

Reaching Out

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



Guidance for Practitioners from Social Care and Health Services in Developing Culturally Competent Practice

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foundation for
people with
learning disabilities

Introduction

The Reaching out to families project set out to find new ways of addressing the inequalities that people with learning disabilities from Black and Minority Ethnic Communities and their families experience in health and social care. The project paid particular attention to the role of third sector organisations and used action learning techniques to identify 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 which were more appropriate and meaningful to their individual requirements and circumstances. This project was produced with funding support from the Department of Health. Written by Richard Poxton, Jane Taylor, Debbie Brenner, Angela Cole and Christine Burke the report from the project can be downloaded at www.learningdisabilities.org.uk/publications.

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, and do not ensure continuity of contact and knowledge

The project concluded that practitioners 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
- take responsibility for guiding people to community services or groups that can help them
- ask people what they think of the services and supports they receive, rather than being reactive and waiting for a complaint
- follow through and do what they say they will do
- demonstrate cultural competence (see below)

Culturally competent practice involves:

1. Knowledge and understanding of:
 - your own culture
 - any culture bias you have
 - the concept of culture and how this can affect beliefs and behaviours
 - specific cultural knowledge
2. A range of values and attitudes, including a commitment to:
 - valuing and celebrating difference
 - respecting individuality and the role which culture plays in this
3. A range of skills, including:
 - culturally competent communication
 - culturally competent assessment
 - culturally sensitive care provision



Kirwin Maclean Associates Ltd

www.kirwinmaclean.com/cultural-competence-in-social-care-and-health

During the project it became clear that many families were left frustrated by their contact with statutory social care and health services. The themes revolved around culturally competent practice, but also basic good practice around contact with families – applicable to people of any ethnic origin. We concluded that some guidance specifically for practitioners could be a useful addition to the body of resources available.

“People have tried to understand my brother and our culture but it has never worked. Every ethnic minority is different. We need ethnic minority staff, but being Asian is just not enough. Staff need to be willing to adapt and make the effort to find the correct service and information that’s right for us”.



This guidance

Some of the guidance in this document may seem very basic. We make no apologies - getting the basics right can be extremely important for people from BME communities who are less familiar with the systems and processes of social care and other support. It can also make the difference in gaining a family's trust, essential to finding out about the person with learning disabilities and the support that they and their family need.

“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”.
‘Reaching out’ report

The guidance is also necessarily general. However, there are two core elements of 'good practice' with people with learning disabilities from BME communities that we believe underpin all others:

- 1) We should not assume that people from the same "minority community" share the same beliefs or aspirations, or the same social circumstances. Person-centred approaches are central to an effective response. To that end, a person-centred tool 'Guidance for Families of People with Learning Disabilities and Practitioners in Developing Culturally Competent Planning' to use with BME families to identify what matters to them is available for download from www.learningdisabilities.org.uk/raceandequality/ethnicityandequality.
- 2) It is important that practitioners go beyond a person-centred approach and consider the whole family. The income, education, housing and health of family members are important factors that need to be taken into account when practitioners are planning for a person with learning disabilities from a Black or Minority Ethnic community. A 'whole system', family focused approach is needed.

Further resources from this project

The main report 'Reaching out' (including accessible summary) and 'Guidance for Practitioners from Social Care and Health Services in Developing Culturally Competent Planning' are available to download at: www.learningdisabilities.org.uk/publications.



An accessible workbook 'My Cultural Life Plan' to be used by families and people with learning disabilities as a planning tool will also be available soon from our website.

All quotes in this guide have come from the action learning sites and names have been anonymised to protect peoples identities.

This guidance has three parts. It contains:

- 1 - Essential Do's**
- 2 - Essential Don'ts**
- 3 - Things to Check Out**

It is deliberately brief so that you can read it swiftly and easily. It is interspersed with quotes and vignettes that were gathered during the Reaching out to families project. As mentioned earlier all of the names have been changed.

“Issues and disputes arose when the family’s main support, Indira from the carers group, was on holiday overseas. The family subsequently lodged a complaint. The response was in English and not easy to read. Abdul’s brother had to translate”.



1- The Essentials Do's

✓ Do ...

- ✓ - find out about the 'cultural etiquette' that the family may follow – before you go to meet them – and then make sure you follow it unless the family give you permission not to do so. For example, removing your shoes at the door, who you should/shouldn't shake hands with, etc. Follow their cues. Prepare by looking at guidance on websites like: www.kwintessential.co.uk/resources/country-profiles.html or www.culturecrossing.net
- ✓ - find out in advance if an interpreter will be needed to aid communication. Don't just turn up in the hope that someone will be there who can speak your language. If parents say that a son or daughter will interpret check out with that person in advance that they are comfortable doing so.

“Mani lives with his mother and older brother in a rented flat. His mother’s health is poor – she has mental health problems and mobility problems. She doesn’t go out very often. His brother is unemployed. He often acts as interpreter for his mother, and gives a lot of help. The family do not have much money”.

- ✓ - offer to visit at a time that is best for the family. Be flexible so that you can meet all the members of the household, and make it clear that you don't mind if they want other family members to be there as well. It will help you to see how decisions are made, and who makes them. You may also be able to get input from siblings and grandparents, which may be very different from the parents views.
- ✓ - allow enough time so that you can be relaxed and unhurried. It will enable you to be sensitive to, and show respect for the family's cultural norms. See the list of 'Don'ts'!
- ✓ - be positive: a smile really helps to build bridges. Show interest in the learning disabled person but also in the family as a whole.
- ✓ - be prepared to accept offers of hospitality i.e. some food or a drink, which may be an important part of the culture – but don't do so greedily. If you don't like the type of food on offer then decline, politely.
- ✓ - build a relationship with the family so that they trust you. What you do and how you do it is important. Use 'active listening' and do the things you say you will do.



Active listening

There are five key elements of active listening. They all help ensure that you hear the other person, and that the other person knows you are hearing what they say.

1) Pay attention

Give the speaker your undivided attention, and acknowledge the message. Recognize that non-verbal communication also 'speaks' loudly.

- look at the speaker directly
- put aside distracting thoughts. Don't mentally prepare a rebuttal!
- avoid being distracted by environmental factors
- 'listen' to the speaker's body language
- refrain from side conversations when listening in a group setting.

2) Show that you are listening

Use your own body language and gestures to convey your attention.

- nod occasionally
- smile and use other facial expressions
- note your posture and make sure it is open and inviting
- encourage the speaker to continue with small verbal comments like yes, and uh huh.

3) Provide feedback

Our personal filters, assumptions, judgments, and beliefs can distort what we hear. As a listener, your role is to understand what is being said. This may require you to reflect what is being said and ask questions.

- reflect what has been said by paraphrasing. 'What I'm hearing is.' and 'Sounds like you are saying.' are great ways to reflect back
- ask questions to clarify certain points. 'What do you mean when you say.' 'Is this what you mean?'
- summarise the speaker's comments periodically.

Tip: If you find yourself responding emotionally to what someone said, say so, and ask for more information: 'I may not be understanding you correctly, and I find myself taking what you said personally. What I thought you just said is XYZ; is that what you meant?'

4) Defer judgment

Interrupting is a waste of time. It frustrates the speaker and limits full understanding of the message.

- allow the speaker to finish
- don't interrupt with counter arguments.

5) Respond Appropriately

Active listening is a model for respect and understanding. You are gaining information and perspective. You add nothing by attacking the speaker or otherwise putting him or her down.

- be candid, open, and honest in your response
- assert your opinions respectfully
- treat the other person as he or she would want to be treated.

www.mindtools.com/CommSkill/ActiveListening

- ✓ - explain, explain, explain – and check out what people have understood. You may know what an assessment or review means, but don't assume that the family does!
- ✓ - make sure the family understands the learning disabled person's entitlements, and theirs as carers.
- ✓ - explore 'what good support would look like for the person', and specifically:
 - gender requirements
 - faith practices
 - food requirements
 - dress codes
 - relations with the opposite sex
 - any cultural no-nos (such as drinking alcohol, going to pubs, etc)
- ✓ - be aware of safeguarding issues (as a matter of course) but if you have concerns check out people's reasons for doing things before jumping to conclusions. Get to the *real* heart of the matter.
- ✓ - tell the family what will happen next, and make sure it happens and phone them or write to them within two weeks of your visit to repeat what was agreed and what will happen next.

“The family have had no further contact with the social care team for almost a year. Meanwhile, their son is at home with little to do. Their view is that ‘when things go wrong professionals should give enough time to get it all sorted out, and not let things drift on’.



- thank people for their time, and leave the family with your name, role and contact details, in writing.





- prepare the family if you are moving on or going away for a period of time. Let them know it's happening and who will take over your role with them.

“I don't know what our rights are as a person with a learning difficulty or a carer. Nobody tells us unless you go out and try to find out... Why don't we get sent all the information we need.”


2 - The Essential Don'ts


Don't


 - work on 'myths' or commonly held beliefs. For example, BME communities 'look after their own'; 'people in that community are wealthy and will not need support'; 'people in that community won't accept support', etc. Each family is unique and needs to be treated as such.

 - assume that siblings are always happy or able to carry on giving help and support. Check out what they feel happy and able to do.

“My parents are getting old. I’m having a baby soon and I won’t always be around to support my parents with my brother.”

 - try to visit on a festival day that's important to the family.

 - jump into talking about services. Talk about what the person needs and wants, and their aspirations.

 - ignore issues affecting the whole family, like the housing environment, financial concerns, health issues. These may be having a significant impact on the learning disabled person, and need to be addressed in order to progress plans for the individual.

Dilawar lives with his parents and brother. His mother is nearly 60 and his father is 71. A sister lives locally. Mr Hamid can read English, but Mrs Hamid (Dilawar's main carer) cannot. Her understanding and use of spoken English is very limited. They live in a rented house. Mrs Hamid has health issues and mobility problems and can't get upstairs. The stairs can't be adapted and a lift is reportedly not possible. She has been sleeping in the lounge on the floor.



- ask financial questions until you've built trust. It could be offensive.



- judge! We all have cultural beliefs and values, and things that are no-gos. Respect theirs, and don't show that you are shocked by any.



- assume that the family will want to link up with an other family from their community who have a relative with learning disabilities. They may see this as breaking family privacy.



- leave the family to make contact with a statutory service without first checking that they know how to do it, that there won't be language issues, that they know why you have suggested it.





- ignore gender issues. For example, is it okay for a young woman to stay at home but a young man be supported into work? A sensitive approach may be needed to address the issue, but don't ignore it.



- forget about gender issues for carers too. Don't assume that a mother doesn't go out to work, or that a father doesn't need support!



- accept gifts. Families may want to express their gratitude through a gift. Simply explain that it's your job and politely refuse.



- forget to leave a 'calling card' or write down your name, role and contact details before leaving.

“There should be more ladies only services. More families would use them if they were ladies only, with female staff”.

“After leaving school my daughter was at home for many months. I was very lucky that my husband had just retired and was at home to take care of her. If he wasn't home I would have had to leave my job”.

3 - Things to Check Out

? Check out

- ? - how members of the family want you to address them e.g. Mr / Mrs or first name – but always start off with a formal form of address.
- ? - what the family understand about the process for accessing social care support. Explain things clearly and then check what they have understood so that you can clarify any misunderstandings. Make sure they know what *they* need to do.
- ? - that the family aren't expecting referral to a service to be automatic because they receive some other kind of support, such as benefits.

“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 doesn't materialise”.

'Reaching out' report



- ? - how the family view 'learning disability'. Some cultural norms may need to be challenged - especially a non recognition of Learning Disability or an association with punishment of some sort. Safeguarding may be a consideration.
- ? - some examples of excellence, where support has been culturally appropriate and has helped open up community opportunities for a person. Use the examples with families to stimulate their thinking.
- ? - opportunities for you to continue developing your cultural competence and good practice. Don't wait for things to be offered – do your research, and then ask. It's in everyone's interest.

Further reading

If the guidance stimulates you to explore the issues and develop your practice further you may like to have a look at:

Developing Cultural Competence in Social and Health Care by Rob Harrison, Rachel Harvey and Siobhan Maclean
Kirwin McClean Associates Ltd
www.kirwinmaclean.com

Services for All: A guidance manual for providing culturally competent services for people with learning disabilities.
www.arcuk.org.uk/publications/servicesforall

The BME Resource Guide (Version3) April 2012.
HFT
www.hft.org.uk/Supporting-people/family-carers/Resources/BME-Resource-Guide

Learning Disabilities and Ethnicity: Updating A Framework for Action
FPLD/DH 2012
www.learningdisabilities.org.uk/publications/180085

The Foundation for People with Learning Disabilities

We work to break down the economic and social barriers and prejudice that people with learning disabilities face throughout their lives.

We promote the rights, quality of life and opportunities of people with learning disabilities and their families. We do this by working with people with learning disabilities, their families and those who support them to:

- do research and develop projects that promote social inclusion and citizenship
- support local communities and services to include people with learning disabilities
- make practical improvements in services for people with learning disabilities
- spread knowledge and information.

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