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Cultural diversity

The population of United Kingdom is diverse and complex in terms of ethnicity, culture, language and religion. The increase in ethnic diversity is also apparent in the population of children and young people with learning disabilities. The focus of this chapter is children and young people with learning disabilities (LD) from Black and Minority Ethnic (BME) communities as they face inequalities, discrimination and marginalisation. This chapter will highlight the key policy initiatives in addressing the need of people from BME communities in the UK and will explore the barriers in accessing mental health services. This chapter will conclude with the findings from a research study to explore self-defined service models for children and young people with learning disabilities from South Asian communities.

Introduction

The UK population is becoming gradually more diverse and complex in terms of ethnicity, culture, language and religion. According to the 2001 census, nearly 92% of the of the UK population are white and about 7.9 % of people are from different ethnic groups, which consist of about 4.6 million people. (www.statistics.gov.uk). Recent estimates from the Office for National Statistics stress that this figure had grown over by 11 % by 2006 and could be as much as 15% today(Health Care Commission 2009). The Health Care Commission report on *Tackling the Challenge: Promoting the Race Equality in the NHS in England* (2009) suggest that if the current migration patterns continue there will be a significant increase in the number of people from BME communities in future years. The 2001 census data show that amongst the population of various ethnic groups, Indians are the largest, followed by Pakistanis, those of mixed ethnic backgrounds, Black Caribbeans, Black Africans and Bangladeshis. The 2001 census also collected information on ethnicity and religion. Majority of the White population are considered to Christians and there are number of other religious groups. Amongst these groups the Pakistani Muslims were the largest, followed by Indian Hindus, Indian Sikhs, Bangladeshi Muslims and White Jews.

The Valuing People White Paper (DoH 2001) outlines the Government's strategy for improving the lives of people with a learning disability and their families. The agenda is based on the recognition of their rights as citizens to be socially included, have choice in their daily lives and to have opportunities to achieve independence. The *Valuing People* White Paper (DoH, 2001) states that many people from minority communities are even more excluded than white people with learning disabilities and state that “ the needs of people from minority ethnic communities are often overlooked (p.2). Valuing People calls for an improvement of services so as that they not only meet the needs of all people but value them as citizens.

It is well recognised that people with a learning disability from Black and Minority Ethnic (BME) groups are underrepresented in services compared to their white counterparts (Nazroo 1997). They may experience even further isolation, as many of these people face greater inequalities in relation to race, disability and gender and exclusion in employment, education and health (Mir et al. 2001). The nature of experiences such as discrimination and social exclusion of people from BME communities will make a negative impact on their health, well being and the social networks.

Often the terminology used by services and the general public about people from different cultural / religious groups is “ethnic minority”. This may be very insulting to those described, indicting that only ‘minorities’ have an ethnicity (Ratcliffe 2004). We all belong to an ethnic group, and it is important to emphasise the ethnic majority. In this chapter the preferred term ‘minority ethnic community or groups’ is used. In this context it is important to explore the related terms used widely such as culture, race, ethnicity and cultural diversity prior to examining the issues of people with LD from minority ethnic communities.

Culture

Historically, the word ‘culture’ has been used to describe many aspects of social life. Helman (2001) describes culture as a set of guidelines (both implicit and explicit) that

individuals inherit as members of particular society, which informs them how to view the world, how to experience it emotionally, and how to behave in it in relation to other people, to supernatural forces and Gods, and to the natural environment.

Cultural background has a significant influence on much aspect of people's lives which include their beliefs, behaviour, perceptions, emotions, language, religion, rituals, family structure, diet, dress, body image, concepts of space and of time, and attitudes to illness and pain and other forms of misfortune (Hellman 2001).

Ethnicity

Ethnicity is a common term used in health and social sciences and the definitions include references to place of origin, or ancestry, skin colour, cultural heritage, religion and language. Ethnicity is defined as a the group a person belongs to as a result of certain shared characteristics including ancestral and geographical origins, social and cultural traditions, religion and languages (Mackintosh et al. 1998).

It is important to understand that we all belong to ethnic groups even though the term 'ethnic' is often incorrectly used to only refer to individuals from black and minority backgrounds.

Race

The term 'race' originated in relation to assumed differences on biological grounds with members of a particular racial group sharing a certain distinguishing physical characteristics such as bone structure and skin colour (Giger and Davidhizar 1999). The expansion of the knowledge base about biological variations through population and genetic studies show that there is little genetic deference between the various racial groups and hence the term race has been discredited. The Parekh Report (2000) argues that race is a social and political construct, and not a biological or genetic fact.

Cultural Diversity

Cultural diversity encompasses issues of perceived and real differences with respect to age, gender, ethnicity, disability, religion, lifestyles, family and kinship, dietary preferences, traditional dress, language or dialects spoken, sexual orientation, educational and occupational status, and other factors (Purnell & Paulanka 1998). In

valuing diversity and the awareness of diversity, an understanding of values, beliefs, behaviours and orientations are essential.

The Act sets out explanations of what discrimination covers.

Key policy drives

The National Service Framework for Children (Department of Health 2004) emphasise *tackling health inequalities by addressing the particular needs of communities, and children and their families who are likely to achieve poor outcomes.*

The Race Relations' Amendment Act 2000 sets out the key areas of discrimination as:

Direct discrimination - treating a person in a particular racial group less well than someone in the same or similar circumstances from a different racial group. The motive for such treatment is irrelevant.

Indirect discrimination- when a provision, criterion or practice, applied equally to everyone, puts people from a particular racial group (based on race or ethnic or national origin) at a disadvantage because they cannot comply with it. This will be unlawful unless it can be shown that the provision, criterion or practice is a proportionate means of achieving a legitimate aim.

Indirect discrimination also occurs when a requirement or condition, applied equally to everyone, has a disproportionate adverse effect on people from a particular racial group (based on colour or nationality) because they cannot comply with it. This will be unlawful if it cannot be justified on non-racial grounds.

Segregation - segregating a person from others on racial grounds constitutes less favourable treatment.

The Race relations legislation emphasises the general duty of all National Health Service organisations to promote race equality. It suggests that NHS Trusts must have due regard to the need to:

- Eliminate unlawful racial discrimination

- Promote equality and opportunity
- Promote good relations between persons of different racial groups.

Prevalence

It is estimated that nearly 985,000 (2% of the general population) in England have a learning disability (Emerson and Hatton 2008). The overall prevalence estimate of learning disability in BME communities in the UK is not known. What we do know is that there is an increased prevalence of severe learning disability in the South Asian community in the UK. (Emerson et al 1997, Emerson and Hatton 2004). A number of factors contribute to this high prevalence learning disability in this community. Evidence show a strong link between socio-economic factors such as lack of nutrition, poor housing conditions, poor child rearing practices and high prevalence of learning disability (Mink 1997, Emerson and Hatton 2007). First cousin marriages or consanguinity is suggested as cause for poorer birth outcomes in the South Asian community. However, this practice should not be singled out as the main causative factor, and other important factors such as access and use of antenatal health care, lack of awareness and use of genetic screening to identify the risk factors; and the problems associated with communication as a result of language barriers are significant risk factors for higher prevalence of LD in the South Asian community. For example, the higher prevalence has been linked to high levels of maternal and social deprivation combined with factors such as inequality in health care (Emerson and Hatton 2007). It is interesting to note that often professionals use the consanguinity to shift the blame for disability to parents and reinforce negative stereotypes of other cultures and traditions (Ahmad 1996a).

Barriers in accessing services

Children and young people with LD and their families from BME communities experience a number of barriers in accessing and utilising health services. Research with children and young people with learning disabilities and their families from Pakistani Bangladeshi communities in Bradford (Raghavan and Waseem 2007) identified a number of key barriers in accessing mental health services. These consist of:

Knowledge and awareness of services: A key factor that affects service access and utilisation by many people with LD from minority ethnic communities is the lack of adequate knowledge and awareness of the kind and types of health and social care services in their locality. Ability to communicate using English language is a problem for many families from South Asian community and this is clearly identified as a reason for the lack of knowledge and awareness of services (Mir et al 2001, Hatton et al 2002). Many families are not equipped with enough information about the help and support they need. Chamba et al (1999) argues that given the lack of awareness and service support reported, it is not surprising that unmet needs are reported so highly in BME communities.

Language issues: Many people from BME communities have difficulty in the use of fluent English language for communication. In most of the South Asian families, mothers have a greater responsibility in caring for their disabled son/daughter (Mir et al 2001). Family carers who are unable to speak English face particular problems in communicating their concerns to professionals and also in understanding the meaning of consultations. Access to interpreters or family link worker schemes remain inadequate with most of the families relying on their non disabled children for interpreting. Even where families who can speak English, poor communication between them and the professional, rather than language difficulties itself, limit their understanding of the diagnosis and the interventions prescribed.

Families with children with learning disabilities face problems in contacting health or social services to explain the nature of their difficulty and the type of help required for their disabled son or daughter. Family carers from South Asian community indicate that the lack of a single point of contact for the families' who are aware of their young person's condition and difficulties (Raghavan and Pawson 2009). Families are reluctant to access some of these services as they find it very traumatic to continuously explain the history of the young person to professionals and support staff who are not familiar with their case.

Same service for all: A 'colour blind' approach, where services are offered on the same basis to all pose a major barrier for people from minority ethnic communities. This type of approach ignores the cultural values and belief systems of the young person and the family and fails to acknowledge that services are geared towards the

dominant white majority culture. This ignores the needs of BME communities and the barriers that they face in accessing services.

Inappropriate nature of services: Another major barrier in accessing services is inappropriateness nature of services offered. The types of services offered may not be appropriate to meet the needs of the young person and their families. For example, the offer of a support worker who lack satisfactory awareness or knowledge of learning disability creates more stress and work for the families rather than helping them. Moreover, the lack of awareness of the family's cultural and religious beliefs by the support worker is also likely to cause more strain for the family.

Religious beliefs: Service utilisation maybe affected by particular beliefs and perceptions held by families especially those from south Asian communities. Religious beliefs play a crucial role for most of the families, who may consult religious or traditional healers, in the hope that they would make their child 'better' (Raghavan et al 2005). It is suggested that many Pakistani and Bangladeshi people feel that religion was very important in the way they led their lives (Modood et al 1997). Cinnirella and Loewenthal (1999) examined religious and ethnic group influences on beliefs about mental illness and reported that faith and prayer was effective in treating mental illness and preferred to see a 'holy person'. Naturally, some members of the south Asian community may make more contact with religious healers, however, this does not mean that they are less likely to contact medical professionals and use the existing services. Often families may access the religious or traditional healers abroad because of their belief that the professionals and services in the UK are not helping to "cure" learning disability.

Stigma of having a child with learning disabilities is an issue for many South Asian parents in accessing services. Families may be worried about what others may say; especially when communities are so close knit and people don't want sensitive issues to be found out by others in the community. Stigma and family reputations are crucial with regards to learning disability and mental illness and most south Asian people want to keep such issues concerning their family members within the family structure, with carers taking extra precautions to hide any conditions associated with mental health (Bashford et al 2002). Ethnicity alone may not provide the explanation for increased stigma. Information and resources play a crucial role to support caring for a

disabled child. It is suggested that parents are more likely to move away from looking at disability as tragic when they have more information that promotes a positive approach and when they are able to manage the circumstances without struggling (Mir and Tovey 2003)

There are also a number of stereotypical assumptions that have been made about South Asian families communities holding different attitudes from the white population. The South Asians are often described as being a close-knit community where the main characteristic of village life is that everyone knows each other: close friends are classified as 'brothers' and 'sisters' (Khan, 1979). The stereotypical view of South Asian families is that they stick together and help each other in times of need and hardship. Among single-parent families who have a disabled child support from outside the immediate family can be limited or even non-existent in some cases. Some service providers have been slow to acknowledge this. It is inappropriate to assume that all Pakistani and Bangladeshi parents will hold the same views (Begum, 1992). There is heterogeneity of views and opinions in this community as in others. Some of these stereotypical views have been used to explain why minority ethnic families have lower uptake of services than white families, which is a way of blaming the victim and minimizing the problem of institutional racism (Ahmad, 1996b). Research has also demonstrated that South Asian families with a young person with learning disabilities receive less support from extended families than white families (Chamba et al, 1999; Mir et al, 2001). However the myth of the large extended family giving support has led to the view that people from minority ethnic communities do not need formal support (Atkin & Rollings, 1996). There has also been a tendency to blame religious beliefs and shame of having a disabled child as reasons for low service usage (Bywaters et al, 2003).

Cultural sensitivity: South Asian families may not access learning disability services because of their experience or their belief that the services are not culturally sensitive to their needs and wishes. This often relates to lack of having women only groups in day care services or for respite care. There is a need to provide gender sensitive services for people from South Asian communities. The lack of minority ethnic staff in services to help with the language and other cultural issues are also known to affect access to services. Carers may feel that that services are not culturally and religiously

sensitive to their needs (Azmi et al 1997). As a result, family carers may feel that self-reliance is justified and prefer to look after their child with learning disabilities at home with little or no access of learning disability services.

Accessing leisure and recreational services pose problems for many South Asian families. Most of the carers showed dissatisfaction with the social and recreational activities available and felt there wasn't enough for the young person to do and wanted more daytime activities, as well as things to do at weekends and in the holidays (Raghavan and Pawson 2009). Uptake of day services was low, as parents felt these were either not appropriate to the cultural and religious needs of the young people, or not available, or not preferred or the fact that carers just didn't know about them (Azmi et al 1997, Emerson and Robertson 2002).

The *Valuing People* strategy emphasise the planning of local services to meet the needs of people with learning disabilities and their carers. This is to be achieved through Partnership Boards with representation from people with LD and carers and all service providers and agencies. The *Learning Difficulties and Ethnicity: A framework for Action guide* (Valuing People Support Team/ DoH 2004) stress that Partnership Boards should have representation from minority ethnic communities. This framework is beneficial for partnership boards to examine their local population and to explore their links and representation from minority ethnic groups. Moreover, this document stresses the need to recruit and retain workforce from minority ethnic communities and to review the policy and practice in the locality with special reference to ethnicity. It should be borne in mind that for effective inclusion of people with LD and their carers from all sections of the minority communities in the locality in the partnership board, every effort should be made to hear the diverse views of users and carers from this community. Token representations from only one section of a community provide a skewed view of their needs for services. Services should engage with all sections of the community in their locality to get a realistic picture of their views and experiences in service planning. For example, South Asian community consists of people from India, Pakistan, Bangladesh and Sri Lanka. They follow different religions which include Hinduism, Sikhism, Islam and Buddhism and may have different cultural beliefs and views about disability. Hence it is important

to engage and involve all section of the South Asian community in service planning and delivery.

Services

It is widely recognised that minority ethnic groups experience social and material disadvantage when accessing statutory support services particularly families that have a disabled child. Research has shown that overall minority ethnic families who care for a severely disabled child were even more disadvantaged than White families. Such families were likely to have lower levels of employment, particularly among mothers and fewer families were receiving disability benefits and less likely to receive higher rates of Disability Living Allowance (DLA). There are particular cultural barriers such as lack of language skills in English can hamper access and there remains a need to have interpreting services and translated material in languages other than English.

The use of a key worker has been suggested by Hatton et al (2002) and Emerson and Robertson (2001) in supporting young people and family carers from South Asian community. The key emphasis here is for the key worker being a person from the minority community so that they are able to communicate effectively using the appropriate language. The key worker might also help to link up the family with a range of service providers and professionals, thus helping to access the range of services. Such a service model, through the use of liaison worker, was tested with young people with learning disabilities and mental health needs from Pakistani and Bangladeshi community (Raghavan et al,2009). This was a pilot Randomised Controlled Trial (RCT) to evaluate the effectiveness of a liaison worker with this community to increase the access to services.

Liaison worker Role
<ul style="list-style-type: none">◆ Liaising with families/ young person every month or more, if required, via home visits and over the phone

- ◆ Discussions with family's concerns and work on the types of help required for the young person and the family
- ◆ Reflecting on the family's issues/problems and working on ways to move forward
- ◆ Exploring services required and gaining access to them
- ◆ Liaising with agencies, teams and individuals who provide services, making them aware of the needs of the family and young person and discussing how service providers could take action to meet them
- ◆ Communicating information back to the family and helping families to get in touch with services, by networking with family and service providers
- ◆ Monitoring the access to services and help with any further issues or concerns
- ◆ Exploring possibilities/ long term support.

Two randomised groups of young people with LD and mental health needs were set up, a treatment group (n=12) and a control group (n=14). Both groups were able to access the standard statutory and voluntary services, but the treatment group had the additional help of liaison worker and the control group had no additional help from the liaison worker. This RCT trial was conducted for a period of nine months, and the main outcome measure agreed at the start of the trial was number of contacts with services, since this best reflected the aim of the study to determine whether introduction of the specialist liaison worker could enhance access to such services. It was predicted that those allocated to the liaison worker would have more contact, greater variety of contact and more outcomes of contact with services than those in the control group. Baseline assessments were conducted with young people and their family carers at the beginning and end of the trial. The findings of this trial indicate that the liaison worker model was found to be useful by families. Families receiving input from the liaison worker had more frequent contact with more services than did families not receiving this input and had more results from such contacts. There was also some indication that family carers receiving support had a better quality of life and the young person with LD had less behavioural problems than controls. This shows that the model of a liaison worker may be effective in supporting people with LD and their carers from minority ethnic communities.

Cultural sensitivity and cultural competence

In this context it is important to explore the key factors that promote diversity and inclusion. This consist of developing cultural knowledge, cultural awareness, cultural sensitivity, cultural reciprocity and finally, cultural competency (Husain 2007)

Cultural knowledge involves familiarisation with the selected cultural characteristics, history, values, beliefs systems and behaviours of the members of another ethnic group (Adams 1995). Cultural awareness involves developing sensitivity and understanding of other ethnic/ cultural groups. This may involve changes in terms of attitudes and values. Cultural awareness and sensitivity often relate to openness and flexibility that people develop in relation to others. Cultural sensitivity is knowing that cultural differences as well as similarities exist without value judgement. Cultural competence refers to the ability to work effectively with individuals from different cultural and ethnic backgrounds, or in settings where several cultures co-exist. It includes the ability to understand the language, culture and behaviours of other individuals and groups, and to make appropriate recommendations.

Cultural competence is developmental, community focused, family oriented, and culturally relevant. It is the continuous promotion of skills, practices and interactions to ensure that services are culturally responsive and competent. Culturally competent activities include developing skills through training, using self-assessment tools, and implementing goals and objectives to ensure that governance, administrative policies and practices, and clinical skills and practices are responsive to diversity within the populations served. Cultural competency promotes the workforce to position themselves in such a way to listen, understand and clarify the needs of people from minority communities without any presumptions. This enables the workforce to examine their own beliefs, stereotypes and helps them to come to terms with their assumptions about other communities. This will help them to shift to inclusive modes of thinking and behaviour that will enrich the nature of our care and service delivery to people with learning disabilities and their families of all cultures.

Developing culturally sensitive services is a high priority agenda for commissioners and service providers. Malek (2004) argue that delivering culturally sensitive services

requires recognition of cultural beliefs and practices at the grassroots level of service delivery and also at the strategic level of service planning. In order to do these, Malek indicate key range of activities such as:

- A policy framework that supports a culturally sensitive response at all levels
- Data collection on minority ethnic communities generally and the number of people from minority ethnic groups attending each service
- Research into theory and practice issues necessary to develop and deliver culturally sensitive practice
- Collaboration with ethnic and other agencies to ensure that the needs of specific ethnic groups are understood and addressed.
- Education for staff
- Administrative structures that support the delivery of culturally sensitive services.
- Training of clinical and administrative staff to respond sensitively and competently when dealing with people from a range of cultures.

It is not just cultural sensitivity that is paramount in shaping and delivery of services to people from minority ethnic communities. Along with cultural sensitivity the workforce need to be culturally competent. Cultural Competence is the development of skills by individuals and systems to live and work with, educate and serve diverse individuals and communities. It is the willingness and ability of services to value the importance of culture in the delivery of services to all segments of the population. This should be reflected at all levels of the service organisation in their policy and practice through training and support.

Developing cultural knowledge is of fundamental importance in working towards race equality in mental health services for children and young people with learning disabilities. The Race Relations (Amendment) Act 2000 asserts that there is a general duty for all public service providers and authorities to have a due regard and need to promote race equality by:

- Consulting minority ethnic representatives
- Taking account of the potential impact of policies on minority ethnic communities

- Monitoring the actual impact of policies and services and take remedial action when necessary to address any unexpected and unwarranted disparities
- Monitoring the workforce and employment practices to ensure that the procedures and practices are fair.

Conclusion

Children and young people with learning disabilities and their families from BME communities face exclusion and discrimination in accessing and use of Child and Adolescent Mental Health services. As we have seen, a number of factors such as cultural and religious beliefs, language barriers, lack of adequate knowledge and awareness of services act as barriers in accessing and use of a range of services and professional help. Respecting human rights and equality, services need to take on the challenge of providing services to all sections of the community. Service commissioners should have a clear understanding of the population that they are serving and this requires having up to date information about the number of people from various minority ethnic communities in their geographical area. Having this information in the service database alone will not contribute to shaping a culturally sensitive and culturally competence service structure. This will require real effort and commitment by service agencies through consultation and active dialogue with these communities in understanding the needs of minority ethnic communities and having their involvement in service planning.

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