

# Diverse perspectives

The challenges for families affected  
by autism from Black, Asian and  
Minority Ethnic communities



Accept difference. Not indifference.

# Contents

---

<b>Foreword</b>	<b>3</b>
<b>Background</b>	<b>4</b>
<b>Main findings</b>	
Challenges in getting a diagnosis	8
Awareness and understanding of autism in people’s communities	9
The impact on families	12
Barriers to accessing support and services	16
Communication with professionals	18
<b>Discussion and conclusion</b>	<b>21</b>
<b>Our recommendations</b>	<b>22</b>
<b>References</b>	<b>23</b>

Written by **Guy Slade**

# Foreword



Families in England from Black, Asian and Minority Ethnic (BAME) communities, who have a child with autism, can be hit by a double whammy when it comes to their health and wellbeing. Firstly, services for people with autism are still lacking in many areas. Although progress has been made since the Autism Act 2009, many families are still waiting for the support they need. Secondly, ethnicity remains a key determinant of health inequalities in England. BAME communities can face inequality of access to healthcare, poorer health outcomes and lower levels of knowledge about health issues.

So I was very pleased when The National Autistic Society (NAS) announced plans to research the experiences of families from BAME communities who are affected by autism, and was delighted to host an event in Parliament to launch the project.

My own constituency in Hackney is one of the country's most diverse, including a large Orthodox Jewish community, diverse Caribbean and Turkish communities, and significant numbers of people who have come to the area from Africa and South Asia since the 1950s.

The experiences of autism in such diverse communities inevitably vary considerably. However, this report draws attention to a clear, common message. Policy-makers and commissioners must properly assess the needs of BAME communities when producing autism policy and commissioning autism services. The evidence is that communities typically need more accessible information, culturally sensitive support and innovative forms of engagement, whether to improve diagnosis or ensure families can access services.

I hope that this report will contribute to the ongoing battle for *all* families affected by autism to be included in their communities and get the high quality support many so desperately need.

**Diane Abbott MP**

# Background

## About autism

Autism is a serious, lifelong and disabling condition that affects the way a person communicates with, and relates to, other people.

Autism is a spectrum condition which means that, while all people with autism share three main areas of difficulty, their condition will affect them in different ways. Some people with autism are able to lead relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. Everyone with autism has difficulties in the following three areas.

- **Social interaction:** it can be harder for people with autism to recognise and understand other people's feelings and express their own, making it difficult for them to 'fit in' socially. Many adults with autism are socially isolated and their family may be their only form of social contact.
- **Social communication:** people with autism have difficulties with both verbal and non-verbal language. Many have a very literal understanding of language, and think people always mean exactly what they say. When talking to professionals, adults with autism will benefit from meetings which are set up to take account of their preferred style of communicating. They may like to have an advocate present who can help them express their needs and aspirations.
- **Social imagination:** people with autism may often find it hard to understand and interpret other people's thoughts, feelings and actions, predict what will happen next and therefore prepare for change and plan for the future, understand the concept of danger, for example that running on to a busy road poses a threat to them, engage in imaginative play and activities or cope in new or unfamiliar situations.

In addition, people with autism may experience over- or under-sensitivity to sounds, tastes, smells, lights or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech, but still have difficulties with understanding and processing language.

## About The National Autistic Society

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism. We were founded in 1962, by a group of parents who were passionate about ensuring a better future for their children. Today we have 20,000 members and over 100 branches, and provide a wide range of advice, information and support as well as specialist services to 100,000 people each year. A local charity with a national presence, we campaign and lobby for lasting positive change for people affected by autism.

## Project launch and formation of advisory group

This project was officially launched in February 2013 at an event in the House of Commons, hosted by Diane Abbott MP. The development of this project and production of this report, was supported by an advisory group. We would like to thank the following members of the group: Lauren Barnes, Amanda Batten, Venessa Bobb, Trudi Clay, Amy Crinnion, Parmi Dheensa, Felicia Higgins, Dee Johnson, Faria Khan, Daniel Knox, Nana-Ama Kyefi, Sam Mukherjee, Prithvi Perepa, Akib Qadir, Imran Safdar, Shakil Salam, Diana Seach and Nichola Smith.

## Definitions and Terminology

Language and concepts of ethnicity and cultural identity are complex. A person's sense of ethnic and cultural identity can be complicated, fluid and highly personal. During the focus groups, participants were invited to self-define their ethnicity. For instance, people described themselves variously as 'Black British', 'Asian', 'British Asian', 'Black Nigerian', 'Somali' and 'Vietnamese'.





# Background

In this report, we use terms such as ‘BAME’ (Black, Asian and Minority Ethnic) and ‘community’. We recognise that such terms are ambiguous, fluid and open to discussion, and indeed this view was expressed in the focus groups. Different people have different attitudes towards terminology, and we do not aim to reconcile the differences and complexities in this report. The terms we use are not intended to assert a single identity on participants, or to negate the different circumstances and experiences of individual families. No one person or focus group is able to speak on behalf of all people from BAME communities or all people from a particular community.

Throughout this report, unless otherwise specified, where we refer to autism we are referring to the entire autism spectrum, including Kanner autism, Asperger syndrome and high-functioning autism.

## Previous research and rationale

Previous research has indicated that people with autism from BAME communities are less likely to be diagnosed, receive benefits and access appropriate services.

The National Autistic Society’s *Make school make sense* research (2007) found that children with autism from BAME communities experience discrimination in relation to disability and ethnicity. It found that there was inconsistent evidence about the prevalence of autism in various communities. Services were not meeting people’s cultural needs and there was a lack of awareness of rights and relevant services in some communities<sup>1</sup>.

Lindsay et al. (2012) found that the prevalence of diagnosed autism in pupils of Asian heritage was half of the prevalence in White British pupils. Meanwhile, the prevalence of speech, language and communication needs in Black pupils was almost twice as high as for White British pupils. It was concluded that there is a need to raise awareness of autism among Asian communities, improve outreach and review the extent to which services are configured appropriately for access by ethnic minority groups.

The Equalities National Council and Scope (2012) found that many of the disabled people from black and minority ethnic (BME) backgrounds in the UK are unable to access the services they need. Their research showed that 44% of BME disabled people are living in household poverty, compared with 32% of all disabled people and 17% of the population as a whole. BME disabled people were less likely to be receiving benefits, with Bangladeshi disabled people having the lowest uptake of Disability Living Allowance of any ethnic group. The ‘inverse care law’ was identified as being at play in BME communities, with those disabled people most in need least likely to be receiving care and support.

Following The National Autistic Society’s report, *The way we are: autism in 2012*, we concluded that families from BAME communities had been underrepresented in the survey that informed the report. There was also limited evidence of the lived experiences of families from BAME communities in the UK who have been affected by autism. In 2012, The National Autistic Society therefore decided to carry out focus groups with parents and carers of children with autism from BAME communities to explore the barriers that they face in accessing services which can inform recommendations for decision-makers.


## Methods used in conducting the project

Thirteen focus groups were conducted in England in October and November 2013 in the following locations and by the following organisations or individuals: Tottenham, Peckham, Mitcham (A2ndVoice and Autism Community Project), Enfield (Enfield Parents) and Lambeth (Fleur Bothwick) – all in London; Radlett (Hertfordshire) (NAS); Gloucester (Gloucestershire BME Focus Group); Nottingham (NORSACA); Birmingham, Rotherham, Sheffield and two groups in Wolverhampton (Include Me TOO).

The groups involved 130 participants in total. Of these participants, 71 identified themselves as either Asian or specified Indian, Pakistani, Bangladeshi, Chinese and

<sup>1</sup>Corbett, C and Perepa, P. (2007). *Missing out? Autism, education and ethnicity: the reality for families today*. London: The National Autistic Society





Vietnamese; 56 identified themselves as black; two as white; and one as Middle Eastern. Almost all participants were parents, siblings and carers of children with autism. Two were adults with autism. 106 participants were female and 24 were male. A number of these were people who accessed support groups for people from BAME communities and therefore some of these issues could be specific to certain groups of people within BAME communities.

The discussion focused on the needs and experiences of children with autism and their families and carers. The organisers worked from a structured discussion guide and were advised to run two-hour groups. In practice some groups lasted up to four hours.

Participants were asked to consider three key questions.

- > What support do you and your family need in relation to autism?
- > What are the challenges in getting the help that you need?
- > If it has been difficult to get help, why do you think that is? Participants were encouraged to consider the possible impact of ethnicity, faith and religious beliefs, gender and language.



# Main findings

To a large extent, the themes that emerged from our focus groups reflect the challenges for families affected by autism, including White British families. Many participants stated that their difficulties were primarily related to their child's autism, not their ethnicity. However, many also faced additional challenges that appear to reflect shared experiences within BAME communities. This project investigated families' difficulties. However, our results also showed that families and communities can also be a valuable source of support for people with autism and their carers. Similarly, services do provide a lifeline for many families.

## Challenges in getting a diagnosis

Participants reported difficulties and delays in getting a diagnosis. They highlighted the problem that without a diagnosis, it is difficult to access any services and funding. Previous research by The National Autistic Society<sup>2</sup> has found that developing a pathway to diagnosis is one of the key actions that local areas are struggling with following the 2010 Autism Strategy. Furthermore, families identified a number of reasons why they had not sought out or been recommended an assessment.

## Schools not noticing the signs of autism

Families often depend on schools to identify indications of autism in their children. However, some parents thought that there was an initial tendency, especially within schools, to label their child with a behavioural issue. Some parents felt that there was an assumption that black boys are badly behaved and more liable to social exclusion. Participants felt that further assumptions are made that families are to blame for bad parenting that causes behaviour. They said that it was hard to convince schools, even following a diagnosis, that autism was the cause of behaviour. They felt this was due to persistent assumptions that their child was being 'naughty'.

"They're almost pre-programmed to see the bad stuff." – Parent

"The barriers that BME families can experience are misdiagnosis or no diagnosis. My son was originally diagnosed with emotional and behavioural difficulties, but after much persistence on my behalf was eventually diagnosed as autistic on the Asperger spectrum." – Parent

Assumptions about a child's expected language abilities can also delay their diagnosis. For instance, participants thought staff in schools had believed their child's delayed development and speech was due to them speaking another language as their first language.

## Low awareness of autism and child development

While there may not be widespread understanding of autism among the general public, some participants considered levels of understanding of both autism and normal child development to be lower in some communities than in the wider population. Parents had not accessed diagnosis services as quickly as they might have done due to their lack of knowledge of autism.

In some cases, when a child's development had been recognised as different, views within families or communities that someone or something was to blame for the child's behaviour caused a delay to assessment and diagnosis. The solution or cure was therefore seen to be, for instance, physical discipline or prayer by some.

<sup>2</sup>The National Autistic Society (2013). *Push for Action*. London: The National Autistic Society



## Awareness and understanding of autism in people's communities

Whilst tight-knit communities can be an important source of support for people, many participants reported encountering hostile and judgemental attitudes. For instance, they felt people made assumptions that bad behaviour was due to their parenting. Parents felt unwelcome in public places, including shops, on transport, places of worship and libraries.

### Shame and blame

Shame and blame were recurrent themes in the focus groups, relating both to within families and the wider community. Shame was felt when a child's autism was thought to reflect badly on a family or a parent. Participants felt that their families were judged by other people for not being 'normal'. Blame was commonly experienced as a view that the child's condition was not natural, and therefore was the result of something wrong that someone had done.

### Shame and blame in the local community

Many parents had chosen to hide away their children. They did not take them to social occasions or public places in order to avoid awkward situations and the embarrassment or shame that can result from disruptive behaviour and other people's judgement of this behaviour. Some participants emphasised that their faith gave them strength and helped them to be resolute and accepting of their circumstances. However, others reported that they face judgemental attitudes and a lack of support from faith groups and at places of worship. Some participants reported low awareness of, and intolerance towards autism, as well as other disabilities, at churches and mosques. Therefore, families are not able to turn to others for support, and some stay away from public places and social occasions, increasing their sense of isolation, stress and despair.

### Case study: Pam and Aisha

Pam has three children, including her eldest daughter, Aisha, who is nearly 19. Aisha was diagnosed with severe autism and learning disabilities when she was three. Pam lived in London for 15 years where she had access to great personal and professional support for her daughter, including a specialist school where Aisha was very happy. She moved to Leicester to be closer to her parents and now works from home to help with Aisha's care. However, she has found it challenging living in a predominantly Asian community in a smaller city.

Pam is Sikh and believes that attitudes in the community itself are having a detrimental effect on families like hers living with autism. She thinks that there is still a lot of stigma associated with having a disabled child, so parents prefer not to talk about their child's autism diagnosis. She knows families who have been discouraged from attending events with their children at the Gurdwara because they have experienced negative responses.

Pam is very open about Aisha's diagnosis and passionate about raising awareness of autism within the Asian community. She regularly receives positive feedback from parents in similar situations. Pam feels that families would benefit enormously from access to tailored autism resources, available in Punjabi, and would like Asian family autism networks to be established in places of worship. She hopes that by talking publicly and celebrating her daughter's life, this will encourage others to be more open about their own experiences and will help to change attitudes.

# Main findings

## Case study: Bose and Ayo<sup>3</sup>

Bose is married, with three children, including her 18-year-old son, Ayo. He was diagnosed with autism at the age of two. She was born in the UK but lived in Nigeria until she was 21, when she returned to England. She now lives in a small Nigerian community based around the local Christian church.

She had not heard of autism until her friend suggested that Ayo had communication difficulties. Bose decided that Ayo should be assessed. She took him to Nigeria to see the family doctor, who said that he may have autism. This was confirmed by a specialist when they returned to the UK.

Ayo has complex needs and requires support to do things such as getting dressed and going to the toilet. He attended a mainstream nursery before his energetic behaviour and support needs became too much for staff. Bose had to cut her working hours so she could look after him at home. She managed to secure a statement of special educational needs for her son when he was three. He was then placed at NAS Radlett Lodge School, which caters specifically for young people with autism up to the age of 19. Bose is looking for adult centres to support him when he finishes school next year.

Although Bose has received a good level of support from professionals and her immediate family, she has had a different experience in her local community. She feels that most people stay aloof from Ayo's struggles. She partly attributes this apathy to some people from her local church thinking that disability and bad experiences are a spiritual attack. As a result, people can be reluctant to interact with people with disabilities in practical ways, unless they are part of the immediate family. There have also been a few occasions when people have told Bose that her son did not have anything wrong with him and that he was just badly behaved, suggesting that her parenting was to blame.

Bose has learnt not to expect any direct help or support from the majority of the local community and instead relies on her husband, social services and professionals for emotional support. However, Bose and Ayo are very active in the church and local community, and attend various social functions. Bose believes that there is a growing understanding of autism in her local community, but there is still a long way to go until people like Ayo can be properly included.

<sup>3</sup>Names have been changed to protect identity.

## Shame and blame in communities beyond the UK

Participants said that the attitudes in a family's 'home' country can also have a strong impact on their lives. Families who speak with and visit family in their 'home' country reported being exposed to influences and beliefs that are more prevalent in that country.

It was reported that their 'knowledge can be reversed' by such visits. Families can be exposed to messages from the culture, which can carry a strong influence and counteract the knowledge that families might have developed about autism in the UK. For instance, people confronted beliefs that disability is unnatural, someone is to blame for a child having autism, or that the child needs to be 'cured'.

These messages can interplay with insecurities and tensions that already exist within families who feel that they are part of different cultures. For instance, discussions about how to respond to a child's autism diagnosis had exposed wider family tensions about whether the second generation is maintaining the 'home' traditions and faith or is becoming increasingly westernised, including through their understanding of autism.

## Cultural stigma and negative views

Many participants talked about the stigma attached to disability in general that was prevalent in some cultures. They described beliefs that autism was caused by bad parenting. These views were accompanied by beliefs that the child's condition might be 'cured'.

Within wider culture, it was felt that there are no role models or high-profile examples of people with autism from BAME communities. Therefore, people had associations with autism as a white-only condition, and not one that they had expected to encounter in their children.

## Case study: Gershom

Gershom is an Ambassador for The National Autistic Society in Bristol. He was inspired to make his community more autism-friendly because he has a son with autism. He especially wants to engage with people from BAME communities. His own experiences, and those of other families, indicated that there was a particular lack of autism awareness in local BAME communities.

With support, Gershom has developed a plan of action. He is identifying key council-run play facilities in BAME communities. He is meeting with staff to tell them about autism and encourage them to adapt their environments as required. Further down the line, he will request to meet with council officers to discuss whether they could develop an 'autism-friendly accreditation' award for these local facilities. Gershom is also working to highlight autism issues through local BAME forums, and BAME issues through local autism forums.

He has also been contacted by some local families, seeking specific advice about coping with autism as a member of a BAME community in Bristol. Gershom continues to provide signposting advice and guidance about autism both locally and internationally.

# Main findings

## The impact on families

Participants reported a range of ways in which their families responded to an autism diagnosis. Close relationships with supportive family members were vital for some parents. Others, however, experienced denial that a child within the family could have autism. Feelings of shame and blame resulted in tension and conflict in people's immediate and wider families. The burden of practical care and emotional engagement with autism often fell more heavily on mothers. As well as coping with their children, many had to deal with denial, frustration and blame from their husbands or wider families.

## Denial

Some families initially refused to acknowledge that they faced a long-term problem, or that their child had autism. Instead, some hoped that the situation would resolve itself naturally and the child would somehow 'grow out of' their condition. In particular, it was suggested that men are often more reluctant to accept a diagnosis or engage with the realities of autism.

*"I thought, 'My son can never be autistic. They are crazy people. Not my son.'" – Parent*

Partly for this reason, many families are keen for their child to continue at mainstream school and hope that the child will somehow acclimatise to being 'normal'. It was reported that some communities attach stigma to special schools and specialist services. People fear that their child could learn bad habits from other children, which would reinforce or exacerbate their child's behaviour and condition.

Denial of their child's autism can be compounded by assumptions about male behaviour. Some families assumed their son's behaviour was 'a boy thing' related to naughty behaviour or late development.

Some cultures traditionally place a strong emphasis on continuing the family line, including arranging marriages

at an early age. Families particularly struggled to accept an autism diagnosis when they also felt a responsibility to ensure their child gets married.

## Isolation of parents and carers

Parents had experienced isolation both due to their child's autism and due to expectations of their behaviour. There are norms within certain cultures that discourage certain contact with the wider community. In particular, some women were expected to restrict their social contact by not speaking with men beyond the family. Some were also expected not to leave the home in the evening. This created a significant barrier to accessing support groups. As a consequence of attitudes in people's communities that have been discussed, families can become isolated and alienated from their extended family as well as the wider community.

In many families, a patriarchal culture was described where fathers expect to exert greater control over households, and childcare is seen as the woman's responsibility. As well as caring alone for the child with autism, women had been criticised for neglecting their other responsibilities as a wife. Female participants speculated that men are more likely to feel that an 'abnormal' child reflects badly on his own status and identity. He may therefore feel threatened by the situation, and less willing to accept it.

Furthermore, participants thought that men are less willing to express their emotions. It is therefore often harder for fathers to access support networks and talk to others as a way of helping them to explore and understand their emotions. It tends to be easier for women to encounter other mothers or carers in the course of their everyday lives, whether when visiting neighbours, the school, their GP, or other places in the community. Women considered themselves more likely to discuss personal matters.

Some families had believed that their difficulties should remain private and not be discussed outside of the home. Parents wished to maintain a sense of pride associated with caring for their children independently.





### **Case study: Sheffield Parent Carer Forum**

The Sheffield Parent Carer Forum wanted to address the underrepresentation of parents and carers from a BAME background within the Forum. In Sheffield, the proportion of disabled children from the Pakistani and Caribbean communities is much higher than for other BAME groups. The Forum therefore initially concentrated their efforts on these two groups.

In order to reach parents from the Pakistani community, they set up a partnership with four nurseries and Children's Centres in areas of Sheffield with a large Pakistani population. They organised two outings to softplay centres for families of children with additional needs who attend these settings. The outings were very popular, mostly attended by families from Pakistani, Bangladeshi and African Caribbean backgrounds who had not previously been aware of the Forum.

A different approach was required for the Caribbean and White/Caribbean community, which is not as concentrated in specific areas of the city. The Forum worked with the Sheffield and District African Caribbean Community Association (SADACCA) to organise and publicise an information event for parents and carers. The event, hosted at SADACCA, featured an information market place with stallholders, a free crèche, activities for children, pampering sessions for parents and a free lunch.

At both events, volunteers chatted to the parents, gave information about the Forum and signed up many as new members. Feedback showed that families really valued the opportunity to meet other parents in a similar situation, which made them feel less isolated. In total, the number of Forum members from a BAME background almost doubled in just three months. The Forum intends to continue building on its links within the local BAME communities to increase membership and involvement with the Forum.

### **Siblings**

It was reported that siblings of children with autism had felt neglected. They can feel that the child with autism receives all the attention. They see the child with autism being 'allowed' to get away with certain behaviour. Indeed, siblings can learn disruptive behaviours from the child with autism.

Siblings also take on the role of carer at home and school and in public places. Many feel responsible, and this can add to the pressures of growing up and finding their own identity. At times, they can feel embarrassed about or resentful towards the child with autism.

Siblings within families identified feeling a particular responsibility if their household was relatively isolated. For example, some siblings' parents are migrants to the UK and do not speak English or do not feel confident engaging with services and other people in their local community.

### **Shame and blame within the family**

Participants described feelings of shame and blame within their families that had created and increased tensions, particularly between parents. For instance, fathers had blamed the mother for having done something wrong in pregnancy, such as having an affair or not living and eating healthily.

# Main findings

The shame of the immediate household in some cases reflected on the extended family, so that people in the wider community spoke badly of the family as a whole. Therefore, extended families have voiced their opinions relating to a child's autism as something which affects them as well as the immediate household, including

adding to accusations and tensions. Extended families have also distanced themselves from the household, or households have felt ashamed and therefore avoided their extended families. This has further isolated families affected by autism, and further reduced the support available to them.

## Case study: Amina and Mussa<sup>4</sup>

Amina was born in Gambia and grew up in Senegal as a French speaker. She emigrated to the UK when she was 20 years old. She now lives in North London, is 35 years old and is a lone parent of three children, including an 11-year-old boy with autism called Mussa. When he was diagnosed in February 2013, Amina had never heard of the condition and struggled to comprehend what it was. She attributes this partly to being a French speaker, who speaks English as a second language.

Amina believes that people with disabilities are stigmatised in Gambia and among the primarily Gambian, Senegalese and Somalian communities with whom she lives in London. She has heard of babies or children with disabilities often being abandoned in Gambia and Senegal, where they are a source of shame. She says that many people believe that women who give birth to children with disabilities are being punished for mistakes made during their lives.

Amina has therefore not told people in her community about her son's diagnosis. She is afraid that she would be ostracised or it would damage his prospects. She also feels unable to tell her family back home or the family of her ex-husband, who is Mussa's father; she is concerned that they would think she is blaming them for her son's condition or would encourage her to leave him. This has left her isolated and without any support outside of the state and voluntary organisations. She is very lonely.

Mussa experiences difficulties with social communication and interaction. He finds it hard to read unwritten social rules and to determine whether his behaviour is appropriate in a given situation. This can sometimes lead to behavioural problems at school and at home with his sisters. Amina used to work in a care home but had to leave her job to take care of Mussa, as his school was often calling during the day asking for him to come home. He now attends a special school, but Amina is concerned that it does not meet his needs. However, with her support, she has seen improvements in Mussa's social understanding and behaviour in recent years and remains hopeful for the future.

<sup>4</sup>Names have been changed to protect identity.





# Main findings

## Barriers to accessing support and services

Once children were diagnosed, families reported a lack of information about autism. Parents found it difficult to find advice on what strategies they could use to support them having a child with autism, and about what services were available to them. Where information was available, it was thought to contain too much jargon. People wanted information and resources that are clear, concise and accessible.

## Language and communication barriers

Many parents and carers, especially migrants from non-English-speaking countries, face a particular challenge when trying to understand autism and what services are available. Often information was only readily available in English. Families did not have access to translators or professionals who could speak their language. Many people explained that they do speak English, but struggle to understand professional jargon or would be better able to express themselves in another language. An example was given that a Nigerian may typically speak English, but might not feel confident asserting themselves in a discussion with a UK professional about their child's health and education. Therefore, some participants emphasised the need for support, information and resources to be available in their preferred languages.

Where interpreters are available, they do not always give accurate information. Examples were given of when interpreters misunderstood or inserted their own cultural assumptions, losing the clarity of what the professional might have been seeking to communicate. Some families are forced to rely on a family member, which might include a child, to act as an interpreter, but sometimes these 'informal' interpreters are only capable of partial comprehension and translation.

## Case study: Tower Hamlets Autism Support

The National Autistic Society's Tower Hamlets Autism Support service provides support to families through home visits, telephone support, group workshops and support groups. The Family Support Worker provides friendly, knowledgeable, autism specific emotional and practical advice and support for all families. As the majority of families using the service are from BAME communities, it is tailored to be sensitive to cultural needs and provides interpreters, as well as translated literature.

Seventy per cent of people using the service speak Bengali. A specific interpreter has been used over time by the service to interpret and translate into Bengali and Sylheti. This interpreter has attended training on autism at the service. She has built an understanding of autism and how best to translate terminology into Bengali and Sylheti. Otherwise, translators can use words that have a negative connotation in those languages, or incorrectly refer to autism as a disease, for instance. People are able to phone the interpreter directly with enquiries, and she then liaises with the service. Some service users cannot read in any language, so being able to speak with someone is particularly important. The service has asked other interpreters that it employs to attend their training on autism so that they better understand the condition and its associated terminology.

Post diagnosis workshops are provided in partnership with other services in both Bengali and English. The Bengali workshop is also tailored to be culturally sensitive. It includes the most relevant issues that have emerged from previous workshops, for instance marriage, self-blame and stigma.



## Difficulties accessing the right type of support

Participants reported not being given full information about available services and funding, being discouraged from pursuing support and being told that they cannot access particular services.

The process of trying to obtain support was described as bureaucratic and complicated, obstructed by a lack of information and a lack of communication. Families' requests for help were passed around between different teams, and parents and carers had to repeat themselves. They felt that they could only access the right support once they reached a crisis point, for instance if their child had been excluded from school. It was considered especially difficult to access support if the child had high-functioning autism.

Participants felt that services were not promoted appropriately for their communities, and that support failed to take into account the specific needs and attitudes that are common in their communities. Furthermore, those who lived in more deprived areas thought that they were offered lower quality services as a result.

Many reported difficulty in accessing personalised support, which was tailored to the particular needs and circumstances of their family. They felt that professionals need to listen to families and value their expertise in suggesting interventions based on their in-depth knowledge of the individual.

In order to relieve isolation and stress, many participants talked about the importance of short breaks and respite services during daytimes, evenings, weekends, and holidays. These would allow parents and carers to restore their energy and have time for other activities. Many participants reported that they did not have access to sufficient respite services, which added to their levels of stress, isolation and exhaustion. However, short breaks and respite care had initially been considered inappropriate by some participants, because they did not want to fail, or be seen to fail, in their duty to care for their child.

"[People with autism from BAME communities can access the services they need] but I do not believe that services are utilised or promoted in BME communities in the right way" – Parent

"[People from BAME communities] face a raw deal as their needs are not understood in their cultural and religious context." – Parent

"I think that BME communities face more challenges than other communities when trying to access services and gain information. One of the reasons is [people from BAME communities are] more likely to live in deprived, disadvantaged boroughs and as there have been many budget cuts (but even before cuts), the services that we (the BAME community) have access to are not of the same high standard as in, for example, the more affluent areas." – Parent

# Main findings

## Communication with professionals

Many participants reported encounters with mainstream health and education professionals who did not understand autism and had no training or experience in autism. Therefore, many professionals lacked awareness about available and appropriate services. Participants faced additional challenges when dealing with professionals. Some lacked the necessary skills or confidence to communicate effectively with professionals. Some also felt that professionals treated them badly, made assumptions about them or misunderstood them due to a lack of cultural competence. Participants also wanted more recognition that they had valuable knowledge and expertise about their individual child.

## Meeting professionals

Many families described feeling intimidated, or lacking confidence, when communicating with professionals. Some felt that professionals had patronised them, or not listened to them properly.

Families, especially those who are first-generation migrants, felt nervous and lacked confidence. Alongside language barriers and a lack of familiarity with the healthcare system, people were reluctant to assert themselves due to their own deferential attitude to figures of authority and concerns that they would be denied services if they were too demanding. Some people had found it difficult to relate to professionals from a different ethnic background, and as a consequence felt excluded.

"White families meet white professionals and seem to be on personal terms. We are made to feel like outsiders." – Parent

Families had also experienced low confidence and self-esteem or had expected discrimination if they were unfamiliar with or felt excluded from mainstream culture. Previous experiences of prejudice had affected

people's confidence, making them feel less able to assert themselves and articulate their needs.

## Professionals' attitudes towards families

Professionals were perceived by some as making assumptions about families, which led them to dismiss or ignore those families' views. For instance, some participants thought that professionals had assumed they lacked intellectual capacity because they have a strong accent or language difficulties.

"Black parents are often branded as trouble makers." – Parent

"[It's assumed that] Asian families are out for what they can get." – Parent

Specific behaviours within cultures were identified which were misunderstood, leading to delays in providing appropriate support. For instance, in some cultures a child is taught to avoid eye contact with adults as a sign of respect, but professionals had interpreted this as unusual. In some cultures, it is normal to eat certain foods with your hands, but children have been expected to use a knife and fork when at school.

It was suggested that people from some communities tend to express themselves more volubly and passionately than most British people, particularly when they feel frustrated or ignored. Professionals can misinterpret this as volatility and aggression, labelling parents as overbearing and difficult.

Participants reported a lack of professionals from BAME communities within services. Some thought a more diverse workforce could help to increase understanding, for instance of different beliefs and stigmas, within services. Some might also be better placed to engage with families directly and provide effective support.

However, others argued that professionals from BAME communities are not necessarily supportive and understanding. They were concerned that professionals from a similar background had also misunderstood them and made false assumptions, based on their own cultural experience, rather than engaged with the particular circumstances of the family.

Many participants emphasised the need for professionals to understand autism and to be responsive to the individual, as well as aware of cultural norms. Therefore, they argued, it is not necessarily better to access a professional from the same or similar ethnic background, but one who understands autism and is able to listen and engage with families' specific circumstances.

*"There are many and varying challenges: in particular cultural differences are not adhered to, one size does not fit all, and there is a perception amongst professionals that we are making excuses for our badly behaved children." – Parent*

### **Perceptions of professionals**

Participants reported that people in their communities could be unnecessarily suspicious of professionals and authorities. These perceptions had been reinforced by some people's experiences in their 'home' country, where government bodies were regarded as corrupt, bureaucratic, unhelpful, and likely to favour particular communities over others. Some participants were critical of other families for assuming in advance that 'white' professionals would discriminate against them and not provide them with support.

### **Inadequate support and understanding at school**

Participants report that schools are not always understanding or responsive to children's needs and circumstances. Some described low awareness of autism among staff. Even after a diagnosis, they felt some staff perceived their child as badly behaved, rather than dealing with a challenging condition. Teachers had made negative comments to parents about the behaviour of their child.

Parents also reported a lack of understanding and empathy among other pupils. In some cases, their child had been bullied, teased and excluded from activities. Schools had reinforced this isolation of their child by asking for the child to stay at home when there was a school trip. Participants felt strongly that their children should not be isolated or alienated because of their condition.

*"We're told that if our children are outspoken they are aggressive, and as parents we are ignored when we express our concerns. Schools should have awareness throughout the schools in different languages." – Parent*



# Main findings

## Case study: Melanie and Raekwon

Melanie, 42, was born in the UK to Jamaican parents. She and her nine-year-old son, Raekwon, live in Wolverhampton.

Raekwon was diagnosed with autism when he was two. He can struggle to communicate and relate to others. He has high support needs, is non-verbal and interacts via Makaton, a form of sign language specifically for people with disabilities. He is highly sensitive to taste, smell and touch, which causes difficulties with clothing, drinking and eating.

Raekwon has received appropriate support ever since his diagnosis. He has a statement which allowed him to go to a nursery for children with special educational needs (SEN) and then to an autism-specific school which he still attends.

Melanie believes that her Jamaican heritage gave her a passionate personality. In the world of SEN, where parents often have to fight to get the support they need, she believes this helped her to secure the support her son needed. This was particularly beneficial when he wasn't receiving the support his statement entitled him to at school.

However, Melanie believes her passionate nature has at times been mistaken for aggression by some professionals and she worries that similar characteristics in other families from a Jamaican background may adversely affect their chances of getting support.

Melanie is a trustee on the board of a charity called Include Me TOO which has helped her to have a voice and represent her son. She now works with them to raise awareness of autism in her community and to ensure that cultural and language differences no longer remain a barrier to getting the right support.





# Discussion and conclusion



This report reinforces previous findings<sup>5</sup> that families affected by autism experience a struggle when trying to get a diagnosis, access the services they need and integrate their child with their local community. Each family affected by autism has an individual experience, and alongside the general need to improve autism services and make communities more autism-friendly, professionals and service providers must work with families to provide personalised support.

The themes that have emerged from this project also suggest that certain additional challenges are more prevalent within BAME communities. Some of these relate to the communities themselves. They include low knowledge of autism or beliefs that it is a curable condition. Stigma can lead to feelings of isolation, shame and blame for families. Families can also feel a responsibility to cope with their child's autism independently or have negative preconceptions of healthcare services. These problems demonstrate a particular need for service providers to be accessible to and engage people from local BAME communities.

However, services are often not accessible. Information has not been available in families' chosen languages and services have not been tailored or sensitive to the specific needs of local communities. Health and education professionals have demonstrated low levels of autism awareness, but also a lack of cultural competence leading to misunderstanding of parents and carers. Families have therefore had poor experiences of services, which discourage them from accessing those services, leading to further isolation.

This report has explored common experiences of barriers for families from BAME communities affected by autism. However, further research is needed to understand the barriers to both autism services and the healthcare system more generally for specific BAME communities in the UK. Further research should also consider how services could best meet the needs of different BAME communities to improve diagnosis and better support families.

Different local communities, however, will have their own specific needs. Our recommendations seek to ensure that the needs of local BAME populations are identified by local authorities and Clinical Commissioning Groups, and appropriate services are put in place and monitored for their effectiveness.

<sup>5</sup>The National Autistic Society (2013). *Push for Action*. London: The National Autistic Society

# Our recommendations

## **The Department of Health should:**

- fund further research to develop the evidence base for how to improve diagnosis and access to support services for people from specific BAME communities
- provide guidance for local authorities and Clinical Commissioning Groups on how best to commission autism services that meet the needs of BAME communities
- support awareness of autism through faith community leaders and other champions in BAME communities through the Autism Awareness and Champions Programme
- monitor diagnosis and service provision for people from BAME communities through the autism self-assessment framework.

## **Local authorities and Clinical Commissioning Groups (CCGs) should:**

- consult families from BAME communities about their specific needs when commissioning autism services
- ensure that the needs of BAME communities are included in the autism chapter of the Health and Wellbeing Board's Joint Strategic Needs Assessment
- record the number of diagnoses of autism in people from BAME communities and whether people from BAME communities are using local autism services
- raise awareness and understanding of autism in local BAME communities, where needed
- ensure service providers' information on autism and their services is readily available in appropriate languages and is promoted to BAME communities
- commission services that are accessible for local BAME communities, including in appropriate locations and at appropriate times
- commission peer support forums for parents and carers from local BAME communities and, where appropriate, tailored support services
- provide advocacy, translation and interpretation services for families from BAME communities who require support during and following an autism diagnosis.

# References

Bancroft, K. Batten, A. Lambert, S. and Madders, T. (2012). *The way we are: autism in 2012*. London: The National Autistic Society.

Corbett, C and Perepa, P. (2007). *Missing out? Autism, education and ethnicity: the reality for families today*. London: The National Autistic Society.

Equalities National Council and Scope (2012). *Over-looked Communities, Over-due Change: how services can better support BME disabled people*. London.

Lindsay, G. Dockrell, J. Law, J. and Roulstone, S. (2012). *The Better Communication Research Programme: Improving provision for children and young people with speech, language and communication needs*. London: Department for Education.

Özmen, A. (2013) *Push for Action*. London: The National Autistic Society.



We are the leading UK charity for people with autism (including Asperger syndrome) and their families. With the help of our members, supporters and volunteers we provide information, support and pioneering services, and campaign for a better world for people with autism.

Around 700,000 people in the UK have autism. Together with their families they make up over 2.8 million people whose lives are touched by autism every single day. Despite this, autism is still relatively unknown and misunderstood. This means that many people don't get the level of help, support and understanding they need. Together, we are going to change this.

From good times to challenging times, The National Autistic Society is there at every stage, to help transform the lives of everyone living with autism.

***We are proud of the difference we make.***

**The National Autistic Society**

393 City Road  
London EC1V 1NG

Switchboard: 020 7833 2299  
Helpline: 0808 800 4014  
Minicom: 0845 070 4003  
Email: [policy@nas.org.uk](mailto:policy@nas.org.uk)