

Ethnicity Training Network

Training Pack



Learning Difficulties and Ethnicity

CONTENTS

Background - About this training pack

Aims of the pack
Who the pack is for
How to use the pack

Activity 1: Finding out about some commonly used terms
Activity 2: What I want from this training
Information: Why this training pack is needed (See Power Point A)
Activity 3: Attitudes to learning difficulties and minority ethnic communities

Section One - The needs, rights and cultural context of service users

Activity 4: What is culture?
Activity 5: What are some of our worries about cultural diversity?
Activity 6: Why do we need to understand different cultures?
Information: Cultural Competence (See Power Point B)
Activity 7: Practical ways to raise cultural awareness within your work/ your service

Section Two - Engagement

Activity 8: Why develop partnerships?
Activity 9: Some barriers and concerns about partnerships
Activity 10: Practical ways to engage with people from minority ethnic communities with learning difficulties
Information: Why develop partnerships (See Power Point C)
Information: Partnership working (See Power Point D)

Section Three – Planning and Action

Activity 11: Introduction to planning and action
Activity 12: What do you know?
Activity 13: Barriers to people with learning difficulties from minority ethnic communities using services
Activity 14: Practical tips for making services more accessible and increasing uptake
Activity 15: Person-centred planning
Information: Making services accessible (See Power Point E)
Information: Helping people access services (Power Point F)
Information: What you need to know to plan services (Power Point G)
Information: Person-centred planning and advocacy (Power Point H)

Ethnicity Training Network

Training Pack



Section Four – Reviewing services

- Activity 16: How well are we doing?
Activity 17: Reviewing the cultural competence of services
Activity 18: Six areas of assessment for community engagement
Information: Reviewing services (Power Point I)

Handouts

1. Glossary of terms
2. What I want from this training
3. Attitudes to people from minority ethnic communities with learning difficulties and their families
4. Some worries about cultural diversity
5. Barriers and concerns about partnerships
6. Who can help you review your current work and help you plan your service?
7. What do you know?
8. Barriers to people using services
9. Case studies: Making services more accessible and increasing uptake
- 10: Six areas of assessment for community engagement
11. Organisational Cultural Competence Self Assessment Tool
12. Some useful websites

The pack is divided into four sections which cover the following areas:

Section One - Introduction

- Raising awareness of the needs, rights and cultural context of service users

Section Two - Engagement

- Engaging with minority ethnic communities
- Developing local partnerships
- Improving information and policies
- Employing people from minority ethnic communities to represent the populations served

Section Three - Planning and action

- Making services appropriate and accessible to people from minority ethnic groups with learning difficulties

Section Four - Reviewing services

- Measuring service user satisfaction and service outcomes
- Assessing and monitoring competence throughout the service

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This training pack has been produced by the Ethnicity Training Network for members of the Regional Ethnicity and Learning Disability Networks. The nine Regional Networks are made up of professionals, people with learning difficulties and family carers. The role of the Networks is to support and promote the development of services in their area for people from BME communities with learning difficulties.

Aims of the pack:

To promote awareness of:

- The needs and rights of service users with learning difficulties from minority ethnic communities
- How to engage with minority ethnic communities
- How to plan, monitor or review services in ways that effectively support people from minority ethnic groups with learning difficulties

Who the pack is for:

The induction training pack is for all members of the Ethnicity and Learning Disability Networks. Because needs of different group members will vary, the resource offers a pick-and-mix approach – some basic information provided for everyone, with additional more in-depth information for people to access if they wish.

You can use this resource in a number of ways:

You can read the information in each section to learn about some important issues relating to minority ethnic communities and learning difficulties. This will help develop your knowledge about the issues and help you in the way you work

You can look at the group activities and power point presentations linked to each section and, on your own, think about some of the questions and ideas raised and what your responses are

You can take part in some training sessions, either as facilitator or participant, using the group activities and power point presentations linked to each section, to share ideas and learn more about best practice

This training pack has been produced to link with two existing resources about ethnicity and learning disability, both available from the Valuing People Support Team website www.valuingpeople.gov.uk. These are:

- Mir G, Nocon A, Ahmed W (2001) *Learning Difficulties and Ethnicity* Department of Health
- VPST/Department of Health (2004) *Learning Difficulties and Ethnicity: A Framework for Action* Department of Health

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BACKGROUND

This resource aims to help change the way that people think and work in health, social care, voluntary and other services:

- by promoting better understanding about the issues
- by improving skills

Local action for local improvement is the real key to change.

Why this induction training pack is needed

People with learning difficulties and their families from minority ethnic communities:

- are amongst the most disadvantaged groups in our society
- often have very high support needs
- have a higher incidence of disability in a number of areas

Yet services:

- are less likely to be offered or taken up
- often don't take account of people's ethnicity, culture or religion - so the services that are offered are not appropriate.

Public services:

- have a duty to promote race equality in their work
- the Race Relations (Amendment) Act 2000 requires this
- Partnership Boards should make sure that their frameworks and strategies take ethnicity fully into account

Partnership Boards:

- The membership of Boards should fully represent local communities and the cultural diversity of the area
- This would make the views and needs of people from minority ethnic communities and their families more likely to be addressed

Local agencies:

- Local agencies working with people with learning difficulties must find ways to reflect the cultural diversity of the local community
- They must make sure that all services meet the needs of all the communities in their area.

Services for all:

- More person-centred, flexible services should mean a better deal for everyone - whatever a person's ethnicity or culture
- At the same time, the barriers to equal opportunities faced by people from minority ethnic communities clearly call for focused and determined action.

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The dangers are that:

- important religious and cultural issues are not properly taken into account by services. This can result in low use or unsuitable provision.
- differences may be exaggerated and people stereotyped. This can lead to wrong assumptions that deny people opportunities.

(Mir 2010; VPST/Department of Health 2004; Mir et al 2001)

Activity 1: Finding out about some commonly used terms

Activity 2: What I want from this training

Activity 3: Attitudes to learning difficulties and minority ethnic communities

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SECTION ONE

The needs, rights and cultural context of service users

Aim:

- To raise awareness of the needs, rights and cultural context of service users from minority ethnic and faith communities
- To help service providers make their service better for people from these groups.

Activity 4: What is culture?

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Some prompts about Cultural Diversity:

Cultural diversity encompasses: age, aspirations, class, country and nationality of origin, gender, intellectual ability, personality, physical ability, primary language, professional experience, race, religion, sexual orientation, socio-economic backgrounds, work styles, personal history, attitudes to family and child rearing, rites of passage, food, leisure activities.

We all make assumptions about people and their cultural identity. We do this by judging how people look, what they say and how they sound, and how they behave. We need to think about our biases and prejudices, question what they are based on, and be conscious of our personal reaction to people who we view as 'different' from us. For example, if someone is speaking with a certain pitch of voice and using certain gestures, we may assume the person is angry or agitated. We rarely stop to think that we might be misinterpreting their behaviour because of our own cultural norms in which this behaviour usually indicates anger or agitation. Cultural competence is about recognising, interpreting and correctly reacting to people who are from a different culture.

There are a number of ways of checking things out and things that may help us:

- ask people about their backgrounds, their views, how they feel rather than making the assumption that we know;
- try to become aware of our own cultural norms and see them as just that rather than the right or only way to approach things;
- develop our awareness of other cultures by learning more about them, becoming more familiar with cultural characteristics, values, expectations, beliefs and behaviours, and learning to understand and appreciate these;
- find good role models of people who have developed cultural competence and work alongside them to develop our own competence;
- share knowledge and ideas with colleagues and together become more culturally competent;
- attend training to improve our cultural competence and develop skills;
- include people with learning difficulties from minority ethnic communities and their carers in training and development of staff.

Bhugra D and Bahl V(1999); Fernando S (2003)

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Activity 5: What are some of our worries about cultural diversity?

Complete these phrases: (write these up on the flip chart)

I don't understand

I am worried about ...

I don't feel confident about

I don't want to

If I say the wrong thing, I might

Activity 6: Why do we need to understand different cultures?

Some prompts about understanding different cultures . . .

Understanding different cultures helps you:

- Know yourself
- Understand your own value system
- Break down stereotypes
- Learn to respect differences
- Adapt your behaviour
- Communicate better with others
- Increase the use of your service
- Improve the quality of care for people using services
- Develop more effective ways of working
- Comply with legislation
- Enhance competitiveness.

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Cultural Competence

- Diversity includes all the ways in which people differ – not just the more obvious ones of gender, ethnicity and disability.
- Developing cultural competence makes us able to understand, communicate with, and effectively interact with people across cultures.
- Cultural competence is more than understanding how to greet a person from a minority ethnic community or know dates of festivals of particular religions.
- It comes from knowing our own values and how they differ from the values of the other person, and then recognising the ways in which these are demonstrated in behaviour.

Cultural competence is about:

- how well an organisation provides care to people with diverse values, beliefs, and behaviours
- how well services are designed to meet social, cultural and language needs
- valuing individuals, families, and communities and protecting their dignity
- using knowledge about diversity to develop specific policies, practices and attitudes
- improving the quality of services and producing better outcomes for all.

We need to:

- Be aware of our own cultural worldview
- Build our knowledge of different cultural practices and views
- Have positive attitudes towards cultural differences
- Develop cross-cultural skills.

Developing cultural awareness means:

- Better understanding and awareness of people from different ethnic origins, religions, countries of birth
- Better knowledge of BME groups within the local community
- Improved relations with service users
- Better understanding of how to observe etiquette regarding religious and cultural practices of different groups
- Fewer misconceptions, better understanding of others
- Improved social and working relationships with others
- Feeling more confident to approach, integrate and work with people from all cultural groups



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- Better respect for the background, religion and culture of others
- Better understanding of what culture, nationality and religion are and what behaviours they influence
- Better understanding of how much we all have in common
- Remember, ethnic identity could differ in groups perceived as being from the same community. For example, the South Asian community is made up of many different ethnic groups, the main ones being Indian, Pakistani, Bangladeshi and other Asian groups. South Asian culture is very diverse, encompassing hundreds of languages and dialects, many religions, beliefs, people of different classes, histories and countries.

Ethnicity:

- Ethnicity is about how people see themselves on the basis of common descent
- It also includes how other people perceive them
- People from the same ethnic background may be different from each other on the basis of various factors, e.g. religion, gender, social class

Activity 7: Practical ways to raise cultural awareness within your work/ your service

Some triggers for the discussion:

- Represent people from minority ethnic communities in local publicity and around the organisation (eg pictures and stories in leaflets advertising the service)
- Develop a list of contacts who you can consult about service development eg voluntary sector groups, diversity officers, specialist posts in the local authority or PCTs, religious organisations, groups affiliated to your organisation
- Get more information or training around specific issues or about particular communities
- Train staff members about cultural competence at induction and to support the work you want to do
- Develop a resource pack of local information for staff that will help them understand and achieve cultural competence (eg local minority ethnic contacts, research publications).

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Case Study: Bradford District Care Trust

The aim of Bradford District Care Trust is to embed the principles of promoting and valuing equality and diversity at the core of the organisation. Its mission and values were developed by staff, users, carers and other stakeholders and it explicitly states that equality and diversity is fundamental to the organisation and all that it does.

They appointed a community partnerships and inclusion manager who:

- ensures that all new community developments take into account the needs of people with learning disabilities ensuring fair access and progress
- monitors how well services meet the needs of people with learning disabilities from minority ethnic communities by asking managers to complete an annual questionnaire about how they provide a culturally competent service
- managers are then interviewed and helped to develop action plans that will improve their cultural competence.

From: Learning Difficulties and Ethnicity: A Framework for Action Appendix 3: Reading, resources and examples p 17

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SECTION TWO

Engagement

Aim:

- To help organisations make links with local minority ethnic communities
- To help organisations develop local partnerships
- To increase involvement in decision-making.

Activity 8: Why develop partnerships?

Why develop partnerships?

Aims of partnership working:

- Services need to build up good links with people from minority ethnic communities to prevent people being excluded from services

Partnerships aim to improve service provision through:

- a greater awareness of user views
- more responsiveness to need
- better co-ordination of services
- more accountability to people from minority ethnic groups through better formal links.

Needs analysis and targeted services for minority ethnic communities :

- Services need to develop an evidence base that helps them understand which communities require targeted action
- For partnerships to happen, statutory services need to have links with minority ethnic communities
- In reality, many places have poor links:
 - For example, local authorities often do not consult with minority ethnic community groups over needs and services
 - This is despite the knowledge that available services are not being used all or any minority ethnic groups

Lack of consultation means:

- Services remain inappropriate and inflexible
- Service staff do not develop a sensitivity to the circumstances of minority ethnic groups

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- Staff do not understand the support needs which minority ethnic groups identify
- Users feel under-valued.

Benefits for service users and carers:

Being involved in a Partnership Forum can:

- Provide valuable learning experiences for people with learning difficulties and their carers
- Help individuals and groups of service users to develop independence and leadership

Using established user groups to reach people:

- A range of active groups exist in some areas
- They may be easy to access, and actively involved in lobbying for involvement in consultation and partnership working
- In other areas they may be a dearth of minority ethnic groups focusing on disability or learning disability and need support to be established
- Or existing groups may be inactive.

(Mir et al 2001))

Activity 9: Some barriers and concerns about partnerships

Activity 10: Practical ways to engage with people from minority ethnic communities with learning difficulties

Some triggers for who should be involved:

- Service users, their families and carers
- Service providers
- Diverse groups within a geographical area
- Different areas of service provision – eg. health, education, leisure
- Voluntary and statutory services
- Local and national agencies

Partnership Working

Process required:

- All relevant stakeholders are identified
- Data is obtained about the needs of a population
- Plans for services reflect those needs
- Investment is linked to needs analysis.



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Who should be involved?

Partnership working should involve joint work on policy and practice issues between:

- Service users and service providers
- Diverse groups within geographical areas
- Different areas of service provision – eg. health, education, leisure
- Voluntary and statutory services
- Local and national agencies

Measuring satisfaction/ getting feedback

- Quality control procedures are often carried out without the involvement of minority ethnic groups
- Feedback is rarely available through complaints procedures
- Complaints procedures are often doubly inaccessible, both to people with learning difficulties and to people from minority ethnic communities.

Local groups of people with learning difficulties from ethnic minority communities are generally:

- small-scale
- under-funded
- have little political power
- have few resources
- may be overshadowed by organisations which have a history of political involvement, better resources and perhaps national connections.

How to make good links:

- Build partnerships with community based groups
- Invest in advocacy and carers groups
- Use "outreach" including using community workers from appropriate minority ethnic groups
- Support community based voluntary organisations

What can help?

- Community workers from social services, health or voluntary organisations can help set up meetings
- Family carers can be involved through focus groups or one-to-one interviews with community workers
- You could set up more joint working between larger, well-resourced organisations which focus on disabled people generally and those which serve the needs of disabled people from minority ethnic communities.

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Mainstream services:

- Can get help from services that are specifically supporting people from minority ethnic communities
- Can learn from the experiences of specialist services in the area

Specialist community-based services:

- Can provide consultancy services to other organisations
- Make sure they are not isolated from other services
- Ensure they have access to training and support
- Working with mainstream services helps avoid them feeling marginalized and insecure.

To help increase involvement in Partnership Boards

- Have open meetings within community settings to talk about what Boards do and share experiences about learning disability services
- Such meetings need to involve as many groups as possible
- Allow time for people to be ready to take an active part and even more time for them to become involved in Boards
 - Some people may not be used to going to meetings
 - Language will be an issue for some
 - Gender issues will need to be taken into account
- All members should make sure issues of race equality are dealt with appropriately
- Make meetings as accessible as possible, for example:
 - varying the venue
 - allowing child friendly hours
 - providing notes and minutes that are accessible to all.

(Mir et al (2001) pp13-20)

Making services accessible

- People from minority ethnic communities should be able to expect access to a choice of services and supports
- The services that meet their needs should be securely funded.
- Many people from minority ethnic communities may not know about, may be suspicious of, misinformed or be unhappy with services
- Knowledge and use of specialist services appears to be low, with the exception of day care in some communities
- Active steps are needed to build trust with people with learning difficulties, family carers and communities.

Low take up of services may be due to:

- Lack of information and awareness of services
- Lack of staff who can speak the same language



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- The cultural inappropriateness of existing services in terms of diet, activities and staff provision
- People not understanding administrative procedures or how to access
- Racial discrimination within services.

People often experience:

- Poor standards of communication
- Delays in diagnosis and treatment
- Isolation, lack of support and high levels of stress among carers
- High levels of unmet need
- Lower levels of access to benefits and/or receipt of lower amounts of benefits

People may not know:

- What services are available eg. for housing, short-term breaks, social security benefits, laundry schemes and other services
- When and how to approach services
- Who to go to for help with what
- The roles of different services, such as the Community Learning Disabilities Team
- Their right to apply for personal care, community nursing or financial benefits until many years after their son or daughter has been diagnosed
- How to access benefits - they may receive benefits at a lower level than White families whose children have comparable disabilities
- Even when they are seen as eligible for benefits or services, they face a long delay before they receive these.

Religious and cultural values:

Services need to pay attention to cultural practices and religious beliefs to achieve quality in service provision:

- Beliefs and values are integral to people's self-concept
- They will affect their willingness to take up any services on offer
- Beware stereotyped assumptions that fail to acknowledge individual choice.
- Religious beliefs play a part in helping parents accept learning difficulties
- Faith may provide the strength, emotional support and resources to help parents manage their caring role
- Services need to respect views about the cause or future prognosis of disabilities which are not based on a Western medical model.

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Helping people access services

Funded organisations should be required to:

- Inform all communities about their services
- Monitor the ethnic origin of users and workers and make this representative of the local population.

Employing people from minority ethnic communities

- Lack of minority ethnic staff in services sends negative messages to staff and service users alike
- Recruitment of minority ethnic staff is needed at all levels within services, with adequate support and training to help them perform their roles.
- Use appropriate publicity to attract workers to health and social care work and to ensure their proportional representation.

Training:

- Provide opportunities and training for minority ethnic staff to gain qualifications and move into more senior positions
- Training for all staff is needed to improve competence in cultural awareness and prevent the marginalisation of minority needs
- Establish minority ethnic workers' support groups to ensure staff from minority communities:
 - are not used inappropriately as 'experts' on all issues
 - Are not seen as trouble makers when they act as advocates for the person with learning difficulties.

Providing a gateway to services:

Key workers:

- Provide information to improve service take-up
- Offer a single point of contact with services and access to appropriate language provision
- This is more effective than having to approach a range of different services and staff.

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Outreach:

- Important for communities where language may be a barrier to access
- Find creative ways of outreach, such as:
 - Use of pictures, photos, tapes, slides and videos
 - BSL, Deaf-Blind Communication and Plain English can help communication
 - Drama and role-play techniques can facilitate discussion.

Local service reputation and word-of-mouth recommendations:

- Support groups for minority ethnic carers and people with learning difficulties can help people support each other and raise awareness
- Groups can act as a gateway to a range of services, with staff addressing a range of information needs
- Being involved with one group can lead to people with learning difficulties and their carers gaining access to a network of other services and opportunities.

A number of services such as GPs, community-based organisations, support groups and statutory services can be used to identify minority ethnic families caring for someone with learning difficulties. Monitoring service take-up and minority ethnic staff numbers at different levels within the service can increase awareness and potentially lead to targeted action on the part of service planners.

(Mir et al 2001 p45)

Raising awareness about services:

- Use community media and events to raise awareness
- Organise groups for specific communities in their languages to explain about learning difficulties, the services available and their entitlements.
- Provide information in appropriate formats and community languages
- Train staff about learning difficulties and culturally appropriate services
- Share experiences through a BME disability organisations network.

Difficulties may include:

- Many languages do not have a word for learning difficulties
- Understanding about learning difficulties may be different
- In some communities, learning difficulties are stigmatized – information and support can help reduce this
- Prevalence rates for learning disability are not known for all minority ethnic groups and ethnicity may not be monitored by services.
- How people understand cause affects their views about interventions and support

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- Socio-economic factors and family composition may lead to higher prevalence
- Professional attitudes about various communities may have a negative impact
- Lack of culturally appropriate services may be a barrier to access.

Remember!

- Don't assume a service is appropriate for all
- Engage your local community
- There is no single right way!

Activity 9: Barriers and concerns about partnerships

Some strategies for addressing problems with partnerships:

Local services could:

- Make sure information is available about the services available, how to access services, and who to contact and how about service needs. Ensure that all information is accessible to minority ethnic communities in terms of language, format and where it is made available
- If there are no existing local user groups, offer support to enable people with learning difficulties from minority ethnic communities and their families and carers to set up a group
- Allow enough time for trust to be built up between services and communities
- Plan a meeting or community event, with user input, for people with learning difficulties from minority ethnic communities and their families and carers to have a say about what they need or want from services, and to get involved in partnerships
- Think about the venue, timing, availability of transport and other aspects of the meeting/ event and ensure they are acceptable and convenient
- Offer support to enable people to get involved in service planning or partnerships
- Make sure that staff have received cultural awareness training and have the confidence and skills to work with people from minority ethnic communities
- Ensure that workers are available with knowledge of the language and culture of relevant minority ethnic groups; if possible, recruit staff with that knowledge and experience as workers within the service
- Liaise with community organisations or local community development workers who have already made links with these groups
- Employ an outreach worker whose responsibility is to make links with people with learning difficulties from minority ethnic communities.



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People with learning difficulties from minority ethnic communities could:

- Get involved with services and make sure their voices are heard
- Prepare what it is they want to communicate to services before attending a meeting/ event to discuss these
- Take advantage of any opportunities available to be involved in partnerships
- Seek out support from advocacy groups or services that speak up for people with learning disabilities
- Communicate any barriers which they experience so that services can do something about it.
- Seek out support from advocacy groups or services that speak up for people with learning disabilities.

Activity 10: Who can help you review your current work and help you plan your service?

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SECTION THREE

Planning and Action

Aim:

- To make services appropriate and accessible to people from minority ethnic groups with learning difficulties

This section is for individuals/ organisations that want to make their services more accessible and appropriate for people from minority ethnic communities with learning difficulties, and their families. This will involve working with people from these communities and planning changes in the way services are delivered with them.

Activity 11: Introduction to planning and action

1. Start by doing a brief presentation about what you need to know in order to make services appropriate and accessible to people from minority ethnic communities with learning difficulties

What you need to know to plan services

When planning and delivering effective services what do we need to know?

- How many people with learning difficulties from different ethnic and religious groups you can expect to be in your area
- How many you know about
- How many people from different ethnic and religious groups are using different local services
- How well you are doing in some key areas of services and supports for people from minority ethnic groups (see section on reviewing services)

You can use Census figures to:

- Work out how many people from minority ethnic communities live in your area (use the Census tool at the end of this pack).
- Then use guesstimates to work out how many may have learning difficulties (based on known prevalence rates from the general population or from evidence about specific minority ethnic communities)

Things to consider:

- How aware are minority ethnic families about the services available?
- How aware are service providers about their needs?
- How much information about the needs of people with learning difficulties is gathered by service providers?
- How accessible is this information to service planners?
- How well is this information used to plan effective services?

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- What differences exist between and within minority ethnic communities in relation to needs?
- Is your service accessed by all members of the community?
- Does your organisation have specific diversity goals?
- Who is going to achieve them and when?
- What is your strategy to reach these goals?

Remember that people from minority ethnic communities with learning difficulties:

- Have high levels of unmet needs and disadvantage
- Receive inappropriate services
- Suffer from poor communication by services
- Experience discriminatory practices and attitudes

Some solutions:

- Adapt services to meet needs
- Provide support to access services
- Increase involvement in decision- making
- Aim for a culture change in attitudes

Activity 12: What do you know?

Activity 13: Barriers to people with learning difficulties from minority ethnic communities using services

Activity 14: Practical tips for making services more accessible and increasing uptake

Some triggers for discussion

- Support groups for people with learning difficulties from minority ethnic communities and their carers
- Information and signs translated into languages that are relevant to the communities in your area
- Language support to people if they need it to use services or get involved in partnerships with the organisation. Offer this without being asked.
- Distribute information about the service to venues used by minority ethnic communities in your area

Review:

- Current ways of working in all parts of your service to make sure they are more inclusive of people from ethnic minorities
- How resources are currently used to ensure they are fairly allocated to minority ethnic groups in the area
- Consider cultural competence in every new piece of work you begin.



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Activity 15: Person-centred planning and advocacy

Person-Centred Planning and Advocacy

- Person-centred planning is a process for continual listening and learning, focusing on what is important to someone, now and in the future, and acting on this in alliance with their family and friends.
- This should take into account a person's ethnicity, culture and religion
- It is an important way to help people get the services and supports that they need to live the life they want.
- It is really important to make sure people from all communities get this opportunity
- It is important to consider what is important to those that love and care for a person
- Schemes promoting advocacy and independent living skills may need to work with families as well as individuals with learning difficulties in recognition of family structures which are different to those in majority ethnic communities.
- For example, an understanding of independence that emphasizes individuality may be seen to clash with the values of collectivism and close family relationships held by some communities
- The idea of personal choice and control can work within a context of interdependence.

(Mir et al 2001 pp 25-28, 37, framework for action pp 30-32)

Independence:

- Many service providers may assume that a Western approach to independence will be shared and understood in the same way by people from all ethnic and faith groups.
- Independence is linked with a focus on individuality, which is taken for granted as the basis for achieving the best interests of a person with learning difficulties.
- This can alienate families which value their collective nature more highly than individualism and may conflict with a tradition of extended family living.

People from minority ethnic communities:

- Often view the family as an important source of identity and support and feel independence can be achieved within a family setting.
- Small steps towards doing things on their own, like coming to a social group for people with learning difficulties, is seen as independence. Leaving one's family and living on one's own is therefore not the only kind of 'independence' that has value.

People with learning difficulties from minority ethnic communities:

- Need information, choice and involvement in decision-making about their life. Barriers to independence can result in limited choices and low expectations.



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- Person-centred planning schemes can help access the things the person chooses:
 - leisure, art and education programmes
 - developing self-help, social and domestic skills
 - in some instances, help to identify and sustain opportunities for employment.

Key points:

- People and families need good advance information so that they can decide if it is right for them and their circumstances
- Families should be involved in the process
- Facilitators need to plan with the person and the family and negotiate a balance
- Identify what is important to the person and the family. Link these things into service development to bring about cultural change in the service. People can then see their plans coming to life.
- Time is needed to build relationships, trust and confidence, help you have a better understanding of the person's lifestyle and culture and help families be more involved
- Two trained facilitators are needed for planning:
 - one should be bi-lingual in the language spoken by the person and family
 - Don't use a facilitator with an interpreter who is not aware of PCP
- The facilitator needs to have a good understanding and awareness around religious and cultural issues so they are able to ask the right questions.

Advocacy:

- Advocacy is 'a way to defend the interest of a person, and to make sure their needs are met, especially someone who already feels disempowered.'
- Advocacy is an important concept for people from minority ethnic communities.
- Disabled people often have little power, are patronised or seen as threatening.
- It is one way people with learning difficulties can get more choice and control in their lives, and needs to be invested in
- People from minority ethnic communities are less likely to have access to advocacy than majority communities
- The benefits of advocacy must be explained carefully by those who understand a person's culture
- Advocates should have a good knowledge of the culture of the person they are working with and often will come from the same community

Types of advocacy:

- Self advocacy - speaking up for yourself
- Citizen advocacy - people who get to know someone with a learning disability so they can help get their wishes understood and heard

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- Short term, issue based or crisis advocacy - where people are (usually) paid to speak up for someone
- Models of advocacy need to be inclusive of a collective family structure
- People need a choice of where they can get advocacy support locally, and it should be independent from services provided.
- Self-advocacy may develop from person-centred planning
- It may highlight that the person has not previously been supported around making their life wishes known
- Self-advocacy is linked very closely with self-confidence. A person may have had their confidence damaged by both racism and discrimination against people with learning difficulties
- People may need much encouragement to recognise and value their own self worth
- A self-advocacy group specifically for people from minority ethnic groups can help build confidence.

(Mir et al 2001 pp20-24; Atkinson 1999)

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SECTION FOUR

Reviewing services

Aim:

- To identify ways to measure service user satisfaction and service outcomes as a way of measuring cultural competence throughout the service
- To enable people to test how good their service is and measure progress.

This can be used by people who want to establish baseline information about service users from minority ethnic communities as well as those who have worked to make their services accessible and want to know if there is anything else they need to do.

Monitoring and reviewing services is based on:

- Service user satisfaction
- Service outcomes across ethnic groups
- Cultural competence within the service

Activity 16: How well are we doing?

Some triggers:

- Keep records of outcomes achieved for service users by ethnic group and analyse these on a regular basis
- Do a survey of service user/carer satisfaction with the service, broken down by ethnic group.

Reviewing Services

Organisations providing services for people with learning difficulties:

- Should make sure that they aim for the best quality of service.
- Need to look at how good they are, and how they can get better.
- Should ensure that they have ways of making improvements.

User involvement, empowerment and participation in research:

- Service providers need accurate and ongoing information from and about minority ethnic communities to meet their needs adequately

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- Currently, monitoring procedures are unable to identify unmet need, general patterns of use or comparative service performance
- User feedback is an essential tool in performance management
- The criteria for monitoring performance should perhaps be set by those receiving the services
- It is not easy for people to make complaints, because the ways of complaining are not accessible.

Services don't know:

- Who is getting which service
- General patterns of use and experience
- The needs and wishes of people with learning difficulties from minority ethnic groups

Shaping and informing services:

- Don't just make assumptions on the basis of information from:
 - other family members
 - communities
 - service planners
 - providers with specialist knowledge

Meeting needs and providing quality services:

- Listening to service users is a continuing and essential process
- Their views will be part of a constantly changing picture
- This will reflect the different views of different generations with different cultural backgrounds

Partnership Board checklist

There are some simple questions that you can ask to check out how you are doing.

- Membership
 - of people with learning difficulties
 - of family carers
 - Professional membership
- Process

The Partnership Board:

- Discusses issues about ethnicity, culture or religion at Partnership Board meetings
- Has an ethnicity action group responsible for action
- Has information on people with learning difficulties across all ethnic communities
- Links with refugees and asylum seeker agencies
- Assesses spiritual and cultural needs.

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Service Checklist

This checklist can be used by services to see if they are:

- Accessible to people with learning difficulties from ethnic minority communities
- Good at meeting peoples' needs.

Services must consider:

- Spiritual and cultural needs assessment
- Language
- Person-centred planning
- Staff
- Same-sex personal care
- Food
- Community links
- Work with families
- Planning for diversity

Activity 17: Reviewing the cultural competence of services

Activity 18: Six areas of assessment for community engagement

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HANDOUT 1

Glossary of terms:

The following simple definitions describe how different terms are used within this resource:

Advocacy

This means having people speak up for you if you have problems expressing yourself.

BME

BME stands for Black and Minority Ethnic. It is a term the government uses to mean all people from minority ethnic communities.

Culture

The term culture has been used to mean a person's life experiences drawn from their family, their community, their disability, their sexuality, their gender and their personal history. Thus everybody has a culture that is unique to them.

Cultural competence

Cultural competence occurs when people understand culture, are aware of its impact and act to ensure that the values of all people are respected

Discrimination

Discrimination occurs when a person is treated differently from others because of their membership of a particular group, eg ethnicity, class, age, sexuality and disability.

Ethnicity/Minority ethnic community

A group of people who share certain background characteristics eg language, geographical origin, customs and history, which provide the group with a distinct identity as seen by themselves and others

Learning difficulty/learning disability

Learning difficulty and learning disability are both terms used to describe the difficulties that some people have in learning things that society expects them to learn at certain stages in their lives.

Racism

The term 'racism' is used to refer to the historical and institutional process which leads to people from minority ethnic backgrounds being treated less fairly because of their racial identity. This is attributed to those who have the power to turn prejudicial beliefs into acts of discrimination or unfair treatment at an individual or institutional level.

(Adapted from VPST/Department of Health 2004)

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HANDOUT 2

Activity 2: What I want from this training

In your group, look at each of these statements and decide if they are important to you. As a group, decide on 3 main goals.

- To make services better for people from minority ethnic communities with learning difficulties
- To find out about how to work with these communities and learn more about community structures
- To know more about recruiting people from minority ethnic and faith communities
- To make services more accessible and appropriate for people from minority ethnic and faith communities.
- To work with people from these communities and plan changes in the way services are delivered with them
- To look at developing partnerships
- To test how good services are now, measure progress and see if there is anything else that needs doing.

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HANDOUT 3

Activity 3: Attitudes to learning difficulties and minority ethnic communities

Look at each of the following statements and decide whether you agree or disagree.

1. People from minority ethnic communities often prefer not to use community organisations and to look after disabled relatives themselves.
2. People from minority ethnic communities rarely respond to attempts to consult by service providers.
3. Minority ethnic carers often adopt a passive role in relation to assessments of their relative with learning difficulties.
4. Many minority ethnic families are hostile towards advocates acting on behalf of their relative with learning difficulties.
5. Some minority ethnic families place barriers in the way of people with learning difficulties achieving independence.
6. A greater awareness of the needs of people from minority ethnic communities will lead to better services that meet their needs.

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HANDOUT 4

Activity 5: Some worries about cultural diversity

Something I Don't Know

There is something I don't know
That I am supposed to know.
I don't know what it is I don't know
And yet am supposed to know,
And I feel I look stupid
If I seem both not to know it
And not know what it is I don't know.
Therefore I pretend to know it.
This is nerve-wracking,
Since I don't know what I must pretend to know
Therefore I pretend to know everything.
I feel you know what I am supposed to know,
But you can't tell me what it is
Because you don't know that I don't know what it is.
You may know what I don't know, but not that I don't know it.
And I feel that I can't tell you, so you will have to tell me
Everything

Geraldine Brown



HANDOUT 5

Activity 9: Barriers and concerns about partnerships

People with learning difficulties from minority ethnic communities may think:

- They never ask us what we need or what we want
- I don't know how to tell them that the service isn't right for us
- I don't know who to tell/ who to ask
- Because I have learning difficulties, they think I am not capable of having my say
- Services put up too many barriers – they don't offer support to help us be involved
- I don't trust social services/ education services because they are intrusive and insensitive
- I am not confident that services would help my family in a crisis.

Local services may think:

- I don't have the time or resources to make links with these groups
- It's too difficult to communicate with these groups – there are language and communication problems
- I don't understand their culture – I may say something that makes things worse
- There are no existing local user groups to link with
- These groups don't come to meetings when invited
- It takes too long to build their trust
- Users may need a lot of support to get set up as a group, get involved in partnerships and in making decisions.

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HANDOUT 6

Activity 10: Who can help you review your current work and help you plan your service?

1. Bring in local external expertise: Local authority/ PCT diversity officers, liaison workers, community development workers, voluntary sector groups, religious groups. Community workers from social services, health or voluntary organisations can help make links and set up meetings.

2. Bring in regional and national expertise: Link to Regional Ethnicity and Learning Disability networks, the Ethnicity Training Network, the National Advisory Group on Learning Disability and Ethnicity and the ARC Ethnicity Network.

3. Invest in advocacy and carers groups. Set up a group of people with learning difficulties, family carers, groups representing their interests and professionals from minority ethnic communities. Family carers could be involved through focus groups or one-to-one interviews with community workers.

4. Appoint people from minority ethnic groups in your area as members of staff.

5. Support and build partnerships with community-based groups to develop links/ long-term relationships with people from minority ethnic communities in your area who can influence practice. Use "outreach" including the use of community workers from appropriate minority ethnic groups.

6. Make sure people from minority ethnic communities are included in decision-making at **all** levels of the service.

7. Set up more joint working between larger, well-resourced organisations which focus on disabled people generally and those which serve the needs of disabled people from minority ethnic communities.

8. Think about who will be responsible for making sure partnerships happen.

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HANDOUT 7

Activity 12: What do you know?

Can you answer the following questions?

1. How many people from black and minority ethnic communities are there in your local authority?
2. How many have a mild/moderate learning difficulty?
3. How many have a severe learning disability?
4. How many people in 2 or 3 above do you/your local authority services know about?
5. What do your answers to the above tell you about your information base?
6. What do your answers tell you about how inclusive race equality work currently is?
7. How can you use your existing skills to include people with learning difficulties and their carers in race equality work? Think about :
 - Communication
 - Involvement in decision-making processes
 - Working across service areas
8. What are your own support needs in relation to carrying out the above areas of work?

Based on the Audit Tool in *“Learning Difficulties and Ethnicity: A Framework for Action”*

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HANDOUT 8

Activity 13: Barriers to people using services¹

For each boxed topic below, different situations are described, ranging from the worst case to the best case scenario.

1. Spiritual and cultural needs:

- The service pays no attention to spiritual and cultural needs of users
- Where a person has a spiritual or cultural need already identified, the service tries to meet this individual need
- The spiritual and cultural needs of some groups of people are met
- The service individually assesses the spiritual and cultural needs of everyone in the service, and works to meet all these needs.

2. Language:

- Professionals in the service speak only English and:
 - All interpreting is done by family and friends
 - Interpreters not trained in disability issues are available if booked some time in advance
 - Interpreters trained in disability issues are available at short notice
- The staff team have a range of relevant language skills. Interpreters trained in disability issues are also available on demand.

3. Person-centred planning:

- No person-centred planning happens
- Person-centred planning is only conducted for English speakers
- Person-centred planning is conducted for all people in the service: spiritual and cultural needs are included if raised by the person or their family
- Person-centred planning is conducted for all people in the service: spiritual and cultural needs are asked about when developing all plans.

¹ VPST/Department of Health (2004) Appendix 2: Audit Tool pp. 42 - 45

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4. Staff:

- All staff in the service are White and exclusively English-speaking
 - recruitment practices are not considered
 - attempts are made to recruit staff from other communities relevant to people using the service but are unsuccessful
- Most staff in the service are White and exclusively English-speaking: specialist workers are recruited to work with people from specific communities
- The staff group broadly reflects the communities of the people using the service: recruitment practices attract staff from all relevant local communities.

5. Same sex personal care:

- Same-sex personal care is not offered to anyone
- Same-sex personal care is only offered when their families consider it essential
- Same-sex personal care is routinely offered to all people in particular communities

6. Food:

- The same food is offered to everyone: no consideration of religious or cultural issues for food or cooking methods
- Specific arrangements are made to meet the religious and cultural requirements of individuals who have demanded them. Cooking activities do not reflect local community diversity
- Individual dietary requirements, including cultural and religious requirements, are routinely assessed and met by the service, and appropriate cooking activities are designed for particular communities
- A range of food is routinely available to meet cultural and religious needs: everyone can choose from a range of foods that are not prohibited on religious or cultural grounds. All people take part in a diverse range of cooking activities.

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7. Community links:

The service:

- exists in isolation from local communities
- has developed links with a restricted range of local communities: everyone in the service only experiences activities in this restricted range of local communities
- has strong links with a range of local communities: people enjoy activities in the relevant community for them
- is fully a part of local communities: everyone in the service enjoys activities in the relevant community for them and samples experiences in the other local communities.

8. Working with families:

The service:

- exists in isolation from families
- has regular consultations with family members from a few communities
- consults with family members from all relevant communities on an individual basis
- fully involves family members from all relevant communities as members of circles of support for individuals and as consultants in strategic service development.

9. Planning and diversity:

The service:

- Only takes referrals when necessary: new people have to fit into existing service practices
- Takes referrals, and tries to adapt service practices to meet the needs of new people when they arrive
- Identifies in advance who will be referred to the service, and what their individual needs are to change service practices to meet these individual needs
- Is proactive in identifying people who may benefit from the service and ensures that the service changes to meet the needs both of new people and people already using the service.

(VPST/Department of Health 2004)

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HANDOUT 9

Activity 14: Practical tips for making services more accessible and increasing uptake

Case study 1: Learning Disability Partnership Board South Asian Sub Group²

Aim:

- To make services more accessible/acceptable to local Asian people
- To encourage Asian community organisations to be more inclusive of people with learning disability
- To build links with Asian service users, community organisations and religious groups.

What we did:

- Developed leaflets about our service, geared to Asian families (including one in Urdu)
- Arranged for staff to run stands at local Asian community events, and in Islamic awareness week – including information about services, and also about membership of and employment within The Trust
- Set up a consultation group, where Asian service users, carers and staff meet
- Organised training events for staff on issues relating to working with Asian families
- Held a consultation event with local imams
- Provided representation on a new group set up within the local mosques to improve access for disabled people, including people with learning difficulties
- Ran a workshop at a local conference on services for people from BME Communities
- Published articles about our work in the local press and in the Trust newsletter

Some tangible results:

- Leaflets have been well received
- Network of contacts is much improved
- Significantly improved profile within the Asian community.
- Good attendance at our groups
- Extremely positive feedback from members of the local Asian community, including religious and community leaders.

² Dewsbury Hospital Learning Disability Partnership Board South Asian Sub-group (see http://www.etn.leeds.ac.uk/document/resources/learning_disability_partnership_workshop.pdf)

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Conclusions and recommendations

- We have built very helpful links, and learnt a great deal about the particular needs of Asian service users.
- The process is as important as the product - knowing people and being known by them is as important as knowing about cultures and religions.
- We have learnt that people respond positively to questions about their religion and culture, if they are asked sensitively, with respect and in good faith. We now feel more able to ask when we do not understand

Case study 2: Antenna Outreach Service, Tottenham, London

Aims:

- To develop an accessible and sensitive mental health service to cater for the needs of young Black African/African Caribbean people aged between 16 - 25 years so they achieve a better quality of life
- To develop a culturally sensitive outreach service to the client's family and community
- To raise awareness about mental health in the Black community

Programme:

Antenna was set up to pioneer proactive and preventative work to address the disproportionate number of Black people experiencing mental ill health.

It aims to engage clients who are failing to engage with the existing support services and are therefore at risk of becoming hospitalized. The entire team of Antenna is drawn from the African and African Caribbean community, to enhance the level of sensitivity and understanding of the psychosocial, socio-economic and cultural needs of the target group.

Antenna offers individuals and their parents support, advice and practical help with regards to mental health by:

- Supporting clients to access training and education programmes – Antenna visits them during lunch times and supports them to complete their training
- Providing a 24-hour telephone helpline with information and support around mental health issues
- Visiting schools, churches and mosques, youth services and educational centres to raise awareness about mental health issues with people from ethnic minorities and tackle stigma
- Working with one school to contribute to the health mentoring programme
- Holding an annual community event to raise awareness of mental health issues within the local community
- Producing videos, shot, directed and edited by the Antenna Young people's Group and including street interviews, mental health facts and signposts to available help.



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- Working in youth clubs, sixth form colleges and community centres to promote the work of Antenna
- Running training for mainstream service providers in health and social services; the police; within nurse and social work training courses; with parents

Pointers to success:

- Improved partnership working between key stakeholders
- Early treatment and prevention of admission/ readmission
- Young people who use Antenna and their parents/ carers feel they have been helped positively in a way not experienced before
- Young people who use Antenna feel better about their lives and feel more independent

Case study 3³:

Aim:

To increase awareness of short-term breaks to South Asian people

Action:

- An exhibition providing information was displayed in places used by the South Asian community - eg. the Mela, the city centre, mosques, community centres, temples, street corners and open events
- Photographs showing South Asian users with South Asian staff were displayed
- Videos in Urdu were used to describe services
- Advertisements were included on a local South Asian radio station, the local press and local South Asian publications.

Results:

- Families did come forward when contact methods were relevant to their background and experiences
- Considerable increase in South Asian referrals to the services publicised
- Increased awareness of disability within local communities, especially as media images of disabled people are currently missing from both the minority and majority media.

³ Taken from Begum N, Hill M and Stevens A (eds.) (1994) *Reflections: The views of Black disabled people on their lives and community care*, London: Central Council for Education and Training in Social Work. See also Mir et al (2001) p45

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HANDOUT 10:

Activity 17: Reviewing the cultural competence of services

Organisational Cultural Competence Self Assessment Tool⁴

Ethnicity monitoring

Ethnicity monitoring of all clients is undertaken.

Look for:

- Records of ethnicity of services users such as mapping information
- Local needs assessment which reflects the diversity of the local population
- Local needs assessment which shows knowledge and understanding of the different ethnic groups in the community.

Communication and Information

All clients can communicate with staff in a language they feel comfortable with.

Services are clearly signposted and enquiry points clearly marked.

Appropriate information is available in an accessible format which facilitates informed choice about their care and treatment.

Look for:

- A workforce that reflects the diversity of the local community
- Knowledge of the languages used by the community and steps taken to meet these needs
- Physical signs and other information available in a format and range of languages that is accessible by the local community

Religious and spiritual needs

Services take account of the religious and spiritual beliefs of clients and staff in accordance with their identified needs.

Look for:

- Provision for staff to make religious and spiritual observance according to their needs
- The spiritual and religious well-being of clients and their carers are facilitated, for example by making available space for prayer and reflection
- The religious needs of service users are taken into account in respect of timing of appointments made for service users, their families and carers.

⁴ Based on: Care Services Improvement Partnership (2008) *Organisational Cultural Competence Self Assessment Tool for Children and Adolescent Mental Health Services*



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Gender and Age

Clients should have a choice of staff of their own gender and a choice of staff and services that are age appropriate, with information readily available about these options.

Look for:

- Information about availability of staff of the same gender as the client is readily known and accessible to staff and clients, and choice is offered to service users and their families and carers.
- Information is readily available and accessible to clients of age appropriate services offered by the provider and other local agencies.

Food

Meals, snacks and refreshments meet the religious and cultural requirements of service users.

Look for:

- Choice of nutritious meals should be available to clients
- Meal and menu planning takes into account the diversity of the local community, service users and their families
- Evidence of how the origin and preparation of food is communicated to services users, their families and carers.

Anti-discriminatory training

Staff respond knowledgeably and appropriately to different individual, social, cultural, religious and other needs of black and minority ethnic service users, their families and carers

Look for:

- Evidence of current and on-going staff training in cultural competence and diversity.
- On-going development of staff to meet the needs of the diverse local community and reflect the changing ethnicity of the community
- Evidence of up-to-date information gathering about the diversity of the local community.

Complaints

A complaints procedure is in place that is accessible to minority ethnic users, including those whose written and spoken language is not English. Ethnic monitoring of complaints is in place.

Look for:

- Information about the complaints process is available in a range of languages appropriate to the diversity of the community

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- Staff are able to explain the complaints process to service users, their families and carers in an appropriate and accessible language
- Complaints by members of ethnic minority communities are registered and evidence is available of steps taken to resolve the complaint.

Involving users

The service has a participation strategy in place for engaging service users, their families and carers and that reflects the black and ethnic minority communities in the locality.

Look for:

- Written evidence of an implementation plan and strategy to engage services users, their families and carers
- Feedback from services users of their involvement in planning services
- Minutes of meetings held at which clients and their families and carers have contributed to the development of services

Employment

The staff team reflects the diversity of the community it serves.

Look for:

- Mainstreaming of equality and diversity matters
- Up-to-date employment policies and procedures in place
- Evidence that the ethnic origins of all staff are known and recorded in a sensitive and confidential manner
- Personnel have been trained in equal opportunities, cultural competence, and diversity
- Staff can evidence understanding and knowledge of their local BME communities.

Based on: Care Services Improvement Partnership (2008) Organisational Cultural Competence Self Assessment Tool for Children and Adolescent Mental Health Services (CAMHS)

www.csip.org.uk/silo/files/occa-tool-final-july-2008.doc

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HANDOUT 11

Six areas of assessment for community engagement

Diversity	Whether community diversity is reflected in the organisation and its processes
Procedures	Whether the way an organisation works supports people to get involved
Communication	Whether ways of communicating allows a flow of information between the organisation and its communities
Staff support	What the organisation does to support and develop staff to engage with communities
Opportunities	Whether communities are involved in the range of decision making taking place in the organisation
Resources	Whether communities have access to and control of resources

Adapted from: South J, Fairfax P and Green E (2005)

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HANDOUT 12

Some useful websites:

<http://www.etn.leeds.ac.uk/links.htm>

Website for the Ethnicity Training Network with links to lots of other materials about cultural competence in health and social care

<http://www.learningdisabilities.org.uk/information/>

Information about the National Advisory Group on Learning Disabilities and Ethnicity at the Foundation for People with Learning Disabilities

<http://www.lden.org.uk/page6/page6.html>

Good practice examples from the National Learning Disability and Ethnicity Network

<http://www.valuingpeoplenow.dh.gov.uk/>

The Valuing People Support Team website

<http://www.statistics.gov.uk/census2001/s104.asp>

Information on the ethnicity and religion of the total population in your local authority area is available from the 2001 Census website.

http://www.ethnicityonline.net/good_practice_guidelines.htm

http://www.ethnicityonline.net/translation_interpretation.htm

http://www.ethnicityonline.net/cross_cultural_communication.htm#barriers

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