

# Reaching Out

to people with learning disabilities and their families from Black and Minority Ethnic communities

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foundation for  
people with  
learning disabilities

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# Acknowledgement

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We would love to hear your thought and comments on the report and guidance.

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# Introduction

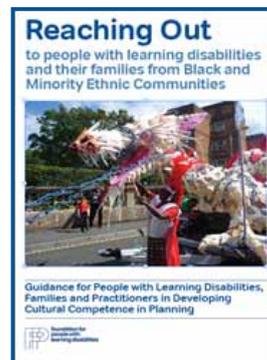
## “We don’t know the system. We’re going round in circles”

People with learning disabilities and their families from Black and Minority Ethnic (BME) communities continue to experience inequalities in health and social care despite various efforts to improve engagement<sup>1</sup>.

The aim of the Reaching out to families project was to find new ways of addressing this issue - with particular attention to the role of third sector organisations<sup>2</sup> and the use of action learning techniques in order to identify examples of good practice. At its heart was the aim of enabling people with learning disabilities and their families from BME communities to have a stronger voice, assisting them to access services more appropriate and meaningful to their individual requirements and circumstances.

The project was commissioned by the Department of Health as part of its Third Sector Investment Programme and was carried out by the Foundation for People with Learning Disabilities (FPLD). The work would complement several other initiatives that were underway or about to commence (see Appendix A). It was envisaged that the work would then be developed further and implemented across the country through the Valuing People Team (or its successor), the Regional Networks and local Learning Disability Partnership Boards.

This report is accompanied by two guides ‘Culturally Competent Planning’ and ‘Culturally Competent Practice’. We will also be releasing a template workbook ‘My Cultural Life Plan’ for people with learning disabilities and their families to use as a planning aid. All quotes in these reports have come from the action learning sites and names have been anonymised to protect peoples identities.



An accessible summary is available at the back of this report.



<sup>1</sup> 'Towards race equality in advocacy services: people with learning disabilities from black and minority ethnic communities', *Race Equality Foundation Briefing Paper*, 2010

<sup>2</sup> The 'third sector' is the term used to describe the range of organisations that are neither public sector nor private sector. It includes voluntary and community organisations (both registered charities and other organisations such as associations, self-help groups and community groups), social enterprises, mutuals and co-operatives. *National Audit Office website*

## How we went about the work

The aim was to establish and work with four local groups that included third sector community-based organisations alongside statutory organisations, thus building strong, sustainable local networks whilst capturing learning for wider dissemination. Four areas agreed to become 'development sites': two London boroughs and two English cities, all with very diverse populations.

Although four sites had originally agreed to become development sites, only three sites went on to take part in the project: two based in London boroughs and one city outside London. This was due largely to the impact of the current economic situation on the fourth site which impeded their capacity to take part in this work.

Progress in each of the three 'active' sites was made easier by involvement of the local authority commissioner of services for people with learning disabilities. Their visible leadership provided an important stimulus to staff from statutory and third sector organisations to come forward and join the local project group. Those who did come forward were either in posts with a specific remit around people with learning disabilities and families from BME communities, or had a particularly keen interest in the issues.

The project used a broad action learning approach, supporting participants to work together to solve real work-based problems, acknowledging and building on actions already being taken in each site. Action learning is 'based on the idea that learning and development has to be about real problems in real life with real people to be effective. Action learning is distinctive because the process stresses that it is not only important that the manager understands a situation but is also able to act in a situation.' (McGill, 1996<sup>3</sup>).

Learning was generated by identifying and interviewing local family carers who it was felt would have 'a story to tell', as well as community leaders. These interviews were written up, with the participants' permission, for analysis by the local project group. In the second London borough the interviews were conducted by the project worker rather than local staff because of constraints on their time. In all, 28 families were interviewed from different BME communities, including Asian Pakistani, Asian Bangladeshi, Asian Indian and Ghanaian.



**In the project meetings an action learning approach was used to identify:**

- what had made a difference for people who had had some success in accessing appropriate services
- what specifically had got in the way where the outcome had been unsatisfactory
- what might be done differently to ensure local improvements were achieved

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<sup>3</sup>'Real Problems in Real Life', Ian McGill, *Management Skills & Development magazine*, 1996

The main 'findings' were shared as the project progressed, through the individual site meetings, two workshops that brought people from the development sites together, and meetings of the project team. Links were made with other researchers working on different aspects of improving services for people with learning disabilities from BME communities. Findings from relevant research and development initiatives were fed into local project groups to stimulate people's thinking, discussion and learning. Appendix B gives an example which focuses on issues facing people of Chinese origin who have learning disabilities (Martin Partridge, 2012).

## Main findings

In general, learning from the Reaching out to families project supported findings from other recent development initiatives (reported in Appendix A). This report focuses on those aspects which have not received so much attention to date.

A number of themes were identified through analysis of the interviews with families and in-depth discussion about the issues:

- a) Effective identification of the needs, concerns and aspirations of different local communities**
- b) Making sure that people understand what's available and how local systems work**
- c) Getting to grips with 'personalisation'**
- d) Developing local responses with community organisations**
- e) A competent workforce**
- f) Working together**
- g) Being able to measure the impact of policies and practices on different BME communities**

### **a) Effective identification of the needs, concerns and aspirations of different local communities**

- Having information and knowledge about local Black and Minority Ethnic communities is crucial to understanding the needs and aspirations of people with learning disabilities from these communities. It is inadequate and unhelpful to refer simply to 'people from BME communities'. To serve people well it is important to know where and when different communities originated, where they have settled in the city or borough, their fundamental social and family cultural practices. A key question to ask is 'how do people behave and live their lives in different ways?'. This allows commissioners and practitioners to take a bespoke approach where necessary, within policy and practice frameworks.

**“In our community people are seen as ‘mad’. When people use that term it hurts me a lot”**

- The project found that, where identification and engagement with the different BME communities in an area worked well it was led on a corporate, local authority wide basis i.e. not just within Learning Disability or Adult Care Services. The local Joint Strategic Needs Assessment is potentially a useful source of information and an aide to decision making about engagement priorities and activities. That requires, however, not just an indication of different BME communities in the area, but also comparison of utilisation of services across communities. This level of sophisticated analysis is not commonly in evidence.
- More fundamentally, up-to-date forecasts of the number of people with learning disabilities from different BME communities - i.e. people potentially requiring support – was still not available to planners in the development sites<sup>4</sup>. It seems reasonable to assume that this is a situation mirrored across the UK<sup>5</sup>. Prevalence of learning disability in different communities needs to be established to identify trends and make future plans. The sites could already see evidence that numbers of young people reaching adulthood with high needs (including autism) who are from particular BME communities are generally increasing above already significant levels.

## **“It is important not to generalise too readily about BME issues”**

- The detailed analysis of interviews highlighted a general dilemma about how to distinguish issues and concerns specific to BME families from those affecting all families of people with learning disabilities. In the sites, people from BME communities were seen as no more or no less affected by current resource constraints than anybody else. There was concern that agencies should make additional efforts to identify and then work appropriately with those who were really vulnerable – such as older carers - who could be from any community. The interviews confirmed that people within specific communities have different needs and concerns, as well as people across different communities. It is important not to generalise too readily about ‘BME issues’.
- Understanding of, and response to ‘learning disability’ continues to be an issue within some communities, affecting whether and how people come forward for support. The project met families who have experienced stigmatisation and cultural rejection by people from their own community, and others who remain reluctant to request support for religious and other reasons, including their own citizenship and legal status.

## **“Children like Mrs Patel’s son would be chained and hidden in their homes. It took some time for Mrs Patel to realise that children with disabilities had rights in the UK”**

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<sup>4</sup>‘The Learning Disabilities and Ethnicity Framework for Action’, (*Department of Health*, 2004) emphasised the need for “each local area led by the Local Authority is knowledgeable about how many people with learning difficulties from which BME communities are likely to be living there, for whom the statutory agencies therefore have some important responsibilities and duties to take action. A key starting point is to be aware of the basic numbers: population, people with learning difficulties in touch with “services”, BME population and people with learning difficulties from BME communities in touch with “services”

<sup>5</sup>‘Learning Disabilities and Ethnicity: Updating A Framework for Action’, *FPLD/Department of Health*, 2012

## **b) Making sure that people understand what's available and how local systems work**

**“To get information is very difficult. You have to be very pushy and scream about what you want. When you have found the information it is good, but to use it is quite difficult”**

- It was clear from interviews that being able to understand how local systems work is important, particularly in relation to:

- **how to get a social care or specialist health assessment?**
- **what is meant by entitlement?**
- **how arrangements around personal budgets affect people?**
- **how the benefits system works and how it relates to social care?**
- **how housing and housing improvement issues are handled?**

These systems have grown up over the years and do not necessarily fit well together or present a clear framework and 'front door' to local people. Many people continue to struggle with these issues, but the three sites showed that some (not all) BME people especially missed out as a result: newly arrived communities and people without a good grasp of English were particularly vulnerable. Having an individual or organisation to turn to outside of statutory services made a real difference.

- Generally there is now more information available, but there remain issues about how people access it. It was clear from the interviews that some families are unaware of what support they are entitled to and where they can go to get information. As a consequence they don't get help. A common assumption is that benefits and social care are provided by the same agency, and that the two services automatically share information about their clients. As a result, people wait for support to come to them which does not materialise.

**“About 5 or 6 years ago he came across that organisation and since then has relied heavily on them for information. He doesn't speak fluent English...that is why he relies on them”**

Where information is available, there remains issues about how it is presented so that people can understand it. New interactive websites linked to personalisation are not easily accessible to people who do not use English or who require support to use a computer. Involving people with learning disabilities and families from BME communities in developing websites and information is an important step.

- Having effective 'advocates' – people who help you to speak up and to access the supports you need - is still a key issue for many families. Developing local advocacy in meaningful ways was a recurrent theme. There was clear evidence of the importance of local leaders/community stars who knew the systems and had the confidence of both local communities and the statutory agencies. Across the sites advocates came from a variety of sources: family members; local community organisations; local people with personal commitment and expertise, who are well known to both families and statutory agencies; and also key officers within statutory agencies (and out sourced bodies) who had got to know local communities. They made a real difference to families, but their reach and spread was generally thin.

- It was found that families particularly need support to:
  - know what help they and their family members can get
  - know, and negotiate the system for getting help
  - learn English, especially where it is council policy to provide material only in English
  - understand how the various statutory agencies and outsourced providers relate to one another
  - speak up if they are not happy about services
- Translation and interpretation remains important for many people across BME communities, although for others their use of English presents few if any problems. There was evidence from the sites that older family carers have greater need for structured translation and interpretation support, suggesting that targeting of resources could help. The importance of local support to overcome language barriers needs to be properly addressed on a continuing basis as local BME communities develop and change.

## Case study

### The Asad family

**Aarzu's parents are very worried for the future. They want to live independently and do not want his siblings to feel they have to look after him. They want him to have support to go out, but not to pubs or licensed premises, and they want him to go to places that serve Halal food.**

**Mr & Mrs Asad want a worker to guide them through until they actually get services, someone who speaks their language. They would prefer Aarzu to have support from someone from the Muslim community because 'then they know everything'.**

**They are seriously considering finding Aarzu a wife from Pakistan, to look after both him and them.**

**“Does my brother have to be in a wheelchair or do we need to have a sign outside our house saying ‘I am disabled’ for them to notice us and give us support. I’m not sure whos responsible, maybe the government is”**

### c) Getting to grips with 'personalisation'



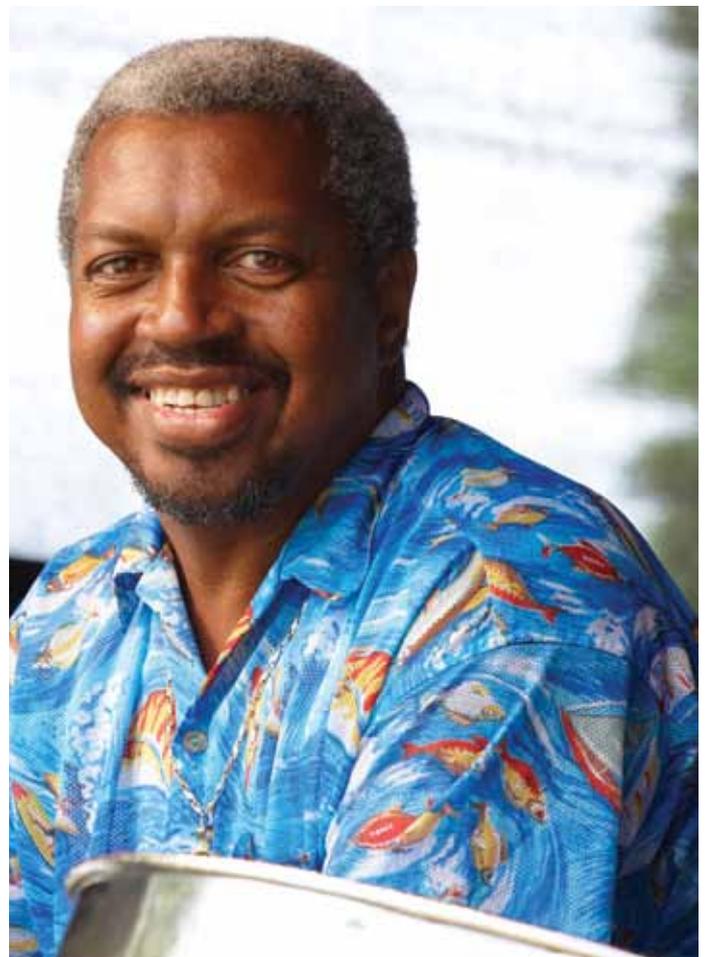
- There was general consensus across the sites about the importance of people with learning disabilities having carers and supporters who understand what is happening under the banner of 'personalisation', including changes to service provision and charging practices. A properly personalised approach to individuals' needs should, in theory, be good news for people from different BME communities for whom the standard 'off the shelf' package is especially inadequate. However, people in the sites warned against an over-optimistic view: for personalisation to succeed across different individual and cultural experiences and expectations requires significant local effort and commissioners, providers and families working together. It seems likely that local advocates and brokers will make the real difference, and local community organisations and community workers may offer the way forward.
- Personal budgets have been designed to give people choice and control over their own support. People's cultural requirements should be specifically addressed in community care assessments, but potentially self-assessment could lead to more accurate identification of needs if families are encouraged to do it. Whatever the mechanism, it is important to get the basics right in the assessment and planning process. Project interviews suggest that, whilst people from BME communities are as entitled to good quality services and responses as anybody, delivery often falls short. Sometimes the basics get overlooked as statutory agencies focus upon the 'additional' components they associate with BME communities. As with other studies, there was a commonly expressed view that people from BME communities do not necessarily want special services, rather they want decent services, however defined.
- Supporting carers to make sense of personalisation is essential. It is of particular importance for people from BME communities who may face barriers to understanding the system and choices on offer. Sites reported that carer consultation meetings are very well attended because families are so concerned for the future. They are keen to know how to use personal budgets and how to employ Personal Assistants.

## d) Developing local responses with community organisations

- For commissioners the challenge is how best to develop new provision for people with learning disabilities from different BME communities, including advocacy support. The project found several independent, community-oriented providers in the sites who offered flexible responses to what local people sought: evening support being a good example. An important way forward is to invest in local community organisations that are looking to expand their range and volume of provision and already have the trust of local BME communities.
- One approach to local service and provider market development is to buy in to local communities in a trusting and trustworthy i.e. mutual way. The Local Authority's role may include appointing or contracting with local people as leaders and brokers to create new ways of responding to needs. Sustainability is crucial – small local organisations and individuals require continued support and time to develop their networks.
- Inevitably, as resources have become scarcer, fewer people are eligible for support funded through local authorities. There is therefore a need to stimulate communities to develop self-support mechanisms through local organisations, as well as encourage development of new provider services. For families of people with learning disabilities from BME communities support may be easiest to access through local community groups and specialist BME organisations.
- Local commissioners of learning disability services need strong links with local organisations, especially generic community ones. It is important for them to reach out effectively. This is likely to mean face to face, getting beyond social care, finding common ground from which to begin to explore issues around learning disability, as well as helping families to help each other. It is possible for statutory agencies to reach out in imaginative ways to make contact with people. In the sites social care staff were reaching out to make contact with people through GP surgeries and health centres, sports groups and other leisure activities. It is clear, though, that it takes an investment of time to build relationships and trust in this way, and staff have little to give at the current time.

**“Word of mouth is the most powerful way to reach people and change hearts and minds...any talk on learning disabilities should be part of a broader one so that people don't feel shy about coming to ask for more information due to cultural taboos”**

**“I feel the community is much more understanding because this organisation has been raising awareness”**





- In the current financial climate, new ways are needed to stimulate local areas to develop new solutions. It is important to consider how local community business people can be engaged in generating ideas for meeting the needs and aspirations of people with learning disabilities. At one site there was discussion about setting up a social enterprise or community business in the Somali community. Local needs-mapping will help to identify what a social enterprise could usefully deliver in practice. The discussion considered the importance of both generic provision (described as 'social solutions for social situations') as well as more 'specialist' responses.
- The current trend of procuring services through fewer providers and larger contracts, with everything going to competitive tender, means that small local organisations are being encouraged to work in partnership to compete. This risks adding another layer of complexity to an already over-complex process, and is unlikely to support the development of smaller community organisations well placed to work with BME communities. Such organisations clearly benefit from an approach that is rooted in needs-led commissioning rather than lowest-price procurement.
- Sustaining small specialist services run by community organisations has proved an issue in the sites, with some organisations not able to secure ongoing funding once local authority monies ceased. There was a strong sense that commissioners do not always appreciate the community networking and investment of time that is required to reach out to people.

**“The carers network is great for the Asian community. I go to meetings, usually in the evenings which is great for me as I work during the day”**

- An important part of developing local responses is being very clear about what 'culturally appropriate' really means for the geographical area in question. This requires getting really good information about needs and aspirations, as discussed earlier. In the sites some clear themes emerged about developments and improvements that people want:
  - **some services that are just for women**
  - **services that they want – not what professionals think they should want!**
  - **good quality support and services**
  - **services or support that guides them through the maze of decision making.**

**“A previous support organisation for Asian carers was highly valued as they arranged events for carers where the person they cared for was welcome. They could relax and know the people around them shared their experience”**

## e) A competent workforce

### “They come and take the paperwork, but they don’t come back and help us”

- Families from BME communities gave a consistent message that too many staff from statutory agencies:
  - do not follow up the action they have agreed and effectively lack professional ownership
  - are reactive rather than planning ahead with the family
  - do not ensure that families have the right information to pursue matters themselves, effectively keeping people disempowered
  - move on too quickly to enable a proper degree of mutual trust and understanding to be developed. If staff turnover is high organisations need to consider how they ensure continuity of knowledge, trust and understanding by other means.

### “I had a review and told the social worker that we want to visit other day centres and choose. It’s been almost a year but no one has contacted me yet”

- The Project found that staff need to exhibit a number of qualities to respond effectively to people and families from BME communities. They need to:
  - take the time to build up trust – which may mean giving local people at least something of what they ask for
  - take responsibility for guiding people to community services or groups that can help them
  - ask people what they think of services rather than being reactive and waiting for a complaint
  - follow through on what they say they will do, preferably with a consistency of response and of member of staff
  - know about people’s culture i.e. to be culturally competent

Attached to this report is ‘Guidance for Practitioners from Social Care and Health Services in Developing Culturally Competent Practice’. The guidance includes **Essential Do’s and Don’ts** when working with families from BME communities.

- Cultural competence was seen as a key requirement for statutory agency staff, particularly in light of their role as gatekeepers to social care and health supports. As well as staff needing good knowledge of the local area, there was a strong recommendation that services invest in mandatory cultural competence training that staff are required to keep up to date. Even where the workforce was clearly diverse it did not necessarily reflect the profile of communities in the area. If staff do not demonstrate cultural awareness then service users may perceive them as racist rather than lacking understanding.

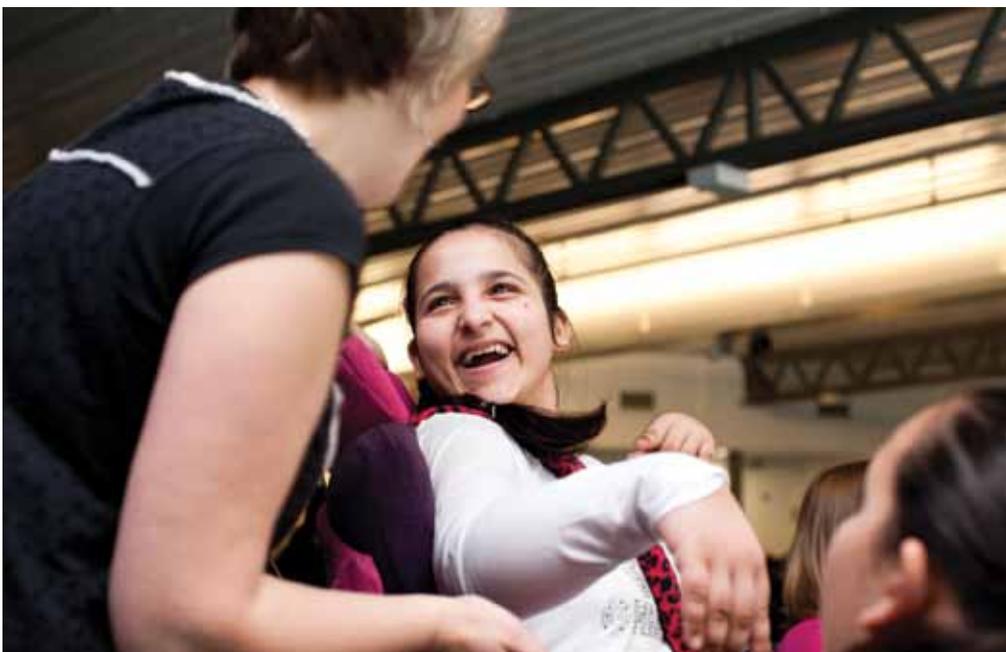
- Although pressed on the issue, BME staff from local community organisations and statutory agencies considered that generally racism was not a factor in people from BME communities getting a poor service. Whilst it cannot be ruled out completely the view was that everybody had a struggle to get a good response in the current financial climate. However, the extent to which many people from BME communities were clearly struggling to understand how local decision making worked in health and social care services suggests that the possibility of institutional racism should be examined.
- At one site, having a member of staff from a BME community in a a senior level post within the statutory agency was perceived as making a difference. It was, however, still seen as unsatisfactory that people from BME communities were under-represented at a very senior level.

**“When things go wrong professionals should give enough time to get it all sorted out, and not let things drift on”**

#### **f) Working together**

**“Look at the whole family. We don’t want him to be seen as separate from his family”**

- Integrated working and partnerships between staff, voluntary agencies, people with learning disabilities and their families was considered particularly important to improve outcomes for people from BME families. When people are struggling to understand how different systems work and are connected, having contact with a stream of different professionals and agencies can compound the confusion. The project found several examples of how a more ‘family focused’ approach would have helped the person with a learning disability and their (often ageing) parents, rather than separate interventions from different teams and services that did not connect.
- Project interviews highlighted that underlying issues of family poverty, chronic ill health of the primary carer (sometimes at a relatively young age) and poor housing were significantly impacting on people with learning disabilities from BME communities. Whilst these were acknowledged they were not given the prominence they required as part of the response to the family member with a learning disability.



**“We need ethnic minority staff who can understand my brother. Every ethnic minority is different. Being Asian is just not enough, there needs to be staff who are willing to adapt and make the effort to find the right services and information suitable for us”**

**“Mr Halkias said he doesn’t want to be greedy but would like more for his son. He is afraid to go for opportunities in case they cost money”**

## **Case study**

### **The Jasem family**

**Fari has had contact with both mental health and learning disability services, and both health and social care professionals. The learning disability social work team supported the family whilst they were waiting for their immigration status to be secured, finding them accommodation, providing a translator and giving financial support. Fari sees a specialist epilepsy nurse at the local hospital, and the community mental health team has also been involved with him. He was referred to the specialist learning disability consultant by the epilepsy nurse, who then referred him to the learning disability psychology team. They have infrequent contact.**

**The family’s main support comes from an organisation called Nyla: Mrs Jasem goes to a carers group that Nyla facilitates.**



**“Nowadays I don’t even know who to call. It has become very difficult. I have been calling social services and leaving messages but no-one has got back to me”**

- Partnership working was found to be important not just across social care and health services but also for ensuring access to general services such as employment support, college opportunities and leisure activities.
- Like any young learning disabled person, young people from BME communities need agencies to work well together to make sure they continue to receive the support they need when they reach adulthood, commonly referred to as ‘transition’. The barriers they face to successful transition are, though, significantly increased by the issues highlighted in section 2 above. The project confirmed that ‘improving transition’ remains a priority for young people from BME communities.
- Engaging and working with the wider family was found to be important, particularly in seeking to ensure the person has an advocate who knows them, their family and their culture. Family members, especially siblings, were seen to be providing information, translation and interpreting support, leisure opportunities, and, in some cases, an element of shared care.
- Working with local people in a mutually beneficial way that enabled people with learning disabilities to connect with their local communities was also seen as important. Time-banking projects were seen as potentially having a lot to offer.
- Across the three sites organised self-advocacy groups of people with learning disabilities from BME communities were found to be fragile. Their role in relation to the local statutory agencies appeared poorly defined, and their contribution ad hoc.

## **Case study**

### **The Odero family**

**Mrs Odero is desperate to move. The family continually has problems with anti-social behaviour from the neighbours, maybe as a result of their race, the fact that they do not have a father figure around and therefore seem more vulnerable, or because of her children’s disabilities. Or perhaps, she says, because they are just unfortunate to live in a bad area. Whichever it is, it impacts on how independent she will allow her children to be, which prevents them from developing their skills. She is worried about her family.**

**“There was some confusion over his course. When he returned to College his name had been removed and they were only able to offer him 4 hours a week on another course. He needs help to access the training he wants”**

**“Mrs Walczak says when her son was leaving school it was the most difficult time for them. There was a total breakdown of communication... with her son having both learning and physical disabilities she didn’t know what was available for him in the future”**

**g) Being able to measure the impact of policies and practices on different BME communities**

**“He finally left College 4 years ago. Since then he has been at home full time. He says he is bored, and wants a job. He occasionally goes out with his brother”**

As indicated elsewhere in this report there has been some valuable work over the years, and especially recently, on how to improve access to services for people from BME communities. There is a history of national encouragement and local goodwill. It is clear now that this is not enough and much more local rigour is required to match the legal requirements and national articulation of good practice.

It is important to be clear about what monitoring is in place to check how well people with learning disabilities from BME communities are accessing support services. It is vital that statutory agencies fulfil their responsibility to undertake Equality Impact Assessments on services and developments. But more than that, those Impact Assessments need to be rigorous and knowledgeable in reflecting the issues experienced by people with learning disabilities from BME communities, and their families. Experience at the three sites highlights that Equality Impact Assessments are not enough: specific action plans are required against which statutory agencies can be held to account. Departmental and agency restructurings tend to divert attention from the detailed monitoring that is needed to really find out which communities are, or are not, accessing support.



When the process for monitoring access is not neat, clear and functioning it is even more important that everyone working in ‘services’ - at all levels - take a personal responsibility for ensuring fair access. But although this personal responsibility is important it cannot take the place of ‘culturally sensitive’ action planning - for individuals and their families (where appropriate) and at aggregate levels to reflect different community aspirations.

## Conclusions and recommendations

During the Reaching out to families project, financial pressures on the public sector increased significantly. As well as making it harder for staff to give time to development work it also meant that resources available to meet the needs of people with learning disabilities from all communities became even tighter. These are not particularly easy times to be developing different and better ways of working. It becomes even more essential that commissioners and practitioners get close to their diverse communities to ensure that progress continues to be made, regardless.

The following recommendations emerge from the project's findings:

- 1. Families are not “hard to reach” they simply have to be identified and contacted. Better partnership between schools and statutory health/ social care services is an essential requirement to prevent BME families with young learning disabled people getting ‘lost along the way’.**
- 2. Local community organisations have a significant role to play in identifying and contacting local families supporting a learning disabled person. To work with community organisations in this way, statutory agencies need a joint strategy, an action plan, effective commissioning and monitoring.**
- 3. More attention should be given to understanding the dynamics of families within the different BME communities, especially the roles and responsibilities of their members, including siblings.**
- 4. It is important to take a person-centred ‘whole system’ approach, that goes beyond health and social care, and that embraces the family as a whole. ‘Guidance for Families of People with Learning Disabilities and Practitioners in Developing Culturally Competent Planning’ is available for download from [www.learningdisabilities.org.uk/publications](http://www.learningdisabilities.org.uk/publications).**
- 5. Joint Strategic Needs Assessments should be used as the basis to collect information on the needs of different local BME communities and people with learning disabilities from these communities.**
- 6. Specific attention should be given to ensuring that individuals and communities have relevant information on local services and how local decision making processes work.**
- 7. Building up and retaining trust between workers and families is the basis for ensuring effective responses. More attention needs to be paid to helping practitioners achieve this trust. When workers change care should be taken to ensure sufficient ‘handover’ time.**

- 8. The contribution of local community organisations should be properly identified and promoted, especially the networks and staff that may be vital. Such organisations and key staff (often volunteers) should then be protected and sustained by the statutory agencies. In particular they should not be passed over by procurement processes that favour large scale organisations without community roots.**
  
- 9. Local statutory agencies should examine their own policies and practices openly and honestly in order to eradicate any element of institutional racism that means people with learning disabilities from BME communities are worse off than others.**
  
- 10. Work on the needs and issues of people with learning disabilities from BME communities should be given the prominence that it merits. In many places such communities should not be regarded as minority at all but central to the responsibilities of the local statutory agencies.**



## Appendix A

### Related work: information and guidance available

#### Valuing People Now, 2009

Valuing People Now (DH, 2009) confirmed that people with learning disabilities from black and minority ethnic groups and newly arrived communities and their families often had to face services that were both insufficient and inappropriate. Four possible causes were suggested:

- policy and services which are not always culturally sensitive
- wrong assumptions about what certain ethnic groups value
- language barriers
- discrimination

The policy document contained little detail on ways of responding. However, numerous initiatives since have produced helpful guidance and resources.

#### **‘Reaching Out: Working with Black and Minority Ethnic Communities’, (2006, updated 2009) *Midland MENCAP***

This research identified four necessary elements to reduce the inequalities faced by BME communities:

- provision of information in community languages and accessible formats
- flexible services that respond to cultural needs
- support to understand the system and use it to meet specific needs
- provision of more support groups to reduce isolation.

#### **‘Giving Us a Voice Project’, 2011**

The Giving Us A Voice Project supported by ARC, BILD and National Mencap produced a National Charter for Inclusion in April 2011. Statutory agencies were asked to commit to achieving the following:

##### **Citizenship**

- people with learning disabilities from BME communities are supported and encouraged to take part in society at all levels of public engagement (take part in important meetings)
- advocacy for BME communities is well planned and funded
- support is offered that enables people with learning disabilities from BME communities to travel safely
- people with learning disabilities from BME communities are supported to live safely and happily, free from abuse and hate crimes.

## Health

- health plans/passports are available to everyone with a learning disability (for all their medical care) that include reference/checks for specific conditions for that person's ethnic origin (where the family is from)
- health professionals are trained to work successfully with people with learning disabilities and understand their cultural needs
- health checks, health screening and illness prevention (keeping people well) are available to everyone and take account of a person's ethnic origin
- health and Wellbeing Boards and any health planning groups include people with learning disabilities and their family carers from BME communities.

## Work

- paid work for people with learning disabilities from BME communities is the goal (what we are working towards)
- the value of employment in terms of living happily e.g. friends, respect, use of time, etc. is recognised and people are helped to find opportunities in a culturally appropriate way (a way that fits with their background)
- links are made with employers and BME communities so they can work together to find opportunities for people with learning disabilities
- families from BME communities are helped to understand all the training and employment opportunities that might be available. This is part of good transition planning.

## Housing

- people with learning disabilities from BME communities are given support and choices in where they live
- planning for housing takes time and people are supported from transition onwards
- families are helped to remain involved and understand that independence does not mean managing alone
- people with learning disabilities from BME communities are supported to have a sense of belonging – a place they choose as home.

## ***'Minority ethnic communities and specialist learning disability services', Report of the Faculty of the Psychiatry of Learning Disability Working Group, July 2011***

This reviewed the use of specialist learning disability services by people with learning disabilities and their carers from minority ethnic communities. It considered that reaching and involving the community in development and delivery of services, and creating an environment for staff to develop and maintain cultural competency should be core business and part of the day-to-day delivery of services. It recommended:

- agencies adopting a strategic approach to meaningful engagement of the community including those from minority ethnic communities
- providing information on mental health problems in people with learning disabilities and the local availability of services is vital in improving access; information must be accessible and convey an informed and genuine effort at engagement, rather than a merely tokenistic approach

- organisations trying to understand the barriers that communities face in relation to the access of services
- importance of a culturally competent workforce, for which minority ethnic communities could play a vital role in the development.

**‘Reaching and Supporting Diverse Communities: a guide to meeting the needs of people with learning disabilities, and family carers, from newly arrived, Black, Asian and other Minority Ethnic (BME) communities’, *Home Farm Trust, updated 2011***

The resource has six discrete sections reflecting the steps to be taken:

- engaging with different communities – including the importance of recognizing different communities and the significance of migrant groups and faith communities
- supporting communities – specific issues such as forced and arranged marriage as well as more usual ones like transition
- supporting communities – specific communities: the importance of getting to know local community groups and being able to support and work with them
- BME families – it’s everybody’s business: understanding and working to legislation including that on human rights
- knowing your local population – finding out about and mapping local populations for inclusion in Joint Strategic Needs Assessments
- good practice examples from around the country.

A key message is the importance of ensuring that mainstream services are able to meet the needs of all communities. This can best be achieved by ensuring investment in and support of local specialist voluntary organisations and groups who can support families from BME and seldom heard communities to get the best from mainstream services.

**‘Towards race equality in advocacy services: people with learning disabilities from black and minority ethnic communities’, *Race Equality Foundation Briefing Paper, 2010***

Key messages were:

- people with learning disabilities from black and minority ethnic communities face ‘double discrimination’ in accessing public services
- the concept of advocacy is itself problematic as it may not be widely or fully understood nor easily translatable for many black and minority ethnic communities
- developing cultural knowledge is crucial in working towards race equality in advocacy services. The advocacy practitioner must, through training and personal development, be able to respond appropriately and constructively to a black and minority ethnic client’s experience of racism
- to promote full and equal access to public services, it is essential to meet the language requirements of those black and minority ethnic individuals who need to use advocacy services.

**'Including migrant populations in Joint Strategic Needs Assessment', Guide commissioned by the Health Inequalities and Local Improvement Team, Department of Health, 2011**

This guide emphasises that a first step to understanding local need must be a basic understanding of the demography of the local population. This should include some understanding of migration and how it might be changing the local population. This awareness can help assess equity of provision including when migrants are amongst groups that are seldom heard. Local perceptions are important and have to be addressed, for example, a service may consider that it is unable to fully meet the needs of a new migrant group, or there may be wider population concerns about competition for resources.

**'Making Things Better' project, Foundation for People with Learning Disabilities, 2006**

The project found that:

- a) Some basics still need to be addressed:
  - know the facts about local minority communities
  - listen to what local people have to say
  - involve lots of people
  - work with families and community groups
  - understand the law – rights and duties
  - take a broad view to service improvement
  
- b) Key issues need to be tackled:
  - stigma and learning disability
  - lack of information
  - not knowing how to access support
  - inappropriate ways of working and service responses
  - institutional racism
  
- c) There are some well documented ways of making progress:
  - Awareness and information giving events
  - Making use of translation and explanation, and interpretation and language support as appropriate
  - Having local 'Champions for Change'
  - Addressing specific training requirements
  - Making use of development workers
  - Using 'link workers' to connect with services and adapting these where necessary
  - Taking a measured and considered approach – not a quick 'tick box' exercise

## Legislation from 'Learning Difficulties and Ethnicity: Updating a Framework for Action', Department of Health/FPLD, 2012

The law is clear and forthright on local statutory responsibilities in respect of race and disability – people with learning disabilities from BME communities are clearly an important part of those responsibilities. The Equality Act 2010 came into force on 6 April 2011<sup>6</sup>. It simplifies and brings together previous laws to protect people from discrimination. The 'protected groups' to whom the Act makes particular reference include race and disability.

The Act places a general duty on public authorities:

- To eliminate unlawful discrimination, harassment and victimisation, and other prohibited conduct
- To advance equality of opportunities
- To foster good relations

The Act states that this involves having due regard of the need to remove or minimise disadvantages suffered, taking steps to meet needs where these are different, and encouraging participation in public life or in other activities.

There are also specific duties, including:

- To publish information to demonstrate compliance with the general equality duty
- To prepare and publish equality objectives
- To provide details of engagement undertaken in pursuance of these duties

The Act makes it clear that it is outside the law to treat somebody worse because they are a carer, including of course BME carers and those with learning disabilities themselves.

It is for public authorities to decide how they will comply with the Act, beyond preparing and publishing equality objectives and publishing information. The duties also apply to services that are 'contracted out'.

Government guidance indicates that published information should include performance information especially around outcomes, access to services, satisfaction with services, and complaints. This should include evidence of the effect of their policies and practices.

The guidance also expands on the general duty 'to have due regard' stating that this calls for an evidence base to local decision making that may be obtained through local engagement with the 'protected groups'.

Public bodies are required to make reasonable adjustments for people with disabilities, and can be brought to account before the courts if they do not comply with equality legislation. They are required under existing equality law to undertake equality impact assessments to ensure that existing or new policies do not unlawfully discriminate against or impact on disabled people, ethnic minorities and men and women. They are also required to give due regard to the need to promote equality of opportunity.

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<sup>6</sup> [www.equalities.gov.uk/equality\\_act\\_2010.aspx](http://www.equalities.gov.uk/equality_act_2010.aspx)

## Appendix B

### People with learning disabilities from a Chinese background who live in the United Kingdom: a case study

People from Chinese backgrounds are a diverse set of peoples who have made their homes in the United Kingdom (UK) for many centuries. According to the 2001 census, there were approximately 250,000 people from Chinese backgrounds who live in the UK (National Statistics, 2001a, National Statistics, 2001b). Research has shown that approximately 2% of the general population in the UK is made up of people with learning disabilities (Emerson and Hatton, 2004). From these figures it is thought that there were approximately 4,500 people with learning disabilities who are from a Chinese background in England. However, these figures are set to rise as it has been reported (National Statistics, 2011) that the 'Chinese' population has the highest growth rate among minority ethnic groups in the UK.

Cultural beliefs and values are integral to how people see themselves and how others see them and this will affect their willingness to take up any services on offer (Mir et al., 2001: 47). Further, disability is culturally defined (Stone, 1998) and 'services', either statutory or non-statutory, may not be culturally appropriate. The issues emerging from research (Evans and Banton, 2001, Singh, 2005, Partridge, 2009) suggest that a number of mainstream and culturally specific services are not meeting the needs of people with learning disabilities from Chinese communities in the UK. This group seem to be falling between mainstream and Chinese specific services and they are likely to experience isolation and social exclusion (Mir et al., 2001, Partridge, 2009, Partridge, forthcoming).

Research in the Midlands (Partridge, 2009, Partridge, forthcoming) has revealed there was a small uptake by people with learning disabilities from Chinese communities of these services that might suggest that learning disabilities was something to be ashamed of. This seems to have placed an expectation on family to provide support for their family member with learning disabilities and placed the family in a position as a 'buffer' between the person with a learning disability and services (Partridge, forthcoming). Attitudes towards learning disability and losing 'face' seem to have had an impact on the uptake of services but also have influenced who the main carers were within the family. Tse (1995) suggested that the low uptake of services by people with learning disabilities was due to family 'losing face'. Children of some families from Chinese backgrounds have been taught to maintain 'face' which can be lost if the individual or the family failed in their caring duties or did something wrong (Chang and Holt, 1994, Dong and Lee, 2007). For some, learning disability appears to be seen as one form of losing face (Hu, 1944, Chan, 2006, Dong and Lee, 2007).

Accessing services has been, for some, a process whereby Chinese specific services have acted as gatekeepers that have enabled people with learning disabilities and their families/carers to make contact with and receive learning disability services (Partridge, 2009). For example, some Chinese specific services provide advice to their members who are seeking help because they may be unsure of what is available, how they may be received, may not have any English language and may be suspicious of government provision (Chan et al., 2007, Partridge, 2009). The process for many people from Chinese backgrounds in accessing services has not been easy because of their lack of understanding of the services and the services lack of understanding of them. For example, the building of trust and having a good relationship between families and services is based on the Chinese concept of 'face'. If 'face' is not given and received, this may create a sense that the dealings between services and people with learning disabilities and their family/carers is not an authentic one, is not taken seriously and is short term (Turley, 2010). Cultural competence should not only be directed towards the service users, but also their families. However, research (Hatton, 2005, Hatton, 2007) has suggested that many services are not culturally competent, and have a cultural awareness based on assumptions and stereotypes (Partridge, forthcoming).

People with learning disabilities from Chinese backgrounds are made up from many different and diverse backgrounds. Many are from different parts of the world such as Asian and Europe and speak many different languages and dialects. As such these people are from many sets of communities with different cultural values, norms and beliefs. It is not enough to provide information based on one Chinese language to a diverse set of peoples, nor is it enough for service to work in isolation without forging links. People with learning disabilities from Chinese communities face isolation not only from and within mainstream services but also from and within Chinese specific services. Mainstream and Chinese specific services can offer expertise in their own field, pooling these resources, forging links and working together might provide a more inclusive approach towards service delivery for those with learning disabilities from Chinese backgrounds.

### **Martin Partridge, BA (Hons), PGDip, MA**

Martin is currently writing up his PhD at the Norah Fry Research Centre, University of Bristol. His research focuses on social care services for people with learning disabilities from Chinese communities. He is also employed by Staffordshire University conducting research into the experiences of people with physical impairments who are from Chinese backgrounds who access social care services in England.

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# Reaching out to people with learning disabilities and their families from Black and Minority Ethnic communities

## Accessible Summary



### Who are we?

We are the Foundation for People with Learning Disabilities.



### What is this project about?

We wanted to find new ways of helping families from Black and Minority Ethnic (BME) communities get good support from health and social care services.



### Why is this important?

People from BME groups who have learning disabilities are still not treated the same by some health and social care services. These services are not offering support in a way that everyone understand or use.



### How did we aim to change this?

We wanted to work with local groups and get their ideas to change the way people with learning disabilities from BME groups are treated by some services.



### **What did we do?**

We worked with 3 local groups in: London and another city in England.



These groups talked about what was wrong. We looked at real problems people from BME communities who have learning disabilities have when using social care and health services.



We talked to local family carers, people who work at councils and people who work in for charities.

We spoke to 28 families from BME communities.



We thought about how we could make things better from what these families said.



## What did we find?

We found out lots of very useful things that were going on each area.

We think there are **7 key things** services can do to help make themselves more accessible to people who have learning disabilities and are from BME communities:



1. Think about the needs of different local BME communities.



2. Help people to know what is available to them and how to access it.



3. Help services to understand what 'Personalisation' is.



4. Work with local community organisations to think of ways to help local people.



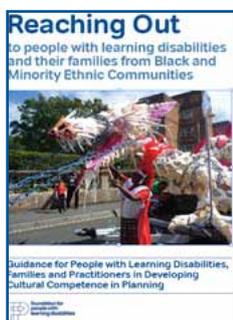
5. Have good staff working for services.



6. Work together.



7. Think about how policies from the Government affect people from BME.



### Further information

A guide for people who work with families has been published to help them build trust and reach families from BME communities.

A guide and workbook to help people with learning disabilities and their families with planning has also been written.

[www.learningdisabilities.org.uk/publications](http://www.learningdisabilities.org.uk/publications)

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