

## **Submission & Overview**

### **25 November 2011**

#### **Suggestions by families with Children on the Autistic Spectrum Condition (ASC) regarding the Children & Young People's Overview & Scrutiny Committee's Review of Autistic Spectrum Condition Services in Brighton & Hove**

Although recent DfE policy has sought to promote and safeguard the welfare of disabled children and those with SEN, and 'Every Child Matters', it is our experience that in Brighton and Hove, provision and services for children with ASC fall short of statutory guidelines.

#### **Main Areas of Concern – ASC Services in Brighton & Hove (Health, Education, Social Services)**

1. Failure to provide timely, diverse and flexible services to meet the needs of children with ASC
2. Services provided being frequently ineffective, counterproductive, harmful or reactive
3. Failure to keep families at the heart of the process, leaving the child and carers without a voice
4. Failing to proactively commission services even where there is an identified need, thus forcing families to find help privately

#### **Autistic Spectrum Disorder Pathways Policy Sussex Partnership Trust**

- Concern that the recently introduced 'ASD Pathways Policy' is not being routinely applied

#### **Diagnosis**

- No treatment or help offered, ignoring concerns, families 'batted' away
- Long waits for assessments at both Seaside View & CAMHs
- Misdiagnosis (ADHD instead of ASD)
- Missed diagnosis (not picked up at all)

#### **Behaviour Management**

- No/very little proactive (or even reactive) management of frequently encountered behavioural difficulties (eating, toileting, sleeping, self-harm, anxiety, aggression, obsessive behaviours)
- Families being left to deal with behaviour issues on their own with little or no support

#### **Mental Health Management**

- No immediate, appropriate help for families in crisis
- Inappropriate settings; clinic-based appointments and procedures often intimidating for children who want support in relaxed settings, outside of those times
- Inappropriate treatment offered' ineffective or counterproductive/harmful i.e. CBT delivered with no sensitivity of ASC
- Lack of a comprehensive assessment as to cause of the difficulty; frequently attributing the child's difficulties to poor parenting or suggesting inappropriate therapy without understanding the underlying cause e.g. bullying
- Insufficient treatment; parents given a factsheet and expected to do therapy at home without guidance, structured input or monitoring
- Insufficient treatment; parents forced to re-refer whether there is any evidence of improvement in child or not
- Insufficient expertise; parents advised to seek 'specialist' help
- Insensitivity towards parents; patronising, 'one size fits all' parenting advice in a clinic-based setting

## **Education**

- LA refusing to amend wording on statements in order to allow 'more flexibility' for schools, thus acting in the interests of the school and not the child
- Exclusions; children with ASC are still being excluded at a disproportionate rate. LA do not flag up children with ASC who are at risk of permanent exclusion
- LA still 'turn a blind eye' to informal i.e. unlawful exclusions
- Individual Education Plans are not SMART and the bar is set very low, i.e. teaching staff are not ambitious in terms of the children's potential
- Lack of adequate monitoring of a child's progress against targets set
- Social skills; school staff are not equipped to plan programmes to help develop the social skills that ASC children find so difficult
- Children with ASC are left in the care of Teaching Assistants who have a very superficial understanding of their condition (maybe 1 day of training) and do not fully know what to do
- Continued promotion of 'one size fits all' interventions for ASC even where there is no evidence the interventions work
- School-based advice and support for children with ASC inadequate and limited in scope
- Meetings are often focussed on the outcome for the professionals involved rather than the outcome for the child
- Lack of accountability throughout the education system

## **Communication**

- Communication between practitioners is poor; parents asked to repeat their child's history again and again, particularly in clinic-based settings
- Professionals seem to 'pass the buck' i.e. one might suggest a certain therapy for a child but the relevant agency or service refuses to provide it on the grounds of 'lack of resources'
- Practitioners will often value the school's opinion over the parents' knowledge of their own children and teachers/teaching assistants are often too busy or lack the training to notice nuance behaviour
- Practitioners copy colleagues and other agencies into correspondence but fail to ensure copies are also sent to parents
- Terminology and acronyms used by professionals can be intimidating for parents
- Some professionals are continuing to use entirely inappropriate, discriminatory terms to describe the various presentations of ASC
- Some professionals are continuing to suggest that parents are the cause their child's difficulties either in terms of the family environment or poor parenting skills
- Parents report that they feel their opinions are undervalued or they are under suspicion. This perception comes from direct and indirect comments from practitioners that are intimidating and threatening; some parents fear if they make a complaint their child will be adversely affected

## **Improving Services: What We Need**

### **1. Diverse and flexible services delivered with ease of access for children – needs-led not resource-led**

Services that include choice for the child and the family in terms of intervention, practitioner and style of delivery in a way that works best for them – see National Autistic Society's 'Young People's Charter for CAMS' <http://www.autism.org.uk/ycgcharter>

## **Solution**

1. Anyone who works with a child or young person with ASC should understand the condition and have received adequate training

2. Anyone who works with a child or young person with ASC should be aware that ASC presents in different ways and treat each child or young person as an individual
3. Anyone who works with a child or young person with ASC should offer different options and be flexible in their approach
4. Professionals should include children in the decision-making process
5. A detailed breakdown of what to expect during consultations and meetings should be provided in advance. Not knowing what to expect is particularly difficult and stressful for a person with ASC
6. Practitioners should give choice about who children and young people work with. Children with ASC have said: "I want to have one person to get to know, not lots of different people"
7. The environment should not disturb the senses. Service providers can help keep sensory sensitivity to a minimum by asking young people if they feel comfortable in the chosen meeting place
8. The environment should have activities suitable for both children and young people
9. The environment should provide a safe space to release stress in a controlled way. Those with ASC sometimes struggle to communicate their feelings verbally so look for other ways to express how they are feeling. It would also be helpful if practitioners could communicate in non verbal ways ie by using anxiety scales, emails, texts, other interventions and therapies
10. Health, social and education services must work together. Practitioners need to tell school what support the child needs and to provide training. Young people need to be able to access support from CAMHs at school rather than travelling to different appointments in unfamiliar settings. With more support in schools children would be less likely to go on to need more intensive support - saving money and improving lives
11. Practitioners should make sure they see a child when they need it (eg a 'bad day' drop-in service) or contact them by phone/email. Long waiting times create further difficulties
12. Practitioners should offer home visits or appointments on neutral territory. It's important to meet where a child feels comfortable
13. Practitioners should be willing to take a child out to help through difficult situations. Owing to difficulties with generalisation it can be difficult for a child or young person to apply techniques learned in one situation to another. They may need to learn those techniques in the situation in which they will have to apply it
14. LA must be an advocate for the children and young people with ASC in their care. They have a responsibility to ensure the law is upheld
15. LA must foster greater accountability in schools, by following up every exclusion of a child with ASC
16. LA must ensure that wording on statements reflect the needs of the child and not the resources available

#### **For parents – needs-led not resource-led**

A timely and pro-active response from NHS and Education services working with parents to secure a fast and supportive assessment procedure at a 'one-stop shop' with a holistic approach and not a protracted assessment process by different practitioners at different locations with contradictory responses – see National Autistic Society's & Centre for Public Scrutiny 'Difference In Mind' a tool for Local Authorities to help scrutinise Child & Adolescent Mental Health Service for Children with Autism <http://www.cfps.org.uk/what-we-do/publications/cfps-health/?id=164>

#### **Solution**

1. Services need to proactively advertise their services via schools, health centres etc with a more open approach so parents feel they can discuss issues without having to wait for GP level referrals
2. Once referred correspondence and communication between all parties needs to be transparent with the parents involved at every point
3. Professionals should include families in every step of the decision-making process

4. Does the child need an assessment for ASC? This question needs to be at the forefront, being one of the first things to be considered and not a last option after months or years of a child presenting with difficulties
5. Practitioners need to be trained to spot the initial signs of a child or young person presenting with ASC and to diagnose appropriately
6. Waiting lists are unacceptably long ie child referred by GP April 2010, seen by Occupational Therapist May 2011, OT report finalised August 2011
7. Therapeutic treatments need to be commissioned based on identifiable needs, not on 'what is available' ie it is ineffective and ultimately more costly to give parents information on handouts when structured weekly input by a fully-trained therapist is required
8. All professionals should actively promote 'parents as experts'
9. There must be recourse for parents when things go wrong. Parents should have a voice and be listened to, not passed 'from pillar to post'

## **2. Needs-based and appropriate services**

Services that are individually tailored to the needs of the child including more help in schools/ home rather than clinic-based 'advice' sessions that often lack value, in terms of parents' time off work/care. We need services that parents feel are truly effective, monitored to ensure progress is actually being made and alternatives offered if not. The commissioning of appropriate services is the key to positive outcomes for ASC children in the long term. Questions that need to be asked;

### **Solution**

1. How does an understanding of needs influence commissioning?
2. How can services support better outcomes for children with autism?
3. Are practitioners skilled in autistic spectrum disorders?
4. Is there specialist autism support in the area? How much and is it effective?
5. What support is there to help families in a crisis situation?
6. Are care pathways for mental health support clear and being delivered?
7. Are children, young people and families involved with service planning and delivery?
8. What support is available for children with autism who are inpatients?
9. Do CAMHs services work effectively with parents and schools? What arrangements exist to prevent inappropriate child protection referrals being made in respect of ASC children and their families?
10. Recommendations should be SMART – stretching, measureable, agreed, realistic, time bound.

## **3. A change in perception & culture of working with families**

### **The promotion of the child's right to be themselves**

The new Pathways policy refers to spectrum conditions as 'disorders' rather than conditions of 'difference'. This fails to challenge the prevailing stereotyping of a spectrum child, allowing for children to be marginalised and excluded when health/education workers lack the will to make an effort to understand or accommodate 'difference'. 'We can't accommodate your child because she is 'disordered' instead of asking 'how can we accommodate your child who has some differences'. Ignorance and apathy allow equality, disability and children's rights legislation to be breached by service providers who still promote the use of the word 'disorder'.

### **Solution**

1. Don't label - use the term 'Condition' not 'Disorder'
2. Only refer to the child having a 'disability' if the child themselves describes their condition as a disability or dysfunction for them

3. Proactively promote understanding of extent of the autistic spectrum by raising awareness in venues that children and families use

### **A recognition that parents must be treated with respect**

Practitioners need to provide a supportive culture. However, there appears to be an overt culture of workers often attributing the child's problems to the parents. Mothers are questioned about their mental health background and fathers are deemed as uncaring and 'absent' if not at a session. Parents are repeatedly asked inappropriate questions. This is undermining parents who feel criticised or suspected. Families are then disengaging with services, feeling 'pushed away' by inferences made about their parenting. We want a respectful and knowledgeable response from NHS and Education services and for them to work in partnership by consulting with us and demonstrating 'positive regard' and valuing the family as a whole.

The difference between the customer service culture in the private sector and the NHS is now extreme. We appreciate NHS/Education resources are stretched to breaking point but that does not excuse the disrespectful 'top down' culture that has become entrenched. If you see a clinician privately they will query information to clarify it, in the NHS they query and then make value-based judgements about the parents.

### **Solution**

1. Who supports the parents who support the children? Validate and support - don't undermine.
2. Review prevailing cultural assumptions about parents and parenting and increase training and awareness that ASC is neurodevelopmental not environmentally created
3. Privately sought opinions and assessments must be treated by the NHS with the same level of respect an NHS clinician would like to receive. Disregarding clinician's opinions because they are not in the NHS is both disrespectful to the clinician and to the parents who have chosen, or felt forced, to seek a private route
4. Proactively and consistently seek ongoing customer feedback for satisfaction levels

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Endorsed by mASCot -managing Autistic Spectrum condition online together

### **Key references**

National Autistic Society's 'Young People's Charter for Child & Adolescent Mental Health Services' <http://www.autism.org.uk/ycgcharter>

National Autistic Society's & Centre for Public Scrutiny 'Difference In Mind' a tool for Local Authorities to help scrutinise Child & Adolescent Mental Health Services for Children with Autism <http://www.cfps.org.uk/what-we-do/publications/cfps-health/?id=164>

National Autistic Society's 'You Need To Know' report detailing upto 70% of ASC children are suffering needlessly from a mental health problem because local services are failing to meet their needs <http://www.autism.org.uk/youneedtoknow>

Hoyle, David (2008) 'Problematizing Every Child Matters', *the encyclopaedia of informal education* report exploring a culture of blame that has developed post Victoria Climbié [http://www.infed.org/socialwork/every\\_child\\_matters\\_a\\_critique.htm](http://www.infed.org/socialwork/every_child_matters_a_critique.htm)

