

Reaching Out

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



Guidance for Families of People with Learning Disabilities and Practitioners in Developing Culturally Competent Planning

Christine Burke with Angela Cole

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 (BME) 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 the 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 are 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.

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.

The main report from the project Reaching out to families, as well as ‘Guidance for Practitioners in Developing Culturally Competent Practice’ are available at: www.learningdisabilities.org.uk/publications.



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

The Reaching out to families project found a consistent message from families from Black and Minority Ethnic Communities that it is crucial to understand the needs and aspirations of people with learning disabilities from these communities.

“It is important to know their cultural practices, how they behave and live their lives in different ways if we are to be effective in developing a bespoke and personalised approach”.

A properly personalised approach to individuals’ needs should in theory be good news to families from different BME communities for whom the standard ‘off the shelf’ package is especially inadequate.

An important part of developing local responses is being very clear about what ‘culturally appropriate’ really means. This means really good information about needs and aspirations of individuals and families. (‘Reaching out’, 2012).

Families from BME communities gave a consistent message that too many staff from statutory agencies:

- are reactive rather than planning ahead with the family
- often ignore cultural information that may be important in support
- do not follow up the action they have agreed and effectively lack professional ownership
- do not ensure that families have the right information to pursue matters themselves, effectively keeping people disempowered.

This guide is written in response to the Reaching out to families project's conclusion that practitioners need to demonstrate more cultural competence in planning.

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. And a range of skills, including:
 - culturally competent communication
 - culturally competent assessment
 - culturally sensitive care provision

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



This guide

This guide has been developed to give an opportunity for families of people with learning disabilities from different communities to make sure that information that is important to them in having a good life is included in planning. It also aims to help practitioners when they are planning support with people from diverse communities.

The guide contains ‘important’ questions to ask people with learning disabilities and their families that help to create a ‘rich’ picture of their identity, history, preferences and requirements in order to create a picture that is unique to them and is family centred. A good ‘facilitator’ or support planner will remember all these questions as they are important in making sure people have a good life. It offers practical ways to help gather information about people’s culture, spirituality and what matters to them and their community.

Some people may feel that this guidance is basic and we make no apology as getting the basics right is extremely important.

As in our ‘Reaching out – Guidance for Practitioners in Developing Culturally Competent Practice’ we recommend 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.**
- 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.**

“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 guide is to be used alongside other methods of planning. Its aim is not to replace your support planning/person centred planning, but to include information that may be useful in identifying all aspects of life that may be important to the person. We often miss important aspects of someone’s cultural identity and the identity of their family so we recommend that the areas addressed in this guide are used as part of planning.

Accessible guidance

To ensure that a person’s culture is incorporated into their personal plan, we have created an accessible workbook with all of the questions and exercises in this guidance for practitioners, families and people with learning disabilities to use. We hope that this guidance will start practitioners thinking about the importance of culture when planning and that the workbook can be used to take this forward into action.

The ‘My Cultural Life Plan’ workbook will be available in August 2012 on our website:
www.learningdisabilities.org.uk/rightsandequality/ethnicityandequality

The five principles to person centred planning

The following principles need to be at the forefront of planning with families:

- 1 The person is at the centre**
- 2 Family members and friends are partners in planning**
- 3 The plan shows what is important to the person – now and for the future. It shows their strengths and what support they need**
- 4 The plan helps the person to be part of the community and helps the community to welcome them**
- 5 The plan is ongoing – the plan puts into action the things the person wants to get out of life.**

The guide (alongside the accessible workbook ‘My Cultural Life Plan’) are designed to be interactive to allow families and practitioners, to be fully involved in the process. They are divided into eight sections that we feel should support a conversation around the cultural and spiritual aspects of a person’s life.



The sections:

1. Understanding my family and friends

In this section we ask that you lead a conversation on the history of the individual and family.

2. My culture

This section focuses on the concept of culture and how this can affect beliefs and behaviours. Respecting individuality and the role which culture plays in our feelings of identity and belonging.

3. Celebrating together

This section is designed to identify all those important dates that are important to the person and their family.

4. Language

The intention is to focus on the different aspects around language, from everyday speaking to needing interpreters.

5. Faith and spirituality

This section focuses on the difference spirituality and faith make in someone's life and the importance it plays in how people think about their life.

6. Food

The aim of this section is to find out any important religious/cultural choices around food as well as favourite foods, the significance of food in culture and community activities.

7. Community

The focus of this section is to understand the role community plays in developing a lifestyle and the barriers that may exist.

8. Support

This section focuses on the importance to us of good planning around support.

Getting started



Before getting started you may want to consider who the best person to support the individual and their family through the guide is. You may want to consider finding a facilitator that speaks the same language as the family if required. If you do, you will need to stress confidentiality to both the facilitator and the family.

It is important to stress that this guide should not be used in isolation but as part of a plan. (For further information on person centred planning go to Resources section at the back of this booklet).

1. Understanding my family and friends

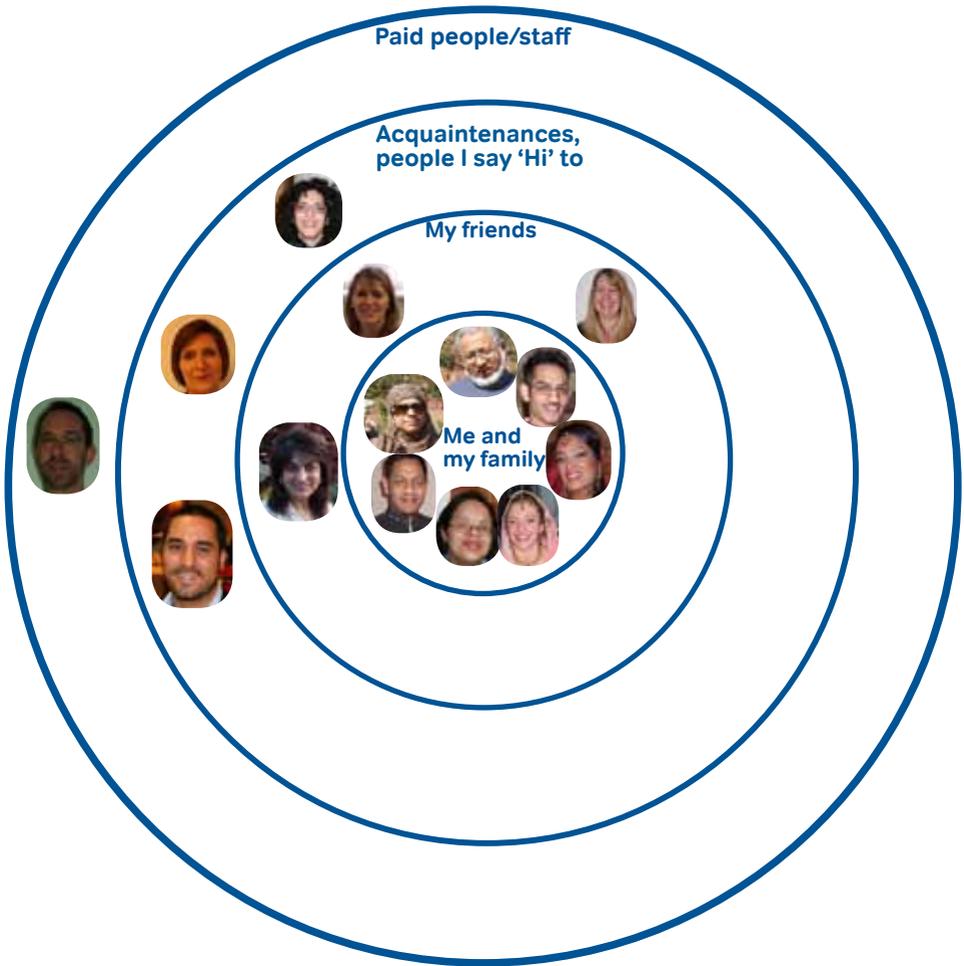
We believe it is important to build a portfolio of the person who has a learning disability around who is important in their life.

Building a portfolio has many benefits. This requires the use of pictures and items of importance to the individual that describe who they are or what is important to them. It will help you to ask questions about the families history in a natural way and through pictures find out about cultural information. The portfolio is also a way of building memories that can give an individual a way of communicating to others who they are.

This is easiest done with the whole family rather than the person alone. Ask the family to gather pictures of their family and friends. Explain that you want to help them write their story so that together you can work out the things that are important to them and their family.

Remember the important thing here is to create a meaningful conversation around what matters to the person and the family. It should not be forced but used as a way to find the best way to support the individual and the family. This exercise sets the scene to think about who are the important people in the person's life? We suggest two ways to gather this information:

1.1 Draw a relationship map



A relationship map can be used to show who is in the person's life. Those closest to the person (such as family and friends) go in the inner circle whereas those who may be acquaintances or people they work with go in the outer circles. (See 'My Cultural Life Plan' workbook for a relationship map template).

1.2 Who I am

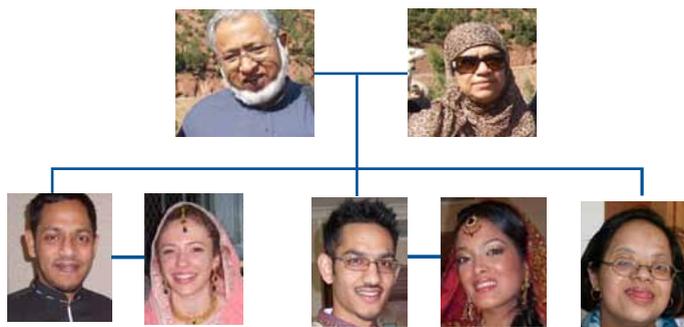
We recommend doing this by preparing a life line or family line. You can do this as shown in the BBC programme 'Who do you think you are?' or use a photo album and help the person to include pictures of their family (see examples below).

This opens the conversation of cultural background and the things that are important to the person and to the family. You will get clues from this as to any cultural issues and country of origin of the family. You can use this opportunity to explore the place of birth or country of origin and ask if they know a lot of people from their country of origin who are living in England, if they see them and where.



My Photo Album

If the country of origin is England for example, ask if they are the third generation living here, or if they are from traveling families – which part of UK/world do they originate from? If from the UK then explore the same questions. People's culture varies as to which part of the country they come from and the values of their family.



Example of a Family Tree

2. My Culture

It is important to consider what is important to the person and their family in terms of their culture. Use the pictures and information gathered from the previous section to have a conversation about culture.



Questions to consider:

- how would the person describe their culture?
- what are the important things in their culture? (What makes it different, what do they do and value?).
- what does the family think are the important things in their culture? (These could be beliefs, cultural identity, faith, etc.)
- is it important to the person to have a plan for support with all the things to do with their culture?
- is it important to the family that the person follows certain traditions to do with their culture?

3. Celebrating together

Celebrating together or celebrations are important in building community life, friendships and having a sense of belonging. A celebration is an occasion that is special like birthdays, religious events (Christmas, Passover, Diwali, Eid), community activities, weddings etc. These occasions make people feel that they are part of a group and that they have something important in common with others.

Questions to consider:

- what events does the person and their family celebrate?
- what are the important events to the person?
- what are the important events to their family?
- what do these events mean and why are they special?
- what does the person do at these events, do they have to dress differently?
- does the person have to prepare for these events? For example, not eat during the day.
- what does the person do before during and after these celebrations?
- does the family have a special way of dressing in special occasions? Is there any acceptable and unacceptable ways of dressing or behaving in their culture?
- are there events that the person would feel that they are not welcome at? (Are there events that would exclude disabled people?)

4. Language

There are many aspects to consider when thinking about language and communication e.g. everyday speaking, English as a first/second language/no English. The question as to what is the persons preferred language (e.g. 'do you speak English?') needs to be asked at the very start of your conversation along with the offer to have an interpreter, family member or other, or as to whether you are the best person to be supporting the family with this plan.

Similarly it is important at the onset to consider people that may not use words and designing a communication chart if needed. (See Resources).



Questions to consider:

- what languages does the person speak, if any?
- does the family speak any other languages?
- is it important to the person to speak these languages?
- is it important to the family to speak these languages?
- what language do they speak at home?
- is it important to the person to know and speak this language?
How can you help with this?
- does the person need to know important words in other languages to help with participating in cultural activities?

5. Faith and spirituality

People with learning disabilities have described spirituality as 'a friendship with someone who makes them feel wanted and accepted and gives them a purpose for their lives. Some people like beautiful pictures or music or being in the countryside. For some people God is important. Each person will have their own ideas about what is important to them.' (Faith in Practice – Foundation for People with Learning Disabilities – see Resources).

Questions to consider:



- does the person or the family belong to a faith group?
- is believing in religion important to the person?



- what does this mean? Do they go to Church/mosque/chapel/synagogue etc.
- what do they do when they are there?
- what do they enjoy doing when they are there?



- what is important for the person to remember when going to religious places? (For example, celebrations, rituals that they might do).
- how does the person or the family like to dress when they go to their faith group, or to special occasions?



- does the person have special times when they go to church/mosque/chapel etc?



- what are the things the person does day to day that relates to their culture and beliefs? For example, praying at specific times in a day, Friday night prayer.

- is it important to them to pray?

- is it important to the family to pray?

- are there special times for the person to pray?

- do they need anything in order to pray?

**“Anthony goes to church every Sunday and follows the whole service and all the church celebrations. He has deep faith.”
- A parent.**

6. Food

Food plays an important part in our life not only in terms of diet or choice of food but in terms of the significance it has in our culture. For many, food plays an important part in celebration, friendship and community. (If the person/family indicates that some foods are important to them, it may be helpful to get pictures and recipes from the family).

Questions to consider:

- what type of food does the family like?
- what type of food do they cook on special occasions and what are they?
- is there any food its important to the person not to eat for religious reasons?
- is there any food its important to the family not to eat for religious reasons?
- is there any food the person dislikes?
- does the person cook or want to learn to cook?



7. Community

Understanding the communities that the person has interactions with is important. Building community is crucial in supporting people to build inclusive lifestyles. Working out the best way to include people requires thought and understanding in order to develop a sense of belonging and feeling welcome. It is the difference from just participating to being accepted, belonging and having the opportunity to make friendships and relationships.



Questions to consider:

- what does the person's faith or local community think about disability?
- does this stop them in taking part in special activities and cultural events?
- are there community events and activities that the person and their family like to participate in?
- what are they?
- what do they do there?
- are there particular places the person goes to with members of their community (e.g. groups, clubs, faith establishments etc.)

8. Support

Planning support that is culturally sensitive is important and needs careful consideration. We recommend you include the questions below in your support planning.

Questions to consider:

- what does good support look like for the person?
- what are the desired characteristics of people who will support the person? (For example, same sex, particular faith group, language).
- are there any no go activities? (For example, pubs/alcohol, mixed groups).
- is it important to the person for their supporter to speak the same languages as them and their family?
- is it important to the person for the supporter who accompanies them to cultural or faith activities to be of the same culture?



- is it important for the person for their supporter to be the same gender as them?
- what is important to the person for their personal care? (For example: washing, dressing, going to the toilet).
- what is important to the family in relation to the persons personal care?
- are there things that must/must not happen with the persons personal care? (For example: do they have to use specific products for their hair. Is there something they would need when they wash or comb hair? etc).



Questions to ask siblings and grandparents

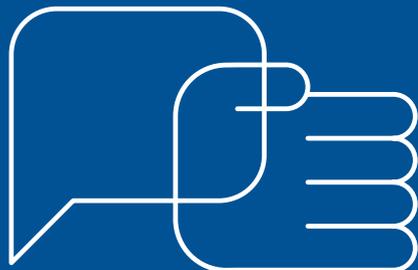
What are the important things to consider when supporting your relative?

- to be part of his/her community
- to take part in religious activities
- family events
- spiritual or cultural events
- what are they, what do they mean, what do you have to do during these events?
- any other information that is important to you?

Conclusion

There are many questions that could have been added to this guide. Our intention was not to develop an exhaustive list of questions but to create the beginnings of conversations with individuals and families in determining what is important to them in the way they want to live their lives.

We hope you find this guide useful and that it helps with developing more culturally sensitive planning. We would be happy to discuss any aspect of this guide and offer support.



Resources

1. The following links are useful on information around person centred planning.

- **Person Centred Planning - Inclusive Solutions**
www.inclusive-solutions.com/pcplanning
- **Person Centred Planning - Families Leading Planning**
www.familiesleadingplanning.co.uk
- **Personalisation through Person-Centred Planning**
www.familycarers.org.uk/
- **Helen Sanderson Associates**
www.helensandersonassociates.co.uk/

2. The following publications provide useful information around communication and skills of facilitation.

- **An Ordinary Life and Booklet 'All about me**
Page 42 - Communication chart
<http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/>
- **Building Community Through Circles Of Friends**
This book outlines practical steps to developing circles of support and the skills of facilitation.
<http://www.learningdisabilities.org.uk/publications/building-community/>
- **Person-Centred Approaches and Older Families**
This report is intended for people who are already informed about person-centred planning approaches and want to make sure they are planning with older families in the best possible way.
<http://www.learningdisabilities.org.uk/publications/person-centred-approaches/>

3. The following resources have useful information on spirituality and faith.

- **Faith In Practice (DVD)**

This film shows how people with learning disabilities contribute to their faith communities. It indicates the ways in which they might need support and what faith communities can do to be more inclusive.
<http://www.learningdisabilities.org.uk/publications/faith-in-practice/>

- **What About Faith?**

This guide is designed to help services meet the religious needs of people with learning disabilities
<http://www.learningdisabilities.org.uk/publications/what-about-faith-briefing/>.

4. The following resources have useful information around culture and working with people from BME communities.

- **Services for All: A guidance manual for providing culturally competent services for people with learning disabilities.**

www.arcuk.org.uk/publications/servicesforall

- **Learning Disabilities and Ethnicity: Updating A Framework for Action**

FPLD/DH 2012

www.learningdisabilities.org.uk/publications/180085

- **Developing Cultural Competence in Social and Health Care** by

Rob Harrison, Rachel Harvey and Siobhan Maclean

Kirwin McClean Associates Ltd

www.kirwinmaclean.com

- **The BME Resource Guide (Version3) April 2012.**

HFT

www.hft.org.uk/Supporting-people/family-carers/Resources/BME-Resource-Guide

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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