

Minutes

Meeting of the APPG on Autism – *Diverse Perspectives*: launch of an NAS report on autism in Black, Asian and Minority Ethnic (BAME) communities

14th July 2014

15.00 – 16.30, Committee Room 12, House of Commons

Chair: Tom Madders, Head of Policy and Campaigns, National Autistic Society

Speakers:

Baroness Pola Uddin

Dr Laura Cockburn, Specialist Consultant Educational Psychologist

Ken Greaves, Specialist Consultant Educational Psychologist

Venessa Bobb, Parent of a child with autism and founder of A2ndVoice

Tom Madders welcomed and thanked visitors for attending the meeting and provided an explanation to the absence of Robert Buckland MP. He wished him the best for his new role - Solicitor General, which came as a result of the Conservative Party reshuffle.

Tom introduced the NAS report, *Diverse Perspectives*, which explores the difficulties that families or carers who have a child with autism from BAME communities face when accessing appropriate services.

The report also suggests policy recommendations for the Department of Health (DoH), local authorities and Clinical Commissioning Groups (CCGs).

He then introduced the speakers to talk more about the report and their personal and professional experiences.

Dr Laura Cockburn

- People affected by autism can be at a disadvantage as services often fail to meet their needs.
- The NAS *Push for Action* report looked at what progress has been made since the Autism Act. It concluded that services are still lacking in diagnosis and professionals are not receiving autism awareness training.
- However, people from BAME communities face additional disadvantages. *Diverse Perspectives* gives an indication of why autism is not diagnosed in BAME communities. This is often due to low levels of autism knowledge within BAME communities and teachers making wrong assumptions of children's expected English language abilities, and behaviour.
- Language is also a challenge during the process of diagnosis. Some people may not fully understand the language used and this can cause confusion. Even where translation services are available, interpreters or materials may not always communicate information about the condition correctly or in a way that the family understands. For example, some languages do not have words for certain terms that you would expect to use when discussing a diagnosis of autism.

- Due to language difficulties, families can often feel a lack of confidence when communicating with professionals.
- Some professionals can also lack 'cultural competence', in that they do not know how to communicate well with people from different cultures and backgrounds. This can have a detrimental effect on how they convey the message of a diagnosis, which often results in a lack of understanding.
- Dr Cockburn cites an incident whilst working in China, where she worked with an interpreter specifically to understand how they were using language to convey messages clearly to the family.
- Where communities are concerned, families can feel isolated from the rest of the community because of a negative stigma attached to disabilities.
- A key observation in the report is that services need to be more accessible and make an extra effort to engage with members of the BAME community, to counter the isolation that some families can experience.
- The report also contains positive examples of how the local community does support families and how services do adapt and respond to the needs of their local communities, addressing their concerns in a way that the family can understand.

Ken Greaves

- Ken Greaves gave a brief overview of his background. A qualified education psychologist, he currently works in Barking and Dagenham. He works with children and adults, and has been involved in establishing a network for educational psychologists with autism.
- In Barking, he works primarily with West African families. He emphasises the importance of considering the wider environment and community as well as other factors, following a diagnosis.
- Ken has found that young black boys with autism in particular can suffer a disadvantage when it comes to diagnosis. Education is often the route to diagnosis but misconceptions about the behaviour of young black boys can lead to misdiagnosis, and the wrong support or interventions being recommended.
- Ken cites a case where a 49 year old man from Jamaica facing deportation was diagnosed with autism. He found it difficult to come to terms with the diagnosis due to the negative perception of people with disabilities in his culture and community.

Venessa Bobb

- Venessa comes from a BAME background and has a child with autism, who was diagnosed in 2008 at 5 ½ years old.

- Some of the findings in the report mirror her own experiences, such as being 'shamed and blamed' for her child's behaviour, with members of her family and community, as well as professionals inaccurately claiming it was due to bad parenting.
- She sought help from various services and most had very little training in autism. Others had some understanding but were unable to apply this knowledge to her son's specific behaviour and needs.
- She wanted to speak to other parents and share her experiences with others but found that online, most of the discussion and support was provided by families who were not from BAME backgrounds. She was concerned that not enough families from backgrounds similar to her own were talking about autism and raising awareness.
- Venessa believes that to minimise the isolation of families, services must make themselves more accessible to the wider community and understand the challenges which specifically face them, actively countering problems which prevent people from seeking support.
- The project 'A2ndVoice', was established as a result of the difficulties she faced as a mother from a BAME background with a child with autism. A2ndVoice aims to tackle cultural diversity by raising awareness about autism and Asperger syndrome and breaking down the barriers to cultural prejudices.

Baroness Pola Uddin

- Baroness Uddin explained that she is a qualified social worker, of Bangladeshi origin, who has worked with mothers and families in BAME communities in London for a number of years. She is also the mother of an adult son with autism. When her son was a child, she faced barriers to diagnosis. She has also struggled to access appropriate services for her son since he was diagnosed.
- Baroness Uddin supports *Diverse Perspectives* and she spoke about how she was glad that such strong messages about the need for more support for families in the BAME community were coming from a large organisation, with a good reputation and a powerful voice.
- The report will reach and inspire new people who are not only a force of change, but also have enough of a social standing in their communities to challenge traditional perspectives and misconceptions about autism.
- Baroness Uddin is currently conducting her own research into the availability of services to the BAME community and has found similar difficulties around language difficulties, access to services and stigma.
- From her experiences in Tower Hamlets, there were many instances where many families spoke of experiencing isolation and criticism from their community because their child had a disability. This was often due to a lack of education and

understanding about disabilities. She highlighted the experience of two particular parents she had spoken to.

- Tailored and appropriate services are paramount in combating these stereotypes. However professionals can often lack the training and understanding to provide this support effectively, given the cultural and community differences between service providers and service users. This can lead to miscommunication and misunderstanding, and can make some people reluctant to access services altogether.
- The Department of Health, local authorities and other key decision-makers must take on board the recommendations from *Diverse Perspectives* to improve access to services for people with autism, and their families from BAME communities.

Question and Answer session

Lord Ken Maginnis

- The problems that the report has identified are common experiences of all families, not just those from BAME communities.
- Lord Maginnis has been campaigning for improvements to autism services in Northern Ireland for a number of years. The delays in assessment and diagnosis are still a major problem and some families are reporting delays of over 13 weeks for an assessment. For a family who has a young child, this is too long to wait and it creates unnecessary anxiety and pressure on the family who have to wait for a diagnosis.
- There are support services which specialise in diagnosing and providing support to children, however the young adults can often be over looked and there is a lack of appropriate services for this age group.
- If appropriate adjustments were made in the system, through the recommendations in *Diverse Perspectives*, then the problems that people in BAME communities face, as well as those experienced by all families, could be significantly reduced.

Questions from the audience were taken in groups of three.

Carrie Grant raised the issue of education, health and care (EHC) plans, which will be introduced for children who currently have an SEN statement in September 2014. She said that often teachers and professionals have had minimal training in autism but can be narrow-minded in their understanding of how each child is affected by their condition. She asked how parents can begin to educate professionals who think they already have the answers and fail to listen to those that know best.

Dr Juli Crocombe, chair of the APPGA advisory board and a consultant psychiatrist at St Andrew's Healthcare, asked if the report explored the issue of misdiagnosis within BAME communities, particularly with schizophrenia or other forms of psychosis.

Parmi Dheensa from Include Me Too said that this report highlighted that there has been a failure to provide adequate services for people with autism from BAME communities, and this is incompatible with the Equality Act 2010. The Government recently announced funding for SEN champions to help parents navigate the new SEN system but it is not clear how many of these will be in areas of high ethnic diversity, and will have the knowledge and understanding of the local population to deliver effective services for that community.

In response to the question from Dr Crocombe, Ken Greaves agreed that misdiagnosis is an issue and Afro-Caribbean young men can experience this disproportionately. Treatment and intervention for a condition that has been misdiagnosed in a person with autism can often confuse the individual and have a negative impact on their health and wellbeing.

In answer to Parmi Dheensa's question, Baroness Uddin said that it is important to coordinate a response to Government from all sections of the community with an interest in this. She will be working with those involved in her research to make recommendations to the Government about what can be done to improve services and awareness.

Lord Maginnis suggested that change will only happen if pressure was added at a lower level, through liaison with local services and general awareness raising in the community.

In response to Carrie Grant's question, Dr Laura Cockburn said that some professionals may have had basic training in autism, but not necessarily an understanding of the condition. Through initiatives like *Think Autism*, the Government has committed to ensuring that healthcare professionals, community care specialists and teaching staff are adequately trained in autism.

Orland Bolt, an ambassador for the NAS, raised concerns about young people with high-functioning autism or Asperger Syndrome who have appropriate support at school but then are unable to access the support needed to secure suitable employment when they leave full-time education.

Ola Bankole said that any approach to reaching people in BAME communities would need to include work with faith groups in churches and mosques, and asked if the NAS would lead this engagement.

Helena, a consultant psychiatrist, reiterated the problems that Carrie Grant has faced with training. She said that often professionals will receive basic training and assume this covers everything, when actually what is needed is a more developed programme of training. She often received referrals from people working in the criminal justice system, and these only happen because that person has some personal experience of autism, rather than recognising it through training.

In response to Orlando Bolt's question, Ken Greaves suggested that young people with Asperger Syndrome or high-functioning autism should use their knowledge and talents to organise and campaign on this issue.

In response to the question about faith groups, Tom Madders offered to meet those interested in this to discuss it in more detail. Venessa Bobb said she works quite closely with a number of faith groups. She has good links with churches and mosques. Baroness Uddin also said that part of the development of her project will include engagement with

imams and other faith leaders to discuss how support can be provided from these sections of the community.

Rita Grootendorst said there is still a lack of coordination between health services, local authorities, the police and other agencies, and people with autism can often miss out on vital support.

Leslie Stanberry said that one of the barriers to diagnosis is a GP referral and that professionals can discriminate against people from BAME communities and prevent them from getting a diagnosis. He also asked if the research or any other projects had considered the experiences of children from BAME backgrounds in care who do not have parents to fight for their access to appropriate services and support.

Juliet is the parent of a son with autism in prison. Her experience is that there is very little support for people with autism in prison due to lack of resources and training.

Eileen Hopkins, an independent autism consultant, asked how these experiences could be coordinated, and what opportunities there were for joint-working with other organisations.

In response to all of these questions, and by way of summing up, the panel provided their final comments.

Ken Greaves said that there are areas all over the country where services are good and people are getting the support that they need. But this needs to be consistent, and the Government needs to implement an over-arching strategy to address this.

Dr Cockburn agreed that coordination was a key factor. She said that the NAS has been exploring developments in the criminal justice system, and although there are some examples of excellent support, again this is isolated.

Baroness Uddin said that she intends to work with a diverse range of organisations to develop the themes and ideas raised in the report. She will be contacting women's groups, faith organisations and disability charities, and hopes to return to the APPGA at a later date to report back on her findings.

Venessa Bobb said it was necessary for charities, groups and individuals with an interest in this area to come together, connect and share experiences, to present a coordinated picture to key decision-makers.

Tom Madders thanked everyone for attending and closed the meeting.