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Autism, Race & Culture

resources for
autism



Research looking into the Intersectionality of Autism and Race in the London Borough of Newham

Newham London

compass wellbeing

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Scope and Objectives of Research

1. Our research aimed to identify themes and issues which can be used on a practical level to influence policy, the local offer and support offered by VCOs, and to stimulate further debate on this important area.
2. Within the ethnically diverse community in Newham, our focus was on autistic people and families of a Black African, Asian Bangladeshi and Asian Pakistani heritage, given that these are the most well-represented ethnic groups in the Borough.¹
3. We specifically sought to understand the barriers to accessing services, and the intersectionality of autism, mental health and ethnic diversity, with a focus on three key factors which we believe to affect ethnically diverse households in Newham most profoundly:
 - a. Stigma
 - b. Language barrier
 - c. Cultural perception of autism

¹The ethnic make-up of Newham is diverse, with a substantially higher percentage of people from diverse backgrounds than the London average (respectively 72.4% to 43.5%). Those from an Asian heritage account for a total of 36% of the Borough's population (Indian 14%, Bangladeshi 12% and Pakistani 10%) (Newham, 2021). The ethnic profile of RfA's service-users who live in Newham closely matches that of the Borough. In Newham, we currently have 369 autistic individuals on our waiting list (259 are ethnically diverse), all of whom do not have access to other support.



Executive Summary

- 1.** Families from ethnically diverse backgrounds experience a high level of challenge following an autism diagnosis of a family member, including lack of support and understanding from the community, peers and schools; limited access to support structures and services; and financial pressures.
- 2.** Families can feel socially isolated and experience stigma following an autism diagnosis.
- 3.** Religious and community leaders have a vital part to play in creating acceptance and inclusivity within ethnically diverse communities, and would benefit from autism awareness training.
- 4.** Strong support, which is both culturally and linguistically specific, will allow for greater access to help and better outcomes for the autistic family member.
- 5.** Cultural and linguistic support and understanding of autism should be given to close family members as early as possible.
- 6.** Further research on the intersectionality of race and autism would be instructive in further influencing policy and provision and ensuring that an intersectional lens is applied by all professionals when working with autistic people of colour



Background

Resources for Autism seeks to work on a practical, data-driven level. At the time of our application for funding, our waiting list for ethnically diverse individuals awaiting support numbered 259, representing less than 10% of our total waiting list. However, we know that this is not reflective of the national picture, given that 48% of our beneficiaries are from ethnically diverse backgrounds. We also know that there are significant barriers facing ethnically diverse autistic people who can face a 'double discrimination', and that they are less likely to be diagnosed, receive benefits or access services and support.

We were thus grateful to receive funding from Compass Wellbeing, to explore the experiences of parents and carers of autistic people from ethnically diverse backgrounds.



Summary of Previous Research

1. Ethnically diverse communities can face significant barriers in accessing statutory services that are not inclusive and/or sensitive to their needs and culture.²
2. According to a YouGov poll commissioned by Autistica (2022),³ there remains in the UK a significant lack of understanding about autism:
 - a. 46% of adults believe *'we are all somewhere on the autism spectrum'*
 - b. 30% of adults are unsure whether autism "can be cured"
 - c. 35% believe that autism is a learning disability
3. Research consistently suggests that early diagnosis, autism-specific interventions and support for carers can improve outcomes for both autistic individuals and their carers.⁴ Identification at an early stage of those who would benefit from interventions and support is key.
4. Individuals from ethnically diverse backgrounds are amongst those cohorts least likely to access health, mental health and care services⁵ and autism support services⁶.
5. 'Collectivist cultures' (which place priority on community interdependence and shared group norms and values) are generally more likely than individualist cultures (which place priority on personal independence, goals and values) to stigmatise people who deviate from the norm. This is partly because such people are more likely to be identified in the community due to high surveillance levels, which such cultures rely upon in achieving their goals of interdependence and group conformity. The two main consequences here are that:
 - a. those identified as deviating from group harmony are vulnerable to being devalued, rejected and stigmatised
 - b. families fear such stigmatisation and consequently hide their circumstances from their community. This in turn has a range of harmful consequences⁷
6. Research in this area can often be ethnocentric in its focus, relying on White British participants rather than utilising a more representatively diverse cohort; this can result in inappropriately designed services or recommendations.⁸



Summary of Previous Research Cont.

7. There is a growing recognition of the need to understand the barriers faced by individuals from marginalised groups which prevent them from accessing and engaging with autism support services.⁹

8. Language barriers, institutional racism, cultural differences, religious beliefs, and family traditions are some of the barriers ethnically diverse groups report as hindering access to services.¹⁰ Other barriers include stigma, lack of respect and stereotypes among professionals, limited knowledge and awareness of autism in some cultures, isolation, and lack of consideration to the intersectional identity experienced by minority ethnic groups.¹¹

9. Ethnically diverse people often do not recognise that they have a mental illness because mental health may be stigmatised or rarely discussed in their community.¹² Moreover, professionals that do not work regularly in the autism space may lack awareness of ethnically diverse cultures and struggle to spot the nuanced differences between a mental health and an an autism diagnosis. It is not surprising that autistic individuals with mental health challenges from ethnically diverse backgrounds report to us a 'triple discrimination' which creates even greater barriers to accessing support.

10. Our findings suggests that awareness is at the root of the stigma that some families felt. This may also lead to late diagnosis and to not accessing relevant services after being diagnosed.

²*Improving the Experience of Community Mental Health Services for Black, Asian and Minority Ethnic People in Tower Hamlets, Newham and City and Hackney* – by Samuel Ogunkoya, East London NHS Trust (<https://www.eleft.nhs.uk/sites/default/files/2022-02/BAME%20Let%27s%20Talk%20Report%202021.pdf>)

³<https://www.autistica.org.uk/news/attitudes-index-news>

⁴Dawson et al. 2010; Smith, 1999; Corsello, 2005; Rogers, 1996; Carter et al, 2011; McConachie and Diggle, 2007

⁵Ajayi, 2021; Ogunkoya, 2021

⁶Slade (2014): *Diverse perspectives: the challenges for families affected by autism from black, Asian and minority ethnic communities* - The National Autistic Society; Burkett et al, 2015

⁷Papadopoulos et al, 2013

⁸Sheikh et al, 2009; Munroe, Hammond and Cole, 2016

⁹Kandeh et al, 2020; Slade, 2014

¹⁰Bobb, 2017

¹¹Kandeh et al, 2020; Ajayi, 2021; Autism stigma and the role of ethnicity and culture, Papadopoulos, 2016

¹²Mental Health Foundation, 2022



Research Methodology

1. We sought to build a foundation for our research by developing a strong understanding of previous findings in this area, through a literature review and a review of reports within the sector. Key themes are noted in the Literature Review section.
2. 54 families completed a carefully constructed questionnaire, which we designed following our research and literature review:
 - a. We included 13 questions regarding participants' demographic and ethnic backgrounds.
 - b. A Bengali version was made available to maximise access.
 - c. We circulated the survey to families who are registered with RfA from ethnically diverse backgrounds who live within the London Borough of Newham. We also promoted it to our partners and contacts across the Borough, and asked them to share it with relevant families.
3. 9 parents participated in private, in-depth interviews over Zoom, with the aim of growing our understanding of challenges during the early stages of their child's autism and their journey as parents of an autistic child. In addition, 53 parents/carers participated in facilitated group discussions at RfA support groups in Newham.

We are aware of the limitations of our findings, particularly that:

1. Our data pool of survey participants and in-depth interview participants is not academically rigorous, nor does it necessarily represent all ethnically diverse people in the area. However, our research does provide a fairly consistent steer and hopefully offers a series of practically attainable recommendations.
2. There were inconsistencies in some survey answers; for example people from a Black heritage answered the question regarding language barriers very differently, but this is likely to be because English is their first language and language barriers were not an option.
3. It may be that harder-to-reach families chose not to respond to our request for involvement, despite our efforts to encourage people to complete our survey in ways that were as accessible as possible, such as over the phone.

In our efforts to mitigate against these limitations, we:

1. co-produced the survey with support from Black and Asian professionals.
2. phoned people to help them to complete the survey over the phone.
3. supported people to complete the survey at RfA parent groups and drop-in surgeries.



Research Findings

1. There is a widespread lack of awareness pre-diagnosis and lack of understanding post-diagnosis about autism in ethnically diverse communities.

Most interviewees acknowledged that they did not know what autism was prior to receiving their child's diagnosis.

- *'When they said my son's autistic, I didn't have a clue what it meant. It was all new to me and to our family as well. It's available now on the internet. There wasn't much when he was diagnosed.'* – Asian Bangladeshi Parent
- *'I didn't know anything about autism before my son was born. So no, we were told they're just ill. Years after my son was born [at the age of four], when they told us he's autistic, I didn't have a clue what it meant, what it was, so it was all new to me.'* – Asian Bangladeshi Parent
- *'So back then in the community, not everyone knew what it was or most people hadn't heard of it so I didn't get much as a support from the community.'* – Bangladeshi Parent
- *One mother noted that only when her son was eight and had been diagnosed as autistic only a few years earlier did she start to understand what autism: 'Now when I go outside I can tell straight away that's a special needs person or if that's autism whereas before I would've thought, if it was an adult misbehaving, he's probably drunk.'*
- *'Most people from my community never heard of autism so I didn't get much support. The older generation don't know as much about autism.'*
- *'In the very beginning I was understanding when my son was diagnosed as an autistic child, then I understand as it theoretically not practically. It's a very basic information they provide when he was diagnosed.'*
- *An African Somali parent said that her extended family viewed her (pre-diagnosis) son as 'ill' and did not know about the condition. At 2 years' old, her son's health visitor did not recognise the signs of autism, which also delayed access to services. He was 3.5 when he received his autism diagnosis. 'The health visitor kept sending me back saying, it's ok, he's still young, just discipline him, just tell him no.'*



Research Findings Cont.

2. Stigma and lack of acceptance can lead to a sense of isolation for a family with an autistic member, whether by their own family, friends or community.

For most survey participants, receiving a diagnosis and raising an autistic child had a markedly negative impact on relationships with immediate family, extended family and friends:

- 65% felt their child's diagnosis created strains within their immediate family, particularly for those with an Asian heritage (68% versus 60% for those from a Black ethnic background).
- 67% noted that their child's diagnosis created strains within the wider family, again at a slightly higher rate for those with an Asian heritage (68% versus 65% for those from a Black ethnic background).
- 55% noted that their child's diagnosis created strains with friends, again at a higher rate for those with an Asian heritage (61% versus 45% for those from a Black ethnic background).

Sadly, stigma remains prevalent, which can lead to a sense of rejection, blame and isolation, precisely at a time when support is most needed, in communities that rely heavily on the family unit.

Comments from interviewees also highlighted this challenge:

- *'It was really hard, not even as a family but in my own house. His father was saying he is going to grow out of it, he is going to turn better.'*
- *'From the day our child was born, our family changed. It impacted a lot in our family, especially with my other two children who couldn't get as much time as my son. Everything now revolves around him.'*
- *'There is a lot of shame I think when he was about four and I brought him to meet my family. We visited their house and it was my mum who recognised something was different. It was really hard for him to have that relationship with his grandma because she didn't want to interact with him much because he is different. It is really difficult with my parents. I tried to explain he has autistic [sic.] but I don't think she really believes me.'*
- *An Asian Bangladeshi parent with an autistic child told us that her husband and extended family (whom her son visits) still don't understand that the child is autistic: 'They don't understand that he's got problems because he's like normal. I do because I'm always living with him. And his dad also doesn't understand that he has problems.'*



Research Findings Cont.

On a positive note, we found that 40% of individuals from a Black ethnic background and 22% of people from an Asian ethnic background felt the diagnosis actually strengthened relationships with family and friends:

- *'It brought everyone a lot closer and my son likes that family is doing things together. We probably wouldn't have done as much things together if my son wasn't autistic.'*
- *'My daughter was 3 years old when my 4-year-old son was diagnosed with autism. She was at nursery and I couldn't spend enough time with her because of my son's special needs. My daughter had a few tantrums growing up so it definitely had an impact on her. She's graduated as a nurse so she understands more now.... My son is sociable and brings the family together. He has a phone with all the family members and contacts them all every day. No other child in the family does that, phoning his gran every day to ask are you ok.'* -Asian Bangladeshi Parent

Some parents also noted that their child's school had been very helpful in providing support and increasing their understanding of autism. The school had provided plans to support the child's needs and also offered an opportunity to meet other carers in similar situations, thus reducing isolation.

3. Lack of support from cultural and religious leaders can reduce a family's participation in communal or religious activity and structures.

A lack of awareness of autism can extend to religious and cultural leaders, impacting on a family's choice to participate in social gatherings, further contributing to a sense of social isolation. Although for many ethnically diverse people the local place of worship offers a vital opportunity to engage with their cultural and religious community, many parents or carers of autistic children experience a sense of exclusion. Our survey notes:

- Only 35% felt that news of their child's autism diagnosis was well-received in their community (45% for Asian families versus 20% for those from a Black African background).
- Only 43% felt supported by their cultural/religious community (55% for Asian families versus just 25% for those from a Black ethnic background).
- Only 45% believe their cultural/religious community has a good understanding of autism (48% for Asian families versus 40% for those from a Black African background).



Research Findings Cont.

- 59% believe their cultural/religious community holds stigma around autism (58% for Asian families versus 60% for those from a Black African background).
- 60% of those from an Asian heritage felt that the leader of their place of worship understands autism and supports their child's needs, while strikingly only 30% of those from a Black African background felt the same.

One interviewee noted a sense that their religious community was unable to include their autistic child while also allowing his parents the opportunity to engage with prayer in the same way as other adults:

- *'He went to the mosque but he's not going at the moment because he runs away. When I'm praying I have to give concentration. I can't look after him. Me and my wife go together, but not at the moment. When our son runs, they get upset. So I said, he has needs. He has a need to run and thinks that this is big, quite open space he can run. Yeah, he's not like me and you, thinking that he needs to sit down.'*

In interviews some parents noted positive experiences and acceptance of their autistic child within their mosque:

- *'Just before Covid first started, all these one-to-one classes, special needs for small groups and all that. Whereas before you would never, so that shows they're more understanding now. I think the schools and speech and language and all that there are sort of coming together and teaching them to think more about it. Yeah, I mean I would like a bit more understanding but before there was nothing.'*
- *'I saw a leaflet that said if you have an autistic child, you can take them to this mosque and I was interested.'* – African Somali Parent
- *'In the mosque, there isn't a separate room so a child with autism would need a certain level of understanding. My autistic daughter attended after-school Koran Studies at the mosque and was well supported by the young, female Muslim teachers. They were mindful and they understood autism.'* – Asian Kashmiri Parent

4. Connection with, and support from, professionals is challenging to obtain.

Many of the parents and carers interviewed felt that professionals do not effectively promote and provide services for ethnically diverse communities. This can lead to a sense of mistrust and lack of crucial support for children. Our survey noted that:



Research Findings Cont.

- Only 29% of participants felt that support was easy to find when seeking diagnosis (32% for Asian families versus 25% for those from a Black African background).
- Only 30% felt that when seeking a diagnosis support was easy to understand (33% for Asian families versus 25% for those from a Black African background).
- 51% agreed that, if needed, services can provide information in your home language (58% for Asian families versus 40% for those from a Black African background).
- 33% of participants feel that professionals understand your cultural background and respect your needs (39% for Asian families versus 25% for those from a Black African background).

Our interviews noted the frustrations of some parents around the lack of support and potential judgment given their ethnic background:

- *'Even the professional people know how there's so much help groups nowadays. When my child was diagnosed, professional services were not supportive. We thought no one really cared.'*
- *'Some of them see that I'm Asian and treat me differently.'*
- *'Raising [an] autistic child is a hundred times harder than [professionally] working with an autistic child.'*

5. Language and communication barriers and a lack of understanding of the 'system' can influence support obtained for an autistic family member.

For many of the parents and carers we interviewed, English is not their first language. One carer with whom we spoke is deaf and communicates with British Sign Language (BSL). This can present problems in multiple ways; for example, a diagnosis entails a new set of vocabulary and terminology around autism, behaviours and support structures or options; those for whom English is an additional language may struggle to respond with effective speed and understanding to a diagnosis as a result:

- *'If I don't speak English, I could have a Bengali translator. I could speak in Bengali, they could misunderstand me and tell the doctor something different.'*
- *'And they didn't send the report. They did diagnosed [sic.] on the day and they said this and that, but they didn't send me the report and all the documents. So I cannot get the support from the right department for his needs for his speech and language. Occupational, any sort of sensory he has. It is a difficult, I couldn't get the support until then.'* – Bangladeshi Parent



Research Findings Cont.

- *One father said that, due to language barriers and not knowing the care system, receiving the support his child needed was a struggle: 'You are making his life worse because the support you're not giving, the delay you are doing. You're not destroying the only children life, you're destroying the parents' life as well. Because I'm the one suffering, I'm the one who's dealing this kind condition. See that my son didn't get the right support in the start. My son didn't get the right support from the social services when he has needs.'*

6. Assimilation into, or equal treatment from, the wider community can be impacted through having an autistic family member.

Assimilation – which is already challenging for many individuals from ethnically diverse backgrounds – is made even more difficult with an autistic family member. A lack of wider societal understanding about autism, which provides challenges for families of all backgrounds, is only deepened when ethnic stereotypes, bias or judgments come into play. This is again exacerbated when a parent or carer may not feel confident in the potentially complex care required for their autistic child, or supported within their own community.

Stereotypes around young black men and criminal intent or behaviour also affect families challenged by their child's behaviour:

- *'So when you need to restrain them [the child, for their own safety], a stranger sees you, they're thinking, why are two big people acting like that towards a child? Can you not, blah, blah, blah, etcetera. Them not knowing that you have to restrain them to do your job because okay, you could let them go. Then what? They come and attack you. So sometimes if the public need to be educated.'* – Father of Black Caribbean heritage
- *'That's the whole thing that happened with the police, where the police had to be educated. Especially with black boys. They could be a black teenager and you could be upset, so he starts smashing, maybe he kicks a car and all that. Or he kicks the shop. Or he's acting in a way where people might say something. So the police come, just sees he as a black youth, just want to arrest him. So making a situation worse so he can't communicate properly. He don't know what's happened. So you made the situation worse.'*



Recommendations from Parents and Carers

During our research process, we asked parents and carers to share constructive, achievable ideas that would help families like theirs:

1. Support community and religious leaders to understand more about autism, so as to make local spaces and places of worship more accessible.
2. Provide information on autism and support services in different languages – in Newham, this particularly includes Bengali.
3. Provide local autism services that are relevant to people from ethnic backgrounds.
4. Provide parent support groups and one-to-one discussion groups with autism specialists.
5. Bring together personnel from schools, social care, health, CAMHS and the Borough to collaboratively shape services, care and education.
6. Offer autism-friendly childcare in the Borough where parents and carers can take their autistic children during non-school days.
7. Support schools to offer opportunities to bring together and educate parents around autism.



Resources for Autism's Recommendations

We would suggest that all recommendations below are designed, planned and delivered through co-production with members of the communities to which they are targeted.

- 1.** Our findings suggest the need for increased awareness-building in, and support for, families and communities to address the stigma and isolation experienced by families with autistic children. This will help to improve access to diagnosis and support, reduce the sense of isolation, and build an acceptance of autism. Our study underscores the importance of cultural sensitivity and diversity in autism research, diagnosis, and support services. With this in mind, we would recommend development of community-based autism awareness programmes that target Black African and Asian communities, to cover early signs of autism, how to access services and how to support autistic children. Programmes should involve community leaders and extended family members
- 2.** The lack of awareness of autism in the Asian and Black communities was a common theme among our interviewees and is an important one to acknowledge because it is likely to have implications on the ability of autistic people to receive an early diagnosis, gain acceptance and the support they require early on.
- 3.** This proves that there is an urgent need for services to support the improvement of autism awareness in society and within the criminal justice system.
- 4.** Information should be provided in different languages to maximise reach and impact.
- 5.** Offer autism awareness training that is specifically aimed at religious leaders, to support them to build truly inclusive, accepting communities lacking in stigma. The need for support is particularly high for religious leaders within the Black community.



Resources for Autism's Recommendations

6. Promote anti-stigma messaging to challenge negative attitudes towards autism and autistic people. Messaging could focus on the strengths and abilities of individuals with autism and emphasise the importance of accepting and supporting them. Messages could be disseminated through social media, local media and community events, potentially supported by respected local figures or influencers.
7. Develop support groups for families with an autistic child, to build emotional resilience and provide useful resources, as well as to give an opportunity to connect with other families going through similar experiences.
8. Encourage collaboration between healthcare providers, educators and community organisations to better support families with autism.
9. Conduct follow-up research to better understand the experiences of Black African and Asian families who have an autistic child and how that experience compares with that of white families. This could include the impact of culture, language and stigma on diagnosis, treatment and support. This research could inform the development of more effective interventions and support for families.



Acknowledgements

Resources for Autism expresses its warmest thanks to all those who participated in our research. We appreciate that, for many parents and carers who shared their personal experiences, there are many emotional challenges inherent in a family member's diagnosis.

Our thanks go to RfA's Project Co-ordinator Kenny Shaw, who oversaw the project and led the interviews, and to RfA's Co-Production Lead Daniel Bendelman, who was the lead researcher the project.

It is our hope that our findings make a difference to the lives of those involved, as well as to all those families and communities seeking to support autistic people and allow them to be free and happy, and able to lead fulfilling lives.