

## **Diverse approaches to Autism: culture, religion and ethnicity**

### **Paving the future for Autism in BAME UK**

#### **Introduction**

People living with Autism in the Black Asian and Minority Ethnic (BAME) community in the UK have not had access to the relevant supports and services. They are less likely to be diagnosed. Families of autistic children are also less likely to accept autism as a lifelong condition (Slade, 2014). There is a heightened interest in the way autism is approached, interpreted and accepted among the BAME populations. This issue paper will shed light on and discuss some of the challenges impeding autism acceptance, care and support services in the BAME community in the UK. Towards this goal, this paper will also address the need for communities to join hands in raising awareness about the Autism Spectrum Disorder (ASD). The intention of the author is to voice a call to action to expand the inclusion momentum of people with ASD in BAME so that it reaches far and wide and lead to improved living conditions for them. It also aims to alert autism stakeholders to help imbibe a culture of acceptance and recognition within a framework that will be accepted by people from diverse cultural and religious backgrounds.

#### **Diverse approaches to Autism: culture, religion and ethnicity**

The prevalent rate of people living with ASD in the UK is rapidly increasing. It is unlikely that many of these diagnoses are coming from people within the BAME community. This is due to cultural challenges that prevent people from the different BAME population from accepting or going for diagnosis (Slade, 2014). The Slade (2014) study highlights some of the challenges families in BAME face in getting diagnosis for their children. This stems from stereotypes by school authorities about a BAME child's behaviour to low or no knowledge about

autism by the family. It is also common for some families to deny autism completely due to religious beliefs that consider acceptance as an endorsement of autism.

Religion could be a major source of support for families of autistic people (Pitten, 2008).

This could include emotional support, strength to carry on, defining and accepting diagnosis and living with the day to day challenges autism brings. There are two major religious denomination within BAME: Christianity and Islam. While Christianity is mainly popular within the Afro-Caribbean community, Islam is mostly popular with the South-Asian community.

These belief systems play a major role in the acceptance of a child's autism. Faith gives autistic parents the strength, hope and feeling of all shall be well (Pitten, 2008). However, misconception of autism by people of faith could have negative consequences on the wellbeing of autistic people and their families. For instance, some people believe autistic people are mentally retarded. Others believe autism is caused by demonic spirits or djinn which sometimes calls for exorcism. This makes it difficult for families to accept diagnosis. This could lead to deteriorating mental health condition for both the autistic child and their parents, especially the mother who holds strong emotional attachment to the child.

Low level of awareness about autism has also caused some parents to believe that prayers can eradicate the condition naturally. As a result, some parents have refused to accept autism and view any advice by professionals (mainly school authorities) to take their children for diagnosis as 'labelling'.

Attitudes in some places of worship could worsen the condition of autistic persons in BAME.

It normally leads to further isolation of autistic people and their families. Some religious leaders warn parents not to accept autism diagnosis as continuous denial will eventually eradicate the condition. While this myth leads to late or no diagnosis, a large number of

people in the BAME community still believe this because of the important role religious leaders play in the cultural lives of the people.

Cultural variables can be critical in determining how well a family accepts a diagnosis and thus the outcomes (Pitten, 2008). Family and cultural values shape our thoughts and perception of every new happening in our lives. And the way families accept or deny autism could have significant impacts not only on the autistic child but also on the carer. Slade's (2014) survey shows that families within the BAME community can experience isolation and alienation from their extended family members and their community because of their child's autism. This put additional burden on the parents or carers. Other factors that affect acceptance of autism in the BAME community include cultural beliefs like the once shared by some that girls speak earlier than boys thus parents are not eager to take their sons for diagnosis even when they experience delayed speech (Wilder et al, 2004). Some families also deny autism and relate their boys autistic behaviour to a male behaviour (Slade, 2014). Culturally, it is accepted for boys to show extremely wild behaviour while girls are expected to be shy and quiet.

Autism can also be affected by the way developmental behaviour is interpreted by a group of people. Children from certain ethnicities tend to be more quieter and reserved while children from other ethnicities whose cultural values allow for them to be more sociable and outspoken tend to be overtly wild. These factors could lead to autism denial by families when a child is diagnosed. Professionals need to be aware of these cultural values when diagnosing a child for autism. For instance, eye contact interpretation by different ethnicity can affect autism diagnosis. Within the culture of many BAME communities, for a child to

have direct eye contact with an adult is viewed as being rude. Yet, lack of eye-contact is considered one of the first signs of autism in children. Cultural misunderstanding of eye-contact could lead to misdiagnosis of autism.

People in BAME face poorer access to healthcare (The Kings fund, 2015 in Papadopoulos, 2016). This include access to autism services (Slade, 2014). The reasons for this range from cultural misunderstanding by professionals, lack of rapport, discrepancies in conceptualization of autism between professionals and parents, lack of training in providing culturally sensitive care, language and communications issues to challenges in getting parents to advocate for themselves and their children. If people accessing the health services experience lack of cultural awareness and what they presume as judgemental attitudes by professionals, they may reject these services. This further hampers the care children with autism in BAME communities get.

Autistic people in BAME are more likely to be stigmatized due to the cultural nature of people within the BAME community. Papadopoulos (2016) blames collectivist culture for this and describes it as a culture “which place priority on community interdependence and shared group norms and values”. People who deviate from the norm are more likely to be stigmatised because of the “high surveillance levels” (Papadopoulos, 2016). A major implication is that families tend to hide their autism circumstances from their community which further leads to isolation and loneliness for the autistic person.

## **Paving the future for Autism in BAME UK**

### **Inclusion**

Previous studies (EHRC 2010, National Audit Office 2008,) have shown that people from BAME are less likely to be employed compared to their white counterparts. While 74% of white people at working age able to find a job, this is 13.7% lower for people from BAME communities (Hudson and Radu, 2011). The situation is even bleaker for people with disabilities. The rate of employment for people with autism is alarmingly low. According to Redman et al (2009) only about 15% of autistic adults in the UK are in full time employment. The number could be even lesser for autistic people from the BAME community. Since autism is a life-long condition, it is important for autistic people to be accepted and included in every aspect of the sociocultural lives of the BAME community and the society as a whole. There is a need for all sectors of society including places of worship, communal gatherings, theatre groups, schools, colleges, universities, and workplaces to become more inclusive of people with autism in BAME who are normally not included due to the lack of or limited available resources for their needs. Programs and supports to foster integration into community activities and all other social programs are needed. Types of services to be offered, as well as the intensity and quality may vary greatly among these programs.

The movement to include people with autism and other developmental disabilities in social and education sectors emanated from several different factors. Parents of children with disabilities have begun advocating for the rights of their children to be included in social programmes. The creation of several parents' support groups and community-based organisations have been instrumental in this path. The setting up of several governmental services that provide advice, information and support to parents have also played key roles. In the school setting, there are special education need coordinators (SENCO) that help autistic chil-

dren receive educational support services in schools. Albeit there are issues of cultural misunderstanding by professionals versus autism misconception by people from BAME which normally lead to late or misdiagnosis.

The result of professional investigations and parental advocacy has led to laws and policies that have dramatically changed special education services in schools and private sector institutions. This is supported by the establishment of several special needs schools across the country. Yet, there is a limited number of such schools to meet the demands in boroughs with huge number of autistic people from BAME community. In the private sector, some of the main supermarket chains have introduced quiet hour for autistic people. Others have included a policy of employing autistic people. However, it is not the same for other communal settings like churches and mosques. Lack of recognition and acceptance of autistic people in communal spaces in BAME have increased the level of vulnerability of autistic people and their families, lead to self-imposed ostracism, social isolation and loneliness. This could have a debilitating effect on autistic people and their families including mental health issues.

### **Awareness**

Autism is still poorly understood by many people in the BAME community. While most may have come across people with autism in the community, cultural and religious misconceptions about the condition may blur understanding. The future of autism mainly relies on the ability of key stakeholders to raise autism awareness among people from BAME, there is also the need to improve autism professionals' understanding of cultural values of the different populations within the BAME community and create a common understanding and trust among them. Lack of trust for autism professionals and lack of understanding of the

BAME culture are detrimental to autistic people who are in dire need of the support to enable them to live a happy life. The most appropriate kind of awareness campaign structure should involve family support, friends at communal levels including all sectors of society working with the public. Everyone coming into contact with an autistic person/s must understand autism.

### **Collaboration**

A critical requirement for success with autism is collaboration among stakeholders (Kwang-sun et al, 2010). These stakeholders may include service agencies, advocacy groups, parents, schools, family members and friends of families, religious and community heads, disabilities services offices, residential homes for autistic people, career services, the metropolitan police, customer services, and transport and prison services. Collaboration is essential for enhancing social inclusion of people with autism within BAME and their families/carers and also to promote communal awareness and acceptance of autism and to reduce stigma and discrimination. Service providers need to broaden the support menu from currently available services to include community integration for autistic people; culturally sensitive approach to support services; and family-specific care and support services. The Slade (2014) study found that it was necessary for stakeholders to come together to ensure that the needs of different BAME populations are identified and appropriate services are put in place.

### **Conclusion**

This paper has elaborated on some of the challenges autistic people and their families face within the BAME community. With adequate support and understanding of autism, it is possible for autistic people in BAME communities to involve in meaningful social integration programs and also achieve academic development. Achieving that could involve a culturally specific programme for inclusion, family-specific care and support services, awareness programme in improving the understanding of autism and collaboration among stakeholders. With that autistic people could lead a happy and fulfilling lives.

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