

We asked our members to share their experiences of:

Disjointed communication & assessment process

Which CAMHS: Brighton & Hove

Your experience: After a school referral that went nowhere, I raised a referral directly to CAMHS using the Wellbeing service. I received an initial consultation on a cancelled appointment at short notice which was within 4 months of sending in an initial CAMHS screening assessment.

It took me constantly pushing CAMHS to go visit the school for an assessment so the Stage 1 could be completed. The school visit was carried out in the Autumn term. The visit was useless. It witnessed my son at his favourite subjects, did not give details of my son's inability to attend on time on any school day and the issues surrounding transition for him. There was no detail of the revised timetable for my son, nor the constant twice daily incidents reported which meant he was under review throughout the day for behaviour. The information school constantly updated me on with my son's behaviour was not even relayed.

I then had to push CAMHS to review the dual diagnosis of Autism and ADHD because I was getting nowhere fast, and issues had ramped up with a whole class needing to be evacuated because my son wasn't coping. This could have been avoided along with a whole host of 'incidents' requiring my son to be labelled a bully and troublemaker.

Considering I raised issues when my son was 14 months old, and in year 5 he has received a diagnosis and EHCP shows the system is broken with SALT, SSV and CAMHS, but the process for our children to go through so many people to receive an accurate diagnosis for support and assistance is just ridiculous.

How to improve things: *We need schools to sign up to receiving our children on reduced timetables from the off when issues are arising. They need small groups to be developed quickly so they can see that school is accessible and stop the constant refusal for schools.*

We need CAMHS to be alerting school nurses and SENCOs to refer if children are showing signs of acute anxiety early, so we can work with parents to support them in developing strategies to help children stay in school.

Working in groups like this with each school could prevent so many exclusions and issues for families. We've all seen what having children at home does for all our mental health over the last year. Time to step in early and intervene before anxieties become overwhelming for our beautiful children who deserve so much more.

We also need the whole school to be taught the Just Right programme - children and teachers. We need to show everyone we understand, and we accept their differences, and they are wanted.

Which CAMHS: Brighton & Hove

Your experience: After waiting for a year for ASC assessment, we were told by SSV that we will be referred to CAMHS for ADHD assessment. That was in March 2021. We were then told that there was a waiting list of 3 years approximately. No one has ever contact us since or acknowledge that we are in that waiting list and that someone by phone, told us we were in.

How to improve things: *Speed the process. Meanwhile, support the financial impact for private assessments while CAMHS is unable to deal with their backlog. Specially in cases where the situation become unsustainable or difficult to endure. At the moment many families have to assume the costs themselves due their desperation.*

I think it would work best if assessments for both ASC and ADHD could be carried out by the same organisations, will avoid a lot of back and forth and waiting time. Contact families that are not necessarily familiar with the process and explain procedures to set real expectations.

Needless to say, that while we wait for help, a child is left in the middle of nowhere who's suffering in a daily basis. They are real victims of the society with the only support of their families. What's the alternative while we wait? What options do we have to help our kids? Schools are not always collaborative or even understand our kid's needs. They must think about this. We cannot leave KIDS behind which is absolutely the current situation.

Which CAMHS: Brighton & Hove

Your experience: My son had a very traumatic experience when we went to CAMHS and got so upset by the questions being fired at him he cried and froze. He has not seen or spoken to anybody else since this happened, we have had no support at all from them throughout the whole of lockdown.

How to improve things: *Communication from CAMHS*

Which CAMHS: Brighton & Hove

Your experience: 1. Daughter walked out of ASC stage 2 assessment the Psychologist suggested a chat, daughter agreed (gave her control). She acted throughout the chat (about 1/2 hr). Psychologist came back and said definitely not ASC. Closed the door to ASC pathway after 18 months waiting. Report that followed was inaccurate and referred to previous reports stating this formed part of their decision (also inaccurate as other reports suggested ASC including initial assessment conducted by same psychologist)! Complaint ignored. Told 2nd opinion has to go through GP and can't be referred to Sussex partnership NHS (so Brighton, East and West Sussex were out). GP referred to Evelina. Evelina said too complex and CAMHS have to refer. Been waiting 6months for CAMHS to put this to panel for funding approval.

Daughter does role play ... and she identifies as having quite serious MH issues. Also, many incidents of self-harm and suicide attempts and detained under MH act...I was monitoring and

asking CAMHS for help. Daughter needed to understand why she thinks she has Bipolar Disorder or Dissociative Identity Disorder. CAMHS wouldn't help (offered once a month chat with daughter). Daughter now under investigation with police for online incidents and following some online incidents was triggered to a breakdown, absconding, dissociation and being detained under MH act again.

How to improve things: CAMHS should not offer a chat in place of stage 2 assessment and base decision on a chat if YP refuses to do assessment. CAMHS should follow NICE guidelines and conduct assessment accordingly, CAMHS seniors should not ignore complaints, CAMHS should ensure their staff are held accountable if they don't conduct assessments properly, CAMHS to offer more psychiatric support and support to parents if parents unsure how to manage certain behaviours, CAMHS to be funded properly so more staff can be recruited/ more staff recruited if funding available assessments should be tailored to young people's issues (i.e. for adolescent with high intelligence or thinking they're more mature offer a less babyish assessment) so there's more chance to engage.

Support available shouldn't only consist of groups as this is a barrier to engage for some young people. CAMHS should understand they have neglected my child and are partly responsible for escalating high risk behaviour - offer help when parents ask.

Which CAMHS: Brighton & Hove

Your experience: My daughter was referred around Easter in 2019 for an ADHD assessment by a Dr at Seaside View (she had been diagnosed with ASC by Seaside view 2 years earlier). She was accepted for a stage 1 assessment and in December 2019 my husband and I had an appointment to talk to someone at CAMHS about our daughter and what we were seeing, but they didn't want to see our daughter. At the end of the appointment we were told that they would visit her in school "in the new year" to observe her and decide if she would go onto a stage 2 assessment. We chased this up in February 2020 and heard nothing, and again in March 2020 but then Covid and lockdown happened so they said they were unable to visit schools obviously. No support or advice was offered in the meantime.

We started chasing them up again in June 2020, as we were stuck in limbo waiting between stage 1 and 2. Our daughter's behaviour was becoming so violent to us and her younger sister that we were referred to Front Door For Families at the end of the summer.

We continued to chase CAMHS to see if they could do a video assessment or something, as other services were and just to see what was happening. We heard very little back and when I was contacted it was to tell me that the member of staff who had done our original stage 1 chat with myself and my husband has since left so they weren't sure where that left us. They said they would get back to us. It took over a month of us contacting them, our family caseworker from Front Door For Families contacting them, and eventually our caseworkers boss contacting them for them to finally email our caseworkers boss (not us) and say they would take her case to panel that week ...

at the beginning of October.

We didn't hear anything back, despite chasing up, until the end of November 2020 (almost an entire year since our stage 1 appointment) when we were told they had decided to put her through to a stage 2 assessment, but there was at least a 17 month wait.

At this point, it had been around 19 months since she had been referred and not a single member of CAMHS staff has even laid eyes on my child, let alone observed her. It's been 7 months since then and we have heard nothing further from CAMHS, we haven't been given any advice or support, we didn't even know about the parents Zoom group that I've recently heard someone mention. My daughter had just turned 6 when she was referred, and it's looking likely that no one from CAMHS will even meet her until she's 9, maybe 10, for probably more than half of her years at primary school.

She is struggling massively, and she has been truly let down by the CAMHS system and we've just been left to get on with it.

We have often considered trying to get a private assessment, even though we really can't afford it, but the red tape that seems to be involved in this regarding CAMHS and school accepting a private diagnosis has made us worry it would be for nothing. So, we're stuck between a rock and a hard place, and our poor daughter is losing out on a huge chunk of her childhood.

How to improve things: *We all understand that Covid brought up massive issues for CAMHS, but the lack of communication was extremely stressful, and was a problem before covid came along. Only being able to access an answering machine (and one where the recorded message essentially told you that they wouldn't be calling you back if your query was regarding stage 1 or stage 2 assessments!) and not hearing back was incredibly stressful and would have been made much easier if we'd just been kept in the loop about what was happening. Just be open about it.*

Being able to continue with assessments over video call. We had video appointments with many other departments over lockdown/covid, including assessments with NHS Occupational Therapy and NHS physiotherapy, and video appointments with The Wellbeing Service. We managed to co-ordinate with educational psychologists and assess and make an entire EHCP plan for my other child during the first tough months of lockdown. So, I don't understand why CAMHS had to come to what seems to be, a complete shutdown.

Which CAMHS: Brighton & Hove

Your experience: Very scary experience, feel very intimidated as though you're lying. Had to have a second ASC assessment because the lady said he wasn't autistic for whatever reason she said which didn't make sense, but he wouldn't communicate with her for an hour (a very autistic trait). Just gave us one-word answers... Two very experienced ladies in autism diagnosed him straight away a few months later because we disagreed with the decision! Absolutely disgusting! We should feel like they

are on our side and support us but it's not like that. Seeing the same person every time you go is not an option... We've had phone calls regarding medication who didn't know what he was taking if any. There's no communication within the system and it absolutely stinks! My daughter is now on the pathway, and I don't hold out any hopes. It's a shame because the earlier our kids are diagnosed the better help they get and the more they succeed!!

How to improve things: *More professionals who actually can see problems rather than going by what the government rules and going by what things cost!!! We've had this for years money money money... what matters is our children get what they need to live a fulfilling life. I've seen autistic children rejected and I'm not even a professional. Absolutely disgraceful. We shouldn't have to beg for help!!*

Which CAMHS: Brighton & Hove

Your experience: My son was first referred to CAMHS in 2017 due to not attending school. But due to no school input he was discharged. I then was referred again in 2018 and he was discharged again with no assessment. He then was referred by the function first team at the Alexander as he was still avoiding school and visibly showed difficulties. We had a Stage 1 assessment for ASD after waiting years early 2020 and we haven't heard anything since about stage 2. So, I took it upon myself to go private. This cost me £800 my son was diagnosed with ADHD and showed significant executive disfunction. I then contacted CAMHS who said they won't accept his diagnosis unless I filled out some forms. I agreed and was told we would have an appointment then within two weeks. I also stated the school pack couldn't really be completed as he only has tutoring. CAMHS said they would take that into consideration as his tutor only sees him once a week via video link for 1.5 hours. My son doesn't have a Web cam so isn't visible at the time.

They then write to me several times at a very old address even though they had my current one and have discharged him and refused to continue with his assessment based on the teacher pack. Even though he's been diagnosed, and they'd said they'd take it into account he hasn't attended school since primary. My son has been failed. He's had no high school education or social interaction for five years with any peers. This has affected him a great deal. The lack of cooperation and empathy is disgusting. I asked several times to speak to someone about it and got told to speak to pals and that was it.

How to improve things: *Respond to distressed parents when they ask a question! Have a telephone line where someone actually picks up. Accept private diagnosis.*

Which CAMHS: East Sussex

Your experience: Our first appointment with CAMHS, we were referred to after attending a drop-in clinic for mental health at the local surgery, as our daughter could not get into school, due to intense anxiety. After waiting 3 months to finally see someone, we were brushed off, with no help and no recognition that there might contributing factors to the anxiety. We were released with no help, even though our daughter was continually unable to attend school for those 3 months leading up to the

appointment. Our daughter's mental health became worse, and I was continually contacting the GP, they sent me back to CAMHS. This time they acknowledged that we should have an assessment for ASD, also that our daughter had very high anxiety, OCD and needed support. They also said she should have CBT (Cognitive Behaviour Therapy) for OCD. We have now been waiting 2 years for this support. We have yet to receive CBT therapy through CAMHS.

We have had the stage 1 assessment for Autism and have been moved on to stage 2, but this had still not happened, and we were told at least another year. We have been left without any support from CAMHS.

How to improve things: *More awareness, and training on how to determine the depth of anxiety, how it will affect the lives of each person differently and their families. Not to brush people off on a first appointment, thinking this suffering and condition will pass. There should be check in with families who are let go, to see if this was the right decision. A review of their situation within a month or two.*

Access to treatment when its advised.

If you suggest therapy, have it available.

I do understand there is a funding issue and the Government need to listen and hear the voices of those suffering and give more money to CAMHS, and this needs to be used to improve the timing and access of assessments and therapy.

Which CAMHS: Brighton & Hove

Your experience: Well, talking about CAMHS is a real pain, we were forward and backwards for about 4 years and still without ASC result completed by CAMHS. To have any improvement I had to pay for a private doctor which in less than 1month I had my son diagnosed.

In my journey to CAMHS I think they experiment on my son and I'm sure it worsened his condition (they put his hand into the toilet and eat a peanut without washing it) he was told to keep his hand until 5pm without washing. When I picked him from school, he said Mum I want to cut my hands off. Was heart breaking for me.

How to improve things: *To take more serious on our children mental health. To have a good and promptly professional (waiting list is a killer). We as parents when we search for a help at CAMHS our strength are already gone.*

Which CAMHS: Brighton & Hove

Your experience: My son was diagnosed ASC via SSV (Seaside View) 5 years ago, shortly after he was referred to CAMHS for an ADHD assessment, despite me chasing I have literally never heard

back. He is now 13, about to start year 9 and I have no idea if he's still on a waiting list or dropped off.

How to improve things: *To respond, to have more resources to respond, assess and follow up care although I question why ASC and ADHD is managed by CAMHS as they are not necessarily mental health conditions and sadly once diagnosed there is no availability or resource for related psychological support, so you are left with a diagnosis to research and self-manage.*

Which CAMHS: Brighton & Hove

Your experience: Daughter struggled with debilitating anxiety to the point of a complete shutdown at 14. Several requests to be seen by CAMHS but was told by GP she wasn't going to bother referring to CAMHS as wait was too long, so given basic counselling through wellbeing. ASD and ADHD not picked up by school, GP, or Wellbeing.

I then pushed for a ASD assessment from CAMHS. Waited several months for a first appointment after they lost our referral. Lots of unreturned phone calls. Eventually seen by a graduate worker who whilst understanding, wasn't qualified to assess ASD. Her notes were sent to a panel. No communication, impossible to speak to anyone at CAMHS. In the meantime school refused to arrange EOTAS (Education Other Than At School) lessons even though my daughter could not leave the house for months unless she had a formal diagnosis (anxiety or ASD) which would only be given at consultant level. After chasing constantly, I was told by CAMHS she may be put forward to stage 2 assessment, but the wait was quoted at 24 months.

We had no choice but to obtain a private assessment. Daughter diagnosed with ASD and ADHD and anxiety. After our diagnosis I informed CAMHS and sent her report. She was offered group ADHD counselling. My daughter has social anxiety and hadn't left the house for months, so I declined so our case was closed with CAMHS. Zero follow up, zero support we are left to navigate on our own.

How to improve things: *More staff. More fully trained staff who are aware and sympathetic to neurodiverse children and also who are trained to spot ASD and ADHD in girls in particular. One worker who takes on a child's case from start to finish with weekly communication with parents /Carers. CAMHS Panel meetings held weekly, and children given longer than a few minutes for a panel to make a decision if a child should be put forward to stage 2 assessments. Maximum 6 weeks wait between Stage 1 and Stage 2 ASD assessments.*

Which CAMHS: Brighton & Hove

Your experience: My son was diagnosed with ADHD by a private assessment completed by (private practice). He is struggling with his condition particular in areas around mental Health therefore my Doctor made a referral to CAMHS for further help and support. After waiting nearly a year for even an acknowledgement I finally received a letter from CAMHS stating they had decided not to accept the private diagnosis due to certain criteria's not being met according to the 2019 NICE guidelines and therefore no support was available for my son on the CAMHS ADHD pathway, and I would need to

with the help of his school to complete screening forms to be able to access any support. But this would mean being at the bottom of the queue and enduring another year long wait for even a response.

How to improve things: *Accepting a private diagnosis without challenge. Offering support to our children without a yearlong wait for even acknowledgement.*

More mental health support for children with ADHD/anxiety disorders. Currently children are left to struggle, and parents have to carry the responsibility of dealing with mental illness conditions unsupported and alone.

Which CAMHS: Brighton & Hove

Your experience: Massive delay in assessment. School referred late in year 6. Lots of problems scheduling appt. finally got appointment after child turned 11. Went to bottom of wait list at CAMHS waited 2 more years for stage 2. Was not clear that support options e.g. mASCot etc available for kids waiting for stage 2 i.e. why would we join stuff only to find not given a diagnosis.

Delay affects school SEN provision and could not get BHISS because no diagnosis. Result massive deterioration in mental health due to continued stress and inability of school to manage child needs, self-harm, violence etc break down in relationship between child and school.

How to improve things: *Make better arrangements for referral Process for children who are about to age out of seaside view and better and more efficient communication about appointments. Answer the phone. Have the child's birth date correctly recorded. Send texts for appointments.*

Stop this outdated method of passwords and emails. Make arrangements to send diagnosis and assessment documents by email. Do not refuse to provide information electronically.

Which CAMHS: West Sussex

Your experience: Despite having massive problems with our son (school refusal, suicidal ideation, physical and verbal violence to parents, constant destruction of possessions and our home), who has since been diagnosed with ADHD, ASC & PDA (Pathological Demand Avoidance), we were repeatedly rejected by CAMHS & ended up having to get help through (private practice) (at great expense). I have absolute contempt for the way CAMHS kept turning us away. When we were desperate for help it was not provided.

How to improve things: *I am sure there are people doing good work at CAMHS but equally it feels as though it lacks appropriate leadership, which filters down to the rest of the staff. I would like to see investment now in helping children with mental health problems, not only because families are desperate, but because it will be a long-term cost benefit to society (less people with ADHD etc. will end up in the prison system, more will be able to function and work).*

Which CAMHS: East Sussex

Your experience: My son started to have serious mental health difficulties in 2017. I took him to a CAMHS drop-in centre in Lewes. We were seen and he was severe enough concern for that CAMHS worker to be put on Tier 3 intervention.

We waited nearly a year for therapeutic intervention and because we were going through a family crisis at the time (divorce), it was deemed appropriate that we have family therapy. At the time my son was extremely anxious about attending appointments as he could barely leave the house so out of the 8 appointments given, he only managed 2. It was a total waste of time and resources. I was no better off as parent to a very vulnerable unstable young person. I was told to attend Anxiety workshops which taught me nothing I did not already know. I had to cope on my own. The phone line was all I could turn to. The thought of hospital was even more stressful so I could not get him to A&E. He had multiple MH conditions at this time and was a shell, he was so fragile and withdrawn, depressed and terrified and I was extremely stressed as his main parent carer. I had to give up work as he stopped attending school. He was full of fear about school. I knew he needed one to one therapy and ASC assessment, but he was on the cusp of age where paediatric assessment was still needed. So I took the decision to push for GP referral to Scott Unit.

They did not recognise autism as it was a tick box exercise based on outdated autism understanding. I had read and knew more than this supposed Dr about my son's innate masking and his anxiety being so well hidden through compliance that this exercise was followed by total physical, mental, and emotional collapse in the aftermath for weeks. The Scott Unit recommended re referral to CAMHS. We waited months to be seen again but my son masked well in this meeting with the family systems therapist, and we were told no therapeutic intervention could occur as he was not of serious concern.

I knew there was little point in talking to CAMHS after that and that they are woefully inadequate in their service. I felt dismissed and patronised, and it left me in a state of humiliation and betrayal (as I had opened myself up, giving detail of family history, which at times was traumatic, in the family therapy process, for it to come to nothing in helping my boy).

I had to have a break and 2 years later I recharges and re attempted ASC referral via GP to get CAMHS back on to the screening processing. I only succeeded getting the screening form (which I've just completed, 25 pages encapsulating my son's life on those pages) because I found and paid for a Psychiatric mental health screening /assessment, and she recognised ASC and wrote a report to back me up with my concerns. 5 years later after my son's initial breakdown, we still are waiting for answers never mind a diagnosis. I have been totally alone in dealing with boys' mental illnesses and he has become totally depressed and abandoned. The whole process is like being on an eternal hamster wheel as a parent.

How to improve things: *CAMHS need to wake up. The powers that be need to re assess the whole system. There needs to be an entirely independent and self-governed body for ASC pathway. There*

needs to be a quicker wait time from the initial drop-in clinic to screening.

There needs to be far greater up to date autism awareness and training in CAMHS as on speaking to many parents like me, we all know and acknowledge that this is totally inadequate and outdated knowledge within the MH sector. The volunteer groups and separate support bodies such as mASCot, CLASS, AMAZE, NAS all know this to be true and that CAMHS is well behind. CAMHS has enough to deal with and does not want to deal with autism. this is what is clear.

Create a separate body to tackle emotional based school avoidance in children, and a separate body to help parents of children with ASC get far swifter, easier access to the support systems desperately needed. The delays and obstacles in our way just lead to further and more long-term mental health conditions into adulthood. I know my child. Parents know their children. CAMHS needs to respect and get parents on board, not dismiss them, and diminish their self-esteem by denying and making excuses to cover over their lack of resources.

Which CAMHS: Brighton & Hove

Your experience: We were referred for assessment and did not hear from CAMHS that they had received our referral (we know now that referrals are (not) acknowledged but as this was our first interaction with them we assumed perhaps that was how they worked) - over 18 months later we chased this up with our GP just in case, it turned out that CAMHS had received our referral and were 'waiting for a report from the school'; we had clearly stated on the form that our child was home educated so this would not be possible. We received a letter of apology, but this was written to our child (aged 9 at the time) who was extremely confused by the whole thing. We had heard nothing from them during the wait or could have cleared things up far sooner.

How to improve things: *Acknowledge patient referrals and clearly communicate to all health care professionals that if nothing is heard to contact them and check. Ensure staff understand that not all children are in schools. Check DOBs before sending out letters.*

Which CAMHS: Brighton & Hove

Your experience: 2015 GP said get school to refer for ASD/ADHD, 2016 Referral made for ASC - was rejected and told manifestations of anxiety, 2017 Referral made for ADHD - school rate zero and parent questionnaire wasn't properly considered, and assessment rejected.

2018- CAMHS called as my son had suicidal thoughts and was very much struggling. 2019 - ASD stage 1 assessment done at Seaside view. Due to his mental health and no help offered from CAMHS we fundraised to raise the money to get assessment at (private practice) children's development centre. 2019 - full assessment complete and diagnosed with ADHD scoring 99 on the QB test and ASD along with other issues. Paediatrician works for NHS and adheres to NICE guidelines and above. Also, I would never have undertaken an assessment costing £2000 if I knew it wasn't going to be accepted. I was reassured by CAMHS, and Seaside view it would be accepted due to their thorough and high standards of practice. Report was sent Jan 2020 as I wasn't aware it needed signing off by

CAMHS to receive help.

My son masks massively his difficulties and differences to the point where he internalised and holds everything in. He has recently had to be hospitalised for 6 nights and ended up with a general anaesthetic due to stress/anxiety triggered due to his neurodiversity.

School didn't report any ADHD traits despite other evidence apparent to them e.g. TheraBand on chair, movement breaks, fidgeting, intention, and inability to complete a task as overly distracted. Lack of focus. A further report was requested but was not completed by a trained person familiar with ADHD in a child who masks ASD.

School observation requested but he was unable to attend since lockdown last year despite a part time timetable saying he can't cope.

Still waiting for his diagnosis to be signed off and for him to be assessed by a psychiatrist but been told they are only prioritising review med patients and not new patients so there is a huge wait. GP refused to prescribe antidepressants as on ADHD pathway but still he has no help and is rapidly deteriorating daily.

How to improve things: *Smoother service - is very clearly needed. 3 years wait for stage 2 assessment is just not acceptable.*

Not Signing off on a report that is clearly above NICE guidelines written by a known NHS paediatrician would allow to create less work and undue stress for the patient, family and CAMHS team. Appears to be a huge lack of direction and pathways are not clear for children with additional complex needs.

Which CAMHS: Brighton & Hove

Your experience: My son was referred for an ASC assessment by a professional and myself. It was refused on the grounds that he had friends.

How to improve things: *CAMHS could have considered the family history and his behaviour and his sudden and complete disengagement with education after having been in the gifted and talented stream.*

Which CAMHS: Brighton & Hove

Your experience: My son was first referred 6 years ago for behaviour issues. He was seen and awarded counselling. This never took place. 6 years later and now in secondary school he was referred for ADHD his application was refused. SENCO has now reapplied with added ASC concern. Terrible service that is failing our children.

How to improve things: *The whole systems needs to be changed from how they deal with referrals to how long assessment takes. They need to take onboard parents views more. I also feel once a*

child is diagnosed there needs to be more support in place. I have had bad experiences but also heard some terrible outcomes for people.

Which CAMHS: Brighton & Hove

Your experience: When my child was assessed for ASC the psychotherapist that did the assessment told us he needed referral for ADHD assessment as they felt he had it, which, was done by them at the time (May 2017). We were duly sent forms to fill in which we sent back, and we waited. After 9 months I contacted CAMHS to be told that because the school had not sent the forms back, he had been discharged. There was no indication that they had chased the school for these at all and we had not been notified by them that this was the case. The SENCO assured me they had not received any forms and requested more. These were then filled in and sent back. After some considerable time, I was asked to attend for a chat, and he was then assessed at school for his stage 1 assessment. We were then advised that it was a 14 month wait (pre-covid) for stage 2 assessment. This has still not happened and is unlikely to occur until late autumn. He was in year 1 when he was assessed for ASC, and it is unlikely that his stage 2 will have occurred prior to his applying for secondary school placement in year 6.

How to improve things: *There needs to be an integrated assessment process for ASC children. It should be their responsibility to chase other agencies and inform parents of any discharge and why. There needs to be more funding in place and more staff to deal with the workload and there should be a cap on how long children are having to wait as early intervention could change the trajectory of their life particularly when they are still developing cognitively and young.*

Which CAMHS: Brighton & Hove

Your experience: We had been waiting for 16 months for our daughter's Stage 2 Assessment. Due to Covid we got added to a Virtual Neuro-Developmental Discussion group. We joined this meeting to ask some questions on how to progress our case as we were concerned as our daughter would be turning 18 within the next 6 months and would this affect the assessment process. We spoke to a clinician who was most helpful and informed us that we shouldn't worry, and she would look into it for us, and she would call us back. She never did call back, instead we simply received an email and a letter telling us that they had looked into us and due to our daughter's impending birthday they had moved her across to the Adult Service which has a longer waiting list and we would therefore no longer be eligible for any help or support from CAMHS. They literally dumped us from one list to another with no help, support, or advice. It was disgraceful. Another 8 months has since passed, our daughter has turned 18 and still we are awaiting our Stage 2 assessment. This is now a total wait of 2 years and we have heard nothing! We are paying for a Private Assessment as Adult assessments are a lot more affordable than Children's ones. But at the time when we most needed help during Covid they literally dumped us.

How to improve things: *More frequent updates on how your case is progressing and not to be dumped from one service to another just because you had a birthday!*

Which CAMHS: Brighton & Hove

Your experience: Hi, my son was seen for his first stage ASC assessment nearly two years ago, we are still waiting for his second stage. I have called numerous times, and nobody ever calls back. My son has struggled for 14 years, with seaside view being just as negligent and now he has been hugely let down again by the dreaded CAMHS, I have absolutely no respect for this joke of an outfit. In the 2 years we have been waiting, we have had 2 maybe 3 letters to say they haven't forgotten but they have a huge backlog of work... Absolute disgrace!!

How to improve things: *Where do I start... better communication, shorter time scales... I could go on and on about what could be done better.. everything could be done better.*

Which CAMHS: East Sussex

Your experience: Before 2, I knew my son was different. No one did anything. Doctors and the school tried to refer him to CAMHS, and it was always brushed aside. Finally, he attempted suicide - stood in front of train. Train services shut for 5 hours on the line. Only going to A&E did CAMHS come and say "Oh wow, I see you've been referred many times. He's now 16, and still not diagnosed, even though CAMHS have written to the school to say it's highly likely he is, and they should make accommodations for him. It's been deeply frustrating."

How to improve things: *I don't think CAHMS make clear what's needed for a referral, and it's wrong that they turn away people too soon. What they should do is share what's needed for an effective referral, so that people don't waste their time.*

Which CAMHS: East Sussex

Your experience: Our child was referred to CAMHS for ADHD assessment. Her first stage assessment was accepted after a year of ongoing battles to get the referral accepted. We're now waiting for an appointment for the second stage assessment with a psychologist to hopefully get her diagnosis. A few months ago, I received a letter saying the CAMHS waiting list was currently at 2-2.5 years. Then a few months later, we receive letter stating that the current waiting time had gone up to 3.5 years. My child will be in secondary school by the time she is seen by a Psych. In the meantime, she has no EHCP, no medication, no support from seaside view for her ASC. I find it totally unacceptable.

How to improve things: *CAMHS desperately needs more trained full time Psychiatrists to get through the growing waiting list. The ADHD referral questionnaire is extremely outdated and relies too heavily on matching particular profiles. This particular questionnaire makes it difficult for children with other developmental/neurological differences to be identified.*

Which CAMHS: Brighton & Hove

Your experience: As ADHD and Autism are heritable conditions, it is highly likely that at least one birth parent is neurodiverse. CAMHS actions towards parents when their child is in crisis (A&E for self-harm or suicide attempts) can be at best considered dismissive, and at worst, contemptuous. When that parent is also traumatised by what they have had to deal with, cannot

speak to the child's lead practitioner at CAMHS, has had no notification that CAMHS are aware of the incident and are themselves a neurodiverse person, the situation is dangerous. I have raised red flags with CAMHS on so many occasions about our child's decreasing 'mood', return of dangerous behaviours, plans to harm themselves etc, and no interventions have happened. And when something dangerous **does** happen, CAMHS go silent. There shouldn't be a sense of 'I told you so', but this has happened to us on many occasions. When this has happened to me, I have been told to complain via PALS (Patient).

Also, notes are not accurate - we have had so many different practitioners, when I have seen the notes, as the only consistent person in my child's life, and have asked for things to be highlighted in a summary, this hasn't happened. This means that I am the only person holding the chronology of my child's experience: this is dangerous for my child.

CAMHS have told me that they know what my child needs - this absolutely **hasn't** proven to be the case over the last 5 years, and if they were less contemptuous of the role of parents in that child's care, I truly believe that the outcomes for children would be more positive

How to improve things: *Stop treating parents/carers as Them and Us, believe parents provide a mechanism for parents to communicate directly with lead practitioner. Phone parents back, share notes with parents (where possible) and allow parents to review summary notes whenever a practitioner changes, stop treating parents as amateurs - all they want is what is best for their child. Listen to parents' collective experiences and CHANGE things at CAMHS*

Which CAMHS: Brighton & Hove

Your experience: Numerous independent experts flagged that our daughter may also have ADHD back in 2017/18. School/parents completed referral forms and CAMHS turned us down for assessment. Seaside view didn't want to know once she had her autism diagnosis - 'why is that important?'. She has just been reviewed by independent OT and EP who both feel ADHD is an obvious need when you spend time with her. We have never seen anyone from CAMHS as the form says 'no' but anyone who meets our child flags it as an issue that needs addressing for her EHCP and learning. It doesn't feel as if this 'threshold' form is appropriate.

How to improve things: *Someone should have seen our daughter - especially as she masks and camouflages.*

Which CAMHS: Brighton & Hove

Your experience: My child was referred to CAMHS in early 2019, aged 6 following a referral by Seaside View for an ADHD assessment. We were then sent the questionnaire relating to ASC by mistake and it took many emails to ensure the correct forms were sent to myself and his school. Eventually I was spoken to at the first stage of assessment by a nurse who then sent a report which was accepted for a stage 2 diagnosis for ADHD - in November 2019. We have been waiting since, my child has not seen a mental health professional from CAMHS since referral despite his current

behaviour having a severely detrimental effect on his life.

How to improve things: *The lack of secondary care has caused great strain on the wellbeing of my child and our family. He has been excluded, bullied, missed education, experienced trauma, and placed the whole family under huge strain.*

The lack of medical care has ultimately meant we have relied on social care and other NHS services to 'plug the gap' that CAMHS has left untreated. This also has the potential to cause a greater financial burden on adult mental health services in the future - please can stage 2 assessments be prioritised to ensure children are seen by a CAMHS Consultant in months rather than years.

Also, more admin staff to ensure referrals are dealt with accurately.

Which CAMHS: Brighton & Hove

Your experience: Our Child was assessed for Autism after a catastrophic break down at the end of Yr7. The diagnosis of ASC was received in Feb of Yr8, but it wasn't until December of Yr12 that he was finally assessed for and diagnosed with ADHD.

The interplay between ASC and ADHD is very well known, and apparently it was very clear from his notes that he should have been assessed for each (Diagnosing Psychiatrist stated this).

Additionally, due to a total lack of adaptation of therapies for neurodiverse young people with co-occurring mental health conditions, our child wasn't offered any adapted therapies, either acknowledging the ASC or again the ASC and ADHD, leaving him without access to care in the hugely extended period between the two assessments.

My child's education has been irrevocably damaged by the failure to recognise he is both ADHD and Autistic. CAMHS should also have a very clear list of criteria for acceptance of NICE compliant assessments for the above conditions: I know that this is apparently 'under development', but until it is published and shared, the waiting lists are increasing, the time until assessment is ever extending, and young people are being denied access to educational and therapeutic adaptations that could potentially support them and prevent mental health decline

How to improve things: *ACS and ADHD should be assessed together as standard. There should be no child waiting more than one school year from referral to assessment, and if this is the case, private providers should be used.*

It should be known that 50% of people are both ASC and ADHD, and in my opinion, there is no reason to not assess for both at the same time, not least as it would save money and prevent having two parallel waiting lists

All young people who have co-occurring mental health difficulties should receive therapeutic intervention that is ADHD/ASC accessible even before they are diagnosed.

Which CAMHS: Brighton & Hove

Your experience: We received a letter to inform us of the assessment starting.

We received a phone call to do a risk assessment before we were given a date for the first assessment. We have not received anything else, and this was over 6 months ago.

Lewes Wellbeing Centre is assisting with things. They phoned CAMHS to try and find out what is happening. CAMHS couldn't find my son's file. Someone then phoned me up and was really rude and told me off for chasing. She was so rude I was in tears.

How to improve things: *Communication! Don't just stop the process without telling me it has been stopped due to covid. A letter with what is happening. Not all services have stopped!*

Don't be telling me off like a child for chasing something that is extremely important and life changing to my son. Guidelines on what to expect. What are the stages?!

Which CAMHS: Brighton & Hove

Your experience: without you pushing and pushing (exhausting) I wonder how much they'd have helped.

Apart from an art therapist who told us constantly that "autism wasn't her field of expertise" and told us we were too keen to "seek a label for her", our daughter didn't see anyone for 5 years despite being on a Section 47, subject of police reports due to running away and being taken to A&E after threatening to jump out of a window during that time. She is still on their waiting list for assessment despite us having an ADOS level 2 diagnosis for ASC and ADHD that was given by a fully qualified Consultant Paediatrician who also works for the Scott Unit and despite numerous requests CAMHS still refuse to tell us about their reasoning behind their refusal to accept the diagnosis. We were also told in January 2020 that the assessment would be a "matter of weeks" because our daughter had been classed as an emergency.

We're trying to get EOTAS, but need input from CAMHS, I wouldn't be pursuing otherwise. There is nothing they can do for us anymore and have caused more damage but will at least get some form of letter from them to help the EOTAS referral.