

AUTISM VOICE UNITED KINGDOM SYMPOSIUM 2018

Topic: Autism in the BAME Community

Theme 1. Diverse Approaches to Autism: culture, religion and ethnicity

Theme 2. Paving the future for Autism in the BAME

Theme 1 - Diverse Approaches to Autism: culture, religion and ethnicity

CULTURE – In my experience, having a family member diagnosed with autism makes life more challenging for the family. What part does “culture” play in the way the person who has been diagnosed and her family live their lives?

There are some concerns parents in any culture, of any religion and ethnicity all share. For example, parents will worry about what will happen to their child when they are no longer able to take care of her – when they die or get old. In the more developed countries such as the UK, there may be acceptable housing options open to the child/adult- such as residential schools, residential homes or sheltered housing. However, Parents from the Black and Minority Ethnic group in the UK may find themselves asking “follow up” questions - will she get her roti, yam or jollof rice? Will she still hear her favourite music? What about grooming and personal appearance, traditional festivals and rituals?

Which brings me on to the subject of religion. Jamaican by birth, my religious upbringing is based on Christianity. In the Psalms we are told “Children are a

heritage from the Lord and the fruit of the womb is his reward.” It is not always seen in this light when you have an autistic child. Many Black Christian churches have worship services which go on for 4 hours! Not many children can sit still through these events. Some parents may bring a colouring book or toy to occupy their child but sometimes these are not entertaining for long enough. My son enjoyed going to church. He really enjoyed the singing and although he uses very little speech, he would sing verse after verse of many hymns. I still marvel at his listening skills since I do not remember him ever looking into a Hymn Book. He really enjoyed and benefitted from going to church but he was also a distraction. What I do remember is him moving from his seat as the sermon progressed and wanting to touch the ornaments on people’s clothing – the decorative hand kerchief and brooch being two of the ornaments he was strongly attracted to. This really frightened the women! A real “Georgie Porgie Pudding and Pie” he did not have to kiss the girls to make them cry!!

At our week-day prayer meetings, the woman leading the service used to pray for “the demon” inside my son to be cast out of his life. There was one woman who prayed for “The curse” on him to be removed!

In my church it is common practise to invite each other into our homes to eat together after church. My son and I were never invited and my invitation to

others were politely refused. The attitude of my fellow church members left me in no doubt they were wondering “What sin did he or his parents commit?”

The sense of isolation among people from BAME groups is greater than that experienced among those of the resident population. In the UK, many of the families living with Autism are 2nd or 3rd generation immigrants who are seeking to “assimilate” and be “accepted.” The stress of being a member of a minority group, coupled with the “peculiar” behaviour of the person who has autism, decreases the chances of becoming “integrated” – whatever that means! Even when you go to events among people of your own ethnic group, the distinguishing behaviour of the person with autism is not viewed sympathetically. If it is a birthday party being held by Jamaicans, you are likely to hear “Ah two slap him want! Him spoil eeh?!”

Theme 2 - Paving the Future for Autism in the BAME

Prithvi Perepa, BME development officer for the National Autistic Society said:
“It is the right of all children in the UK to access a full education. As a society we must ensure that children from BME communities do not lose out. All

children must be able to access appropriate support and a range of educational provision in order to ensure that their individual needs are met.”

For those affected by Autism, there is a struggle on to be treated as a person with “Rights” - even for education, despite the existence of the Special Education Needs (SEN) tribunal.

National Autistic Society –

Nearly a quarter of autistic children from black and minority ethnic communities have been excluded from school and face “double discrimination” in the education system, a report by the National Autistic Society reports.

American Publication - Autism’s Race Problem: By Carrie Arnold

Pacific Standard Staff

May 25, 2016

“ For years, the medical community has studied and treated autism as a “white person’s” disease, and, today, research and therapy remain geared toward affluent, white people and families—leaving people of color in the lurch.”

My son was not dealt with in keeping with the NICE Guidelines by the professionals involved with his life. Although he was assessed as of average or near average performance for tasks that did not require language, and sent to a school for “Delicate Children” after his first SEN assessment, he was subsequently placed in a weekly boarding school. There he was put on anti-psychotic drugs and he moved from being “average or nearly average” to being described as “severely learning disabled.” He was removed from his family and although medication was successfully withdrawn, the authorities refused to send him back home

In 1996, when I spoke with a health care professional identifying my son’s need for a diet free of dairy products, artificial additives, flavourings and sugar, the response was “NOT FOR HIM!” Despite the reputable test results and my personal records and the evidence I had gathered over years, of my son’s response to these foods, his need for a special diet continues to be ignored. His current Consultant Psychiatrist is weaning him off medication which was re-introduced with disastrous consequences, following the successful withdrawal.

The medical community then diagnosed my son as having Bi-Polar Disorder and took me to court to have me removed as Next of Kin, when he was sectioned. I refused to agree that he should be given a mood stabiliser called Lithium. The Court decided that the recommendations I had been making about

Diet, Speech Therapy Input and Behaviour Management should be implemented under the s3. My son has been in a Mental Hosp. since Nov. 2014. In 2017 the Hospital decided he did not have Bi-Polar Disorder or any Mental Illness. They have been withdrawing the medication and preparing him for return to the Community.

One Professional involved in his care encouraged me to remain a persistent, informed Advocate for my son. The Professional had gone on to say “If you were different, he would have been dead already.”

As is reflected in the general population statistics, BAME people diagnosed with Autism are more likely to be treated as though they are mentally ill than their white counterparts. The notion of “Valuing People”

(‘A New Strategy for Learning Disability for the 21st Century’) was a government White Paper published in March 2001, by the Department of Health, who during the consultation process assumed the role of ‘lead department’.

“Valuing People takes a life-long approach, beginning with an integrated approach to services for disabled children and their families and then providing new opportunities for a full and purposeful adult life. It has cross-Government backing and its proposals are intended to result in improvements in education,

social services, health, employment, housing and support for people with learning disabilities and their families and carers.”

15 years later, the families affected by Autism Spectrum Disorder are still struggling to have their voices heard and people with learning difficulties and their carers continue to have poorer outcomes in all areas of life, including physical health.

From my perspective and based on my experience, the BAME population needs:

- (i) form cells/branches which provide up-to-date info on statutes affecting those affected by Autism e.g. the Carers Act 2014 and the guidelines put out by NICE
- (ii) to become part of organisations such as Autism Voice, which provides a relaxed space in which BAME carers can come together to express concerns, share solutions and form supportive bonds.
- (iii) to develop its own Advocacy System - one in which the advocate involved in your case is YOUR advocate, paid by you to present your concerns and views, not an “impartial” advocate paid by someone else. They say he who pays the piper calls the tune...

- (iv) to partner with other organisation and form an interest group with no other task than to be “Autism Watch Dogs” – informing community and requesting accountability.

- (v) to set up residential facilities for adults that offer life – long education, assistance with getting jobs, complementary therapies e.g. herbs, homeopathy, massage

- (vi) to develop- friendships and support each other as individual and as part of the wider social group – befriending each other.