

Black and Minority Ethnic (BME) Communities

Definitions

Ethnicity and cultural differences encompass a broad range of factors. They are influenced by social, political, historical and economic circumstances and have no universal or fixed definition. You should not make an assumption about a person's values or belief systems based on their ethnicity or apparent culture.

Be aware that a person's sense of culture, ethnicity, religion and spirituality are related but essentially separate entities. Religion may not be bound by ethnicity or where a person is from. People from the same ethnic grouping, for example people from India, may practice Hinduism, Islam or Christianity.

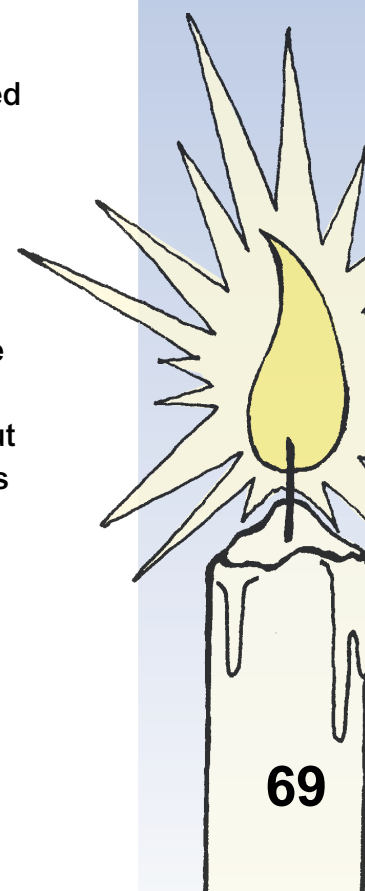
Ethnicity is part of a person's identity. It helps to create and maintain tradition and is often related to country of origin of a young person or their family. James Nazroo from the University of Manchester asserts,

"Ethnicity is a social identity that carries with it a personal meaning, a meaning used and a meaning imposed by others in social relationships."
(Nazroo, 2007).

For example, the way of life in Pakistan may not be a relevant indicator to the beliefs, values and experiences of the Pakistani community living in England. For many younger people or individuals who are 'second generation' this can lead to a mix of emotions, with how they are perceived by their family clashing with how they are perceived by the outside world and then again with their perceptions of self.

Culture refers to the way we do things. We all have a culture and this is heavily embedded in how we were brought up, our family and beliefs. In order to retain identity, people can closely follow the culture of their home country, sometimes even after that culture has evolved, so that their understanding is of an older, stricter way. This may be indicated by devout and very moralistic behaviour, food preference or dress. Traditional rituals and celebrations are observed stringently.

Conversely, some people move towards becoming part of their adopted country, integrating, especially with school friends, work colleagues and



through relationships and marriage. This can lead to inter-generational or inter-family conflict. Both scenarios can cause confusion and understandable fears of displacement in young people. This is especially true for people with learning disabilities who are trying to unravel the complex messages from those all around them.

Religion is the adherence to an organised set of beliefs usually including faith in a higher being or beings, a god or gods. This impacts on a person's lifestyle as all religions make recommendations for how people should behave in everyday life and religious settings. Religion provides many people with an important focus to their lives and is a great source of comfort to them. How religion is practised can depend on ethnicity, for example, Thai and Chinese Buddhists have different ways of observing their religion based on the same principles and teachings. Different Christian faiths have varying views on women leading religious services.

Spirituality is a person's perception of our reason for being, the explanation for who we are and how we feel. It can be influenced by religion, culture and science and evolve with a young person as they learn about the world around them, listen to different opinions and come to their own conclusions. John Swinton spoke to people with learning disabilities about what spirituality meant to them.

"People with learning disabilities recognise the importance of the spiritual dimension. They describe it as relating to value, acceptance, love, care, and connectedness with God and others. Grief, loss and a sense of relational disconnection were a common phenomenon amongst the people we spoke with."

(Why Are We Here? 2001)

Swinton goes on to say that spirituality has increasingly been recognised as a basic human need and a human right, which is a necessary part of both mental and physical health. Don't be afraid to ask and talk about elements of culture, spirituality and religion. They are deeply personal subjects but with sensitivity can draw out important information about a young person that will enable you to better support them.

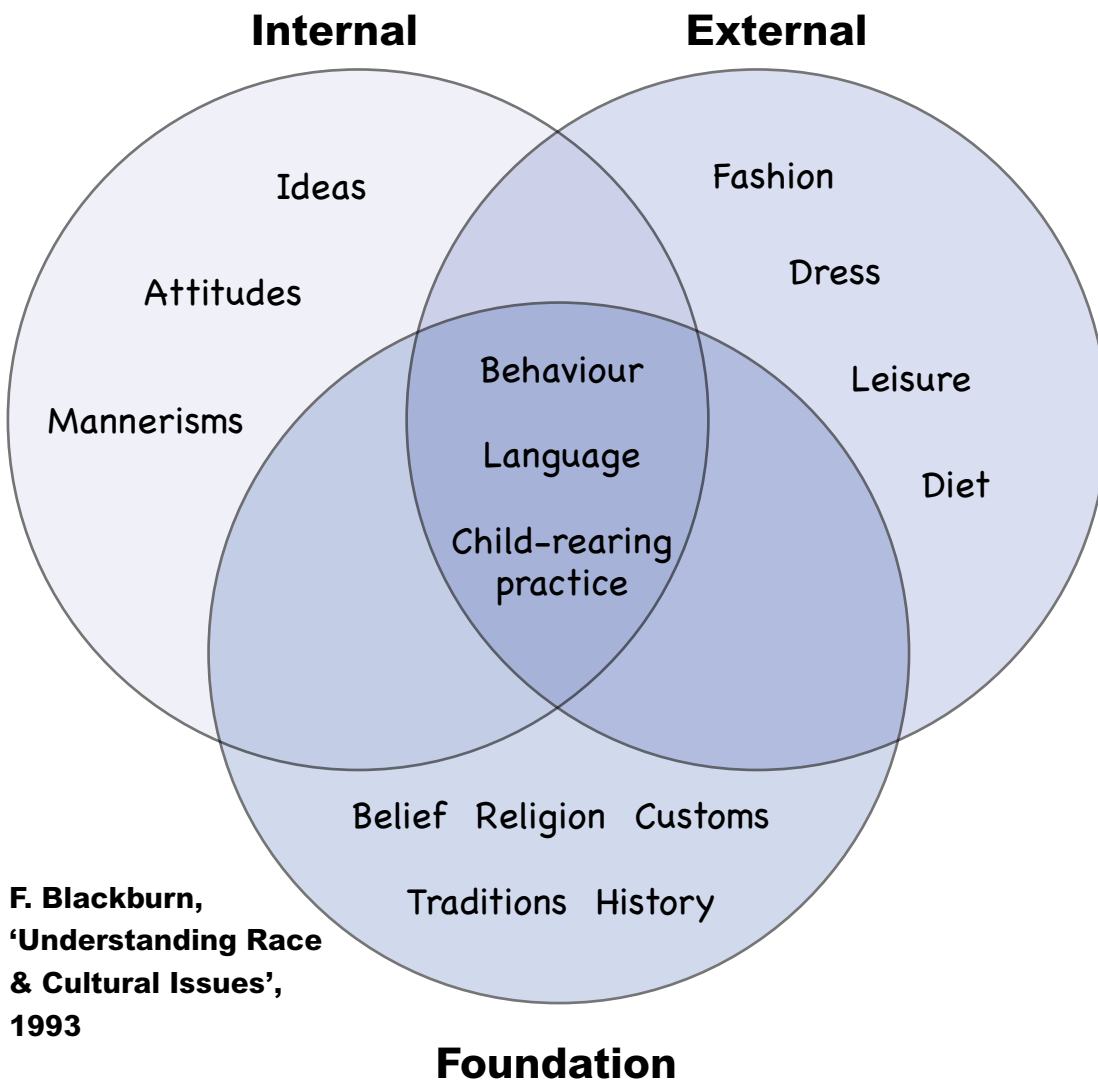
Where does our culture come from?



Exercise

Think about how culture manifests itself. Each of these elements could mean different things to people from the same cultural background. This shows how important it is NOT to assume anything about a young person and their family.

Think about the **Internal**, **External** and **Foundation** elements of your culture.



F. Blackburn,
'Understanding Race
& Cultural Issues',
1993

Assumptions about Services and the People who Need Them

People from minority communities may well have a history of poor experiences when dealing with services. Research shows that Black African-Caribbean men and women are over represented within psychiatric institutions and can be stereotyped as violent and diagnosed with schizophrenia. 'Count Me In' (2005) states that in England people who are black or of mixed ethnicity are three times more likely to be admitted to psychiatric hospital. Black people are eight times more likely to be in high security psychiatric hospitals.

(Healthcare Commission 2005)

The DRC reports one individual stating, "My doctor struck me off her list last week because she sent a letter saying I had upset her staff. I try to put my point across clearly but none of them listen to me...She told me 'you people are all the same' – she is Asian and I am an African Caribbean male."

(DRC 2006 p52)

There may well be frequent misdiagnosis due to health professionals not recognising cultural differences and trying to "cure" emotional reaction:

"Culture must play a large part in determining the way in which a particular event or emotional distress is conceptualised in the first place, for example whether it is seen as an illness to be cured or endured, or as a spiritual crisis to be resolved or experienced; the former will call for coping and the latter for understanding."

(Fernando, 1991)

If non-western views of health concentrate on the whole person, physical and spiritual then the inappropriateness of western psychiatric methods becomes apparent.

"Over 75% of the professionals from all agencies interviewed concurred that black clients were more likely (than white clients) to be perceived as dangerous."

(Browne, Ethnicity and Mental Health, 1997)

Roland Millewood finds no evidence that Caribbean men had higher rates of psychosis than white men and, interestingly, *"The alarmingly high rates of psychosis among people of Caribbean origin in Britain seem much less when measured in the home by members of the same ethnic group than*

when they are assessed by white psychiatrists in the hospital.”

(Millewood, Ethnicity and Mental Health, 1997)

If a family has experienced poor levels of service in the past, or is aware of it due to the negative media portrayal, they may be less likely to engage with services or admit that their child has a difficulty.



Exercise

Emmanuel is a 15-year-old young man with mild learning disabilities and his parents are from Africa. Over recent weeks Emmanuel has talked about hearing God speak to him and wanting to change the world to a better place. In the previous months Emmanuel has not been interested in his schoolwork and not mixing with his peers. He tells his teacher that his family belong to a church, which understands what he is talking about, and agree with him.

- Is Emmanuel expressing ideas in keeping with his family cultural and religious background or is he developing the early onset of a severe mental illness?
- What could you do?

Suggestions

The fact that Emmanuel is not functioning well at school and not mixing with his peers when he has in the past may indicate we are seeing an illness requiring referral onto a the local child & adolescent mental health service.

(Example given by Jane McCarthy, Clinical Psychiatrist, 2006)

A large proportion of South Asian people, women especially, have been diagnosed with depression and their experiences have been repeatedly reported to be negative, particularly by professionals who do not have enough knowledge and make assumptions about the Asian community.

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The 1998 Department of Health report 'They Look After Their Own, Don't They?' investigates typical ideas people have about Asian communities, as suggested by the title.

The report shows that often families live together out of economic need rather than choice and within communities, people with mental health issues or learning disabilities and their families can be cut off by their communities with a lack of knowledge of these conditions.

The research also shows that mental illness in South Asian people was much higher for those people not born in the UK and those who could not speak English fluently. This would lead to the suggestion that it is because of the lack of culturally appropriate services, support and information that people are not accessing services rather than simply lack of need.

Belioppa in 'Illness or Distress? Alternative models of Mental Health' (1991) found that mental distress was lowest among Asian families that had maintained their cultural and community links. Given that these are disappearing and family support does not prevent illness, symptoms may be unrecognised, unreported and increasing.

Within some communities the risk of stigma remains strong and people may not see their GP as a viable option to talk to about mental and emotional issues. Bangladeshi Muslim people may visit community leaders at the mosque for advice and support for themselves and their families before seeking medical help. South Asian women in particular have been found not confide in their GP due to concerns about confidentiality. (2006 **Husain et al, Annals of General Psychiatry**). Somali and Horn of African people, similarly, have reflected in research that they try all other forms of support before trying their GP.

There is the additional on-going stress of racism allied to the general abuse of people with a learning disability. Day in day out name calling and bullying can have a cumulative and very negative effect on their wellbeing. Two thirds of those questioned in a Mencap survey said they were bullied on a regular basis.

(Mencap, **Living in Fear, 2000**)

It is the duty of care providers to work against this and to build sufficient understanding of their clients to recognise manifestations of mental

illness, rather than putting unusual behaviour down to learning disability, or worse still, some assumed culturally based behaviour.

Finding out about what a young person and their family believe in terms of culture, ethnicity and spirituality is vital to gaining their trust and providing culturally sensitive support.

“Efforts to improve mental and emotional well being for people from BME communities should be anchored in an understanding of history, broader societal conditions and contexts and black people’s experiences: not just their experiences of racism, but also how they have survived in the face of multiple adversities.”

(Keating 2006)

Faith

In Britain belief can sometimes be seen as something that can be dipped into and out of at will. Belief really means a ‘firm conviction’ and an, ‘acceptance as true’ therefore not open to question or doubt because of risk to the soul.

To work effectively with people from different cultures we must develop empathy and constantly question, *“Would I accept this service for myself or my family if it went against my way of doing things?”* Is it individualised and with what is important to the person, their culture and belief system at the centre?

The Golden Rule or the ethic of reciprocity; the way you treat others should be the way you would like to be treated yourself, is found in the scriptures of nearly every religion and cultures. People from many backgrounds will understand if you work in this way. Look at these examples:

“One going to take a pointed stick to pinch a baby bird should first try it on himself to feel how it hurts.”

(African traditional Religions, Yoruba Proverb – Nigeria)

“You shall love your neighbour as yourself.”

(Judaism and Christianity, Bible, Leviticus 19:18)

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“This is the sum of duty; do naught to others which if done to thee would cause thee pain.”

(Hindu Faith, The Mahabharata)

“No one of you is a believer until he desires for his brother that which he desires for himself.”

(Muslim Faith, Hadith)

Make sure that the person has adequate support to maintain their familial beliefs. If they choose not to do so it is important that they understand the reasons for the original requirement and the spiritual consequences of refusing to do so.



Exercise

A young man attends a youth group and is going away with the group on a weekend holiday to Scotland. The young man's parents have told you that he is Muslim and must not eat any meat unless it is halal. They say that it is important that you support the young man with this as he does not understand and will eat anything he is given. At breakfast on the first morning, the young man reaches over, takes a sausage from another young person's plate and eats it.

1. What should you do in response to the incident?
2. What could you have done prior to this happening?
3. How far do your personal beliefs about choice affect your response to this situation?

Natural Law

Natural law, or Karma, is common to many Eastern and South Asian religions and was a belief system at the time of Buddha. Karma answers the perpetual questions of why good is not always rewarded and why some people, such as children, suffer when they cannot be at fault. These apparent injustices can be explained as suffering a punishment for wrong done in a previous life, or an earlier misdeed in this life.

This can have a significant effect on those people of an Asian background with a learning disability. For example, one family who had failed to visit their ancestor's graves believed that this resulted in their child's learning disability.

Karma teaches the cause and effect cycle that behaviour in life will affect the next incarnation. The way to end this cycle is to live the Middle Way, to use the Noble Truths and by meditation, morality and wisdom to eliminate suffering. Generosity is key; all Buddhists oppose selfishness. Therefore, should a person have a disability, this may be viewed as a punishment for them and their family but they should still be treated with kindness.

Language and Communication

"My Grandfather was colored, my father was negro and I am black."

Henry Louis Gates. (1994).

The language used to describe people, and the language they use to describe themselves, is an important indicator of how they perceive themselves and are perceived by others. Language changes and terms used in the past are not now viewed as acceptable, the same terms can also mean different things in different settings. One young person may be a client, service user, patient, (special needs) student, resident, family member, team-mate or friend depending on the 'role' they are undertaking at that point in time. Always ask the person and their family what they would like to be known as and which terms they are comfortable with.

Communication is essential - it is vital that workers are clear and that they check the understanding of the individual and their families. Communication is highlighted as a significant factor in the barriers to support in the recent DRC report:

"(There is a) lack of health information available in community languages where people can access it (places of worship, community centres, refugee centres)."

(DRC 2006 p79)

It is important to access a good translation service and look around for written information in the person's language. A good start is the Citizens Advice Bureau who would be able to recommend local translation services and may have leaflets in minority languages. The Multikulti website can also be very helpful www.multikulti.org.uk.

Translators or interpreters are an excellent way of ensuring a family understand what is happening. However there can be difficulties, for example around confidentiality – a family may prefer to have information translated anonymously than have a person present at their meetings. Be aware that there can be differences in translation, certain concepts do not exist in other languages or can be perceived very differently. For example, there is no word in Hindi for autism. It is important to speak to the translator before the meeting and ensure that if they have not worked with people with learning disabilities they are aware of making themselves clear and speaking in a way the person understands. Check that the translator has an awareness of health and social care terminology that you use and is therefore able to translate the concepts effectively.

Translating material is important and a hard copy means a young person and their family can take it away to refer to. If at all possible, make sure you check written information with someone before you distribute it or at least make sure you are present when the family read it to gauge their reactions and identify potential difficulties. Also be aware that just because a person speaks a language does not mean they are able to read it.

The Law

Ensuring understanding is not just good practice but under the Race Relations Amendment Act (2002) it is law. The two main parts of the act are:

- a) to eliminate unlawful discrimination,
- b) to promote equality of opportunity and good relations between persons of different racial groups.

This means making sure that people can have access to the information they need in a way that they will understand.

This information should also be accessible to people who have a learning disability - again the DRC state, *“Producing information in accessible formats...is not an optional extra. The DDA (Disability Discrimination Act) makes it an obligation...”*

(DRC 2006 p59)

Link and Community Workers

Research has proven that a Link Worker allocated to a community can greatly improve their access to and take up of services. This was particularly evident in the report 'Making Us Count' (FPLD 2005). Link Workers would be able to assist families across a range of disciplines; health, education and social care, and advocate and translate for them on an ad hoc basis. There are not very many schemes where a Link Worker exists but contact your local council department responsible for equality and diversity. The Delivering Race Equality Action Plan, issued by the Dept of Health recommends BME Community Workers work within CAMHS services, ask if one is available when they make a referral.

Within many families and communities there is a need to create a positive ethos and be more open regarding mental health.

One of the siblings from a Vietnamese family with a child with a learning disability and mental health issues said that they never talked about her brother's condition. She said that as if by not referring to or speaking about it within the family or community there was the appearance that everything was fine. However, she felt this put an enormous amount of pressure on her mother and was very unfair on her brother. (Information gathered during research for this project.)

There is a need to 'put mental health on the agenda' within communities and this could be achieved creatively through outreach work, using local media and celebrities or drama presentations. One group organised an evening including a meal and a local comedian to host the event and lighten the mood between the important messages about mental health. It could be through a key worker or link worker scheme where an individual establishes links with the community mental health services and the people in the community who use that service. It doesn't always have to be a grand gesture, little actions can be just as effective. **Try pinning up some of the handouts included in this pack where people may read them to help raise the profile of mental health.**

Delivering Race Equality

Delivering Race Equality in Mental Health Care (DRE) is the Dept of Health action plan 'for achieving equality and tackling discrimination in mental health services in England for all people of Black and minority ethnic

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(BME) status, including those of Irish or Mediterranean origin and east European migrants. Their 2005 report states:

“Mainstream child and adolescent mental health services (CAMHS) are not meeting the needs of BME children and young people. Not all CAMHS are commissioned with the needs of BME children and their families in mind. There are a number of issues, including a lack of basic ethnic monitoring data, a workforce that does not reflect the diversity of the population it serves, and a failure during assessment and treatment processes to meet the needs of a diverse population.”

<http://positivestep.actiondre.org.uk/inex.html>

Knowing What's Out There

Find out about local Community Mental Health Services, what they offer and be able to signpost people to them if necessary. Get to know the young person, discuss issues and establish a link with the family and support them to get to know about the services on offer. That way, what exists is known and on-going support and promotion of positive mental health is possible, there is less chance that a crisis will be reacted to in a panic and 'ill found' judgements made.

Ensure appropriate services and referral systems are in place and that these services and their staff are working together sharing knowledge of a young person. This applies to all the professionals working around the young person – children's and adult's social services, transition workers, youth workers, doctors, teachers, teaching assistants, community mental health team, residential social care workers and respite support workers. Try and establish one lead worker who draws all the pieces of information together for the young person and their family and is the main point of contact for them. They do not have to be from the same ethnic background as the child and their family but they need to be aware of the issues they face.

Do not condemn other people's views as 'weird' and therefore wrong. The views, values and beliefs of communities must be respected. If a person is being accepted and their reasoning for why they feel as they do is acknowledged they will be more likely to be open about this. Some people have a strong belief in the spirit world and can attribute the causes of learning disability and mental ill health to it. If this is the case it may mean they have tried various different options for their child before considering Western style medicine.

Alternative methods are not always highly regarded in the Western Medical Model. Holistic and herbal therapies can be disregarded and if the person and their family have a deep belief in their importance this attitude can further exacerbate a mental health issue and the relationship with a family and their doctor. If a young person and their family have a particular belief it is vital that this be part of their care. If doctors are not informed of alternative therapies, the medication they prescribe may be in conflict with what the young person is already undergoing. The importance of beliefs should be recognised and discussions take place to ensure that the young person is accessing the best of both models of support.

Recent research by the Foundation for People with Learning Disabilities around the importance of faith has shown the benefit people with learning disabilities gain from their beliefs. Have a look at their DVD for ideas of how young people with learning disabilities can be fully participatory in their place of worship, 'Faith In Practice'.
(FPLD 2004)

From a Minority Community But An Individual First

The Foundation for People with Learning Disabilities also comments on key findings from studies with families from minority communities. They suggest that despite the complexities that arise from cultural and ethnic differences, minority ethnic families have similar needs and concerns to other families who have sons and daughters with learning disabilities and mental health concerns.

These include:

- Having needs recognised and not diagnosed as part of a person's learning disability.
- Being responded to promptly and appropriately.
- Knowing what services are available.
- Having access to services made more straightforward.

(Making Us Count, 2005, FPLD)

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These improvements to service delivery should be made and available to all young people and their families, irrespective of one's cultural status.

Debbie Kramer-Roy from Brunel University comments that young people from minority communities can miss out on the important and positive aspects of a "disablist culture". Families can set limits for their children and find it difficult to recognise their skills and preferences. Ensuring that young people and their families are aware of positive initiatives like person centred planning and given the resources to develop and thrive.

People from minority communities need a person centred service that incorporates their culture but sees them as an individual first.



Exercise

Our Individual Cultural Identity - Who Are you?

1. What are the four key influences on your life?
2. To what group of people do you ascribe yourself?
3. How are the four key influences and the group to which you have ascribed yourself linked?
4. How does this manifest itself?
5. Does this picture of you reflect religion, education, diet, leisure, relationships, citizenship and how?

(Services For All, ARC, 2000)

The issues that coming from a BME community raises can be difficult for both the individual, their families and those supporting them. In the same way that the person not the disability should be seen first the same is true for those coming from a BME community. See the person not the race, colour or creed first and if you are unsure ask.



Candle Case Study

Wasim is a young man you support in the residential special school you work in. After a period of assessment and clinical input from the local CAMHS team Wasim has recently been diagnosed with a mental health problem. As part of the management of this problem medication has been prescribed which he takes three times a day.

Whilst taking the medication Wasim appears to be more settled and his mental health appears to be balanced, allowing him to make improvements in his schoolwork. Although Wasim takes the medication without apparent problems he asks what it is for every time he takes it and you are unsure if he fully understands the reasons even when he says he does.

Wasim has a large extended family who support him and he enjoys spending time with them, especially during the breaks from the school terms. Despite being on the medication when Wasim's close family recently went on holiday to visit their grandparents his mental health suffered - highlighting the importance of the contact.

However, when Wasim is at home his medication management appears to be erratic at best. His family tell you that they 'forget' as they spend a lot of time visiting friends and family and he often spends time in different family members homes.

You are not sure that all the family members agree that Wasim should be on medication and some are certainly unsure what it is for.

- Q1. Can you identify the positive aspects of Wasim's support?**
- Q2. Can you highlight any issues that need to be improved?**
- Q3. What might you be able to do to support Wasim and his family?**
- Q4. What support might you need from other people or organisations?**
- Q5. Do you know how you can access these individuals or organisations?**

Continued over

Suggested Answers

Q1. Can you identify the positive aspects of Wasim's support?

The treatment is ongoing and appears to be working.

Wasim's family have had and continue to have an input and support, this is essential for success.

Wasim is taking the medication, although it is difficult to say he has given informed consent to this.

Q2. Can you highlight any issues that need to be improved?

Wasim needs to better understand what the medication is for.

Wasim's family need to be supported and encouraged to prompt and give Wasim his medication.

Wasim may be able to manage some of the process himself so self-medication should be looked at. This would also increase Wasim's self-confidence.

Q3. What might you be able to do to support Wasim and his family?

Discuss the medication, what it is for, the potential side effects, the apparent success it is having with them.

Link in with the CAMHS team and whoever has prescribed the medication to ask questions on the family's behalf. You should think about how long Wasim will need the medication, will the dose need to go up or down, does he require regular blood tests, medication reviews and will it compliment his other medication.

Highlight to Wasim and his family the recent improvements he has made at school.

Suggest a medication recording system and/or prompt for Wasim and his family.

Continued...

Give a positive reward for improved medication management.

Q4. What support might you need from other people or organisations?

Wasim and his family must agree with the medication and give their support. This seems obvious but is often missed and without their support, it will not work.

The staff team within school should encourage and praise Wasim and offer any required medication prompts in joint working with the family and the rest of the professionals involved.

CAMHS professionals, who can offer advice and support and continue to review Wasim.

The person who has prescribed the medication – who can undertake reviews and any tests required regarding the medication.

Possible nursing input, this may be from the school nurse, community nurse or the nurse attached to the GPs surgery. They will be able to offer advice and support about taking medication.

A translator or family support worker, who will be able to assist you with your work with the family.

A Social Worker can sort out liaison between the relevant organisations and can organise and chair meetings as required.

Q5. Do you know how you can access these individuals or organisations?

This will depend on your local situation, but a telephone call to your local social services can clarify what is available.



Top Tips for Supporting BME Families

Don't be afraid to ask

ASK people about themselves, their culture, ethnicity and sense of spirituality. This can be done formally through a care plan or informally over a cup of tea but should be recorded and shared amongst the staff team. Do a bit of research about a person's religion and culture – find out about holidays, celebrations, fundamental beliefs, traditions.

Your culture is important

Think about your own belief system. Identify the four key influences on the way you live your life and the group of people you ascribe yourself to. Does this picture of you reflect your religion, education, diet, leisure, relationships, citizenship and how?

Key Worker

This person should draw all the information that is important to the young person and their family and make sure that it is available to other professionals. The person does not have to be from the same ethnic background as the child and their family but they need to be aware of the issues they face. They can ensure basic communication supports are in place and be a point of contact for the young person, family and professionals.

Cultural Differences

Don't assume that behaviour you are seeing is a sign of mental ill health, it could be a cultural behaviour that a young person has learned; for example a young person rocking backwards and forwards might be what they do when reciting the Qu'ran or in prayer. It is, however, important to monitor the behaviour and flag it up to the family and other staff.

Local Area

Involve local communities and religious where possible in your service. Get creative and involve in fun activities as well as important decision-making or advisory meetings.

It's not weird!

Don't condemn others views, remember we all see the world from a different perspective. We're all weird in some ways! If you show a person that you think what they do or what they believe in is weird they will be more wary about talking to you in the future.