BRIGHTON & HOVE CITY COUNCIL

SCRUTINY PANEL ON SERVICES FOR CHILDREN WITH AUTISM

2.00pm 17 SEPTEMBER 2013

COUNCIL CHAMBER, HOVE TOWN HALL

DRAFT MINUTES

Present: Councillor Jarrett (Chair)

Also in attendance: Councillor Pissaridou and Wealls

Other Members present: Rosie Moore, co-optee

PART ONE

12. PROCEDURAL BUSINESS

There were no declarations of interest or party whip. Substitutes are not allowed. No reason to exclude press and public.

13. CHAIR'S COMMUNICATIONS

Thank you all for attending. Welcome to this public information-gathering meeting of the Scrutiny Panel looking at services for children with autism.

The Panel have set their terms of reference as:

“To consider what services are currently in place to help children with ASC and their families including: issues around diagnosis, health, education, social care, and home support; to look at areas of best practice; and to make recommendations for action.”

The Panel are keen to hear your views and experiences. I will ask you each to say who you are and then speak for 10-15 minutes and then the Panel will ask questions.

For clarity, this meeting is being held in public but I will not be asking for any contributions from members of the public. There is one change to the agenda – Steve Harmer-Strange will now talk to the Panel at the end of the session.

14. MINUTES FROM THE CAPACITY BUILDING MEETING ON 9 JULY 2013

The minutes are not yet available.

15. WITNESSES - MASCOT

DRAFT MINUTES

Paula Donovan (PD), Ambassador for National Autistic Society and mASCot, Sam Bayley (SB), Chair of mASCot and parent of a child with autism and Mimi Banks (MB), Committee member of mASCot and parent with a child on the autistic spectrum. mASCot gave a powerpoint presentation (for copy see minute book)

SB - has a 16yr old son who was diagnosed aged 3. She started mASCot because she had no support as a parent and to meet other parents. Now mASCot has over 150 members all of whom have at least one child with autistic spectrum condition (ASC). They are the only support group that are just for ASC. They provide parent-to-parent support groups. Most members have children in mainstream school, some started in mainstream but had to move to special schools or home schooling and some have always been at special school.They have members who are pre-diagnosis too: a key point when people need support. mASCot run coffee mornings and on-line forums. They have funding to provide workshops and talks including 'social detectives' working with children. One of the common threads with families is the need to be heard.

PD – two years ago mASCot decided to map out where the problems were and put together all the difficulties people were facing into one document. In 2011 this was taken to MPs. Key issues are: failure to provide timely, diverse, flexible services to meet the needs of ASC children; services provided frequently ineffective, counterproductive, harmful or reactive; families not included at the heart of the process and left without a voice; inconsistency in support provided even by the same service; and failure to proactively commission services.

Diagnosis and mis-diagnosis are big issues. Mental Health services are a big problem – they are often clinic-based which children often find upsetting. There is inappropriate and ineffective treatment, often putting the 'blame' on bad parenting. In some cases, intervention is suggested but it doesn't deal with the other issues (eg bullying). After diagnosis, people are given factsheets and dismissed from the service. They often end up re-referring themselves several times. Parents are forced to gain specialist help. In schools, the Statements are school-focused and not child-focused. There are lots of exclusions of children with ASC – including silent exclusions. There is a lack of monitoring against children's targets and children area often left with TAs who aren't ASC-aware. There is a feeling that meetings are focused on the outcomes for the school rather than the child. There is very poor communication between professionals and families which leads to people having to repeat the same information over and over again. There is a lack of joined-up services and a lot of passing-the-buck. Some professionals still say parents are the cause of a child's difficulties. There is a patronising 'one size fits all' approach. Parents feel threatened if they flag up difficulties.

The survey was repeated a year later to see if there were any changes.

the survey was carried out with the assistance of the University of Sussex and the University of London and Southbank who helped in validating the findings. The survey found that services were not pro-active but only reacted when things when wrong – crisis management. There was little support for common issues such as eating, sleeping, toiletting, behaviour, sensory. ASC

has many associated difficulties and this can lead to crisis if left unchecked. Parents are dong their own research – which is re-inventing the wheel. Often this is at crisis point. Early intervention is needed to prevent the tidal-wave in a child as they get older.
There are inconsistencies in the diagnostic process. This is highlighted when children with asperger and high functioning autism slip through the net and only get picked up later. Parents are left feeling they just have to get on with it. There is no support or recognition and parents get blamed. There is no home advice – which is a gap in provision. There is nothing in place for when issues arise later on. Often children are only observed in school and not at home and children may be able to hold it together at school but fall apart at home – or vice versa. mASCot advocate assessments in home and the social environment.

In terms of communications and the dynamics of communication, services communicate with schools but parents (don't get to contribute). Contribution is not standard requirement.

Diagnosis is still a big issue with generic advice given. Private professionals are not recognised – parents who can afford to use the private sector do so because of the high levels of expertise, communication and levels of rigour but often are told they can't bring this to the discussion because of a 'risk' of conflict of interest.

The view of professionals is seen to be paramount and parents' views don't have the same status; the parents' view isn't integral to the discussions.

Around 50% of parents said their child had been bullied and 34% had been excluded – there are clear links between exclusions and bullying. Children are excluded after reacting to long-term bullying or because of a lack of knowledge of ASC by teachers. The child with ASC is removed from class rather than the bully!

The key message is that ASC comes with a very complex set of issues (social, medical, daily living etc) and a bespoke response is need for each child not a generic approach. ASC is incredibly complex - "When you've met one autistic person, you've met ONE autistic person". It can be as dehabilitating for a child labeled with 'traits' of ASC as with a full diagnosis. Children get a full diagnosis because they tick enough boxes – there is no single test for ASC. Lots of children don't get a full diagnosis but still suffer without the support and recognition of the difficulties.

Awareness in schools needs to be raised – and raised to at least a standard of minimum awareness by all. 1 in 100 people has ASC this is part of our society and people need to live with this in a positive way. It is fantastic that training is going to take place in schools – but how will this be monitored?

It is important to include parent/carers as experts working in partnership with services: they are a valuable resource. Parent/carers have expert knowledge of their child and when resources are scarce, a parent empowered by training can take on more responsibility.

mASCot recommends that: there is an independent Autism Champion who is fully accountable; a hotline is set up to help isolated families; a bespoke team is set up to support families and maintain an action plan for each child; the SEN partnership plans reflect mASCot's views; and that there is innovative working with all working together. How can we start again with transparency and trust – not a 'them' and 'us' mentality? Could parents club together to get Occupational Therapy? Could OTs run training for parents?

SB – mASCot do accept that people are listening but they don't want to be a 'tick-box' exercise. When the Panel's report comes out, it needs to be monitored and followed up otherwise it is a waste of time. Parents aren't seeing any differences. Officers need to recognise children should come first not rules or money or schools – the importance of putting children first.

Q - What is mASCot's impression of CAHMS?

SB – It is generally not a time issue but what happens when parents get to CAHMS. There is no information for parents going through the journey – no information on what is the next stage. People are scared that they will be sent home if they don't get a diagnosis. There is also a lack of sensitivity in meetings such as reports of professionals eating their lunch in front of children during assessments. Stories are still coming through.

PD – the Parent Carers' Council and Amaze ran a Talk Health event and suggested that there was an autism specialist on all teams. CAMHS noted that they were happy with the level of specialism they had. Is anyone asking parents if they are happy? It is a question of assessing the assessors and looking at the quality of expertise.

SB – there is a real problem that after the assessment families are given a piece of paper and a checklist. There is no intervention or support –this is a long standing issue.

Comment – it is an issue around educating professionals and other families who don't know about autism

MB – it is important that there is a two-pronged approach. Children with autism can make a valuable contribution to society but schools and peer groups need to be educated.

SB – parents need to be included and there shouldn't just be one approach: what works for one child may not work for another. Tailored information is required. One example is about going to a Tribunal about exclusions and having to explain autism to the Governors. There needs to be more understanding.

PD – the Mumsnet campaign 'my child' is a great campaign to raise awareness. People wouldn't tolerate racism or homophobia so bullying autistic children shouldn't be tolerated either. Everyone needs to support each other to work with children with neurodiverse conditions. It's about better understanding, accommodating and enabling ASC children to thrive: educating each other to make unhelpful attitudes about conditions of difference a taboo.

16. WITNESSES - AUTISM SUSSEX

Autism Sussex – Samantha Fievez (SF), Children's Services Manager and Emily Christie (EC), Project Manager for Autism Sussex in Brighton.

SF – Autism Sussex is active in East and West Sussex. A lot of parents from Brighton & Hove contact them and they do a lot of signposting, often to mASCot. They do not offer services in B&H. The inconsistencies cause frustration: because they deliver services in East and West

Sussex but not Brighton, parents in the city can't access their services. Autism Sussex offers holidays and outside hours support, social skills groups, routes to employment, and advocacy in schools. They work with CAMHS in Hastings and offer support pre and post diagnosis. In West Sussex they offer short breaks services on 1-2-1 basis between 2 and 5 hours per child. In East Sussex they offer group support.

In Brighton they take on spot purchases from the Children's Disability Team or direct payments from a family. They only support 6 children in B&H. They support 86 families each month in East Sussex (in group support) and around 30 families in West Sussex (1-2-1 support) and 8 in group support. This support includes entertaining children to give respite and also giving advice. During 1-2-1 outreach they may go into people's homes but usually they see children in the community.

The cognitive range of those they support was around 80% of children with high functioning autism or asperger.

EC – Autism Sussex has just received lottery funding to fill gaps in provision in B&H, particularly when people don't hit the adult social care thresholds to access services. They have just finished a 6week scoping exercise looking at demand for services and are working on an over-view of what services would look like in an ideal world. The lottery funding just covers the salary of four project manager's salaries in B&H, East and West Sussex and they are waiting for match funding. There will be a volunteer-based structure set up to self-fund or get match funding. The plan is to replicate what is done in East and West Sussex with family support groups, drop-in clinics and workshops on particular areas. They would like to develop and expand into B&H but are dependent on fitting the criteria and children with high functioning autism and asperger don't hit the support thresholds.

There is a need for more individualized input and a training programme that moves away from the concept of 'them' and 'us'. There is work to be done to educate teachers further in the nuances of behaviour – children can look as if they are coping, but behaviour escalates at home. Small changes at school may help address this gap.

Autism Sussex intend to set up new social groups for children and young people in Brighton, and a be-friending scheme. Sussex runs social groups for children and a be-friending scheme. There is 1-2-1 support for adults with autism and they would like to extend it to children and transition (to secondary and older). A lot of support goes into primary but less into secondary. Children with high functioning autism may not find school challenging in primary but more so in secondary when the schools are less nurturing.

In an ideal world they would develop a sensory deprivation programme, pre-diagnostic help to parents to deliver therapeutic services and behavior management in the home. The proposals are at a very early stage.

Q – are you talking to B&HCC?

A – match funding at the moment is coming from the Monument Trust not B&HCC. It would be helpful to have an ongoing dialogue with the LA.

17. WITNESSES - AMAZE

Janet Poole (JP), Amaze

Some parents come to Amaze through the helpline, more are referred from CAHMS and Seaside View. They realise that they can't given emotional support post-diagnosis and signpost Amaze. Amaze support all parents with disabilities and remain impartial.

Around autism, parents refer themselves in but need to be aware that not many people will contact to say they had a positive experience! So it needs to be recognised it is a skewed picture. Children with autism who are picked up as toddlers tend to be those with learning difficulties. Amaze help with disability living allowance and getting people a compass card. B&HCC pay for the compass information – children are 80% less likely in East Brighton to get a statement of autism but more likely to get a diagnoses of BESD. This is starting to even-out but is still a factor. Middle class parents can use the system but in the past it was harder. The tick boxes for single parent, poorly housed etc are ticked first – even parenting suggested as a cause – and then you may get a diagnosis. There is now a wealth of information out there and it is amazing that professionals think that parents just want the label of autism.

SB – children may get a diagnosis and then the problems accelerate and lead to mental health issues and they end up back in CAHMS and they start all over again. It ends up going through family history again as a process not providing intervention.

JP – further work is needed in education system. Parents need support post-diagnosis but teachers also sometimes say 'they don't seem autistic to me'. A family may have jumped through hoops and got a diagnosis and proved it is not down to parenting but still meet this attitude. Teachers are stretched, but they need to deal with each child.

Amaze have a new family support worker who is there 2 days a week and the phone number is advertised. People find that they can't get on the children's disability list because they are not deemed in severe enough need, so they then don't get a social worker – parents can feel they are being examined the whole time.

Without a diagnosis, there is no access to services. So parents push for diagnosis. Statements are seen as currency by schools – schools pressurise parents into getting a statement because there are a number of hours associated with this. Secondary school is often difficult and children with autism get set up to do silly things and get caught. They are often bullied and are isolated and vulnerable.

Private Educational Psychologist's reports are no longer deemed to be acceptable when a child is on the ASC pathway. CAHMS have said that families who get a private assessment must be 'over anxious'.

PD – it is important to state that some parents feel the focus is disproportionately placed on their parenting (rather than on their child's neurodiverse traits) and some feel 'blamed' for their child's behaviour. A huge amount of damage is done by professionals blaming parents. Calling a parent's ethics and morals into question needs to be eradicated.

JP – neuro-psychiatric disorders can have an inherited component and parents can be very black and white in their thinking. This is not always taken into account. There should be a question through the diagnostic process on how parents were as children.

Amaze have run 2 ‘Triple P’ parenting courses and most parents attending have a child on the spectrum. Parents have found these courses very helpful.

Q – where are the examples of good practice? Examples of schools working well? Or other LAs?

JP – the special schools are good, and the special units at mainstream schools.

SB – there is always praise for teachers -but they can only go on the advice and paperwork of SEN. Changing the 1-2-1 TA to curriculum TA which means they support the teacher rather than the child’s specific needs. One child may be academically behind but not disruptive; another child the same age may be very academic but have behavioural issues. Schools need to stop having a block attitude to children. In secondary schools, there are broader numbers of teacher or TAs and children get lost.

MB – there are reports of good stories. But these are dependent on individual teachers and supportive peers and there is a lack of consistency. The mASCot survey showed satisfaction in special schools and we can learn from this. Good practice involves lots of input, communication and follow up.

JP – We don’t want to paint a black picture of B&H – it’s a pretty good place to have autism. Amaze are here to show where the gaps are. We don’t want schools and individuals to be attacked. There is a lack of resources and too many hoops to jump through. If you are assertive and not frightened then you get more. Amaze do a lot of modeling on how a meeting can run, how to plan a meeting and to help parents set an agenda, sum up and get a next meeting date. Amaze support and enable parents to get points across. The ASC SS is very short-staffed.

SB – there is a concern that Hove Park School is where all the children with autism are sent with the consequence that nothing is invested in other secondary schools so what will happen when Hove Park is full? The Steve Huggett report noted that there aren’t problems in the special schools and units.

Q – what can children themselves do to make their needs known?

PD – it is very important that a child’s voice is heard. The National Autism Society have a Children’s Charter which came from children. It is a national charter but can be applied everywhere – it can be flexible to reflect what children want.

MB – the ideal circumstances are when children can be involved. Hearing the parents’ voices is the first step: parents are their children’s advocates.

Q – in the city there is a push for excellent schools supporting other schools and rolling out best practice. Is this happening? There is a concern that training is provided and then it isn’t sustained.

JP – there is a big push from senior management and SENCOs to do this. There are examples of good practice. Amaze are only funded to work with education issues – not social care. There is a gap in parent support around accessing services.

SB – ASC SS is brilliant but should there be others providing training so there is more than one view of autism. The training is not currently compulsory so you find that only the interested turn up. It should be compulsory. Also schools need to use what is available – use parents too. We need to move away from the ‘them’ and ‘us’ mentality. mASCot are ‘just parents’ but parents need to be taken as seriously as everyone else in discussions.

PD – schools and teachers have to want to get it right. Could there be an accreditation scheme or a kitemark?

EC - any teacher training should also include TAs. Accreditation is a good idea and it needs to be monitored.

SB – Governors also need SEN training and an understanding of the children in their schools. CAHMS also need training. It is about consistency across agencies and a common approach.

Q – parents are understandably worried about negative reactions to what they say – how can they be made more confident to come forward?

JP – Amaze supports parents and enable them (rather than represent them).

PD – we hear of parents who are unsure of how to complain or uncertain what will happen if they ‘rock the boat’. One family felt it was made clear to them that complaining would affect their child’s access. That is why mASCot think there should be an autism champion who will be an advocate across services. The idea of a critical friend. People need to feel safe – they won’t complain if the system is difficult. CAHMS may say they have only had one complaint a year (or 3 complaints in 3 years) but many complaints usually reflect a genuine problem but a lack of complaints does not necessarily equate to there not being a problem. People may know how to complain but feel prevented from doing so for any number of reasons.

JP – Amaze are a parent-partner organisation in education and this is statutory. There is no equivalent in CAHMS/Health/Social Care.

Q – can the mASCot survey be repeated? Very useful.

MB – we would like to do so.

SB – there is an ASC intervention group been set up, Chaired by Jenny Brickell and a joint effort would be good.

JP - Compass database has 1700 families on it and that information can be used for a survey.

Steve Harmer-Strange (SH-S), parent

SH-S was a Councillor between 2007-11 and Chair of the Scrutiny Panel looking at adults with autism. He was also the Chair of the Learning Disability Board and a Trustee of Autism Sussex, and a Governor at Hillside for several years. There is lots of good practice and examples of best practice. The work in the special schools is good and they provide quite a lot of out-reach to mainstream schools but there is a funding issue around teachers time providing this support. It is a difficult decision for Head Teachers around teachers. It is very disturbing that medical and other professions aren't listening.

One of the recommendations of last report was an autism specialist and there still isn't one. An independent role is needed. It is shocking that the adult autism strategy still has two more years until it is implemented fully.

There is a trend recently that tendering is going out on a larger scale and looking at general rather than specific care.

There is an issue around what social workers report and what they don't. There are some bad experiences with the way people are treated. If you are fighting for funding, then parents aren't encouraged to go to the meetings and the social worker will go – but they can't replace parents. There is a potential conflict of interest with the social worker paid by the LA. If a parent does attend, the social worker says they should speak for themselves. There are serious issues around access, openness and transparency of these funding panels.

Education – most of the problems and gaps are in mainstream settings. Individual teachers are often doing the best they can but the ethos flows from the Head. LAs should ensure Heads are delivering the right attitude throughout the school.

It is very stressful for parents dealing with agencies all the time and having to fight constantly and struggle day after day. This is fundamentally wrong. Stress brings illness which affects children too. In some areas people are very good and supportive but lots aren't. There is a lot of ignorance and people don't understand how difficult it is.

They have had disturbing experiences with the ambulance and NHS. A GP had contacted the family to say immunisations were due. They explained that it is very challenging to do injections or blood tests so restraint may be needed. However, some medical professionals won't restrain a child/young adult because of his human rights. But if a child doesn't have the capacity to understand, the parents need to look after their human rights. He is still not immunized. In another example, after his son had a fall, they had to call an ambulance but three of the people who came wouldn't lift him and left it to the parents. They wouldn't restrain him and he was fighting strongly. There are some great people in the NHS but this was a bad experience. Struggling to lift and restrain a grown child is very difficult and physical and people don't help but stand and watch. Getting an x-ray was incredibly difficult without a restraint. NHS staff need to be aware that there are times when appropriate restraints are required. On occasions they have found a nurse willing to use restraints, but not often. In contrast, the dentist service is superb and they have an excellent attitude.

SB – a traffic-light system is used in some hospitals and they should be an autism-specific version of this in place.

SH-S – there should be a flag on the NHS records so people don't have to re-count their circumstances repeatedly.

SB – each child needs a good team around them that ties education, health and social aspects of care together.

JP – Seaside View offer a key worker to a child who requires more than two services – this could be extended.

Q – do you use respite services?

SH-S – we have devised our own respite with a team of carers. But many parents don't have this choice. We have a personal budget – although there are issues around staffing and dealing with absences through illness of regular carers.

MB – this is what we mean by a bespoke response and it should be across the board.

SB – there is an issue around transport. Schools do have a budget they can access for independent transport but many don't. If children can't access education they won't get a job. Children need to learn life skills and be kept safe.

S H-S – Autism Sussex are working closely with Jobcentreplus to help educate them. Around 90% of those with autism don't find employment. Autism Sussex are running a café in Hastings that provides work experience for people with autism. The skills of people with autism need to be used and there is a role for the local authority to educate employers. The justice and criminal justice system should be considered as young people with autism can end up in trouble.

18. DATE OF NEXT MEETING

The Chair thanked everyone for a most useful and informative session. The next meeting is on 19 September at 10am and will start in public and go into private session.

The meeting concluded at Time Not Specified

Signed Chair

Dated this day of