

BRIGHTON & HOVE CITY COUNCIL
SCRUTINY PANEL ON SERVICES FOR CHILDREN WITH AUTISM

10.00am 19 SEPTEMBER 2013

COUNCIL CHAMBER, HOVE TOWN HALL

MINUTES

Present: Councillor Jarrett (Chair)

Also in attendance: Councillor Pissaridou and Wealls

Other Members present: Councillors

PART ONE

19. PROCEDURAL BUSINESS

20. CHAIR'S COMMUNICATIONS

Thank you all for attending. Welcome to this information-gathering meeting of the Scrutiny Panel looking at services for children with autism. I would very much like to thank those of you who willing to share their personal experiences as parent/carers with the Panel – both here today and in writing.

This meeting will hear from parent/carers in public then will go into private session at around 10.45-11.00am. We will then move into Committee Room 2 to listen to people in private.

The Panel are keen to hear your views and experiences. I will ask you each to say who you are and then speak for around 10 minutes and then the Panel will ask any questions. Please note that as timing is tight, I will have to ask people to keep to their allotted time slot and Panel members to keep their questions brief.

21. MINUTES FROM THE LAST MEETING 17 SEPTEMBER 2013

The minutes will be circulated in due course.

22. TO HEAR FROM PARENT/CARERS

DRAFT MINUTES

Parent/Carer 1 (PD)

Families have very strong feelings after years of dealing with services. PD has three children two of whom have neuro diverse conditions. One child has autism who is now 14yrs old. PD is a full time carer and every inch of her resources go into her children – personally everything else has been given up and to see her children thriving is the most important thing.

As a parent you are the expert on your child and for some professionals to have the audacity to blame the parents as a standard response is shocking. Some parents feel that this is the first response and huge damage is done when parents' morals are brought into question. Parents feel attacked to the core of what being a parent means: it is a form of institutional abuse to blame parents.

Being family-centred means asking parents and children – especially mothers - for their input. There are cases of people who can't work (and lose their homes) when schools keep sending children home. Parents end up begging for help when their child ends up with mental health issues. Parents are ending up with shoddy, sub-standard interventions. Professionals shouldn't blame families, nor send families away because there are no resources to help. Stop insisting that parents are neglectful, or disinterested. Stop blaming mothers.

PD filed a complaint against CAHMS some years ago. The positive change came about for her son when they went privately and found a fantastic psychotherapist. One of her daughters is 10yrs old and was referred to Seaside View who carried out an hour's assessment and diagnosed OCD and referred her to CAHMS. A private assessment at The Priory said it wasn't OCD but a clinical range of difficulties that can't be shoe-horned into a diagnosis. They now use private professionals. The Learning and Assessment Centre in Horsham is fantastic.

All three children are in private education because of the smaller class sizes. There is a psychotherapist in the background who supports the family – sometimes unpaid. They ended up going privately because they were either denied access to a service or it was useless. They pay huge sums of money for a range of professionals to support them. When you go privately you are treated as a partner in your child's care: in the NHS you feel as if you are being treated as the culprit.

Examples include: an ASC assessment worker in CAHMS asked a child "when your mum nags you about your food it must make you nervous" or "Dad's away a lot – that must upset you." This was in an ASC Stage 1 assessment session and these are inappropriate leading questions to a child. Another example was at Seaside View when a comment about her son being sleepless was put on record as 'the mother is envious of other people's babies'. A further example was a dyslexic child who was a little ADHD and took time to be toilet-trained being referred to a clinic where they were asked who was in the family and who was sleeping in the child's room. They appeared to be looking for signs of sexual abuse. The experience is terrifying – not knowing why you are being asked lots of questions that pick away at your family structure.

PD has tried to design a bespoke service for their children and they have a bright future. But this is because they can afford to do so – many can't. There is a fundamentally different culture and outcomes in the private sector to the NHS: the private sector offers timely and flexible services.

The Royal Alex hospital is positive and has made sensory adjustments.

Q - what factors make parents feel blamed?

PD - it is the way of communicating with parents which comes from social service training. They start off looking for mental health issues and levels of parental absenteeism. Assumptions are made and parents feel they are being judged. One comment that has been made is 'it is always the mothers with CAHMS'.

Q – what about education?

PD – nothing but praise for Brighton & Hove High School who have a great SENCO who can be contacted anytime.

Parent 2 (DB)

DB's son gets sent home regularly. It is exhausting now with her son starting secondary school – he has already been sent home from school - everytime her phone rings her heart sinks and she despairs. On two occasions in the past her husband picked their son up when he was sent home and he ended up being excluded for 5 days (once for kicking a teacher and once he almost ran in front of a car.) So it all falls to DB. She has 3 children and her 12yr old son was diagnosed 2 years ago. They didn't want to rush into getting a diagnosis. Her other son has some special educational needs and some traits of ASC, but probably isn't on the spectrum.

Her son with autism was at mainstream school for two years then the speech and language unit. He started at a special unit in mainstream secondary (Swan Centre at BACA) 2 weeks ago. He has had behaviour problems since the age of 2 –it has been a massive struggle until his diagnosis at 10yrs old (and continues to be). It isn't always apparent that a young child has ASC and there is a black hole in terms of behavioural support when children are younger – particularly pre-diagnosis. This lack of support leads to problems later. There is a massive gap in the city in terms of behavioural support. They got sporadic physiotherapy and OT, lots of speech therapy but nothing at all around behavioural support. DB thinks that perhaps the lack of behavioural support for these children is because no-one has quite known what to do. How can this be addressed in an effective and cost-effective way?

Things that have worked well are: 'portage' that they had between ages of 2-4yrs was fantastic and great emotional support; the counselling for DB at SeaSide View was an amazing help; the educational psychologist support was very good. At the ICAN nursery the educational psychologist was the first professional to provide a better understanding of her son's behaviour and how to deal with it (although services were very stretched); the Speech and Language (S&L) unit at Carden had a specialist teachers who knew her son and they worked together to build up strategies to be used at school and at home. Working with people who know your child is brilliant.

Things that haven't worked include: behavioural advice from professionals who don't know enough about your child, or ASC/disabilities. In year 5 it all fell apart for their family and exclusion is a very stressful experience, and so it appeared that the family weren't coping. Behavioural advice that isn't useful can make you feel as if it is your fault - it took DB years to realise it wasn't her fault, and the behavioural problems were not down to flaws in her parenting. Most parents feel insecure anyway and with an autistic child it is very hard – especially when people make you feel that you are doing something wrong.

CAMHS was not particularly helpful. E.g., her son was taken off the list when he was in the middle of being repeatedly excluded. CAMHS said they weren't the right people to help – but didn't say who was!

Support for parents is crucial, both in terms of attitude and practical support. Different parents need different things in terms of emotional and practical advice and support.

Joined-up strategies between different services are required. Early intervention is needed. Every teacher should be an ASC teacher as part of classroom learning.

Q – can you explain 'portage'?

DB - 'portage' has been discontinued but was funded by the Children's Society and volunteers came in weekly with a task for your children for an hour. They were volunteers who had been trained and also had children with similar difficulties.

Q – does your son have a 1-2-1 TA?

DB – a specialist TA from the Swan Centre is in class with him and some other autistic children. He does not have a specific TA allocated to him. DB is included in discussions about his exclusion policy. He has been excluded but it needed to be made clear what he can and can't do. Early interventions will help reduce exclusions. More joined up thinking is needed in early years.

Q – what behavioural support is needed?

DB – it needs to be tailored support. For her son it would have been someone working with her when her son was little. He had a speech and language diagnosis so someone who understood that and also knew her son.

Parent 3 (AH)

AH has three children and the middle son was diagnosed 3 years ago with high functioning autism. Her two daughters have high levels of anxiety which affects sleep, schoolwork and ability to make friends. There is an issue around what support there is for siblings of children with ASC –they witness difficult behaviour and go into school traumatised by what they have seen. SIBs does provide help for siblings whose siblings have general SEN. What can be done to support the siblings of those with ASC?

AH's son is in Yr8 and had a very difficult transition into Yr7 and was home by lunchtime on the first day, although they had warned the school. He - and the family – were in a state of crisis. Her son was terrified by the crush of pupils, the size of the school and noise – it was sensory overload. Following a meeting with the SENCO, parents and ASCSS, the school proposed that someone meet her son at the school gates every morning 10 minutes after the bell had rung and took him to a quiet learning support room. This was a place of safety. Gradually the TA brought work in from subjects he enjoyed and built it up, bringing in teachers. This took a term but he started going to a class a week with the TA, then another class. He has two cards – one says 'I need to leave and I can't explain', and the other 'I need to leave before the end of the class to avoid the crush.' The TA was excellent and met him to take him to classes. Now he has started in Yr8 and it feels like he is in a place where his needs are listened to.

Her son was referred to CAHMS for ActionPlus and someone came before school once a week to talk about his anxiety and to suggest tips for coping. These tips may not always work but some do: one good example is 'mind switch' where you talk for 10 seconds about an object then something you fear for 10seconds. The ASCSS was really helpful and AH is now working there as parent liaison.

There is an issue around private education – there are no services available to you if you go to private school (can't access ASCSS). AH has attended ASCSS coffee mornings when her son was in private school but it is really for state schools.

Meetings at Seaside View are not accurately recorded – important bits are either missed out or inaccurate.

Q – what was your experience at primary school?

AH – at private school it was a very stressful time. Her son is very clever but messes around. The school didn't recognise the 'stimming'. In yr3 it was a state school teacher who said she thought her son should be assessed for ASC. The parents offered to pay for teacher training in the private school and the school then did send the SENCO on a training course. The majority of teachers were very caring but not trained. AH has seen good practice at B&H High School.

Panel comment – perhaps all teachers should get ASC training to ensure children are set on the right path.

Parent 4 (HH)

HH- has a 19yr old son who is autistic with severe co-morbid anxiety. He is currently in an acute care psychiatric clinic recovering from a breakdown. The clinic has been outstanding

Things that have gone well include Adult Social Care Direct Payments. Another positive earlier was that her son had 'portage' as a young child which was great. He now has direct payments so buys his own support and has had people working with him. This allows him to have a social life and go out into the community – these people are vital in creating a bridge to a wider life. It is really important for independent living skills and for him to have fun (without always being with his mum). This has made a huge difference and they will continue to help him transition from the clinic back home. It is a flexible service that can grow with him.

Her son was lucky to be assessed when the criteria for adult social care was lower than it is now. It is a concern that young adults now won't be able to access these services. Yet they are relatively inexpensive and good value for money (allows supported living and prevents potential family breakdowns).

Things that haven't gone so well (and were partially responsible for his breakdown) were anxiety over transition from FE college and a lack of support. When a statemented child goes to a FE college they automatically lose their statement.

HH's son has high cognitive function but because of his high anxiety he struggles to cope in mainstream education. It is very difficult to find a place where he can meet his academic potential – mainstream education is no good for him and the alternatives are not academic enough. They finally found a place in B&H but by the time they appealed it was too late.

There should have been specific transition support early and this may have prevented his breakdown. There is specialist ASC provision in B&H but it is limited and the application process is too lengthy. Her son had to apply to mainstream colleges to prove he couldn't go – and the interview process was very traumatic for him. The process should be shorter – and better. Her son's anxiety over waiting 6 months and still has no decision on FE college has contributed to his breakdown. This needs to be made better – the family are working with adult social care services to ensure her son is protected in the future.

There is a lack of choice in educational provision.

Speaker 5 (B)

B is the Grandmother of a 12yr old girl who was diagnosed with high functioning autism/asperger by a paediatrician who was a consultant in ASC. This was a private consultation from a specialist but it was over-turned by a court-appointed psychiatrist who didn't have NICE training.

B is a retired nurse and her husband a retired consultant psychiatrist in adult psychiatry and they didn't recognise the signs of autism in their granddaughter. It was a medical friend who first suggested they consider ASC. The parents of her granddaughter were in the middle of divorce proceedings but since the diagnosis was overturned by the Court, her granddaughter was removed from her mother. This was three years ago and it is still unresolved. The family law courts in Brighton have no idea of what is required. The subtleness of symptoms in girls means it is often missed.

The court appointed child psychiatrist didn't talk to her granddaughter or look at her sensory problems. He noted aloofness and gaze awareness but omitted these important symptoms in his report. The Minister for Justice states that where there is a difference of opinion on key medical issues a judge may order more than one expert, but his judge used her discretion instead of evaluation and chose a general child/adolescent psychiatrist and not the consultant paediatrician specialist in autism. How can we get help when judges don't know about asperger and ASC. There should be guidelines and more people trained to make assessments. They have been fighting for 3 years to get their granddaughter re-assessed but she is now copying behaviour which makes it harder. Diagnostic assessment is inadequate in family law court.

Judges need guidance and should follow NICE guidelines. Social workers need ASC training and teachers need to work closely with SENCOs.

Parent 6 (DW)

DW has a 15yr old son who has fallen into a big black hole and been failed by everyone – CAMHS, social services, LEA and others. He was statemented at primary school but at secondary school it all fell apart. The mainstream school he attended was too big but the alternative of Patcham House wouldn't work for him either. One example was that he couldn't use the school toilet but the only suggestion give was to go home. At the end of Yr7 he was very anxious, stressed, hitting and breaking things and this got worse and worse. He didn't get his timetable in advance which made things worse. He should have got 25 hours support but he only got 7 or 8 hours each week. He ended up put in lower classes but then he got less support. He was out of school for 2years and there was only the 2 of them at home with no

help. DW couldn't leave the house, didn't have friends, and ended up a prisoner in her own home with no help or behaviour strategy. CAMHS said he had no mental health issues but he does now.

He has sensory problems and didn't sleep in a bed for over a year but slept in a chair and tried to control his surroundings. They had to move house because it was damaged. OT would have been great. The CAHMS person was late every time and this made her son very anxious. DW told CAHMS that her son could not attend appointments for CBT as he could not leave the house – the response was that her son had to go to CAHMS for therapy and they could not come to him. DW had asked for help to address the issue of not being able to go out. When DW said he had to keep cleaning the bath in repetitive manner, CAHMS said it was okay and then asked about any other 'timewasting' activities - which is unacceptable. DW was told her son can't have help until he is in school but there is no help to get him into school.

After DW's son's annual review, his statement should have been amended and send to DW for comments, then a final statement from LEA. Only after a paralegal sent a legal letter to the LEA reminding them that the statement was overdue did DW get the amended statement. It took 8 months which prevented DW for appealing for a special school – her son was not at school during these months.

Q – what about primary provision?

DW – They were in America in the very early days. It was a fight to get her son statemented but the primary school had a brilliant SENCO. It was in secondary school that it all fell apart when so much could have been done. DW felt that she was blamed for many things and not supported. The ASCSS did not support her but made her feel she was too anxious. DW asked the school to ring her if her son doesn't turn up but she saw an email that this indicated that her anxiety was increasing when it is a perfectly reasonable request.

Parent 7 (MA)

MA was going to talk in private but felt supported to talk in public now others have. She has been a mother for 20 years and a stay-at-home mother for 15yrs. She has 4 children – 3 daughters 2 with anxiety and mild depression who have been to CAHMS and a son with ASC.

They moved to B&H in 2009 and after 6 weeks there was no local school place so then her son had to travel across the city. The school suggested her son might have ASC and S&L difficulties in February 2010 but the referral was not taken further. In July the school nurse and GP suggested a medical referral and during the summer holidays her son was given a place in his local school due to his referral for a special needs assessment. He finds it hard to leave the house and struggles in public, for example anywhere where there is piped music. In November 2010 her son had a stage 1 assessment. In January 2011 MA was diagnosed with a mood disorder. In May 2011 her son received a formal diagnosis and they received a lot of paperwork but no direction on who does what or why and it was overwhelming. In July 2011 they received an inclusion grant, which gave 1-2-1 support for 12 sessions in 6 weeks.

At the time, MA felt very isolated and had been discouraged from joining Amaze by a nurse. mASCot and Pebbles didn't appear to operate where MA lived. Her son finally got a statement of special educational needs in December 2011. There is no funding for support during the

school holidays. Her son was getting very depressed and MA went into the school to ask for support for both her and her son – she kept asking for help as she knew she needed help too.

Transition is a nightmare – and starting again after school breaks. Her son was left to take his SATs completely on his own with no support or help. He was very distressed and anxious. They requested help and respite via the SENCO who asked for help from the disability social service but were denied twice. They finally got a social worker who didn't know about their circumstances who pointed them back to disability social services. Their Seaside View Paediatrician was able to get disability social services involved and an LD CAHMS appointment for her son. The appointment was set but then withdrawn as this tier of CAMHS was not available to her son because he was in a mainstream school instead of a special school. They asked to see community CAHMS and were given a stage one ADHD assessment but were not given any help with his anxiety as it related to his ASC. They went once to Tier 2 CAHMS but weren't offered any strategies and were signed off.

MA's mood disorder became worse in the recent summer holidays and escalated terribly.

The Panel went into private session.

23. TO HEAR FROM PARENT/CARERS IN CONFIDENTIAL SESSION

24. DATE OF NEXT MEETING

The next meeting is 15 October in Hove Town Hall.

The meeting concluded at Time Not Specified

Signed

Chair

Dated this

day of