

## **Attention Deficit/Hyperactivity Disorder and London's Black, Asian and Minority Ethnic communities – a discussion paper**

October 2013

### **Introduction**

Between November 2011 and February 2013, ROTA delivered the *Shaping the Future* seminar series, which considered the educational reforms and the current state of play in terms of educational equality in the capital. One of the most concerning discussion points raised at many of the seminars, which included 500 representatives of London's Black, Asian and Minority Ethnic (BAME) communities, was that growing numbers of children and young people are being diagnosed with Attention Deficit/Hyperactivity Disorder (ADHD). Furthermore, many of those diagnosed are being pressurised to take medication by healthcare professionals and schools.

Given evidence of unfair and prejudicial experiences BAME children and young people have of behaviour management processes within schools (Department for Education and Skills, 2006; Vincent, 2011; Rollock, 2007; Office of the Children's Commissioner, 2012), alongside concerns about the subjective nature of ADHD diagnosis and the potentially negative impact psycho-stimulant drugs have on brain development (Howard-Jones, 2007), ROTA felt it important to explore this discussion point further. In particular, we felt it very important to find out:

- If BAME children and young people are over-represented among those diagnosed/mis-diagnosed with ADHD (and which BAME groups are most likely to be diagnosed)
- About BAME children and young people's experiences of treatment following diagnosis (e.g. medication, access to therapies, rates of exclusion from school)
- If educational provision for BAME children and young people diagnosed with ADHD is sufficient
- About attitudes among BAME communities towards ADHD and its treatment.

The purpose of this paper is to stimulate discussion about ADHD and London's BAME communities and to call for evidence in relation to the above points. Additionally, the purpose of this paper is to:

- present findings about ADHD and BAME children and young people from the *Shaping the Future* seminars, and from our initial review of literature.
- raise awareness about ADHD among London's BAME communities, so that community organisations and parents can help ensure children are not being mis-diagnosed and can advocate for the most appropriate treatment where children are diagnosed.

A number of questions are asked to stimulate discussion in this paper. To aide response, these are repeated in an electronic survey, which is available at <https://www.surveymonkey.com/s/PT2VL36>. The survey closes on 20<sup>th</sup> December 2013.

## **Method**

Over the course 18 months, ROTA delivered a series of seminars across London, which included two regional events, five local events (in Tower Hamlets, Hackney, Haringey, Islington, Southwark), five workshops with young people, two workshops with parents, and a two day training programme for representatives of children and young people's community organisations. The 500 participants included representatives of London's BAME communities and their organisations and of a range of statutory organisations responsible for children and young people's services. While not an explicit focus, ADHD came up at many seminars in many different ways. Discussions about ADHD are summarised here.

Following the seminar series, in seeking to learn more about ADHD and London's BAME communities, a basic review of UK produced literature was carried out. Our initial review revealed no new literature since Dwivedi et al. (2005) noted that, "*Despite the large volume of research dedicated to attention deficit/hyperactivity disorder (ADHD), the influence of ethnicity on the condition is still to be adequately addressed*". The review was then broadened to consider US produced literature and considerable amounts about ADHD and BAME communities was identified, some of which is considered here.

Some general guidance and information about the treatment and diagnosis of ADHD in the UK was also considered and some basic analysis from a race equality perspective is presented here.

## **What is ADHD?**

Among mental health conditions, ADHD is one of the most misunderstood and neglected. It is thought to affect about 3 – 9% of school-age children and young people in the UK. Symptoms tend to be first noticed early on, with diagnosis usually taking place between the ages of three and seven. Core symptoms include inattention and/or hyperactivity and impulsivity (NICE, 2009). ADHD can also affect emotional regulation, and cognitive processes, and often exists alongside other conditions, such as conduct disorder, substance misuse, oppositional defiant disorder, depression and anxiety (Young et al., 2013).

Very few people with ADHD receive appropriate diagnosis or treatment. This has been attributed to the lack of public awareness and the stigma around the condition, as well as the lack of appropriate community frameworks to accurately detect and diagnose it. Inappropriate diagnosis and treatment often leads to the worsening of the symptoms, with impacts on quality of life, relationships and educational experience; the socio-emotional component of the disorder is its most debilitating aspect for many sufferers. As well as having long-term impacts on the diagnosed individuals, ADHD can affect family and friends and has wide-ranging associated costs in terms of healthcare and other services (Young et al., 2013).

There are thought to be clear biological aspects to the disorder, with evidence linking ADHD to atypical brain development with genetic links (Young et al., 2013). Many, however, have

strongly argued that it is a socially constructed phenomenon (Singh, 2012; Graham, 2008; Tamimi, 2004; Vaughan, Roberts & Needelman, 2009); it is environmental and cultural factors that give rise to ADHD by de-valuing and pathologising a particular type of brain chemistry and related set of behaviours. Singh (2011) illustrates this point in considering how the characteristics of people with ADHD would have been associated with heroism in Ancient Greece and comments, “*I take it as a given that behavioral interpretation is to some extent culturally relative and that diagnostic practices index (are) social values*” (pp. 895). Within an educational context, Graham (2008) develops this idea, pointing out how current classroom expectations are “*cultural expectations brought about by the advent of mass schooling*”. Brand (2002) considers how traditional approaches to teaching, where attention and impulse control are requirements for success, disadvantage pupils who are usually very capable of learning. In such settings, children are frequently reprimanded, develop low self-esteem and may become defensive, defiant and oppositional.

The National Institute for Clinical Excellence (NICE), a UK non-departmental public body which issues guidance for healthcare practitioners on appropriate treatment for specific conditions, also considers the role educational institutions can play in the worsening of the symptoms of ADHD in recommendations for further research about reducing the cost of ADHD for health services. To date, however, this recommendation lacks progress.

*Shaping the Future* did not consider definitions for ADHD. However, findings by Young et al. (2013) about lack of agreement and limited awareness about ADHD, were reflected during discussions at *Shaping the Future* about disagreements on diagnosis between parents and health practitioners. Furthermore, *Shaping the Future* participants’ concerns about how practitioners distinguish between ADHD and social, emotional and behavioural problems linked to educational inequality and post-traumatic stress, which young BAME Londoners are more at risk of experiencing, indicate a need for greater awareness among health practitioners as well as the public.

*Shaping the Future* participants did not consider the wide-ranging impact of ADHD on children and young people and their families beyond education. The impact on educational outcomes, however, was discussed. Young participants from Southwark considered how the ‘label’ of ADHD is often used to excuse inappropriate behaviour, poor effort and academic performance, leading to low expectations for pupils, low self-esteem and schools relieving themselves of their responsibilities to provide quality education services. Pupils diagnosed with ADHD are frequently excused from lessons to participate in non-academic activities, with teachers condoning pupils using the ADHD label in opportunistic ways, often resulting in educational failure. Young people gave examples of friends who had used their ADHD ‘label’ in opportunistic ways and then went on to regret this on the realization of the life-long impact of their academic failure, wishing someone within their schools would have responded more appropriately to their educational needs.

### **Prevalence of ADHD within British BAME communities**

Rising prescriptions of psycho-stimulant drugs used in the treatment of ADHD seem to indicate rising diagnosis of ADHD in the UK. In 2007, GPs in England wrote 420,000 prescriptions for such medication, but by 2012 the figure had risen to 657,000 – a rise of 56% (Care Quality Commission, 2013). Figures as to the ethnicity of those being prescribed such drugs are unavailable and there is no data on ADHD prevalence rates by ethnicity in the UK. However, the overall rise in such prescriptions may also reflect the rising diagnosis of

ADHD among BAME children and young people discussed by many *Shaping the Future* participants.

Figures reported by Green et al. (2005) would seem to indicate that BAME children and young people may not over-represented among those diagnosed with ADHD. They reported on prevalence rates for conduct disorder (a disorder with which ADHD is often comorbid) as follows: 6.1% among White children, 5.9% among Black children, 0.6% among Indian children, 4.0% among Bangladeshi and Pakistani children; this compares to 5.8% among children within the general population. They reported the prevalence of hyperactivity, a symptom that many sufferers of ADHD exhibit, as follows: 1.7% among White children and 0.6% among Black children, compared to 1.5% among children in the general population.

The broad ethnic categories and small sample of BAME children used in this study limit its usefulness in considering the issues raised during *Shaping the Future*. The broad 'Black' category, when used to consider educational experiences and outcomes, always masks a considerable diversity in experience among different Black communities. The Department for Education has reported that "*pupils from a black background remain the lowest performing group*" (Department for Education, 2013). However, Black African Nigerian and Ghanaian children are almost three times as likely to reach the national benchmark as those from Black African Congolese or Black African Angolan groups (Mayor of London, 2012).

Other figures indicate that certain groups of BAME children and young people might be over-represented among those diagnosed with ADHD. Black Caribbean and Mixed White and Black Caribbean children, for example, are between 1.5 and 2.0 times more likely to suffer from behaviour, social and emotional disorders – a category within which ADHD falls (Ball, 2008; Men's Health Forum (2006).

In linking childhood experiences of stress, ADHD and ethnicity, Dwivedi et al. (2005) hint that higher prevalence rates may be expected among certain ethnic groups: "*a disproportionate number of ethnic minority families live in highly stressful environments, thus making their children more vulnerable to hyperactivity*". However, Dwivedi et al. (2005) then goes on to quote US-based research noting, "*the syndrome is stable across different cultures and similar proportions of children are defined as deviant*".

However, the UK's National Collaborating Centre for Mental Health's (NCCMH, 2008) summary of US-based literature is to the contrary: "*the diagnosis of ADHD is distributed unequally across different levels of deprivation and is mediated by social class and ethnicity*".

In conclusion, the available data on ADHD in the UK is not robust enough to draw conclusions about differential prevalence rates among different ethnic groups.

# Diagnosis and treatment<sup>1</sup>

## Diagnosis

ADHD is diagnosed using a check-list of symptoms<sup>2</sup> focused on behaviour which is deemed to be inattentive, hyperactive or disruptive, such as:

- Making careless errors in schoolwork
- Difficulty in maintaining attention on tasks or play
- Appearing not to listen when being told something
- Difficulty in organising activities and tasks
- Disliking or avoiding tasks that involve sustained mental effort (e.g. homework and schoolwork)
- Squirming in seat or fidgeting
- Inappropriately leaving seat
- Difficulty in quietly playing or engaging in leisure activity

Symptoms should be observed for at least six months and be evident in at least two settings, usually the home and school, before a diagnosis is made. ADHD can only be diagnosed by child psychiatrists, child psychologists, paediatricians, psychiatric social workers, educational psychologists or GPs.

There have been many criticisms of the diagnosis of ADHD largely because many children have some problems with self-control. Whether certain behaviours are deemed extreme enough to be identified as resulting from ADHD is based on a subjective judgment; there is no physical test such as a blood test. Other problems in diagnosis arise because the behaviours associated with ADHD are similar to those exhibited by some children with language or hearing difficulties, dyslexia or who have experienced major life disruptions.

Furthermore, recent research has found that many healthcare practitioners fail to adhere to the standard criteria when diagnosing ADHD, choosing instead to stick to unclear rules of thumb (Bruchmüller et al, 2012). It found that boys are more likely to be diagnosed than girls and pointed to the need for further research into mis-diagnosis.

These latter points echo concerns raised at *Shaping the future*. Accounts of parents disagreeing with assessments of behaviour and diagnosis may indicate that practitioners are paying limited attention to the recommendation that symptomatic behaviour be observed in two settings, typically the home and school.

Young people expressed concern about the possible misdiagnosis of classmates who had been through traumatic life experiences and whose behaviour reflected the lack of support following this, rather than the atypical brain chemistry associated with ADHD. They considered this particularly problematic given the impact of medication, which is usually encouraged by healthcare practitioners, on personality and on the brain.

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<sup>1</sup> Unless separately referenced the information in the sub-section, 'diagnosis and treatment' is taken from <http://www.addiss.co.uk/adhd.htm> (accessed on 28.08.13).

<sup>2</sup> The diagnostic criteria of the American Psychiatry Association DSM-IV or the World Health Organisation ICD10.

Others have considered how BAME children and young people are more likely to live in stressful situations or to suffer from post-traumatic stress, and are therefore at greater risk of diagnosis/mis-diagnosis with ADHD: *“a disproportionate number of ethnic minority families live in highly stressful environments, thus making their children more vulnerable to hyperactivity”* ( Dwivedi et al., 2005).

## **Treatment**

Depending on the needs of the individual child and accessibility of services, one or a combination of the following treatments may be offered:

- Psychiatry/psychology: Psychiatrists and psychologists play a major role in diagnosing ADHD, implementing behavioural programmes, prescribing medication (psychiatrists) and supporting parents.
- Behavioural therapies: Family therapy focusing on management strategies and individual therapy focusing on changing behaviour.
- School-based interventions: Additional help with reading, spelling, maths and organisation; speech therapy; physical education therapy; and counselling.
- Social skills training: children are taught in groups to think how their words and behaviour affect those around them.
- Coordination training: Helps improve children’s coordination; in some schools children receive sensory-motor integration.
- Diet: Removal of some foods and drinks, which can affect behaviour, such as chocolate, coffee, fizzy drinks, cordials and foods with artificial colourings.
- Parenting support: Support for parents in the form of parenting classes and self-help groups.
- Medications: Mainly psycho-stimulants which rebalance the levels of natural chemicals in the brain, helping the child to behave in a calmer way. Tricyclic antidepressants are also used.

NICE places heavy emphasis on drug treatment and limited emphasis on the alternatives described above (NICE, 2009). For those diagnosed with ‘moderate ADHD’, NICE recommends parenting programmes or group cognitive behavioural therapy for children, then, if these do not lead to improvements in behaviour after a short period, medication. For those diagnosed with ‘severe ADHD’, NICE recommends medication as the first line of treatment and encourages practitioners to persistently encourage drug-treatment at various junctures, even to those who are very reluctant:

*“Following treatment with a parent-training/education programme, children and young people with ADHD and persisting significant impairment should be offered drug treatment”.*

*“If the child or young person wishes to refuse medication and/or the parents or carers reject it, a psychological intervention may be tried but drug treatment has more benefits and is superior to other treatments for this group...If drug treatment is not accepted by the child or young person with severe ADHD, or their parents or carers, healthcare professionals should advise parents or carers and the child or young person about the benefits and superiority of drug treatment in this group. If drug treatment is still not accepted, a group parent-*

*training/education programme should be offered.... If a group parent-training/education programme is not effective for a child or young person with severe ADHD, and if drug treatment has not been accepted, discuss the possibility of drug treatment again or other psychological treatment (group CBT and/or social skills training), highlighting the clear benefits and superiority of drug treatment in children or young people with severe ADHD."*

The heavy emphasis placed by NICE on medication was reflected in discussions at the *Shaping the Future* seminars. Parents reported limited access to the alternative treatments described above and some expressed concerns that treatment that BAME children and young people receive is adversarial, with pressure to take medication and, in school contexts, frequent internal isolation and fixed-term and permanent exclusions. During a seminar in Tottenham, two parents from separate families told of the extreme pressure placed on them by schools to medicate their children following diagnosis. One mother refused to medicate her child and began schooling from home. The other agreed she would medicate her son if a second opinion confirmed the diagnosis to avoid exclusion from school.

Due to the concerns about treatment of ADHD with medication (Howard-Jones, 2007; Graham, 2008) and rising prescription levels (Care Quality Commission, 2013), discussions at *Shaping the Future* about rising diagnoses and mis-diagnosis and about differential access to appropriate treatment, need to be taken very seriously. There is very limited information and data about how British BAME children and young people experience treatment following diagnosis with ADHD and this needs to be addressed as a matter of urgency.

In summarising US literature, NCCMH notes that the response to treatment does not vary significantly by ethnicity (NCCMH, 2008). Other authors, however, have considered how doses of psycho-stimulant medication, are generally higher for African American children and young people (Arnold et al., 2003).

While psycho-stimulant medication usually leads to some improvement in concentration, the evidence suggests there is limited correlation with improvements in academic achievement. This has led to questions being asked about whose interests are served by the medication of pupils (Graham, 2008).

### **Cross-cultural diagnosis/mis-diagnosis of ADHD**

Alban-Metcalf (2002) considered the role of culture in the identification of ADHD. While this international study, which compared the identification of pupils with ADHD by teachers in Hong Kong, China and the UK, differs from the domestic multi-cultural educational context being considered in ROTA's paper, it raises points that should be considered. Alban-Metcalf describes the origins of ADHD as a Western concept and questions the value of applying psychological instruments derived from one culture to measure the behaviour of individuals in another; in some cultures, symptoms may be considered less unusual or problematic than in others. The study finds that culture can result in different diagnosis of similar types of behaviour using the same diagnostic criteria. Given the under-representation of some BAME communities within healthcare professions, the potential for the mis-diagnosis that *Shaping the Future* participants expressed concern about, may arise out of cross-cultural misunderstandings between healthcare practitioners and their

patients. This is an issue which, again, has not been researched in relation to ADHD among British BAME communities and which warrants further exploration.

## **Attitudes to ADHD among BAME communities**

There is no literature available about attitudes to ADHD among BAME communities in the UK or the implications this has for access to appropriate treatment for children and young people.

US literature has considered attitudes to ADHD and its treatment among different BAME communities, particularly focusing on African American communities. Concern exists about the over-pathologising and over-medication of African American and other minority children, especially boys. There is considerable parental wariness about the use of medications as a form of social control (Carpenter-Song, 2009), its negative side effects, its limited effectiveness in supporting the progress of children and young people, as well as the potential of leading those who take it to substance misuse (dosReis, et. al., 2006; Schnittker, 2003). These concerns mirror those of the participants at *Shaping the Future*. The basis of such fears, and their implications for children and young people's access to appropriate treatment, need to be explored.

Participants in the *Shaping the Future* seminars did not stigmatise the condition in the way much of the literature has discussed (Singh, 2012). However, there was a sense of fear of the growing diagnosis, which appeared to arise from concerns about the ongoing pathologisation of BAME children and young people within education and evidence of educational inequalities. Furthermore, this apparent sense of fear could be linked to the sense of fear generally, among many BAME communities, of services such as social and mental health services, with which they may have had negative experiences.

## **Conclusion**

Among mental health conditions, ADHD is one of the most misunderstood and neglected. Very few people with ADHD receive appropriate diagnosis and support. While there are thought to be clear biological aspects to the disorder, environmental and cultural factors can lead to a worsening of the symptoms. This is particularly the case within education, where inappropriate responses usually inhibit educational progress at best, and lead to educational failure at worst.

There appears to be a rise in diagnosis of ADHD among London's BAME communities. London's BAME communities are concerned that much of this may be mis-diagnosis and that many children exhibiting social, emotional and behavioural difficulties, who are not receiving adequate support, are particularly vulnerable to mis-diagnosis. Furthermore, there is concern that the treatment of BAME children and young people following diagnosis is adversarial with over-emphasis on medication and limited access to alternatives.

The limited information and data about ADHD and ethnicity make it impossible to ascertain if BAME children and young people are more at risk of diagnosis/mis-diagnosis and if they have less access to appropriate treatment that supports their educational and social progress. Evidence about inequalities in access to appropriate education and mental health services more generally, give genuine cause for concern that this may be the case. Given

concerns about the potentially negative affect medication has on developing brain chemistry, there is an urgent need for further research to ascertain the degree to which the issues discussed in this paper are affecting London's BAME communities and for subsequent action to improve diagnosis and treatment for BAME children and young people who may have ADHD.

## Recommendations for further research

- Systematic collection of data on the ethnicity of those being diagnosed with ADHD.
- Systematic collection of data on the ethnicity of those being prescribed with medication as part of treatment for ADHD.
- Qualitative research to explore the reasons for mis-diagnosis with ADHD among BAME children and young people in the UK.
- Youth-led qualitative research on the experiences of BAME children and young people in being diagnosed with ADHD and subsequent treatment.
- Youth-led qualitative research on the educational experiences and outcomes for BAME children and young people that have been diagnosed with ADHD.
- Qualitative research to explore the attitudes of BAME communities in the UK towards ADHD and its treatment, and the impact of this on access to appropriate treatment.
- Qualitative and quantitative research to explore the links between inequality, deprivation and growing up in deprived and stressful urban environments on prevalence rates for ADHD among different ethnic and socio-economic groups.

## Discussion questions

The following questions are included in the electronic survey that accompanies this discussion paper. The electronic survey is available at [www.surveymonkey.com/s/PT2VL36](http://www.surveymonkey.com/s/PT2VL36) and closes on 20th December 2013.

1. Please tell us your ethnicity (we are particularly interested in your ethnicity if you are sharing personal or family experience of ADHD as this will help us gather information as to how children and young people from different ethnic groups access appropriate treatment and support).
2. Please select the categories which best describe you: Young person diagnosed with ADHD; parent/carer of a child or young person diagnosed with ADHD; representative of voluntary organisation with experience of working with children and young people with ADHD; adult diagnosed with ADHD; healthcare practitioner with experience of working with children and young people with ADHD; educator with experience of working with children and young people with ADHD; other professional with experience of working with children and young people with ADHD; other with an interest (please explain)
3. Do you feel the rates of diagnosis of ADHD in London are staying the same or growing?
4. Do you think there is greater prevalence of ADHD among particular ethnic groups?
5. Do you feel appropriate alternative treatments, other than medication, are easily accessible to children and young people in London who have been diagnosed with ADHD?
4. Does awareness about ADHD vary among different ethnic groups in London?

5. Do you feel that attitudes towards ADHD and its treatment are different among different ethnic groups?
6. Are you aware of any data or academic or other literature or commentary about ADHD and ethnicity in the UK?
7. Do you feel the standard criteria used in diagnosing ADHD are strictly adhered to by healthcare and other relevant practitioners?
8. Do you feel that children and young people from particular ethnic groups may be at greater or lesser risk of mis-diagnosis with ADHD?
9. What type of treatment for ADHD is most accessible to BAME children and young people diagnosed with ADHD?
10. Do you feel the treatment received by BAME children and young people with ADHD is appropriate and adequate?
11. Do BAME children and young people with ADHD face any particular barriers in accessing appropriate treatment?
12. Do you have any further comments that you would like to add (thoughts that the questions have not picked up or general comments on the discussion paper would be very welcome).

This is a paper in development. In addition to the questions asked, any general comments on the paper and suggestions for improvement would be very welcome. Please contact Barbara Nea, Senior Policy Officer, on [Barbara@rota.org.uk](mailto:Barbara@rota.org.uk) or 020 7697 4093.

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### **About ROTA**

ROTA is a social policy, action research, and influencing organisation that supports BAME communities to have a voice in how education, health and criminal justice programmes are developed and delivered. Established in 1984, ROTA has been a registered charity since 1997.

We work directly with people across England who have been excluded from decision-making processes -- young people, people in disadvantaged areas, and refugees – and help them to gain skills, confidence, and knowledge to bring about change in their communities.

Our core work focuses on the following activities: conducting research, piloting innovative solutions to inequalities, developing policy, working with Government and others to influence policy and delivery, brokering relationships, facilitating networks, building capacity of BAME voluntary organisations, strengthening the voice of BAME communities, representing and providing expertise on issues affecting BAME communities, and producing publications and resources to share knowledge and expertise.

You can find out more about ROTA at [www.rota.org.uk](http://www.rota.org.uk).

Follow us on Twitter: [@raceontheagenda](https://twitter.com/raceontheagenda)

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