

## **Report - Parental feedback on CAMHS**

- How was your experience of being referred into the ASD pathway?
- Are there things that went well in the assessment process?
- Are there things which you feel could be improved in the assessment process?
- What gaps do you think there are in Brighton and Hove in the ASD provision (assessment and treatment)?

Following on from the CAMHS review and development of the 2015/16 local Transformation Plan, - Brighton & Hove Clinical Commissioning Group have commissioned Sussex Partnership Foundation Trust to undertake a comprehensive review of the ASD pathway in order to improve assessments (as well as access), treatments and diagnosis and outcomes for children and young people with suspected ASD (which includes support for families).

As the designated review lead Dr Mekayla Zahra, Clinical Psychologist is inviting Parent Carers of autistic children to meet as a group in order to gather feedback around their experiences of the current Autism Pathway in terms of assessment and treatment. This is with the view of understanding the glitches in the current ASD pathway and what things could be done differently to improve service user experience. The feedback will be part of a wider report for the commissioner.

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### **Referral Process**

Following a failure by her school to recognise her autistic difficulties when I sought ASD assessment and who dissuaded me from seeking that assessment at age 8, I made a self-referral to CAMHS for our eldest child at age 11. The referral was made in late July 2012 and the ASD assessment was not until end of March 2013, meaning a wait of **8 months**. This is in absolute breach of NICE Guidance CG128 which states children should be assessed **within 3 months** of referral. Yet in the July 2013 Autism Scrutiny Panel <http://present.brighton-hove.gov.uk/ieListDocuments.aspx?Mid=4954> **Brenda Davis:** "As the bulk of children are seen early, CAMHS do not have a waiting list. People wait no more than 2 months for an assessment (2<sup>nd</sup> line) and 4 weeks for a first assessment."

We were seen for an initial appointment by Di Metson (who incidentally was so rude as to shush me when on one occasion I offered clarification after our daughter had answered a question less than clearly), termed a "stage 1". I strongly believe these types of appointment are to give a false illusion of the assessment process having started for statistical/monitoring purposes, it's a complete red herring and hides the delays in the system. It also has overtones of screening children out of having a full assessment and I know this is an issue that was raised by parents at the LA Autism Scrutiny in July 2013 (<http://present.brighton-hove.gov.uk/ieListDocuments.aspx?Mid=4954> **Brenda Davis:** "As the years go on, the number of children going to Stage 2 has reduced because they are better at doing Stage 1."!). If the clinician seeing the family at the "stage 1" has lack of autism expertise or parents are not eloquent at explaining their child's difficulties (or the wrong questions are asked), potentially autistic children could be screened out, resulting in missed diagnosis. During the stage 1, Di Metson told me the assessment would take place 2-3 months later, which turned out to be entirely false. The report alone from our stage 1 appointment took **3 months+** to be typed, was riddled with mistakes and false claims – which CAMHS did not correct when I pointed them out. Examples are that my name was used instead our child's name, entirely false information about

my own family/parents, which was then carried forward as truth in all subsequent professional reports.

When I referred our daughter, I sent in a meticulous 20 page birth-to-date report on her, which was very informative and ought to have been very helpful for CAMHS, describing multiple examples of her ASD behaviours and difficulties, history of socialising problems at school, phobias, with specific incidents as examples and her traits bullet-pointed. This report alone should have meant a "stage 2" (*an actual assessment*) being arranged under fast-track. I also sent two lengthy past school report copies (*she had been home-educated for 2.5 years by that point*) as they contained some ASD behaviour relevant comments. Bearing in mind she was 11 (*almost 12 by time of assessment*) years old, at a critical adolescent stage and already late to be diagnosed, any delays to assessment were wholly unacceptable. This report was also intended to form part of evidence for the actual assessment, but as you will read later, was ignored entirely.

During the endless wait for the autism assessment, I was offered an appointment with two clinicians at CAMHS in January (*Dr Brenda Davis & Dr Conny Gutjahr*) to "*facilitate the assessment process*" and at this meeting, when I pointed out that her sibling had a diagnosis of autism which was a strong risk factor for my daughter, I was told that this didn't mean any increased risk! And these are two **senior clinicians** (*one of whom is responsible for the autism pathway for the whole South East of England!*) It even says in 1.4.4 of the NHS NICE Guidelines (<http://www.nice.org.uk/nicemedia/live/13572/56428/56428.pdf>) that having a sibling with an ASD is an increased risk factor which needs to be borne in mind as part of the assessment. I was also told during this meeting that our daughter's file had been lost. I assume by Di Metson, who had since left, this resulted in me having to complete a whole new set of SCQ and BRIEF questionnaires. The meeting was a waste of resources and time (*served no purpose*), I believe it only happened due to the loss of the file and because I had been chasing for the assessment to happen, so they were just trying to make it look like some action was happening and trying to scabble together some more information because of having no file. They later denied they had lost the file even though I have evidence of it in correspondence.

I was painstaking in providing a lot of information up-front because with her being home-educated I knew they would normally ask school teachers for up-to-date information. As her educator, I should have been treated with the same respect and authority as any other education provider. They may have (*needlessly*) delayed because of not having up-to-date school information, but were disregarding all the information/evidence I provided them anyway. The paediatrician at Seaside View who we saw for my younger daughter, stated that school information is not always useful (*"high-functioning" girls often mask and mimic in school*).

Because of our daughter being home-educated, CAMHS sent Sue Gregory (*CAMHS "Family Worker"*) to come round a couple of times (*with one month in between the two visits*) to spend some time with our daughter to get an "*additional overview*." Again, whilst I didn't mind this action in and of itself, it unnecessarily held-up the assessment and evidences even more how they were disbelieving and not trusting my own expert evidence of our daughter. When Sue came, all she did was complete questionnaires, which may have been the Strengths & Difficulties ones and these could have been posted to us, making the appointments a waste of time.

Before the assessment took place, I was sending CAMHS additional written information periodically as it arose, because having Asperger's myself I can lose focus in verbal conversation and go blank when face-to-face (*such as being asked for examples*) and I didn't want our daughter's assessment to be detrimentally affected as a result, which I explained when I sent the information.

They sent me the "stage 2" appointment letter saying "*The assessment and feedback will be from 9.30am until 12.00*" which did not happen, as will become clear below and no feedback was given on the day.

I cannot say anything went well in the referral process.

**RECOMMENDATIONS:** (1) Autism concerns will already have been raised for a child to be referred in the 1<sup>st</sup> place - dispense with "stage 1" appointments, which causes undue delays for the child and family and wastes resources (*questionnaires can be sent out at referral stage if necessary*); (2) once reports are written, professionals should, in a timely manner, offer a first draft to the parent so that corrections can be made (*and any potential differences of opinion on something that is a matter of opinion and not fact, can have a rider stating the parent's view on that part*) before distribution, so that errors are not carried forward to other reports; (3) start respecting and using parental evidence and information on their child as priceless expertise from the person that knows the child best and has equal (*in some ways greater*) weight, than professional opinion which no matter how qualified, is from the perspective of a stranger, in an unnatural snapshot setting. Instead of treating every case the same in a tick-box manner, where professionals seem unable to think outside of their procedures and formats, take advantage of highly useful, pertinent information where it exists, to the benefit of the child and their family, as well as the process; (4) stop wasting valuable resources on unnecessary meetings causing delays which impact the child and their family, where questionnaires are required to be completed, post them!

### Assessment

I am aware that a properly conducted assessment should take some time and be multi-disciplinary. (<http://present.brighton-hove.gov.uk/ieListDocuments.aspx?MId=4954> **Brenda Davis:** "*Stage 2 is a more time-consuming multi-agency diagnostic assessment using NICE assessment tools and takes a whole morning. As the years go on, the number of children going to Stage 2 has reduced because they are better at doing Stage 1. Stage 2 is a more time-consuming multi-agency diagnostic assessment using NICE assessment tools and takes a whole morning.*") When we arrived for her assessment, we were kept waiting a little while and then told that they were going to take **15-20 minutes** to read her file before the assessment started. This took me aback, because I was told in a meeting I had with them in January (*referred to below*) when I specifically asked, that everyone involved in her case had read everything in her file (*and it was vital that they had done so*).

However, after **5 minutes** they returned, clearly having not read it (*I knew the amount of information I had sent could not have been read in that time*) and I was shocked that they hadn't in fact read it upon receipt - or at least some point in the days/weeks **before** our actual

assessment appointment (*which I believe hugely affected the assessment process*). So they proceeded, not having read it and instead relying solely on the ADOS-2 and ADI-R. The psychologist took my daughter to another room and the psychiatrist interviewed me (*that's as far as multi-disciplinary went, so the claims about multi-agency were untrue in our case and as no apology was made for missing staff, I assume this is their **normal practice***). Our daughter's interview finished in around 50 minutes, and my concurrent one only took about an hour (*our appointment was for 9.30am, the assessment started at about 10am, the letter said it would be finished by 12.30pm but we were finished at about 11.15am*). An hour and 15 minutes from start to finish is **not** a whole morning! It is also an appalling **sham** of an autism assessment.

During my ADI-R interview with the psychiatrist (*which I later found out was the **shortened version** of the questionnaire too*), she seemed keen to finish up as quickly as possible, she kept checking the time and clearly wanted me to give as short answers as possible (*several times I was cut-off when answering questions*), just to be able to go through the questionnaire. There was no discussion, it was all just responses to the questions on the form. I was assured again when I asked, that my daughter's file had been read. But I could tell by questions that were asked in my interview that it hadn't been read. (*I could also tell this by things that were said at the feedback session at our next appointment*).

Because (*as I found out later*) Tansy Walker upset and offended our daughter at her assessment (*they asked her, an 11yo autistic child, who as is normal in autism, has an emotional and developmental age 3-4 years behind her chronological age as well*) whether she had a boyfriend! Tansy Walker also said to her about the subject of her special interest (*a children's cartoon character*) that it "*isn't as if it will come alive*", when to her it was very much alive (*and still is, over 3 yrs later*) which was very distressing to her.

CAMHS claims the ADI-R is scored with the parent at the end of the interview (<http://present.brighton-hove.gov.uk/ieListDocuments.aspx?MId=4954> **Brenda Davis**: "*At Stage 2 the psychiatrist will use standardised NICE recognised Autism Diagnostic Interview that will be scored at the end with the parent/carer.*") but this **did not happen** in our case. We were given **no feedback** but were given an appointment **a week later**, which was **terrible** to do to us, leaving us hanging all that time not knowing the outcome. For someone autistic like me it was even more cruel because autistics find uncertainty and waiting very hard.

When we had the feedback meeting, they told me they had not diagnosed her and they tried attributing her high scores to anxiety and OCD (*which she was not assessed for or diagnosed with – despite that ASC assessments should be differential and include mental health assessment*) even though they stated "*autistic behaviours*" in her report. She fell 2-3 points short (*borderline*) of clinical range on the ADOS-2 (NICE CG128 "*1.5.11 Do not rely on any autism-specific diagnostic tool alone to diagnose autism*" and also that "**a negative score does not rule out autism.**") but was well within clinical score on the ADI-R.

I immediately challenged their clinical decision. They suggested assessment of anxiety and OCD; observing her at a social gathering (*she was almost 12yo by that point, not a toddler and highly observant to her surroundings!*) - which was clear from their report to be entirely due to lack of up-to-date school evidence and **lack of trust in my own**; and recommending waiting 6 months to potentially reassess her. I had told them she was about to start secondary school, that I knew she would have problems and that without a diagnosis it would be very difficult for

her to cope without support. But it made no difference. So whilst they had said they wanted to see her to assess anxiety and OCD (*incidentally both often co-morbid to ASD*), they were so inept at engaging her that she refused to see them again, which I felt was professionally negligent as this is their role - knowing how to work with children and overcome barriers to engagement. She even subsequently hand-wrote them a letter telling them she hated them and would not see them again. This is yet another example of CAMHS not understanding autism.

When I received their report, it was again full of errors and most of them they would not correct. They cited it as "*clinical opinion*" when it was their misrecording of things **I had said!** I also discovered that in one instance, the total opposite of the truth was put, because I had misunderstood the question, but the facts of the matter had been sent prior to the assessment in written information by myself. So this lowered her score, but still they would not correct it.

<http://present.brighton-hove.gov.uk/ieListDocuments.aspx?MIId=4954>

**Brenda Davis:** "*By secondary school age, the service is much better than it was at recognising ASC as more people are diagnosed earlier and better.*" clearly is **not the case** when our daughter who was about to start secondary school in a few months, experienced diagnostic failure by CAMHS.

<http://present.brighton-hove.gov.uk/ieListDocuments.aspx?MIId=5053>

School Governor: "*Diagnosis is not a quick as it could be and by the time a child reaches secondary school there is an urgent need for diagnosis.*" which CAMHS don't seem to see!

I immediately requested a 2<sup>nd</sup> opinion and put a detailed case to the funding panel. She was diagnosed through the out-of-area 2<sup>nd</sup> opinion in January 2014 (*a whole 18 months after my original referral*), but even that diagnosis was negatively impacted by CAMHS' provision of their own assessment reports (*along with a very misleading chronology/description of events*) to the clinic in the referral process, making the 2<sup>nd</sup> opinion less than independent and the wrong autistic sub-type was diagnosed as a result – she has Asperger's and meets the full triad of impairments but she was diagnosed with PDD Other!

**"Brighton & Hove CAMHS Autism Spectrum Disorder Care Pathway"** by Brenda Davis

[http://present.brighton-hove.gov.uk/Published/C00000824/M00004955/A100035630/\\$ASCScrutinycommitteeopathwaypresentation2.pptA.ps.pdf](http://present.brighton-hove.gov.uk/Published/C00000824/M00004955/A100035630/$ASCScrutinycommitteeopathwaypresentation2.pptA.ps.pdf)

According to the above link, post-assessment (*I assume this means with a diagnosis*) specialist services, care planning and T4 services are supposed to be forthcoming. CAMHS **were notified** by the out-of-area service when our daughter's autism was diagnosed and we **received nothing from them**, even though the above states that an "*action plan*" and "*information pack*" is provided to parents. Neither was a letter triggered by CAMHS for the the specialist health visitor to offer telephone support, as stated. Nor did CAMHS inform the ASCSS - I had to do that **myself**. Apparently there is also supposed to be an "*Exploring ASD: A Parent's Group*" offered by CAMHS to parents. We didn't need this, as I have Asperger's myself, but they didn't offer it as they claim to.

Incidentally it states in the above "*If possible, a social communication questionnaire (SCQ)*

completed by parent/carer should accompany the referral from Tier 1 or 2, as well as information from the school." This is presumptuous, because not **all** children are at school, some may be home-educated for instance and many autistic children mask their difficulties in school anyway. It also states: "If Stage 1 info alone indicates ASD very unlikely to be present, referral back to an appropriate generic team for intervention." but 'very unlikely' does not mean definitely not and they are likely therefore leaving some families floundering without recognition of their child's autism. It also states: "If, in exceptional circumstances, due to the complexity of the presentation, an ASD diagnosis is unable to be made/unclear, refer to an ASD Specialist Centre for diagnosis/clarification." but this was not done automatically in our daughter's case, I had to request and fight for it. So lies are being told.

I cannot say anything went well in the assessment process.

**Updated on 5.4.18 to add:** It was clinically confirmed in June 2016 through consultation and screening tools, that our daughter additionally matches the PDA subtype of ASD, making it two missed diagnoses by CAMHS. Sadly, because her ASD was diagnosed so late and she rejected the diagnosis, plus having pathological demand avoidance, it would not be possible to physically get her to an assessment to receive the formal diagnosis. This created great difficulty in getting the LA to include her PDA profile within her EHCP to recommend the DfE educational guidance for PDA be recommended under provision, meaning I had to have mediation with the LA. It was also evident from the LA's behaviour before and right up until that mediation, that they did not understand that the NHS ASD diagnosis our daughter received in London, was an ASD. Therefore they had not put ASD as her primary need on her EHCP for a very lengthy time and during a malicious referral made against me by the LA, they claimed that I was "insisting she has ASD" implying I was fabricating. So CAMHS' utter failings have caused tremendous trauma to our family. As SPFT have also produced a written statement saying they do not recognise PDA as a diagnosis (*bizarre because it is an ASD and would be diagnosed as such*) they have also created problems for parents of children with PDA, with the LA's SEN Department who claim PDA doesn't exist!

**Updated on 19.7.20 to add:** It was clinically confirmed in January 2020 through NHS assessment that our daughter also has ADHD. So this is yet *one more* diagnosis that CAMHS failed to make and she had to wait 7 years for without recognition or support. Bringing this to **a total of five disorders** (ASD, PDA, ADHD, anxiety disorder, depression disorder) that **CAMHS failed to diagnose. This is breathtakingly appalling.** I know she also has sensory processing disorder also, so that would make it **six**. Her sibling has an SPD diagnosis as do I, so I know how to recognise it and it's a very well-known co-morbid/integral disorder in autistics. I suppose it's a small mercy that they at least recognised she has OCD, even though they quietly added this to the diagnostic list on her reports, when she was seeing them for medication reviews, without actually informing us they had diagnosed it. This child was found by her schools right through until the age of 18yo, to need a lot of additional support by way of a key worker and TA and her last school had to apply for additional funding for her. She has had to have extra time in exams and support with every single thing at school and they wrote reports on this. Yet CAMHS, claim she is barely autistic to cover themselves for their failings. During a malicious safeguarding referral, made when she was receiving LA tuition due to medical reasons of her mental health, CAMHS told a multi-disciplinary meeting that on the scale of autism she was at the really mild end. This is a complete lie.

**RECOMMENDATIONS:** (1) bear in mind when assessing autistic children a parent may be autistic too, know your legal duties regarding disabilities and equality and offer reasonable adjustments; (2) do not use shortened versions of tools, it disrespects the serious nature of the assessment and may result in diagnostic failure; (3) start respecting and using parental evidence and information on their child as priceless expertise from the person that knows the child best and has equal (*in some ways greater*) weight, than professional opinion which no matter how qualified, is from the perspective of a stranger, in an unnatural snapshot setting. Instead of treating every case the same in a tick-box manner, where professionals seem unable to think outside of their procedures and formats, take advantage of highly useful, pertinent information where it exists, to the benefit of the child and their family, as well as the process; (4) read information sent to you! (5) spend a decent amount of time assessing children; (6) don't claim it's multi-agency when you use 2 clinicians completing forms! (7) don't lie about what you are doing! (8) learn how to engage children – anosognosia sometimes happens with autistics (*and mark anosognosia on their records too!*)! (9) remember that assessing for autism is not a tick-box exercise; (10) don't leave parents waiting, feedback at the time; (11) stop relying solely on the ADOS-2! (12) provide information and support to families that you claim you do as standard, but in fact don't (13) think flexibly! (14) even if you think a child isn't autistic and you declare autistic traits, that still warrants autism support; (15) don't claim to follow NICE Guidance when you don't, understand at least the basics of risk factors, such as genetic! (16) all clinicians to have urgent in-depth autism training! Cannot emphasise this enough, especially PDA and female presentation. Second in a **real** expert to give them on-the-job training or something! (*I may know someone who could do this*); (17) prioritise children that are older as a diagnosis becomes more urgent as the child ages; (18) once reports are written, professionals should, in a timely manner, offer a first draft to the parent so that corrections can be made (*and any potential differences of opinion on something that is a matter of opinion and not fact, can have a rider stating the parent's view on that part*) before distribution, so that errors are not carried forward to other reports; (19) stop looking at other conditions as causes when they are likely to be co-morbid to the underlying autism!

### Post diagnostic Care

#### **Child 1 (assessed for ASD by CAMHS)**

Our daughter started mainstream secondary following 3 years of home-education, without a diagnosis of her autism because of CAMHS' diagnostic failure. Despite my best efforts at sending the school details of where she would need support and would have difficulties, they did not pay me much heed. They started her on School Action+ but because she had no diagnosis and being a "high-functioning" and intelligent female, she masked and mimicked and was quiet and passive at school, they deemed her not to be in any difficulty and downgraded her support (*which was already pretty much worthless anyway*), to School Action. From her 2<sup>nd</sup> day at the school she was failing to cope. She was mercilessly bullied, both physically and verbally, was in intense distress at the "bad stuff" they teach in secondary school, was socially struggling and would come home and have huge meltdowns. Her level of anxiety was so great, that she began skin-picking until it bled, banging her head on the floor in her meltdowns and wetting herself in school. She was threatening before going to school that she would throw herself out of the window there and said she wanted to die. This was a **very traumatised** child, I knew she would have problems, but it took even my breath away how bad it was for her. She

school-refused after the Christmas break. I was left alone dealing with this. Nobody would listen to me, I sat in meetings with professionals, where I brought letters she hand-wrote about how school made her wanted to die. Nobody cared. She had no diagnosis, so apparently I was making it all up.

During this time, I had written to our GP to update him as to her difficulties and mental/emotional state, he contacted CAMHS who called me (*Tansy Walker*). It was a normal 2-way conversation, but when I obtained an SAR, I saw she had totally lied and falsely claimed I "*curtailed and controlled the conversation*" a comment which was circulated in a professional network outside of CAMHS.

**Because she had no diagnosis, her DLA application was refused and the LA refused to assess her for a statement of SEN. Once her diagnosis was made they were both awarded.**

When our daughter was finally diagnosed with ASD, she was at the same time (*appointments November 2013-January 2014*), diagnosed with a 'mixed depression and anxiety disorder' as a direct result of the trauma she suffered in school without support. **This was directly due to CAMHS' diagnostic negligence.**

In December 2013, because the school was seeking medical confirmation of her absence, our daughter was seen at home by Brenda Davis from CAMHS (**the clinical lead for the autism pathway for the region and a senior CAMHS clinician!**) for a mental health assessment. Brenda Davis completely **failed** to identify or diagnose the depression and anxiety disorder our daughter had and completely down-played the school-related difficulties that had triggered the condition (*stating she had "generalised anxiety rather than an anxiety disorder"* and that her functioning was "*not impaired by a very low mood*"). Yet the NHS service which diagnosed our daughter's mixed depression and anxiety disorder recognised these **at the same time as this (2<sup>nd</sup>) diagnostic failure occurred**. If this doesn't speak to incompetence I don't know what does. Brenda Davis claimed that our daughter did **not have** "*a level of mental health risk or suicidal ideation*". Since starting secondary school prior to and whilst seeing Ms Davis, our daughter had regularly said she would kill herself and that she wanted to die. When I finally received a copy of the report after it had been issued, there were strange comments in it based on Brenda's own interpretation of what our daughter said which were incorrect, omissions and even things that our daughter told me she didn't say! I emailed Brenda to list these queries and instead of responding or correcting the report, she just replied to say thank you for my email! During this time, I undertook a subject access request (SAR) because I could not understand the attitudes I was receiving from professionals. What I read absolutely horrified me. I discovered CAMHS staff implying I was almost deranged and suggesting I may need forcible mental health assessment, the most unprofessional gossip about me you can imagine – none of which was true, comments about my parenting – of which they knew nothing and falsehoods carried forward in reports such as that our daughter was "isolated". All part of their parent blame culture. All of these lies and Data Protection Act 1998 breaches remain on record to this day. It's beyond disgusting. I complained to Peter Joyce, naming and quoting staff who had transgressed this way and he just said it would be 'dealt with under supervision'. These people need **sacking!**

It became very clear to me that all of these false claims going on in the background had

negatively impacted our daughter's autism assessment, heavily contributed to diagnostic negligence and led to CAMHS treating me with contempt and disbelief. These people need to hang their heads in shame. **You have caused untold damage to our family.**

I had to appeal for her to change schools, but sadly the damage was done, she had a repeat experience of again failing to cope in the new school, due to the trauma she was already suffering and associated lack of mental health support and she school-refused again. She had refused to see CAMHS for more than **a year**, because of how they had upset her at her assessment, until she felt so low whilst unwell with a bug, that she agreed in desperation. Until that time, I'd had to pay privately for her to see an art therapist, ABA therapist and a psychiatrist, all as a result of CAMHS failures. During that time, one of her meltdowns was dangerous and I rang the emergency mental health number – it was constantly engaged! I was left, along with her private therapist, restraining her from self-harm.

It was very hard for me to trust CAMHS again due to their previous failings and shocking behaviour and knowing they did not understand autism as a condition. However, we couldn't continue funding private support, so I swallowed my feelings for our daughter's sake and asked the GP to refer her, hoping they might have new staff who had autism training and perhaps therefore provide the right person for her. I expected that she would be allocated to an experienced psychologist or psychiatrist, instead I found out weeks later, after several sessions, that the person she had been seeing was only a counsellor.

Our daughter felt vulnerable seeing someone alone, so she asked that I be in her sessions with her. Many weeks, our daughter left distressed from the sessions, feeling worse than when she went in, needing a lot of buoying up from me, that everything would be OK. At her **very first** session, the counsellor Jim Watkins, made a statement about medication not being a possibility (*we hadn't raised it*) without any knowledge of what she would need or taking into account how long she had suffered depression and anxiety (*by that point around 14 months already*) and that for some people, therapies are tried and don't work and medication is the only option left. It would be a last resort for us as parents, but to have a potential lifeline for our child whipped away off the bat, without knowing what would transpire, I felt was very poor practice. This is a child that frequently says she wants to die and she doesn't know why she was ever born. I witnessed Jim waste a lot of time waffling, making comments about how she had done her hair, or how she took pride in her appearance and asking inane and irrelevant questions about what she had been up to; undermining the severity of her depression by saying he would refer to it as "*sadness*" (*which he probably intended as taking some of the power of the feeling away from it, but it only served to make her feel that he wasn't taking it seriously or understanding how very deeply she felt it*) and telling her repeatedly that he "*couldn't wave any magic wand*" and even that he couldn't help her!

An autistic child needs practical solutions, NT word-play trickery doesn't work, or talking endlessly about feelings in a loop without any remedy, or without any visible sign of practical things being done to help change things for them.

After quite a few sessions, she refused to see him again because he was making her feel **worse**, at her second to last session he had brought up the issue of her autism diagnosis **despite** me having told him on the phone and over email previously, that she thoroughly rejected and

would not want to discuss it. He was repeatedly probing her about it, making her angry and upset, after which she just hung her head and cried. He ended the session (early) without trying to rectify the distress he caused her and this just upset her even more, he packed his bag and left her wailing in the GP's room, with me left to deal with it. At her previous session he had said he would talk with colleagues about what the plan would be, because for that session too, she had just sat with her head down, non-verbal, crying for most of the session. She had hung on until the following session therefore, hoping for a positive action or remedy after his meeting. However, the only suggestion he came forth with from colleagues was for me to take her for outings (*which he already knew that I do when I can anyway*) leaving her yet again, massively disappointed and feeling hopeless. So she refused to see him again.

So we were allocated a clinical psychologist Judith Jarrett. However, our daughter's rigidity meant she felt an inability and unwillingness to try anything that was suggested such as particular outings. Sessions consisted of her being given work sheets about feelings to complete for the next session. Again, she wanted me in her sessions, so I witnessed how they went. Our daughter started telling Dr Jarrett that she wasn't helping her, on a regular basis in the end. I felt that I had way more understanding of her than Dr Jarrett and over time, Dr Jarrett began complaining about her ego being dented by being told by our daughter she wasn't helping her. I found that unbelievable. I felt I had to spend a lot of time offering analyses to the psychologist about how and why our daughter behaved and felt and what she could try.

Eventually, after around a year of CAMHS sessions (*including the ones with the counsellor*) Dr Jarrett said we should have a break as medication had been suggested as an option. We saw a colleague psychiatrist who spent the whole session minimising the severity of our daughter's depression and ending by saying she was only mildly depressed and she would not prescribe. This left our daughter devastated as she had been hanging on desperately for something to finally help her. I had to push for a second opinion with Dr Soppitt, at which she was finally prescribed medication. It was felt that until medication had worked, the break in sessions should continue, but we were left months without any support, just with an open file. So I eventually asked for a touching base session, Dr Jarrett clearly didn't want to be there, made sarcastic comments about us arriving a little late (*which I had apologised for and explained*) and we were left hanging with no plan for any sessions or anything else at the end of it. Medication should have been offered much sooner bearing in mind she'd been 2 years with her mental health diagnosis without improvement, mental health problems become harder to treat the longer they go on.

So to date, our daughter has been out of school for **19 months**, having had a mess of a 'service' from CAMHS, is no further forward with her mental health difficulties and is about to **lose** her alternative provision educational placement, that I battled through a SENDIST tribunal to get for her. My life has been totally put on hold in every way, in emotionally and psychiatrically supporting her and being physically present for her. She has separation anxiety, her world has decreased more and more, I cannot leave her alone due to her risk. She is in her GCSE year and is surviving on 4.5 hours a week of LA home tuition. Her medication has been increased and she has asked for a different clinician. Amazing she's still hoping after all CAMHS have put her through – probably because when she says dejectedly that nobody can help her, I reassure her that someone will be able to. Her prospects, which should have been amazing considering

how intelligent she is (*gifted & talented*), are now hanging in the balance. She is unable to cope with life or reality and is developmentally stuck, because she was not diagnosed in time and nobody has provided the right support. The **work this has caused me** is incalculable, if costed it would be in the many thousands. The impact on my own health and wellbeing is not fair. Families should not have to go through this. **Children** should not have to go through this. You are paid to help them.

### **Child 2 (diagnosed at Seaside View)- post-diagnostic support**

Our other autistic daughter was referred **urgently** for assistance with **severe anxiety** to CAMHS in 2012 by Seaside View when she was waiting to have her autism assessment, Brenda Davis delegated the referral downwards to Tier 2 - who only offered a general anxiety talking group for primary aged children. She was a 7yo autistic child at the time, please someone tell me how a **talking group** is suitable for a **young child**, with a condition with **communication deficits** - which means being around groups of people is difficult and for whom even recognising their emotions and the reason for them, let alone expressing them - is suitable? Autistic children are also emotionally and developmentally about 3-4 years behind their chronological age so it was akin to asking a 3-4 year old to discuss their feelings. I was flabbergasted. Our daughter refused to go (*expectedly!*) despite my encouragement to try it and instead of providing an alternative option that was more suitable for her, **they simply closed her file**. Two doctors have since stated **on record** that this option was **unsuitable for her needs**. I was chasing people on the phone at CAMHS T2 as to what was happening and they **did not return my calls**. She was left for 3 years with severe anxiety (*so bad it affected her sleep and we had to get melatonin prescribed for her*). Her anxiety-driven behaviour was severely impacting her and the whole family and they **just closed her file with no treatment**. **This is appalling**. Again, I had to pay for private assessments and support for her because of their failings.

Again, when I obtained the SAR I saw a lot of the reason they failed her so much – they were falsely accusing myself of causing her anxiety. Shocking parent blame.

Eventually, I realised she had a PDA/HFA overlap sub-type profile so I requested a specialist assessment. Instead of going to experts, it was kept in-house to save money. This led to an incomplete additional diagnosis of "*demand avoidance*" with a statement that she did not have PDA. She scored well within clinical range on the EDAQ and has a striking list of PDA-specific behaviours in common with PDA-diagnosed children. She also has ADHD, which to date CAMHS have **twice** failed to recognise.

Like autism, the female ADHD presentation differs. CAMHS are totally behind current knowledge on this and when I first requested an ADHD assessment, I was sent a CONNERS form which I scored and returned and no assessment happened, I just got a letter saying that I would be 'pleased to know' she did not have ADHD! The second time she was considered for ADHD was in her more recent assessment for PDA, but because she was diagnosed with SPD they attributed all her many ADHD traits to sensory-seeking, when she is only hypersensitive not hyposensitive. So *another* diagnostic failure for our family.

When she had this latest assessment, she was recommended anti-anxiety medication for her severe anxiety. The same severe anxiety that CAMHS had left her **3 whole years without**

**treatment for.** There was a **delay of 5 months** from when her assessment started to when medication was finally prescribed, due purely to more unnecessary tick-box adherence, during which I was discriminated against by CAMHS staff and I had to raise a formal complaint about the problems. I have far better things to do than have to point out your failings and complain to get the children's needs met. She was diagnosed with panic disorder and other mental health diagnoses and was stated on record to be at risk of school-refusing, despite all this, she was treated like a tick-box number in the system, with not a shred of urgency about her case.

The latest gross failing that I am dealing with right now, is that in her primary school she was allowed to withdraw from distressing lesson content that she could not cope with, an issue arose with her new school saying she could and then changing their mind. They said they wanted a medical practitioner's letter saying she needed this and they would allow her. In speaking to Nimet Key who had seen her for 2 medication reviews, she refused to write this. She said she'd need a "team meeting" to discuss it. When we saw her next, she said she needed **another** "team meeting" to discuss it! She ended by suggesting in her report that if our daughter showed signs of distress she could come out of class for a short while. Totally inappropriate for our daughter's needs, she **masks completely** in school (*which is documented in her most recent CAMHS assessment reports – more evidence of her file not being read*) and once she has been forced to learn distressing material the damage is done.

So as a result, I spent all the summer holidays desperately trying all avenues to get this resolved to no avail. She could not start her new school and has missed 11 days of school and counting. I am having to battle multiple departments to get this resolved, raised yet more formal complaints. All because CAMHS don't understand autism, or SEN law (*there is specific provision allowing this withdrawal*), or how to look at a child as an individual to understand their needs. "*We don't usually recommend avoidance for anxiety.*" So damned what! This is a human being. She is not a text book, she is not neurotypical, she is highly vulnerable and has multiple diagnoses. It's almost a miracle she was in school at all, as she has always found it extremely stressful and had several incidences of school-refusal already. Why is this so hard to understand. These people are like robots.

Her medication has not worked and is being titrated down (*potentially to try a different one*), the whole idea was, that as her anxiety is so severe, medication would reduce her anxiety so she could access therapy. So we now have a severely anxious child, school-refusing, still unable to access therapy, but being referred for CBT in a desperate attempt to have something – which I highly doubt will work out. Having undiagnosed ADHD, there is no understanding of her short attention span when it comes to people talking, or of her becoming very bored quickly and needing to use her legs, so let's see how that one works!

Thanks CAMHS, for giving me two autistic children off school, one with extremely challenging behaviour which is destroying my health, the other with periodically very challenging and very worrying episodes. All with me being autistic myself and with additional physical health challenges. "*Every Child Matters*" – really?!

**Updated on 5.4.18 to add:** It was clinically confirmed in June 2016 through consultation and screening tools, that our daughter additionally matches the PDA subtype of ASD, evidencing

yet another ([seventh](#)) [missed diagnosis](#) by CAMHS including the five diagnoses they failed to make of her sibling, that's beyond belief.

I cannot say anything went well in the post-diagnostic process.

**RECOMMENDATIONS:** (1) Treat urgent referrals as just that and provide the treatment! (2) all clinicians to have urgent in-depth autism training! Cannot emphasise this enough, especially PDA and female presentation. Second in a **real** expert to give them on-the-job training or something! (*I may know someone who could do this*); (3) get urgent female ADHD training; (4) be child-centred – understand individual needs and work with parents to make the right recommendations! (5) stop causing delays, stop being tick-box and bureaucratic; (6) stop being scared to think outside of the box!

**Gaps in provision – multiple and extremely concerning (aside from all the above):**

**Knowledge** - I get the feeling that CAMHS clinicians are very outdated in their knowledge and certainly don't appear to be required to keep up-to-date on autism (or ADHD) research and current knowledge. For instance, the ADOS-2 is researched to be only 77% clinically reliable (<http://www.ncbi.nlm.nih.gov/pubmed/25116834>) in "high-functioning" autistics, as it was researched entirely on prototypical autism cases. Additionally, it was researched entirely on **males**. The ADOS-2 is also stated by it's authors to only be a **part** of an autism assessment and not to be relied upon in making a clinical decision (*and this basic advice relating to **any** diagnostic tool exists also in NHS NICE Guidance CG128 1.5.11 Do not rely on any autism-specific diagnostic tool alone to diagnose autism".*)

Yet in our experience CAMHS clinicians are extremely tick-box (*afraid/unable to think flexibly, which would appear to me to be as a result of simple training in how to administer an ADOS-2 test, but complete lack of any actual autism expertise or experience*) and rely almost **completely** on it. So, instead of looking to see how autism **presents in the individual**, they are looking to see where the individual **meets the tick-boxes** they have in mind. This is a **very** serious issue, all clinical tools are **optional** in assessments, despite them being generally considered a reasonably standard part of one. Yet Brenda Davis has declared the ADOS as the "gold standard" of tools at a meeting I requested with CAMHS in June 2013. (*At that same meeting Brenda also falsely claimed that CAMHS follow NICE guidance and there were multiple breaches of NICE guidance relating to our daughter's assessment - See list at bottom of report for details*)

**Attitudes** – parent blame culture at CAMHS, parents are rarely respected as the experts in their children and are all too frequently blamed for the child's difficulties (*sending parents on parenting courses should not be the first port of call*); there is a resistance to 'labelling' - I had Brenda Davis say to me "*the label is for life*" with much gravity, indicating resistance to diagnosis and yet conversely in the same conversation "*some children grow out of a diagnosis*". Both comments are irresponsible and inappropriate and in fact, the 2<sup>nd</sup> one highly misleading, because someone **remains autistic** even when they have sufficient early intervention to 'manage' and *appear* to have overcome their difficulties and brain scan research has shown this (<https://spectrumnews.org/news/autisms-brain-signature-lingers-even-after-loss-of-diagnosis/>), no matter what a piece of paper says. Every person has the right to have an answer for their difficulties and despite what professionals claim, support is usually diagnosis-based and **not**

needs-based throughout state services (*unless the child has S&L difficulties or is falling very behind academically*), whether that be EHCP's, DLA, school support, correct health support. This council scrutiny report <http://present.brighton-hove.gov.uk/ieListDocuments.aspx?MIId=4954> regarding autism and CAMHS, has a professional having the gall to state that many parents were seeking diagnosis to get access to benefits. *"The Autistic Spectrum Support Service (ASCSS) offers outreach support to mainstream schools but it requires a diagnosis of ASC before you can access the service..."*

Q – Does this put pressure on people to provide a diagnosis?

Yes it can do – and it puts pressure on schools as well. **There is also the issue that allowances (eg DLA) become accessible with a diagnosis."**

This type of parent-blame attitude exists in CAMHS. CAMHS have an automatic culture of suspicion against parents, and a total lack of respect for parental information, when misquoting factual events regarding their child they are labelling it as their staff's "opinion" and refusing to amend the mistakes. They seem to look first for reasons that parenting could be at fault for a child's presentation rather than getting on with investigating potential neurodevelopmental causes. Because of the failings we suffered, when I later obtained copy files under an SAR, I saw that they were disregarding most of what I reported **by their own admission** (*Sarah James admitted to ignoring and filing everything I was sending, in an internal email*) this was vital evidence – gold dust - that they should have been grateful for.

### **Females, presentations & autism sub-types**

Female autistic presentation is different from males and CAMHS simply do not understand masking and mimicking in autistic females (*some males can also have the more female presentation*), therefore the ADOS-2 will be even less reliable than 77% in females (*see P13*). In PDA, less so still, because the ADOS is not the best tool for identifying a PDA profile (*I think it might be the DISCO that is more accurate*), which has for instance slightly better social skills. Therefore inevitable diagnostic failure occurs. This can have catastrophic effects on a whole family. The *"not enough traits for a diagnosis"* conclusion is ludicrous. CAMHS simply **do not understand** the nature of the spectrum and this diagnostic failure can be the outcome, when they don't understand these masking and mimicking coping behaviours. They also do not seem to appreciate the very well-known and documented autistic phenomenon of different behaviour between school and home. This means that lack of school noticing a problem can cause diagnostic failure, because teachers' input is seemingly (*wrongly*) respected more and given more weight than a parent's, purely because they are classified as a "professional". This can also lead to parents being wrongfully blamed for the child's difficulties. Early intervention is key, if a child's autism has not been picked up by Seaside View, the child is **already late for diagnosis** by the time they reach CAMHS and vital support has already been lost.

It is clear that CAMHS cannot continue in its current set up. The same staff who have **no** autism expertise (*yet who sell themselves as having just that*) are still there running the show since our first encounter with them over 4 years ago, these are the same people that behaved very unprofessionally and unethically behind the scenes with our family (*and I know of other families this has happened to*) and breached ethics, NHS NICE Guidelines, the Data Protection Act 1998 and the Equality Act 2010 and others. Their arrogance and apathy is staggering, they seem to

have a robotic, laissez-faire attitude and have all the time in the world for endless meetings but not enough in providing children support to meet their needs. CAMHS needs new leadership, new staff. They are not earning their keep, they are leaving children in distress and destroying long-term outcomes and lives.

**NHS NICE CG128 Guidance *ignored* in daughter's ASD assessment:**

- "1.3.3 Box 1 Factors associated with an increased prevalence of autism"
- "1.2.5 autism may be under-diagnosed in girls" and "autism may be missed in children or young people who are verbally able" (**none of these were borne in mind otherwise the just missing the scoring cut-off would have not prevented her getting diagnosed**)
- "1.5.3 The autism case coordinator should: act as a single point of contact for the parents or carers and, if appropriate, the child or young person being assessed, through whom they can communicate with the rest of the autism team, keep parents or carers and, if appropriate, the child or young person, up-to-date about the likely time and sequence of assessments, arrange the provision of information and support for parents, carers, children and young people as directed by the autism team" (**we had no central point of contact and none of this was done**), "systematic assessment for conditions that may coexist with autism (see recommendation 1.5.15)" (**there was none**)
- "1.1.6 The autism team should have the skills and competencies to: communicate with children and young people with suspected or known autism..." (**CAMHS failed to engage my daughter whatsoever, so clearly lack the skills and competency**)
- "1.2.2 Always take parents' or carers' concerns and, if appropriate, the child's or young person's concerns, about behaviour or development seriously, even if these are not shared by others." (**not done because CAMHS staff were too busy indulging in gossip about false accusations against myself with one another and other professionals**)
- "1.2.5 when older children or young people present for the first time with possible autism, signs or symptoms may have previously been masked by the child or young person's coping mechanisms and/or a supportive environment" (**not understood because they didn't diagnose her, despite her missing the scoring cut-off by only 2-3 points, were too incompetent to see the irrelevance of the fact that her being home-educated meaning the absence of recent school information, didn't matter in light of the wealth of information I provided plus the relevance of her being home-educated in the first place was because of her previous socialising problems and unhappiness at school!**)
- "1.2.10 Take time to listen to parents or carers and, if appropriate, the child or young person, to discuss concerns and agree any actions to follow including referral." (**clearly not done because the ADI-R was rushed (it was the shortened version too) and there was no discussion outside of answering those questions**)
- "1.5.4 Discuss with the parents or carers and, if appropriate, the child or young person, how information should be shared throughout the autism diagnostic assessment, including communicating the outcome of the assessment. Take into account, for example, the child or young person's age and ability to understand." (**not done**)
- "1.5.8 Consider which assessments are needed to construct a profile for each child or young person, for example: ..." (**a list, none of which were done**)

- "1.5.11 Do not rely on any autism-specific diagnostic tool alone to diagnose autism." (they did because the sheer weight of pertinent evidence didn't prevent them relying on the 2-3 points of missing clinical scoring)
- "1.5.13 Be aware that some children and young people will have features of behaviour that are seen in the autism spectrum but do not reach the ICD-10 or DSM-IV diagnostic criteria for definitive diagnosis. Based on their profile, consider referring to appropriate services." (even though they apparently believed this to be the case, they didn't do this)
- "1.6.2 If any of the following apply after assessment, consider obtaining a second opinion (including referral to a specialised tertiary autism team if necessary): disagreement with parents or carers or, if appropriate, the child or young person, about the diagnosis" (I had to push for a 2nd opinion, had I not done so they would not have done this as standard) ...There are probably other parts of the Guidelines they did not follow, but I think this gives you the picture.

(Incidentally, when I raised a formal complaint about the CAMHS failings, PALS sent it (as they do) to CAMHS to investigate themselves, everything was denied, even with much of the above information being provided. This is what I mean by arrogant and apathetic. Why do people do jobs that are supposed to involve helping children if they don't care and don't help them?)

**END**