

Hove  
East Sussex

22nd June 2011

Stephanie Powell  
Chair Children & Young People's Overview & Scrutiny Committee  
King's House  
Grand Avenue  
Hove  
BN3 2LS

Dear Ms Powell

I am writing to draw your attention to a new publication, *Difference in Mind*, a '10 questions' guide for Overview and Scrutiny Committees looking at child and adolescent mental health services (CAMHS) for children with autism.

Autism is not a mental health problem, but as many as 71% of children with autism do also develop mental health problems, such as depression and obsessive compulsive disorder. This is in no way inevitable, and with the right support children with autism can enjoy good mental health, just as anyone else can. But where mental health problems do develop, too often children and young people with autism are often unable to get the support they need.

The guide is a joint publication from the Centre for Public Scrutiny and The National Autistic Society, and can be downloaded at [www.cfps.org.uk/what-we-do/publications/cfps-health/?id=164](http://www.cfps.org.uk/what-we-do/publications/cfps-health/?id=164)

In Brighton & Hove children with diagnosed Autistic Spectrum Conditions are eligible for support via the Seaside View Development Centre, CAMHs or, if in mainstream or special schools, the Autistic Spectrum Condition Support Service. There are currently 226 children with a recognised diagnosis on the ASCSS register and the service is 'very stretched'. The charity Amaze has 363 children with ASC on their Compass database, of which 113 are over 16 years old. They considered that they had details of 'approximately half of the young people with ASC in the city'. 'Children & Young Peoples' Plan Brighton & Hove City Council 2009 - 2012

'Every child matters' yet it is widely accepted that there are children in Brighton & Hove (as there are nationally) who struggle not because they have ASC but because their ASC is undiagnosed and those with a diagnosis are getting insufficient support. Children deserve the right to be supported to live freely with whatever their unique condition and presentation might be.

*'You're one of the worst areas. I think of all those poor schools in Brighton and all those children not getting their needs recognised'*. This comment was made to me by Laura Sanderson DLA assessor in Blackpool, 2010. The Benefits Agency has its own medical assessors and families are free to apply for DLA for their disabled children even if their children's needs have not been officially diagnosed in their locale.

If staff are insufficiently trained, the children with less obvious or more masked ASC traits and behaviours often fail to receive a formal diagnosis yet the impact on their lives is no less severe than for the 'obvious' ASC children. If the undiagnosed children are lucky they may have an understanding school that implement an 'Action Plan' but often they will be labelled ill disciplined or badly behaved. 'BESD' (behavioural, emotional, social difficulties) is often a cheap and convenient option for services who fail to put a child forward for a full Stage II ASC psychiatric assessment. If the child has to seek a private assessment or is in Independent Education there is no co-ordinated support and the level of help received is purely 'pot luck'. Undiagnosed children are all too often 'invisible' and often not recorded in any statistical information. Too often families are left with little or no guidance nor support at home and the impact is often devastating on family life.

Current strategic reviews in Brighton & Hove comment on the rising awareness of ASC in children and rise in School Action, School Action Plus and Statements, with the highest number of new SEN statements issued over the last five years for children on the AS Continuum. However,

*“Children with harder to diagnose, mild or moderate disabilities or more complex needs may not be receiving the services they need”.*

*“1.4 Recommendations for Further Needs Assessment Work: More information is needed on the particular needs of children with Autism Spectrum Condition so services can effectively address their specific needs”.*

*The Joint Strategic Needs Assessment for Brighton & Hove, September 2010*

Anecdotal evidence suggests a significant number of referrals are still not being picked up by CAMHs.

### **Our personal experience**

Our child struggled with their physical and mental health from an early age. Aged five his crippling pain was diagnosed as Irritable Bowel Syndrome induced by anxiety and he was regularly treated at the Whittington and the Royal London hospitals, Great Ormond Street CAMHs and the Tavistock Clinic prior to a referral in 2006 to the Royal Alexander Hospital and CAMHs in Brighton. Our son had endured years of medical interventions and CAMHs Brighton decided he had ‘behavioural/emotional difficulties’ (BEDS) due to his medical history. The lack of training and awareness of staff at the White House CAMHs meant they failed to recognise, or even consider, our son’s anxiety, traits and behaviours actually stemmed from Asperger Syndrome which was finally diagnosed at the Priory Hospital in 2010.

For ten years before we knew he had an ASC, life for our family was horrendous. I consider our story typical of the experience of many families with children with undiagnosed AS conditions. After more than two years of what CAMHs described to me as ‘management of his behaviour’ our son received a short series of Cognitive Behavioural Therapy ‘for pain management’ and was discharged from CAMHs with no further follow up or support. In desperation we employed a private therapist. When our son was forced to change schools in the recurring crisis of poor mental health, our GP re-referred him back to CAMHs but they failed to re-engage explaining that as we had private help they would prefer to ‘stay in the background’ as being ‘more helpful’. Our son’s condition had not improved in any way and had remained chronic (erratic and unstable) throughout the time he was known to CAMHs and we had continued to struggle, failing to understand why he experienced depressive episodes, anxiety attacks and crippling abdominal pain.

Being properly assessed and diagnosed with ASC, which we sought and paid for privately, has liberated our family. Now we have a much better understanding of how to support our child and the affect on his mental and physical health has been immediate and far reaching, resulting in a huge improvement in our family life. We have been able to do so by paying for assessments that diagnosed his condition and educational needs; small environments in private schools; a chiropractor for IBS pain management and family support from a psychotherapist who specialises in ASC. The NHS is lucky we have the resources to do this for our son. Not every child is as fortunate.

The prolonged catalogue of ineffective interactions with CAMHs not only did not help our son in any way but was a very unpleasant, difficult and stressful experience for all our family. As a result of this we made a formal complaint to Sussex Partnership Trust for the lack of meaningful support we received. Our concerns centred on:

- Failing to identify, assess and diagnose our son nor to treat his mental health appropriately.

- Being 'pushed away' from the service and having inferences made about our parenting.
- Being told our son was not eligible for CAMHS support as he is in private school and 'in this case' we would need to pay for advice for school ourselves.

The Trust acknowledged our complaint, described their service as 'clumsy' 'thoughtless' and 'tardy' and refunded our losses of £2,190 which we incurred having to seek private support. We took complaint action as a last resort and then we found other families receiving the same ineffective service. We wish to highlight how CAMHS has not responded to families appropriately and to campaign for a better service for the children coming after us.

**Due to our experience we would like to request**

- For the Children's and Young People's Overview and Scrutiny Committee to review and monitor CAMHS' implementation of the new 'Autistic Spectrum Condition Pathways' policy for children in Brighton & Hove; To ensure that an evaluation of ASC need in the city is undertaken and that appropriate targets for diagnostic assessments are set. This, in view of the fact that services for adults are currently being scrutinised under the Adult Autism Strategy.
- That *all families* who are referred/ request an ASC assessment are supported with prompt and proactive responses; That families are kept fully informed at all stages and for CAMHS to offer advice and support with positive regard for service users, working 'with' rather than 'managing' clients.
- That privately educated children must receive the same level of advice and support as state educated children. Parents who pay taxes to support local services must have access to the same level of service that state school children receive via the ASC Support Service.

Given the high proportion of children with autism who experience mental health problems and access support from CAMHS, this is an area where your committee could help to ensure that local services are delivering good outcomes for this group, and that funding is being used effectively to avoid more costly interventions in the longer term, in some cases into adulthood, as recently illustrated by the Overview and Scrutiny Committee 'Review of Services for Adults with Autistic Spectrum Conditions' in Brighton.

Therefore I hope that your committee will consider using the 'Difference in Mind' guide to carry out a scrutiny of CAMHS for children with autism in Brighton & Hove.

Yours sincerely

Paula Donovan (parent of child aged eleven with Asperger Syndrome)

cc  
 Mike Wetherley, MP  
 Vanessa Brown, Ward Councillor for Hove Park;  
 Tom Madders, Head of Campaigns National Autistic Society  
 Ros Cook, Operational Director, AMAZE  
 Family x (in similar circumstances/same concerns)

### **Snapshot - Comments about Brighton & Hove CAMHs**

- 'Oh it's always the mother at fault with them.' Play group manager
- 'My husband was annoyed his absence was always commented on, 'tell them I go to work to support my family.' Comment from two separate fathers
- 'We suspected our child has autism, I'm a teacher, I'm trained to spot the signs. When workers made a home visit my husband was late, I was embarrassed and got upset, the CAMHs workers levered open my worries, they said they were going to record they suspected domestic abuse. We didn't go to them for help again'. Parent
- 'We fled when we thought CAMHs were threatening social service involvement.' Different parent
- 'CAMHs are restructuring themselves into a more '*sensible*' (ironic) approach.' A GP
- 'This CAMHs has a style of working that is toxic for families.' Health care professional
- 'CAMHs are a law unto themselves; they don't pick up their referrals.' Different health care professional
- 'You're one of the worst areas. I think of all those poor schools in Brighton and those children not getting their needs recognised.' DLA assessor in Blackpool
- 'CAMHs is in chaos.' Ex CAMHs worker
- 'We hear the same concerns about CAMHs all the time.' Local voluntary sector worker
- 'There would be families who would feel they had benefitted from CAMHs but there are many who have problems with them.' Different voluntary sector worker
- 'Referrals to us from CAMHs are working well, the assessment procedure is well developed at SVDC and is developing at CAMHs, yours could just be a minority experience although couldn't comment on how many children get missed. Funding is extremely stretched and services can only deal with the most obvious cases'. Support service manager
- 'I often hear parents with children in private schools say 'we didn't realise when we opted out of state education that we were opting out of the health care service as well". Different Support service manager