

We asked members to share their experiences of:

Disrespectful & insensitive attitude towards families

Which CAMHS: Brighton & Hove

Your experience: My son has been under CAMHS for years and kept being taken off the books without anyone informing me that this had happened and when I did find out they couldn't give me a reason why!!! This happened on more than one occasion!! So, so frustrating when as a parent you are already waiting for months and months on end then find out that your child has been crossed off the books without a clear reason and without being told!!!

Eventually when he was diagnosed it was way, way too late as he was nearly at the end of senior school, the waiting time is absolutely diabolical!!!

Staff were regularly on long term/permanent sick leave which in the latter years I have found out this is why on one occasion he was crossed off the books!!!! This was not a valid reason to cross him off the books when I was patiently waiting for help!!!

There was no ASC therapeutic intervention at all for us, it was just diagnosis and goodbye with a stash of leaflets!!!

He was diagnosed so late that he only had a couple of medication appointments before he had to be passed over to adult services and so his medication has never really been used properly as there was no real help to pursue this with my son!!

Disrespectful and uncaring attitude, my son absolutely detested going there because he couldn't understand the lady and he felt patronised by the way that they spoke to him!! His words "they don't speak to me like that at school!!" He hated every minute of going there!!

I felt undermined and cross examined by them, at one point I was called a liar by the practitioner!!! Absolutely no understanding that this was my oldest child, and I didn't know any different!!!

Practitioners don't understand what life is like with these kids, how full on it is and how we are running to keep up all the time, as parents we don't get time to think about things clearly!!

I'm absolutely dreading going through all this now with my daughter!!!! Not to mention the fact that she "hopes to be seen in a year's time!!! HOPES!!!!!!"

Communication!!!! Just reply to us!! Absolutely everyone you speak to knows how hard it is to get hold of any practitioner!!! And how awful they are, everyone has a horror story of their own about how they have been treated!!

How to improve things: *Employ people who can be nice and kind and sympathetic of situations and people, reduce waiting times and give some kind of aftercare, Just a change of attitude would help, as*

parents we are already there in desperation, we don't need to be thrown even deeper!!!! Communication!!! Reply, just ring back when asked!! Email back!! Anything just please reply to an already desperate parent!!!! The only decent person there when my son was going there a few years ago was the amazing receptionist who took all the flack for the practitioners!!!

Which CAMHS: Brighton & Hove

Your experience: I am writing this in detail as want the experience to be fully documented.

Late 2018, my teenage child was referred to CAMHs following a mental health breakdown and serious self-harm and overdose incidents, an urgent mental health assessment with a clear support plan was needed.

We were referred from the Wellbeing Service for an emergency appointment 5 days after leaving A&E. We were exhausted, I was extremely concerned for their welfare and naturally, we were feeling vulnerable.

I'd not received the CAMHS paperwork in time and was asked to sign it on arrival. It included a leaflet saying we would be treated with respect. I did not sign all sections of the paperwork immediately as said I wanted to read it properly and clarify some aspects of data sharing, (my well-founded concern being my child's school were regularly asking pupils with suicidal tendencies to leave). Having been given a leaflet that we'd be treated with care and respect, when I said I needed a little time to think through how best to inform my child's school (to avoid any reactive response from them) and therefore to reassure myself, the CAMHS worker become immediately irritated as though I was being 'non-compliant' and wasting their time. This is what then followed:

(1) The CAMHS worker was cold, rude, patronising, sterile and almost hostile throughout the meeting. I felt like we were an inconvenience. There was barely a smile. It felt like an interrogation from the start. The meeting room had what appeared to be a two-way wall mirror with a blind only half drawn, it felt intimidating, our reflection was distracting and uncomfortable as I could see my child's distress mirrored back to us. It was not explained if the mirror room was in use. I regretted not flagging this feeling of uncomfortableness but was focused on the conversation as clearly, we were not being made to feel at ease. In addition, the room itself felt like a storeroom, shoddy and intimidating with cluttered boxes on the floor. It felt unkept, unwelcoming and the overall experience felt hugely uncaring from start to finish.

(2) As my child was experiencing severe depression, I asked if a psychiatrist was on duty, to determine if medical treatment was required while a longer-term plan be put in place. I was told there was only a locum in the building, that they wouldn't be required but some "holding sessions" could be offered while mood/risk was assessed and if I wanted anything more comprehensive, then to "go privately".

(3) My child and I were given a RCADS (The Revised Child Anxiety and Depression Scale) assessment to complete although its purpose was not explained and when I asked was told it was in part to **"assess"** my **"emotional attunement"** to my child.

At which point I became extremely concerned. We were seeking urgent medical attention for a young person, not a cod psychology, tick-box assessment of myself as a parent, and in an emergency first appointment. I was even told, in a clearly hostile and patronising way, to “**just guess**” and make up answers at which point I politely declined to continue with the exercise. I gently questioned why, in an emergency, was an emphasis being put on my parenting when urgent medical attention was required at which point the noticeable frustration and irritability towards me increased and continued to the end of the meeting.

Subsequently I was told by a well-qualified psychologist, with disdain, that this was CAMHS twisting use of a tool and “just making it up”. The RCADS is a tool to measure a child’s anxiety and depression scale. Parents can be asked to complete if a child is under 8, unable to complete or if a parent’s perspective on the child’s anxiety would be helpful. It is not to assess a subjective notion of ‘emotional attunement’ aka attachment and utterly inappropriate in a mental health emergency.

(4) It was then strongly and repeatedly suggested to me that I would be offered a referral to Front Door for Families (no doubt for 'emotional attunement' classes). I politely declined the offer/threat of a family support/social worker and repeated my request that my child please be given a **medical** treatment plan, as that was the purpose of us attending and could the duty locum psychiatrist be called so I could ask some questions. This was ignored/declined.

(5) Having been referred as an emergency (young person with suicidal ideation) no further action was taken by CAMHS other than to offer 'holding' sessions. A referral to Chalk Hill hospital feeding clinic was suggested by the worker which I welcomed (although ultimately not made by CAMHS). Alarmist language was used by the CAMHS worker to my child about 'starvation' and it was implied eating issues were causing another health issue, even when I explained they were not medically related. To which the worker made it apparent they felt I was not taking my child's eating issues seriously enough. The jumping to medical conclusions and accusation implied of me, and in front of my child, was biased, judgemental and without any evidence other than a perceived free reign entitlement to imply neglect/disinterest on my part.

(6) A report by CAMHS was then written to my GP that detailed my child's depression and eating disorder and with knowing nothing of the family, other than less than an hour hostile attitude towards us, declared that the child found it "difficult to confide in parents" and that it was "evident" as the RCADs was "difficult to complete for (mother)". My polite decline of wanting/needing parenting support was recorded as a 'refusal' of a referral to Front Door for Families but failed to mention that my request (for meaningful medical intervention via a psychiatrist) had not been provided. I read the report with my GP who was as equally as appalled at the focus and insinuation.

This was an aggressive and bullying approach taken towards the family, a mere five days out of hospital, in a traumatising situation at nearly losing our child only to have then been at the receiving end of a hostile and insidious attitude when at CAMHS. At the end of the meeting the worker merely walked off.

The worker called the following week. They felt, with hindsight, my child should have seen the psychiatrist as had scored highly for depression and anxiety - not just an eating issue - but there had only been a locum psychiatrist on duty, and they were not getting a full-time psychiatrist until February. In other words, short staffed and a referred to another hospital for eating was easier for CAMHS but that with hindsight this was not thought appropriate as depression/ anxiety were the issues - as I had clearly explained was the primary issue.

Due to CAMHS failure to have accurately assessed at that meeting or referred for appropriate and urgent medical support, I then explained I had already set up a private psychiatrist in a different part of the UK. At this point the worker changed attitude completely, rolled back the hostility and said, "it's only a short meeting - it's not very good at getting a true picture".

Outcome

We left the appointment utterly horrified; I promised my child I would never take them to CAMHS again. The same day I secured a private appointment with a child & adolescent mental health psychiatrist in London, who assessed depression and prescribed anti-depressants to stabilise mood while we secured private psychological support. At the same time, I made a referral to NHS Chalk Hill hospital who emailed they felt the case didn't meet the threshold/was insufficient to treat as urgent and a waiting list was offered should we want.

Even privately these services are completely overstretched. We were lucky to find anyone within 100 miles of Brighton able to offer emergency appointments. We were however, treated with kindness, care, and dignity, which was completely lacking in the meeting with CAMHS. I wrote to inform CAMHS we had gone privately and did not hear from them again nor from Chalk Hill hospital.

I asked my child how they experienced the CAMHS appointment and made notes at the time, to form the basis of a complaint.

- "I felt uncomfortable"
- "So, for some of the answers it's like she wasn't taking (notice), she didn't believe me (about concentration) - so I just nodded to (everything) just to get out"
- "I did not want to come back to see her after hearing some of the things she said about focusing, she didn't make me feel reassured"
- "I felt so uncomfortable alone with her"
- "I was looking at the clock all the time"
- "Out of everyone I've met - I feel uncomfortable - I've never felt so uncomfortable" in my life
- "I didn't feel frustrated with the others (private Psychiatrist and Psychologist) I felt angry when I was there (CAMHS) and frustrated afterwards"
- "She didn't really listen to you (either) - about the form"

I did not make a formal complaint at the time as we were supporting our child at a time of crisis. I submit this now as a formal complaint and am happy for this information to be submitted to a solicitor if further group action is required.

How to improve things: *1. Don't give out glib leaflets about treating young people and their families with respect if then be rude, patronising, and hostile. It's bullying.*

2. Campaign and push for the funding to get the staff you need. Contract out if necessary. If young people present with severe mental health and suicidal ideation treat it as the emergency it is.

3. CAMHs and Chalk Hill feeding clinic. Re-evaluate waiting list criteria as if a significant suicide attempt isn't classed as urgent, what is. Stop pinging young people back and fore around services only to make up any excuse not to take them on, leaving families alone to cope.

DO NOT focus on a biased and made-up opinion of parent to child relationship 'problems' via some tick box questions as the excuse to bat the family to Front Door for Families for a cheap parenting course or seek to inflate a symptom issue as excuse to bat to any other service as way of getting people off the books when medical mental health care is clearly and urgently needed. It's a disgusting tactic. We don't treat a family with a physical health condition like dirt, don't do it to family in a mental health crisis.

Take the time to build a trusting and respectful relationship with clients before any enquiry around triggers to depression can be explored sensitively with the client, not barge in within five minutes accusing the parent of a lack of emotional attunement or implying a lack of interest on the parent's part towards why the family are there. What biased culture is this coming from?!!

We all know there isn't enough funding in children's mental health but that's no excuse for unpleasant, hostile, and aggressive attitudes to vulnerable families. Check your culture! It's an attitude problem and it doesn't cost money to rectify. Offer kindness, be able to demonstrate you listen and hear a young person and not create an atmosphere where the family can't wait to leave the building.

Which CAMHS: Brighton & Hove

Your experience: My son was having a lot of anxiety and associated behavioural issues. He got lost in the gap between the learning disability CAMHS and Aldrington House CAMHS, and it was only through chasing that his case got picked up. At this point he was at high risk of being taken into custody and/or residential unit, and police considered him high risk of death.

When we were finally seen, the CAMHS psychiatrist was extremely inappropriate in how she talked to me, basically saying he wasn't in the right place and should be under learning disability service. I really didn't care who saw him, and it was inappropriate to bring this up in front of me. In all my years of accessing services, I have never been made to feel as bad as I was by the psychiatrist. This did improve in later visits, but at a very traumatic time, the input of CAMHS was an extra trauma.

How to improve things: *Ensure children do not fall between gaps in services by having an absolute focus on meeting the child's individual needs. Do not let the structural divisions between services get in the way of this focus.*

Treat parents with respect and compassion.

Which CAMHS: Brighton & Hove

Your experience: My son was diagnosed with ADHD in 2019 I was told I wouldn't need to take notes as I would receive a full report, they also said as they didn't think that he needed medication, if I needed melatonin I could speak to my doctor about it, I haven't heard anything from CAMHS since and phoned them 2 weeks ago to be told they wasn't sure how to tell me but I wouldn't be getting a report as there was a backlog as someone had left. I have had no contact with CAMHS for any support for my son.

How to improve things: *Would be nice to have a check in with families and see how they are coping and maybe a talk on what was discussed as there was someone unable to write up the report .*

Which CAMHS: Brighton & Hove

Your experience: My daughter joined the waiting list at just under 16 for an ASC assessment. She had to wait unsupported for over two years. This caused so much anxiety when she was approaching 18yrs old and still hadn't had her assessment. The communication was poor throughout the wait including a telephone conversation with a male member who refused to write to my daughter to assure her she was progressing on the waiting list as she was extremely anxious and his reasoning was 'I'm also autistic and this wouldn't make me anxious, I don't see how it will help', shocking and not acceptable.

How to improve things: *Better communication throughout the waiting process and staff not dealing with us based on their own abilities and conditions like this man who said he was also autistic and couldn't see why she was anxious. I have his name and email if people need to see it.*

Which CAMHS: Brighton & Hove

Your experience: It was difficult to know which of the four complaint categories to select as all of the above apply. Since moving to Brighton in March 2020 we have had an uphill battle to receive any support at all. This is despite repeated phone calls from myself (to the answerphone) explaining the increasing crisis my son, and my family found ourselves in. My son is now 8 and has become so distressed during the past year he has become a significant safeguarding risk to himself and his younger siblings meaning that other agencies such as social services have needed to become involved. Repeated referrals from different agencies including the wellbeing team, SSV, Front Door for Families, the school nurse team, and the school. When the school nurse asked them to speak directly to me to gather information as she had not my son (Due to Covid) they refused. When our IFS sent a referral, it was clear to her from their response (they suggested that my son may need an EHCP - it clearly stated in the referral that he has one) that they had not even opened and read the document.

When CAMHS did finally start responding to referral requests last month (although not directly to me) they said to some people that they had never received my sons ADHD diagnosis document and to others that they knew they had received it but could now not find it (I have email documentation of both). And then to me said that the NHS diagnosis letter (in the county we came from CAMHS are not involved in diagnosis) that clearly states the ADHD diagnosis at the top would not be accepted by the CAMHS psychiatrists and that my son would potentially need to be re-diagnosed by CAMHS. We, like

all SEN families had to wait years (two and a half) for my son's diagnosis and the idea of having to start again has made a big dent in my mental resilience.

After 15 months of trying to make contact with CAMHS and after some significant intervention from social services I finally spoke to a member of CAMHS for the first time this month. They attended a TAF meeting and said that they thought I was "rushing into medication" and that I thought it was a "magic cure". Not only was this quite unbelievable following the 15 months I have had to think about medication just since moving to Brighton, but it also showed a level of assumption that I feel is dangerous when working with SEN families. When the paediatric consultant that diagnosed my son strongly suggested medication was necessary, I decided I would like to wait and do more research. I have family with the same diagnosis as my son, some of whom medication works for, some of whom it doesn't. I also worked with SEN children in a therapeutic capacity and have seen the pros and cons of medication. CAMHS knew none of this but were happy to assume I knew nothing and wanted everything.

CAMHS then went on to say that they cannot give any timeline for any type of discussion re. medication as they currently have no psychiatrists who can prescribe.

My son is now 8 and has become so distressed during the past year he has become a significant safeguarding risk to himself and his younger siblings meaning that other agencies such as social services have needed to become involved. It is my sincere belief that with the right, timely support from CAMHS my family would not be taking up these other very stretched resources. As a family we are under incredible strain, and I personally am very close to complete burn out. The strain of this fight alongside the daily battle of being a SEN parent has had a detrimental effect on me physically, mentally, and emotionally. Which of course has a knock-on effect to our whole family. This is just some of our experience.

How to improve things: *Communication is key. Refusing to communicate with parents should not be a way of working. Do not make assumptions about families, speak to them, and find out the truth.*

Diagnosis is diagnosis. The NHS should be as trusted as CAMHS.

CAMHS in Brighton and Hove has been massively overstretched in its remit. It should be reduced back to post diagnosis therapeutic support as it is in other parts of the country leaving Diagnosis and medication the NHS who work in a more methodical and ethical way.

Which CAMHS: Brighton & Hove

Your experience: Firstly, I received a letter in April 2020 to say that my daughter was happier without me this was in the middle of lockdown when I was not able to see her, and I was very upset. The second was in Feb 2021 when I was not told of a CAMHS appointment regarding my daughter and when I called to ask about this oversight, they were rude and abrasive over the phone saying it was in the notes to not contact me. This was completely untrue. No apology or explanation was given.

How to improve things: *Notify both parents of meetings regarding their child, deal sensitively with both parents regarding very traumatic and emotional experiences such as a Mother losing her child. I was not under child protection case and my daughter was deemed to be a child in need due to autism and attachment issues.*

Which CAMHS: East Sussex

Your experience: Referred to CAMHS 4 years ago by school. First assessment carried out after 1 year by an art therapist who had no clinical qualifications, and the result was "inconclusive". Put back on the waiting list and after 18 months we ended up on a Section 47 due to a crisis situation. Because CAMHS could still not give an assessment date we paid to have a private assessment with (private practice). Assessment carried out by a paediatrician who also works for the Scott Unit and was to ADOS Level 2 standard. This took place in November 2019. Diagnosis was ASC with Demand Avoidant Profile and ADHD. Sent the diagnosis to CAMHS who initially said they would accept it but subsequently said they could not because of the Demand Avoidant inclusion which is not in the DSG manual. They said they would put us on the list for emergency assessment and where we still are. In the meantime after pressure from Children's Services our daughter was seen by a psychiatrist who has prescribed Setraline. He is the first clinician she has seen since being referred.

How to improve things: *Faster assessment or if this cannot be achieved, recognition of ADOS diagnosis gained elsewhere. Faster access to people actually qualified to deal with Autism. Also assess for multiple conditions and not just one at a time as comorbidity makes single assessment pointless. Support for people post diagnosis. East Sussex policy is they refer you to a private provider (Aspens) post diagnosis which means you have to pay for a service that promotes ABA!*

Which CAMHS: Brighton & Hove

Your experience: Around 2015 my eldest ASC son was experiencing strong anxiety and obsessive thoughts. We applied for CAMHS help only to receive a letter saying they could only help if he became a danger to himself or others. I will never forget the effect of receiving such a letter! There was no referral to other orgs or suggestions. It left us alone as a family.

How to improve things: *If CAMHS cannot help people like my son there should be a joined up process where they make suggestions and try to refer to another service or other help. Sending a dismissive uncaring letter to struggling families could sadly send some over the edge.*

Which CAMHS: Brighton & Hove

Your experience: We were referred to CAMHS for an ADHD assessment via our GP and school in September 2019. At the time we were experiencing some pretty desperate situations at home with our then 5 year old son, such as self-harm, violence towards us and extreme meltdowns, so we were pretty desperate for some help. After being added to a waiting list and not hearing anything back for months (meanwhile the situation at home was escalating), I started to reach out to them for some help. I think eventually they got sick of my emails and phone calls, and I received a one line email stating that 'our child does not have ADHD' and to click on the link for further support. The link didn't work. I remember feeling utterly desperate and bursting into tears. They hadn't even seen him and considering how bad

things were at home we felt like this was a gross misunderstanding and the lack of empathy was overwhelming. Our son has since been diagnosed with autism and we are receiving the appropriate support - through Seaside View, our school, and a private diagnostic centre - all of whom treated us with respect and understanding. I will never reach out to CAMHS for any kind of support again, choosing to save up thousands to go private if that's what it takes. We've been told not to rule out ADHD as a co-condition for our son, but we certainly won't go back to CAMHS for this. We have since learnt how ridiculously overstretched their system is at present - but this does not help the thousands of families who are potentially in a similar situation to the one we were in, or worse. Not everyone has the means to go private.

How to improve things: *Even if they couldn't help my son, just more than a one-line abrupt email and some information about where to go next for help would have been sufficient. Some empathy and understanding would have been nice.*

Which CAMHS: Brighton & Hove

Your experience: We waited years for a medication review for our son who has ADHD. When we got there, we tried to make it clear that we didn't want to discuss the specifics of our son's medication in front of him. So we suggested that 1 member of staff take him to another room to get a blood pressure reading from him, so we could discuss privately with the other doctor present. However they returned after just a few minutes, and in front of our son the member of staff who had tried to take the blood pressure reading said she was unable to get a reading, but that she had weighed him and that he was underweight, and perhaps we should visit the doctor as he may have an eating disorder. then she said, but they will probably just refer you back to us, and I'm not sure what we can really offer for eating disorders - all this was said in front of our son. He was then ushered into a corner of the room we were in, whilst we tried to continue our discussion with the doctor in whispers. The doctor also didn't have any knowledge of the medication he was on. We left feeling horrified, unsupported, and quite frankly we were all far more distressed than when we went in. We have been back since. Instead, we spend the majority of his DLA money on a private doctor.

How to improve things: *It should be common practice not to discuss medication or behaviour in front of children if this is what the family wishes and there should be a facility and plan in place for this. A playroom with a member of staff or 1 parent to keep the child company.*

It should not be suggested to families in front of their child that their child may have an eating disorder. If an eating disorder is suspected information and support should be given - this is a very serious matter.

I don't understand how an ADHD doctor could not be familiar with all ADHD medication - I believe I am and I'm just a parent.

Which CAMHS: Brighton & Hove

Your experience: After first refusal due to private diagnosis. An NHS diagnosis was obtained outside in Brighton and Hove which recommended ongoing care and medication via CAMHS. This was rejected

by CAMHS who felt issues were home based despite evidence that this was not a parental or home based issue. Continued pressure from me re appointments led to suggestions I required parenting support. When issues became worse, and anxiety led to self-harm including a hospital visit as a result. CAMHS then ignored request for support for child and referred to a social worker who visited twice and said that service was unable to help and suggested we speak to CAMHS as issue we're clearly related to autism, anxiety possible ADHD and mental health. CAMHS then suggested we contact ASPENS and pay for support we could not afford. I am still waiting for an appointment 3 years later with CAMHS. I found CAMHS personnel to be rude, disrespectful, challenging and inclined to blame parenting for all issues despite the clear and multiple diagnoses including autism, anxiety, alexithymia etc.

How to improve things: *Actually being seen by anyone at CAHMs for some form of assessment would have been a start. A sympathetic and non-judgement listener would have been helpful.*

Which CAMHS: East Sussex

Your experience: This was about four years ago but we got our child assessed for ADHD (he is autistic too, although that hasn't been diagnosed). He got the ADHD diagnosis after one meeting with a psychiatrist. I was shocked that the psychiatrist delivered the diagnosis with him standing there. We'd only just met the psychiatrist - it was like we were going through a sheep dip or a sausage factory - and I had no idea he was going to give us a diagnosis there and then. It was perfunctory, we were recommended to try medication - which we didn't want - and we were given one photocopied sheet of paper with a support group which was too far away. I don't mind that so much as I know there are not a lot of resources and you have to work to get them, although I do wonder if the disjointed, on your own feeling one gets from CAMHS Horsham has a bit more to it than lack of resources. The real problem was that the unexpected diagnosis in earshot of my son. My son immediately started acting up, clearly feeling somewhat disturbed by having this unexpected label put on him (if I wasn't expecting it, you can be sure he wasn't). This continued at school for some time, with him saying he had ADHD to everybody. There was no follow up from CAHMS - the diagnosis was just dumped on us then we were forgotten about. It was a very bad experience.

The contrast is the Children's Centre at Worthing Hospital where he was seen for autism ... They made sure they saw me on my own to tell me the result of the assessment. It was also a much longer slower process with time taken getting to know me and my child.

How to improve things: *Simple fixes - explain what to expect from the process of assessment. Explain when to expect the delivery of a diagnosis. Ask permission before giving a diagnosis in front of a child. Medium simple fixes - get better information and present it better, make sure it is up to date. More complex solutions - develop a culture that is more supportive and thinks through how things connect together so the patients feel more contained, and less adrift. For example getting to know the family - in particular the diagnosing clinician.*