

Autism in BAME communities – where are we now?

© Paul McKenzie Photography



Venessa's son Nathaniel

Venessa Bobb reflects on the impact of COVID-19 and Black Lives Matter, and what needs to happen to improve support for black, Asian and minority ethnic (BAME) families

COVID-19, social distancing and self-isolation aggressively stopped services for autistic people and their families. Education provisions, local authorities, social services and government were put to the test. Through lockdown, I experienced the uncertainty of not knowing how to support my autistic teenagers. The battle I and many other families face is greater now. Our mental wellbeing has been pushed to breaking point and we all need help, and to be heard.

I would like to make this clear: I cannot speak for the BAME communities, but give an account of my personal experiences during lockdown and what families have shared with me.

In 2008, my middle child, Nathaniel (then aged five), was diagnosed with autism and ADHD, and learning difficulties and severe receptive expressive language in 2019. Between 2017 and 2018, my youngest, Michaela (14), was diagnosed with autism, ADHD, benign rolandic epilepsy and severe receptive expressive language. My oldest, Lashawna (19), is diagnosed with moderate language difficulties and has a two-year-old son, Kairo.

In many ways, 2020 has been positive for me, because I was able to use my passion for

connecting and bringing together all communities and autistic communities via social media.

The pandemic certainly created a stronger force via digital media. National news appeared to ignore the autistic voice, with few mentions of the disability community being caught up in appalling conditions in COVID-19. National and international news hit us with concerns over the lack of recorded data on the number of COVID-19 deaths within BAME communities (but this is old news for anything to do with recorded data), and – as usual – there was a lack of conversation and acknowledgment of those within the BAME learning disabilities and/or autism community.

Saying all lives matter is true; unfortunately, not all lives do matter for the many voices who have been missing at the table.

Autism in BAME communities

BAME parents tend to be less likely to acknowledge autism, and the lack of culturally sensitive support continues within their own communities, as families and friends add to the problem. On top of this is the disproportionate effect of COVID-19 on BAME communities, while government and local services are non-existent.

In areas across the UK, many BAME families will be left out of decision-making. Isolation, cultural-biased views and cultural incompetence have destroyed the livelihoods of BAME autistic people. Poor services and communities are working in isolation when we need to work together to bridge the gap. Autism, race and ethnicity need to be addressed by unpicking and resolving the negative impact across communities.

The death of George Floyd caused a rippling effect, bringing race and divide to the forefront. Online support has resulted in an increase in black and Asian communities seeking advice, help and information. Many local services were unable to meet the needs of BAME communities – the relevant support for those with additional languages, counselling and befriending services for those experiencing domestic violence and

bereavement, families left without resources for their child – before lockdown. In particular, black parents are concerned about police brutality and 'stop and search', while wider communities may never comprehend the additional struggles if it does not affect their groups. Police and emergency services need to be trained on autism, especially with all the negative news around the police in the media.

Connecting people

Over the past four months, A2ndvoice CIC and Lambeth Autism Group have held numerous autism online sessions. I have spoken in the BAME community about my own struggles around autism.

Many BAME families and dual-heritage families have had to deal with tricky questions



Venessa Bobb is Chair of our Lambeth Branch and Founder of A2ndvoice, a voluntary support group run by parents/carers living and caring for a child or adult on the autism spectrum, raising awareness and understanding from different perspectives, outreaching to BAME communities, and tackling the taboos and myths around autism.

Read more from Venessa at twitter.com/A2ndVoice and at www.a2ndvoice.com

around racism and why people are angry. It's these kinds of topics that need to be spoken about – but by people who are able to speak for themselves and not third hand.

Hosting Autism BAME online support for families has been a success in connecting the African, Caribbean, Indian, Spanish and other communities. I have struggled to get help for myself and felt constantly misunderstood by other parents at times – but through my own journey, I am bringing people together and that is good. Working collectively and understanding people's differences, to be able to have healthy discussions about race without assumptions and not denying there are issues for autistic people and their families.

The lack of representation, and understanding, of the different cultural needs and wants, family traditions, language barriers, faith beliefs, loss of translation, communication and sharing of information, all contribute to BAME families being denied a diagnosis, or having one delayed. Many local autism/SEND groups will probably feel uncomfortable talking about race and see it as of no importance. But if you don't understand the cultural needs and wants of a black or Asian family, it can lead to relationship breakdown, distrust and misinformation by misinterpretation.

Over the years, I have attended many autism events and parent consultations that I found via Twitter and my local Lambeth Autism Group. I was often the only black parent to attend these events, through which I connected with many autistic people and specialists. Things are changing slowly, but they need to speed up. BAME and poor white families have complained on many occasions of groups avoiding discussions around race, violence and abuse. These issues need to be included and addressed.

Depending on the geographic areas, many BAME families may have resorted to travelling out of their local area to get support, or to going online to connect with other families who have similar cultural views. It's fantastic news that the National Autistic Society will be looking into how to reach out to the autistic



If the cultural needs of a black or Asian family are not understood, it can lead to relationship breakdown, distrust and misinformation

BAME communities with the help of other specialists and BAME autistic people. Finally, there is something that will help many BAME families nationally.

Schools need to invest in cultural and ethnic books (and not just for annual celebrations), assistive technology, communication tools, and black and Asian autistic specialists' cultural awareness programmes – otherwise, we'll stay missing from the table.