that they rarely see the same social worker twice because of high staff turnover. This means that they have little chance to build up long-term supportive relationships.

“My husband left us and I’m now on my own. I get the mortgage paid, but I’ve been told that when my daughter gets older, they will take my home off me. We will have nowhere to live and I don’t know where to go to get advice.”

Carer

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Narjis, mother of four children, two of whom have a learning disability

Lack of cultural understanding in social services

Many of the carers we spoke to complained about a lack of cultural understanding within social services, especially in relation to the effects of gender in some Asian communities. Without understanding the implications of such cultural issues, services are not able to make the necessary accommodations for them.

SOUBIA’S STORY

“I came to this country to get married. My husband has learning disabilities and needs constant care. I did not know that he had these issues before I came here. We live with my husband’s family and my mother-in-law makes the rules. She does not like me talking to people outside the home. She does not want me to learn English. She will let me go to the library and to the school. I am desperate to get some help, just to have someone to talk to about my situation and my children.

“When I had my first child I had no idea that there was anything wrong with him. I only found out when all the schools in the area refused to take him because of his behaviour. Then I found out from my GP that he has learning disabilities too. I got him into this school and he is happier now but I don’t know how to help him. Nobody can tell me what I can do to help him with his reading and writing. He is slow and needs me to do more for him but there’s nobody to tell me.

“When my daughter was born I was more aware of learning disabilities so I was watching her more closely, so was the GP. She has learning disabilities too but because of what happened with my son, I will know how to make sure that she gets the right school straight away. When you ask me what I need to help I don’t know what to say. I don’t know enough about learning disability to know what it is I need to know. All I know is that I would like to be able to have someone to talk to someone who will listen and maybe help me to get to learn English. Someone who my mother-in-law is not suspicious of.”

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Narjis, mother of four children, two of whom have a learning disability
Removing the barriers

What needs to happen
The research highlighted the following key things that need to happen to reduce the inequalities that people from BME communities face in receiving learning disability services:

• Provision of information in community languages and accessible formats

The thing that BME communities need most is information and services that are provided in community languages and appropriate formats. Most agencies said that many BME service users need face-to-face contact and, in many cases, home visits and advocacy support. As with any ethnic or cultural group, levels of need vary. Primarily, socio-economic class and levels of education account for this variation. Some ethnic groups may have higher levels of needs in relation to basic literacy and education. These needs will exacerbate the difficulties we face in raising their awareness of the services we provide. For example, young mothers who have come from Pakistan to get married may not be literate in their first language as well as not speaking English. This makes the use of community language leaflets and posters redundant. The only way to engage with these carers is through the process of social networking within their community, building relationships with local community and statutory agencies.

Another issue relating to language is the question of how the term ‘learning disability’ is interpreted and understood in different languages and by different communities. Different perspectives on the term itself lead to different attitudes, opinions and behaviours. For some BME communities, alternative models of health together with alternative models for ‘learning disability’ and disability in general, lead to different perspectives about what should be done to help and support people.

To engage with BME communities effectively, we will need to examine their perspectives rather than simply assuming that they understand learning disability in the way we do. This process should involve two-way communication and positive learning among those involved.
Flexible services that respond to cultural needs

There are worrying reports that parents who do not wish to leave their children overnight are being denied respite. This type of inflexibility will inevitably result in discrimination against certain groups. This, in turn, could lead to a contravention of the Race Relations Amendment Act (2000), which places a duty on local authority services to promote race equality and prevent unlawful discrimination.

Carers need services that are tailored to meet each family's individual need. Each family has a unique set of circumstances, which can only be assessed thoroughly by undertaking a home visit. Some services could be tempted to develop 'add-on' services aimed at BME users and, in some cases, this is the only appropriate way to serve the specific needs of a particular group. However, in many cases, it would be better to re-examine and develop existing services to ensure that they are accessible and appropriate to a more diverse range of people. This will promote integration and ensure that everyone's needs are met.

“Any work that is done to more effectively engage with BME users should be planned to fit in with the existing services rather than act as a separate function or add on unit. The current services should be tailored to meet a wider service user group in recognition of the diversity within the general population.”

Professional

Creating or developing services that are culturally appropriate does not necessarily mean creating separate services. For example, women-only services will meet the needs of most cultural groups without being ethnically divisive. Age is also a significant issue in delivering appropriate services – in many cultural groups, young people will not speak out openly when older people are present.

“Culturally appropriate doesn’t have to be around ethnicity, it’s more of a gender need, for example, women-only sessions can be for all ethnic groups. Younger people can be more withdrawn when around older people, there’s a need for young workers with language skills. Transport is always an issue especially as young women will not be allowed to travel alone, particularly with a male driver.”

Professional

Support to understand the system and use it to meet specific needs

A lack of knowledge about services, about the systems behind service provision, and about learning disability in general has significant and negative consequences for many BME service users. An education and information programme aimed at all young families would empower parents and provide them with the necessary tools to support their children more effectively. One strategy to engage communities that tend to stigmatise learning disability is to provide information about financial aid and practical support.

Provision of more support groups to reduce isolation

Another major area of need is for carers’ support groups. For Asian communities it is essential that such groups are women-only because of the attitudes towards mixed groupings. It is also useful to have female workers running these groups, as many women lack the trust and confidence to express their views when a man is present. Engaging with women should focus on leisure and ‘time for oneself’. Groups should be led by people who have the necessary skills to help develop confidence and self-esteem. Once people start to attend them regularly, these groups can act as a point of contact for health education and information about learning disability.

Our research has pointed to the value of regular meetings between mothers. Carers recognise that these kind of informal meetings are a means of emotional support and they create a way for much-needed information to be shared.

The changes that Mencap will make

We are committed to considering diversity in all our work. We have begun work on new initiatives to tackle some of the diversity issues in our workforce, organisational culture and service delivery. This involves diversity in all its forms, including ethnic diversity. In response to the findings of this research, the following section outlines some of our specific plans for developing ethnic diversity in Mencap.
**Rebecca’s Story**

I’m a single parent and as well as my daughter who’s got Smith McGuinness Syndrome, I have two other children. When I was told about her condition at the hospital, they just gave me negative information like, ‘we don’t know how long she will live or whether she will be able to walk’. They didn’t really explain what the condition was or what I could do to help her. I’ve never met anyone else with a child with this syndrome so I still don’t know whether what I’m doing is the right thing for her.

I decided to look on the bright side and make sure that she had as much opportunity as I could get her. I didn’t really know if it was right to send her to school but I knew that I would have to give up work to take care of her properly. I still feel that I’m letting her down, that I’m not doing something that needs to be done. I am always worried about my mental health. I’ve already had one breakdown and I’m constantly thinking about whether I’ll break down again.

One thing that makes it worse is the constant changes to my benefits. Sometimes I’m entitled to certain benefits for caring for my daughter and then suddenly I get a letter saying they’re taking it off me because I’m no longer entitled. I used to fight them to get what was my right and her right, but now I’ve just given up. I’ve decided that I can be in control if I just live on the basic income support. It is less but at least I can count on the same money over time. I don’t know what the future holds for me or my daughter. You can’t plan anything: you just hope that you’re doing all you can for her and you won’t get it all wrong.

• **We will improve the way we share information about Mencap**

Mencap can play a significant role in educating communities about learning disability and its causes. We can help to dispel the myths and reduce stigmatisation and its consequent isolation. At present, our ability to communicate with BME communities is limited because nationally we provide little advice and information in community languages. However, particular BME projects have developed their own resources, and have some staff who speak community languages.

We are aware that we need to make these resources and other information available through our national advice and information service, so that everyone can access them. This includes providing basic information about learning disability, and about where to get support, in accessible formats and community languages. The translation service offered by our helpline, which enables callers to receive advice and information in their own language, is under used. It needs to be more widely advertised among potential users.

Although the research showed that BME families find face-to-face support most effective, it is impossible for us to provide this at a national level. This support will have to be given through local providers, including Mencap affiliated groups and external BME organisations.

• **We will communicate with BME families through local BME organisations and professionals working with these communities**

“National Mencap need to raise awareness of their services generally. I don’t know what they do or whether they operate in this area. It seems strange that they are not the same organisation as Midland Mencap.”

Professional

“Staff in our service don’t know enough about what is available, for example they have no service leaflets or contact names and numbers. If we had this, we would give it out to parents. For example, KIDS runs a day respite service which is an education inclusion scheme (KIDS Cottage) we could give out leaflets there.”

Professional
The significant lack of awareness among both organisations and carers shows that the way we communicate about our services is not working effectively. We need to improve levels of awareness of Mencap and the services we provide both nationally and through our network of affiliated groups.

One way to do this is by targeting professionals in statutory agencies, including social services, health services, schools and voluntary sector agencies that have high levels of contact with BME service users. We can do this both through our local field staff, and through the affiliated groups, such as Midland Mencap. We must focus on developing relationships with organisations and professionals who come into contact with BME families who have members with a learning disability, and identifying how we can work together to better meet their needs.

“Engaging with BME groups is a two-way communication process where the organisation learns about cultural needs and the communities learn about what the organisation can offer.”

Professional

• We will collaborate with local groups to improve levels of engagement with BME communities

In areas where there are active Mencap affiliated groups, they are likely to be in a better position to work with BME organisations and families than the national organisation. This is because of their local presence and familiarity with local providers and professionals. Mencap will aim to work closely with affiliated groups so that jointly, we can better support people from BME communities. This may include sharing training, resources and guidance on working with BME communities where necessary, and support to raise issues at regional and national levels. We will also provide a forum for affiliated groups to share good practice and learn from other local groups’ successes.

By attending community-based events, local groups may raise carers’ awareness of Mencap through BME organisations and professionals. This research shows that the best places to do this are schools, GP practices, health centres, community centres and organised health and education events.
Developing the skills of our workforce to meet diverse needs

• We will raise awareness of cultural issues among staff

An organisation’s workforce defines its culture and values, so for Mencap to be a genuinely culturally diverse and inclusive organisation, staff awareness of cultural diversity is critical. Everyone needs to have some understanding of different cultural perspectives around learning disability and their implications for meeting the needs of minority ethnic communities.

Our corporate diversity action plan includes several initiatives that aim to bring diversity into the mainstream. These include equality and diversity training for staff, building awareness of good practice in work with minority communities and publicising cultural and religious practices and festivals through newsletter articles and intranet content.

• We will increase representation of BME communities in the workforce

Having a diverse workforce is an essential part of creating a diverse culture. Mencap’s recruitment and selection processes are being examined to make sure that they are welcoming and accessible to people from different backgrounds. Our diversity manager is working with other managers to do this. We need to take care to ensure that BME staff are employed at different levels across the organisation rather than just as frontline staff in BME-specific projects. We will also consider the organisation’s ability to retain BME staff and assess how management practices influence people’s experiences in the organisation as a staff member from a minority.

“Think about staff: you need people with languages; you must employ a diverse group across the organisation not just for BME projects. Ensure that women are employed, female carers often won’t talk to men and/or men in their families won’t let them attend meetings etc.”

Carer

One of the major areas of need identified by this research was the need to have frontline staff who speak community languages and have knowledge of BME communities. We are considering this in the context of recruitment and selection criteria.

• We will provide platforms for staff to share their cultural knowledge and expertise

One of the most valuable sources of knowledge that many organisations fail to capitalise on is their own staff. Royal Mencap Society has staff from BME groups, some of whom have experienced great success in engaging with BME carers and service users and some of whom are currently experiencing difficulties in this area. However, through the research process, it became clear that communication between staff across the national organisation is limited; many staff are unaware of projects and the part that they could play in making them a success.

We want to make use of the potential opportunities for sharing expertise and resources by improving the way we communicate internally. For example, we will build pages on the intranet with useful information and resources gathered from different BME initiatives, and from external sources. We will also start a staff ethnicity network that will discuss issues relating to working with BME communities. This group will provide advice and guidance to Royal Mencap on service development in relation to BME communities, and on the growth of a culture that values and fosters diversity.

• We will communicate with other organisations and keep informed of new research and work in this area

We have begun to develop organisational knowledge around meeting the needs of BME communities, both through primary research initiatives – such as this one – and through contact with other academic researchers and professionals in this field. We will continue to keep updated on the latest work in this area, and attempt to integrate it into our own work. Our ethnicity co-ordinator meets regularly with people in similar roles in other voluntary sector organisations.

Providing culturally sensitive services and support

• We will design general services and projects flexibly to accommodate diverse needs

Over the next couple of years, our ethnicity co-ordinator aims to provide Mencap community support managers and staff with tools to audit their existing services and projects. Through this process, they will see whether they are meeting the needs of their local BME populations. Diversity considerations will also become part of all planning processes for new projects and initiatives.
• We will provide some specific initiatives to cater for the needs of particular groups

In addition to making mainstream services more inclusive, we will also continue with some special BME initiatives, aimed at supporting particular communities and generating further knowledge about the specific needs of these communities. One such initiative involves work with carers in BME families in Ealing and Hounslow. Another is empowering young people to work with leisure providers to make leisure services in Bradford more accessible for them.

Bringing BME families’ issues to the attention of others

• We will ensure that we reflect the experiences of BME families in our campaigns

By improving our communication methods and channels, we will also be in a better position to be able to include the experiences of people from BME communities in our national campaigns, and highlight their particularly difficult circumstances in relation to some issues. Mencap has always supported carers in terms of providing a space where they can share their experiences, solutions and stories. Providing a system of groups for carers will also present the opportunity to help carers in ‘hard-to-reach’ communities begin the process of personal and community development.

As carers build their confidence and knowledge, they can act as ‘champions for learning disability’ in their communities. By inviting BME carers to join in the debate and contribute to the organisation, Mencap can truly say that it is wholly representative of the voice of carers and people with a learning disability.

• We will highlight the unmet needs of BME families to statutory organisations and partnership boards

This research identifies many needs that should be being met by statutory providers, or the organisations they contract to provide them. Mencap’s role is to campaign on these issues, as we do other mainstream issues, and to initiate discussion around the current lack of adequate care and provision. We will do this nationally through our campaigns and policy team, and locally through field staff and Mencap affiliated groups.

Working in partnership with other organisations

Throughout this research, we found again and again that Mencap is not the only organisation struggling to engage with BME communities. Both statutory and other voluntary organisations report similar difficulties. Within the statutory sector, there is a clear understanding that joint working is necessary to engage effectively with BME communities, and to ensure that their needs are met.

The NHS now employs BME community development workers in primary care trusts, which recognises the need for them to play a role in developing voluntary organisations to support the needs of service users. This project involves mental health needs rather than learning disability, but it acts as an excellent model for the type of work that needs to take place for learning disability too. We are eager to work with statutory organisations and other voluntary organisations to find effective solutions that will improve the lives of people with a learning disability and their families in BME communities.

What else can statutory services do?

In addition to the general recommendations – which involve making services culturally sensitive, providing information in community languages and so on – this research also highlights specific areas of work for statutory services.

• They must collect data on learning disability in BME communities

Devising an effective strategy to meet the needs of certain user groups requires access to information about the levels of learning disability within those groups. One of the major difficulties we faced in this research was the lack of any robust data that can clarify the prevalence of learning disability in different ethnic groups.

As other research has already highlighted2, any attempts to devise an effective strategy and policy concerning learning disability and ethnicity first requires a process to gather intelligence. This report goes some way towards providing empirical evidence of the experiences, opinions and perceptions of BME carers. As such, it can help to identify their needs. However, statutory agencies must start to collect data that helps to identify the extent to which different ethnic groups require support to deal with the impact of having a family member with a learning disability. This in turn will support the work of voluntary sector agencies, which are required to provide evidence of a need before funders will support any BME focused strategy.

• They must do more to help BME families find their way through the system

In light of the findings that BME families have severe difficulties understanding and getting through the social services system, statutory services must make this process easier. The Race Relations Amendment Act (2000) places a duty on local authorities to promote race equality and to prevent unlawful discrimination. Indirect and unintentional though it may be, the failure to make services accessible to people from BME communities could count as discrimination that contravenes this legislation. Moreover, effective communication with social workers is vital – this is families’ gateway to the information and services they need. Social workers must be able to help BME families navigate through the system. They must work to reduce their helplessness and overcome their isolation.

• They must ensure that social workers have the knowledge to signpost BME families to other culturally sensitive services

It is also very helpful if social work professionals know what voluntary organisations like Mencap can provide in terms of additional support to families. Here at Mencap, we must show our commitment to providing this information, but social services must also require that their staff keep updated about the services and organisations available in their local communities.
Midland Mencap
an example of good practice

Midland Mencap recognised the need to ensure that its services were meeting the needs of all the communities in Birmingham. It created the post for a BME development worker, which was funded by Birmingham City Council's Learning Disability Directorate for two years. The aim of the post was to work with organisations and individuals within BME communities in order to better assess the needs of people with a learning disability and their carers.

This work is informing the development of appropriate, relevant and culturally sensitive provision within the Birmingham area. Evaluation of Midland Mencap's BME development work highlighted the following factors as contributing to its success.

Recruiting the best person

Considerable thought went into choosing the right person for this new role. The person specification listed several essential areas of experience: a proven track record of working with vulnerable clients/service users, knowledge of a community language, some knowledge of the cultural practices of BME communities and evidence of success in engaging with hard-to-reach groups was needed. The worker who took up the post was identified through contact with another voluntary agency, St Basil's. He began work with Midland Mencap on a secondment and, once funding was secured for the two-year project, St Basil's kindly agreed to release the development worker to Midland Mencap.

In addition to his proven ability to engage and work effectively with hard-to-reach groups, the worker had built up a sophisticated social network of contacts within Birmingham. This meant that he could build effective working relationships with key agencies quickly.

Supervision and support

In any development work the tension between letting things emerge and directing issues is always present. The key to success in this work is to set out clear objectives which allow staff to be creative and innovative in achieving them. In short, a development worker must be supported to feel free to 'make mistakes' and to 'experiment'. The management at Midland Mencap has provided the right balance between allowing the development worker to direct his own work, while also providing guidelines about the future direction of the project. The manager at Midland Mencap recognised his need to learn how to best meet the needs of BME service users. He also recognised that the fastest way to learn was to listen to his staff and respond to the issues that were highlighted.

Raising awareness of Midland Mencap's current services

A multi-channel marketing approach was used to do this. Posters explaining services were distributed to a range of agencies within communities with high levels of BME residents – for example, libraries, neighbourhood offices, health centres and GP surgeries.

The development worker spoke at team meetings in both health and social services, and he made contact with special schools and other voluntary agencies involved with families. Midland Mencap subsequently experienced an increase in enquiries. One difficulty that the project experienced was engaging with both religious groups and businesses.

Establishing relationships with statutory and voluntary organisations

Building relationships with a range of organisations that may have contact with BME service users was a vital part of raising awareness of Midland Mencap's services. It was also vital to building contacts with hard-to-reach service users. This process was achieved largely through a 'cold calling' process undertaken by the development worker. Links were established with a range of community-based agencies first, and this was followed up by making contact with relevant statutory agencies. After the project had taken shape, contact was made with special schools - this ensured that the team was able to offer a more substantial service than would have been possible at the start.
of the project. Agencies report that they have a high degree of trust in Midland Mencap’s development worker. He has been successful in communicating both Midland Mencap’s and Royal Mencap Society’s agenda of promoting the needs of people with a learning disability and their families and carers. Forming these trust-based relationships is key to creating an environment for organisations to identify areas where they can work together to meet the needs of people with a learning disability from BME communities and their families and carers.

In addition, the strategy to focus on the South Asian community was developed as a response to the findings of a comprehensive study of ethnicity and learning disability in Birmingham (Emerson 2002). It highlighted the fact that the South Asian community is over-represented in both the moderate and severe learning disability categories. Conversely, African/Caribbean communities are under-represented. This demonstrates the need for some robust empirical data against which an appropriate strategy can be carried out.

**PERLENE’S STORY**

My son is 41 years old now and since we’ve moved he has no friends and nothing to do. Where we used to live everyone knew him and watched him grow up so he made friends and he would visit them in the day. Now he is at home all day and he is bored. We sometimes get on the bus and go out for a ride and sometimes we get to church but I don’t know what to do to help him.

“He needs stimulation – although he has difficulties he is quite bright and needs to keep busy. He could do a job or be a volunteer or just to have a social life of some sort. My other children don’t live near us and since the move we are really isolated. I don’t know anyone and people are not friendly. When I went into hospital recently I had to get my sister to come up and stay with him but if she wasn’t there I just don’t know what would’ve happened to him. I’m getting old and I won’t always be here to take care of him – that worries me.”

**Designing and producing multilingual material**

Midland Mencap produced information about its services in a comprehensive range of community languages (Punjabi, Hindi, Chinese, Gujarati, Bangladeshi and Urdu). This information was distributed to social services, community nurses, special schools and other community-based agencies. Translation into some languages was difficult because many terms related to learning disability do not have direct equivalents in many ancient languages. In addition, not all community languages were available over the telephone.

By far the most effective way to raise awareness is face-to-face contact, either directly with the development worker or through workers in other agencies with whom the development worker has made contact.

**Establishing a parent/carer support group**

Building on Mencap’s tradition of working with people with a learning disability and their families and carers, creating a parent/carer support group in BME community areas was essential. The group provides much-needed social and emotional support for carers. It also acts as a conduit between the organisation and the community, building a sense of trust between the two. The development worker highlights the importance of transparency and honesty with carers. It is very important to let carers know what the organisation can’t do as well as what it can do to help. Managing people’s expectations is vital in order to avoid creating false hopes. The group also provides a platform for information to be shared, ensuring that carers pass on their knowledge and experiences. It offers the opportunity to address levels of awareness and education about learning disability in general.

This is a two-way process – carers learn more about services and their rights and gather specialist information about their child’s needs, and organisations learn more about the best ways to meet the needs of a more diverse service user group. The group was developed using existing informal contacts, made through previous networking undertaken by the development worker. The group’s success is attributed to its emphasis upon leisure and personal care activities – as one carer describes:

“It’s time for me… it’s the only chance I get to think about just me!”

Carer
The group organises trips to local areas of interest like the Botanical Gardens, and provides stress-relief interventions such as Indian head massage and aromatherapy. Also, since the group began meeting, parents have started to use each other as an informal support service, often telephoning each other to get support.

Another key factor in the parent/carer support group’s success is the fact that the group meets in the local community. Carers say they prefer services to be provided locally. This is partly a transport issue and partly reflects the desire to stay within the local community, where parents/carers feel safe and have a sense of belonging. An attachment to locale is common to those who are described as lacking in social capital or who are marginalised in society. In addition, employing a worker who speaks a community language and who has some understanding of Asian culture has contributed to the positive outcome.

Using advocacy and translation to support the families of carers and young people

This is a key element in the development worker’s role. Individuals are referred to him from agencies that he has built relationships with through networking. In addition, carers the development worker has worked with often recommend his services to others. The range of services provided includes identifying an individual’s needs, linking in to Mencap services where appropriate, providing information about other services when Mencap cannot help, support with translating and advocacy/support for young people. Through this work, the development worker has been able to gather information concerning both the needs of BME carers and their knowledge and experiences of current services. Some of the information he has gathered is as follows:

- Many carers report a lack of confidence when dealing with professionals and they appreciate having the development worker there to discuss the problem with prior to meeting any professional. This provides a valuable opportunity to prepare important questions to ask the professional.
- The interpreting support offered by the development worker is reported to be of great value; often family carers rely on other family members for translation which can be inappropriate when the family member is a child or can lead to family members acting as ‘gatekeepers’ of information and not fully translating the information (this was reported as the behaviour of some husbands).
- There is a need to improve communication generally because even if an appropriate translator is available, professional terms and medical jargon are often difficult to translate effectively.
- Professionals often generalise and stereotype when dealing with the Asian community. Some assumptions include the idea that family support is stronger than in the White UK community and that all Muslim communities have the same issues.
- Carers also report a lack of consistency with services. It seems that the level of service received depends on the commitment and attitude of each individual professional.

Recruiting parent/carer volunteers

Given that the greatest way to raise awareness is through social networking or word of mouth, it was felt that developing a volunteer strategy aimed at BME carers would promote Midland Mencap within these communities and build the necessary trust in the organisation. In addition, this approach was felt to be an effective way to support the personal and educational development of parents/carers.

This work is still at the developmental stage. It is envisaged that the Asian carer volunteer role will involve outreach activities including:

- interpretation services for carers
- providing a ‘parent voice’ at forum and meetings
- championing Midland Mencap’s services with Asian carers
- talking to carers about positive experiences in the Women’s group.
An important part of the volunteer development framework involves producing a clear outline of roles and responsibilities supported by appropriate training. In addition, the work of the volunteers will complement and enhance the overall strategy for Midland Mencap’s organisational development. Care will be taken to ensure that services are not over-promoted, since this can lead to a sudden increase in demand. If these needs cannot then be met, the result is a negative experience for carers – this could lead to negative ‘word of mouth’ publicity.

**NARJIS’S STORY**

“We have four children: the two girls both have learning disabilities. Neither of them can walk or talk. We live in a two bedroom flat, which is upstairs. So my husband sleeps in with the boys and I sleep with the girls. It is very difficult getting the girls up and down stairs. I need someone to help in the mornings to get everyone ready for school, it takes such a long time with the two girls and the boys have to be helped too. I have spoken to the housing about getting a bigger house and they say that I can get one but I need my social worker to write to them. I have explained that my social worker won’t do this. I don’t really have a social worker at the moment. I’ve had two different social workers and now they say that they can’t get anyone to replace my last one. I have to speak to the duty social worker and he says he’s not allowed to write to the housing for me. So I have to wait until they get a new full social worker. I don’t know if the housing are lying to me or the social worker is but I think that we should be in a bigger house. I don’t know what the rules are and I don’t know who can tell me the rules.

**Success stories from other organisations**

This section describes the processes that some organisations have adopted in order to engage successfully with people with a learning disability from BME communities and their families and carers.

**Birmingham Industrial therapy centre**

This organisation provides supported employment and training for people with a learning disability and mental health needs.

We opened up a centre right in the heart of an area with a very high percentage of people from BME communities (Saltley, Birmingham). We were conscious of the need to employ staff who spoke the local languages and through research we discovered that these were Urdu and Mirpuri.

I had worked with Muslim communities previously in the north of England and through that experience I knew that if we were to get any women users we needed to employ female staff.

Once we were set up, we constantly checked with users to see what we were getting right and what we were getting wrong. It’s very easy to miss some basic cultural needs, for example; we now provide all Halal meals within our service. We now have levels of 50% ethnicity at our Saltley site. We have also been very successful in engaging women; half of our service users at Saltley are female.

What we have learnt through our engagement with BME communities has had a positive effect on our Digbeth-based site, where almost a quarter of the service users are from BME communities.
Ehsas Carers
This organisation provides support to parent-carers and families who have children with special needs or adults with a learning disability from minority communities in Dudley. It is a carer-led organisation. Ehsas is an Urdu word, meaning understanding or empathy.

We started back in 2002 as a group of Muslim parents who all had children at a local special school. We began to meet occasionally to offer support to one another and to share our experiences. We were supported by the school, which provided a bi-lingual teaching assistant.

By 2004 that small group of parents decided to form Ehsas Carers to begin to provide better information, advice and support to families. We were fortunate because Dudley Social Services recognised the value of our group by providing us with a grant and the ongoing assistance of a specialist social worker to support our development. As BME family carers of children with special needs and adults with a learning disability, we already knew what issues face families. We knew better than other services the right way to approach our communities to get them to use services. For example, we made sure that we located our service at a site that is already well used by Muslims, is easy to get to, and has central access (Dudley Muslim Association). We are also staffed almost entirely by women. A simple move like this can just remove so many barriers.

Because we are from the community we work with, we also know how to approach difficult subjects such as the effects of genetics on learning disability. We see our service as a two-way communication process. We provide information to carers, and we help agencies and organisations learn how to engage more effectively with our communities. I would say to any organisation that wants to develop a range of services that take account of cultural, religious and language needs, you need to make sure that staff are very well linked in with local services. We have partnerships with Barnados, Connexions, Dudley Muslim Association and Social Services. Being well networked and recognising how we can help each other as organisations is crucial.

Stepping Stones
This is a voluntary sector organisation, which provides a range of family support services to the local community in Small Heath, Birmingham.

The success of our organisation stems from a number of key factors. Firstly, we are here in the local area and have been for many years. This consistency results in trust between the community and our workers – and families who use us tell others about our services. We listen to our users and, where possible, adjust our services in response to their concerns.

The second major need is to have community languages and staff who come from the communities you seek to serve. We also have a number of community volunteers. Over the years we have expanded our services, so families can come to us for their different needs. When these needs relate to sensitive issues such as mental health or learning disability, there are fewer barriers because we have proved that we respond to their needs in a culturally sensitive way. Within the local Muslim community, the view that a child has been possessed by a Jinn (evil spirit), will lead to a spiritual solution rather than a medical one. Another major issue is the lack of knowledge about the long-term effects of learning disability. For example, one parent came to the service with an older child who is doubly incontinent and autistic. We asked why she hadn’t sought help earlier; she replied that she thought he would ‘grow out of it.’

Working with BME communities requires an understanding of the nuance of difference within communities as well as the way different communities vary. The predominant Asian community view of learning disability may sometimes lead to negative practices, but it may also lead to more positive things. For example, it is not unusual for someone with a learning disability to marry, a situation still fraught with difficulty among the mainstream white community.
Appendix 1 participating organisations

Sure Start Balsall Heath
10 Malvern Street
Balsall Heath
BIRMINGHAM
B12 8NN

Bangladeshi Multi-purpose Centre
Victoria Road
Aston
BIRMINGHAM
B6 5HH

Bangladeshi Youth Forum
163 Gerrard Street
BIRMINGHAM
B19 2AH

Profound Learning Difficulties Directorate
The Greenfields
Monyhull Hall Road
Kings Norton
BIRMINGHAM B30 3QQ

Birmingham Industrial Therapy
201-206 Alcester Street
Camp Hill
BIRMINGHAM
B12 0NY

Dudley Learning Disability Services
Ladies Walk Centre
Ladies Walk
Sedgley
DUDLEY
DY3 3UA

calthorpe School
Darwin Street
Highgate
BIRMINGHAM
B12 OTJ

Birmingham Disability Resource Centre
Bierton Road Centre
Bierton Road
Yardley
BIRMINGHAM
B25 8PQ

Stepping Stones
16 Jenkins Street
Small Heath
BIRMINGHAM

South Birmingham PCT
Learning Disabilities Directorate 192
Hobmoor Road
Small Heath
BIRMINGHAM
B10 9JH

North Smethwick Resource Centre
Cambridge Road Smethwick
BIRMINGHAM
B66 2HR

Autism West Midlands
18 Highfield Road
Edgbaston
BIRMINGHAM
B15 3DU

43 Birmingham Social Care and Health
Birmingham Carers Centre 16
Handsworth Wood Road
Handsworth
BIRMINGHAM

African and Caribbean Health Improvement Service African Caribbean Resource Centre
Thomas Street
WEST BROMWICH
B70 6LY

Ehsas Carers
Northgate House
89 High Street
DUDLEY
DY1 1QP

Apna Group (Our Group)
Northgate House
89 High Street
DUDLEY
DY1 1QP

Coventry Carers Centre
3 City Arcade
COVENTRY
CV1 3BR

Arab Women’s Association
16 Langley Road
Small Heath
BIRMINGHAM

Reachout
St George’s Post 16 Centre
Great Hampton Row
Newtown
BIRMINGHAM

Somali Youth Development Organisation
169 Stratford Road
Sparkhill
BIRMINGHAM
B11 1RB
Appendix 2
BME groups

The range of ethnic groups that require support is extensive and growing as new asylum seekers and refugees settle in the region. By far the largest group is Pakistani users, with Black Caribbean, Bangladeshi and Indian making up the next largest user groups. Of the new ethnic groups, the largest users are Somali. However, there are smaller groups of users from the Arab, Kashmiri, Yemeni, Black African and Chinese.

Carers’ profiles

We interviewed a total of 40 carers, of these 80% were female. The age range is 24-77 years. There is no clear geographical bias with carers coming from both inner city and urban areas of Birmingham, Coventry and Sandwell.

In terms of ethnicity, the sample breaks down as 38% Pakistani, 22% Black Caribbean, 14% Indian, 12% Bangladeshi, 5% Somali, 5% Mixed Heritage, 2% Arab and 2% White UK. White UK parents were included because they care for a child of mixed heritage.

The parents we spoke to cared for children with a wide range of learning disabilities. The largest representation in the sample is autism with mild learning difficulties and moderate learning difficulties making up the next largest group. Other disabilities included Down’s syndrome, cerebral palsy, foetal alcohol syndrome and 13Q Syndrome. A small number of carers were not able to give a precise diagnosis of the learning disability, but gave a list of symptoms.

The gender split of the people cared for by these respondents is exactly equal (50% female, 50% male). The age range is 60% young children (under 13 yrs), 30% teenagers (under 20) and 10% adults.

Organisation profiles

We interviewed a total of 20 organisations. They include range of services: statutory organisations in social care, education and health; voluntary agencies providing a service for specific BME groups; and voluntary agencies targeting carers, disability, family services and education.

Participating organisations represent the Birmingham, Coventry, Sandwell and Dudley areas of the West Midlands.

Some of the organisations that provide for specific BME groups report very little or no contact with people with a learning disability and/or their carers. Reasons given for this were conflicting, with some saying that this was due to the belief within some parts of the community that having a child with a learning disability was punishment for past-life transgressions. It is reported that this creates a taboo around learning disability within the community, leading to subsequent stigmatisation and shame. In contrast, organisations working with the same community reported that there is no taboo, saying that families don’t seek support from community agencies because they have the view that their children with a learning disability are no different from other children, and that all are the responsibility of the family. These conflicting views were particularly prevalent within the Bangladeshi community.

One representative said:

“The shame and taboo surrounding learning disability makes it difficult for mothers to get help and support. They get little practical support from their families and no emotional support either. The situation is so bad that mothers are more likely to seek help from agencies that are outside their community rather than from Bangladeshi specialist agencies.”

Professional

Statutory agencies and disability specialist agencies report that they are experiencing the same difficulties as Mencap in engaging with BME communities. Statutory agencies are in the process of developing joint working strategies with community-based organisations that enjoy significant contact with BME groups. Voluntary sector agencies are experiencing a greater difficulty as there is a need to provide evidence of a need before funders will support any BME-focused strategy. With the scarcity of robust and reliable data on learning disability incidence rates and ethnicity, this places them in a potential stalemate position.
Appendix 3
acknowledgements

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