mAScot
Autism Support Community
Supporting Local Families

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We asked members to share their experiences of:

Lack of ASC & neurodiverse appropriate therapeutic intervention

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Which CAMHS: Brighton & Hove

Your experience: My son is 10 years old and was diagnosed ASC at the age of 4. He has always suffered with anxiety, but it became very bad approximately 3 years ago. He began self-harming age 6/7 and even talked about jumping off the top level of a shopping centre. He had an appointment with a paediatrician at SSV (Seaside View) about his motor skills, but when he saw bite marks on my son's arm he was really concerned and spent the rest of the appointment discussing my son's mental health. He was wonderful and actually listened. He agreed that he needed help and would refer him to CAMHS. He also followed up with a phone call to me a week later because he was so concerned about my son. CAMHS turned down his referral because of his ASC diagnosis. No other reason. No alternative agency or department was recommended or offered to help my son.
If a senior paediatrician has taken the decision to refer a child to CAMHS surely, they should at the very least see the child for an initial consultation.

I am very concerned about what will happen when my son becomes a teenager. I've had to research strategies and therapies myself to help with his anxiety but as he gets older, I think he will need professional help and that help doesn't exist.

How to improve things: *Firstly, CAMHS should stop discriminating against children with ASC. The child's mental health needs should be looked at - they should not be automatically turned down because of their diagnosis.*

There should be a specific team of professionals that work with ASC children. Some ASC children benefit from traditional therapy, while others need individual plans to suit their needs.

Which CAMHS: Brighton & Hove

Your experience: My 9-year-old son was discharged from Brighton and Hove wellbeing autism specialist therapist, experiencing distressing symptoms of OCD (hygiene related) which were worsening, during the first lockdown. Wellbeing Service discharged us to CAMHS, feeling that more specialised OCD support was needed. However, CAMHS said we did not meet the threshold. We did have support from the Autism family support worker however again she said she was not an expert in OCD and could not provide specific advice.

How to improve things: *In this instance, a one-off phone call to provide CAMHS specialised advice as to how I should respond to the OCD would have made such a difference as we felt very alone and out of our depth. I do also feel that it needs to be recognised that autistic children can need specialised mental health support and that professionals who specialise in autism do not always have the required knowledge - sometimes CAMHS specialism will be required.*

Which CAMHS: Brighton & Hove

Your experience: Child has multiple diagnoses ASC, ADHD and extreme demand avoidance, tic disorder and chronic anxiety and mood swings. Have been unable to access adequate support and medication as they will only deal with ADHD. Child has been out of school in total over 4 years, asked for help numerous times but insufficient support given, even when child self-harming and having suicidal thoughts.

How to improve things: *More staff, retain staff, more caring attitude, better knowledge of ASC and mental health issues, quicker waiting times, more support, and services.*

Which CAMHS: East Sussex
Your experience: We first contacted CAMHS when our 10-year-old daughter (not then diagnosed with ASC) was experiencing significant mental health problems and had reduced her intake of food considerably. We were seen by a nurse fairly swiftly but then told in a letter that the nurse thought it was possible our daughter had ASC and therefore CAMHS would not be providing any support. Instead, they referred us to Eastbourne Hospital for an ASC assessment, which would take approximately 1 year. During this time were not offered any support to treat her mental health problems and had to manage by ourselves, which we feel is unacceptable. Our daughter's mental health deteriorated further during that time and Eastbourne hospital decided to carry out a full psychological assessment, which highlighted depressive disorder and anxiety disorder.

They then referred us back to CAMHS for treatment. We were again seen swiftly by a CAMHS representative but were shocked when the questions centred around her (now diagnosed) ASC, instead of the ADDITIONAL mental health problems that the clinical psychologist at Eastbourne Hospital identified. We were then told in an email that CAMHS would not be providing any treatment as our daughter had ASC. Both ourselves and the clinical psychologist at Eastbourne found this to be unacceptable and the psychologist wrote to CAMHS stating that there is 'evidence-based' psychological intervention strategies for people with ASC. We complained to CAMHS and were referred to a psychiatrist who acknowledged the mental health conditions and prescribed medication. He explained that he should not really be prescribing medication alone without any psychological support but the waiting lists for these were too long. It became apparent that the medication did not suit our daughter and the psychiatrist mentioned that alternative intervention would be pursued.

However, when a meeting of experts was called to explore this intervention, CAMHS did not turn up and wrote in their notes that they would not be providing any intervention as our daughter had ASC. In the end, the psychologist at Eastbourne Hospital said they would do their best to provide some support - and we are still waiting for this. We find it totally unacceptable that CAMHS would not provide mental health support to a child diagnosed with depressions and anxiety due to their developmental condition when there are 'evidence-based' strategies in existence. When we put this complaint to the CAMHS psychiatrist directly he acknowledged that it was a problem, and the service were 'looking into' providing services for young people with ASC.

We strongly feel that they should already be providing this. CAMHS should be for ALL young people, not only neurotypical young people. We feel that this is discrimination.

How to improve things: *CAMHS should have a greater understanding of what ASC is, how it affects young people differently, and how young people with ASC can have ADDITIONAL mental health problems which are NOT a direct result of their developmental condition. CAMHS should have evidence-based treatment strategies in place which are differentiated for young people with ASC.*

Which CAMHS: Brighton & Hove
Your experience: My daughter was diagnosed with ASC 2.5 years ago at SSV (Seaside View). We were told she should receive psychological /mental health support at time of diagnosis. Having followed up with CAMHS several times we've been told she's now not eligible. She struggles with extreme anxiety, school refusal, sleep and eating issues and we have to pay for private therapy as what we were told she could receive is not available.

How to improve things*:* *Instead of only having a service for children at absolute crisis point, there needs to be more resource and provision to help manage difficulties before they turn in to a crisis.*

Which CAMHS: Brighton & Hove
Your experience: Diagnosis received then nothing. No queries about any problems child experiences or requests for what support might help. Recommended for ADHD assessment but told to wait 2.5 years, no or negative information provided about private assessment. Child went to A&E, got CAMHS duty, psychologist said that child was struggling to engage, and she would need to learn how to communicate about problems for the intervention to work. Offered 3 random appointments. finally got a zoom group but zoom not effective for group work for ASC kids. Weirdly ASC youth club is able to run?

How to improve things: *Active enquiry into problems, use mass of data gathered during assessment to actively help establish and address areas of concern, post diagnosis support for young people, systemic improvement in ADHD, Anxiety and other conditions routinely found with ASC especially for teens receiving diagnosis and girls, to reduce inequality, more joined up liaison with schools.*

Which CAMHS: Brighton & Hove
Your experience: We believe the care we have received has been substandard and detrimental to my son at a crucial time in his development and education and damaging to our entire family.

Firstly, the delay from diagnosis to initial appointment was over 2 years. He has cerebral palsy and we felt fortunate that the neuro-developmental team at Chailey were able to diagnose ADHD and ASC. The psychiatrist there offered liaison and support to CAMHS in providing treatment. This joined up approach would have been beneficial but there was no contact with him.

We came to a couple of meetings with nurses which we did not find helpful. The substance of these meetings was to introduce possible medications, information we felt could have been given on the phone or in writing. The second meeting seemed identical to the first. In both these meetings we were informed that no other treatment than medication was available.

We then had a meeting with a Junior Doctor who met us in a room full of distractions that our son found hard to cope with. She did not seem particularly knowledgeable and asked if our diagnosis had been private when it was from Chailey. The nurse blamed our son for her difficulties with the blood pressure monitor. We were issued with a prescription which we felt could have been issued at the first meeting had that been with the right person.

We were given no advice on how to identify if the drugs were working optimally. We were told they would seek feedback from the school, but they did not approach the school - we did. School had the general impression things were better but had been given no guidance on what to look for. The management of the drug has been haphazard with no explanation of the signs we can look for to ensure the dose is right.

We have taken private advice on how to manage the drug treatment. We have not been given any behavioural management advice or seen anyone more senior than a junior doctor.

Which CAMHS: Brighton & Hove
Your experience: Our dealings with CAMHS were highly disappointing to say the least. It had seemed like our son had had a really thorough and empathic initial assessment with our assigned Community CAMHS Nurse. I was present throughout; she allowed him to communicate through writing things down or whispering to me, and she had a really gentle, kind manner. He and I liked her a lot. We overran by nearly half an hour, but she said it was important we felt we had been able to cover everything, so it wasn't a problem. During the meeting, I told her about his anxiety related insomnia and his self-harm in the form of skin-picking. He was too self-conscious to show her the lesions on his body, but he allowed me to show her three photos of them on my phone, which she said was fine.

Towards the end of our meeting, she went to check her thinking with a superior. When she returned, we discussed a course of action. She agreed that, whilst technically our son didn't fall under the care of Tier 3 as he didn't seem to have suicidal plans or intensions, it was clear that he was on a negative trajectory that needed intervention. She said she would recommend a referral to a CAMHS Child Psychiatrist for preventative action regarding his self-harm and sleep issues, as well as a group counselling course because of his suicidal thoughts. She also said she would make suggestions to his school regarding ways to support him. Before the end of the assessment, she had to leave the room to gather herself as she had severe pain. It transpired she had been suffering with pain throughout the meeting, but she hadn't wanted to cancel the meeting because she was aware how long we were on the waiting list, and how disruptive a cancellation can be.

I made her aware that we needed her report as a matter of urgency as we were applying for an EHCP assessment, and a deadline was looming. We were advised it would take approximately two weeks to receive her report – this would get us the report in time, with three spare weeks to act on any recommendations she might make.

When I called for a progress report approximately ten days after our meeting, I was informed she had gone on annual leave. It is my belief that she didn't write up her notes until after her absence as it's the only reason I can think of as to why the outcome of our meeting ended up being so vastly different from what we had discussed.

After her return from leave, we attempted to reach her on over 100 occasions without success, the phone rarely being answered. On the five or so occasions we were able to get through to the service and we left messages, our calls were not returned. On two occasions, I visited the office in person and said we would wait until she was available to speak with us, but we were informed she wouldn't see us and were asked to leave.

After threatening to make a formal complaint to her superior, I finally received a call to say our letter was ready to be collected – five weeks after our meeting. It was not the detailed report we were expecting! It was a short, simplistic letter which failed to mention our son's self-harm or sleep issues; it said if we wished, we could self-refer to the Wellbeing Service for counselling, and closed our case. There was none of the support we were promised and no mention of any recommendations for the school.

I contacted CAMHS several more times, and again my calls weren't returned, so I returned to the office and left a hand-written letter for her at the desk, detailing all the things I was expecting, together with a print-out of the three self-harm photographs I showed her, and several others, in the hope it would jog her memory.

After more repeated chasing, she eventually returned my call, insisting she had never been made aware of our son's self-harm in our initial meeting, which was categorically not true. She agreed to amend my letter to reflect the self-harm and sleep issues.

When I collected her amended letter two days later, it stated that 'At the initial CAMHS assessment you did not show me evidence of [your son]'s Dermatillomania. In a handwritten note you left at CAMHS reception on [x date], you acknowledged the omission and stated you have photographic evidence of [your son]'s Dermatillomania.' Neither of these assertions were true. I absolutely did show her evidence in the meeting - my son remembers this very clearly as it was extremely difficult for him - and so of course my letter did not acknowledge any such omission.

Her new letter also referred us back to our GP for his sleep and skin picking issues, suggesting an onward referral to Seaside View. Considering we had already been referred to Seaside View, discharged from Seaside View, and our GP had then referred us to CAMHS specifically for help with sleep and skin picking – help which was promised to us in our initial assessment – we were both frustrated and deflated at this outcome.

Had we not been in the middle of an appeal battle for an EHCP assessment, having initially been refused, we would have made a formal complaint… But with just days until our appeal, we had no option but to focus our efforts on obtaining the EHCP assessment.

Since then, at great personal cost, we have managed to obtain an EHCP for our son, private diagnoses of various anxiety disorders, and local authority funding for a specialist school placement and three separate weekly one-to-one interventions. However, though his new support has helped enormously, his mental health needs are still currently unmet.

How to improve things: *Employ a more failsafe method of recording assessments to ensure information cannot be 'lost' or 'forgotten' - in our case, resulting in official letters missing essential facts containing false information.*

Notes from meetings could be shared and signed off post-meeting to ensure all parties have proof of what has been agreed. If this is impractical for reasons unknown to me, parents should have the option of a voice or video recording of the assessment to be made. This could then be accessed in the case of any misunderstandings or disputes.

Clearer and more accessible lines of communication, as opposed to having to call literally hundreds of times or attend in person just to be able to speak with someone. Messages to be passed on and calls to be returned. Children and parents are at their most vulnerable when accessing these services and a wall of silence is extremely stressful.

There needs to be consistency of tone, kindness, and assistance from staff. Some reception staff are kind, empathic and helpful. Some are rude, patronising and abrasive. Our nurse was extremely empathic in the assessment, but her follow up 'care' was unacceptable.

Which CAMHS: Brighton & Hove
Your experience: It takes an extraordinary amount of time to get an assessment (two years and still waiting). Because my daughter is fast approaching her GCSE exams, I have had to persuade the school to give her the concessions without the diagnosis. Also, to receive counselling at school the parent needs to know they have to request this directly from CAMHS because if they do so through school child is put on very long waiting list. I have consistently found the only way to receive support is though harassing and threatening both CAMHs and the school which I find unpleasant and exhausting.

How to improve things: *The long silent wait is very frustrating especially as the whole time your child's schooling is a source of great unhappiness for all concerned. My suggestions are that all teachers especially in primary school should be trained in how to identify a potentially autistic child and how to assist such a child prior to a diagnosis. Also, not all autistic children are obvious. Which has led to the school presuming there is abuse taking place which is the cause of the seemingly unusual behaviours. This could lead to a child with suspected autism being identified earlier than they otherwise would and thus the parents being able to seek appropriate interventions. Therefore, CAMHS could spearhead a campaign to include autism awareness as part of teacher training or for it to be part of OPD for teaching staff. CAMHS also need to carry out the assessments quicker because children's education and enjoyment of school is being ruined by the delay.*

Which CAMHS: Brighton & Hove
Your experience: My daughter has been assessed by CAMHS twice. On both occasions she had expressed suicidal ideation which was not considered serious enough to warrant further involvement or to share the information with her parents. On neither occasion was it considered that she could have undiagnosed ASC although both siblings and father are autistic. She was sent away without the offer of therapeutic

intervention. On the second occasion it was suggested that we source and pay for art therapy for her. Three suicide attempts followed over the three weeks after the second assessment. The first mental health worker who met her in hospital flagged up the possibility of undiagnosed ASC. She is currently detained under section 2 of the mental health act. After 2nd suicide attempt a CAMHS Psychiatrist saw her for two minutes and prescribed antihistamine. 3rd suicide attempt happened 4 days later. There was very clear evidence of concrete thought by the time the psychiatrist saw her, but they were not interested in listening.

How to improve things: *Considering family history, listening to concerns of the family, psychiatrist listening to the concerns of the mental health workers etc. rather than working down a list of protocols.*

Which CAMHS: West Sussex
Your experience: Delay in autism assessment & diagnosis and intellectual & executive functioning assessment pre covid. Discharged immediately with no explanation, ongoing plan, or support/intervention at 16. No guidance as to access to adult services. Basically, you are autistic with processing issues, get on the best you can. NICE guidelines reflect the Autism Act…a lifelong neurological difference which may need lifelong support which was not offered.

How to improve things: *Realistic information, breakdown of aspects & their likely long term implications with executive functioning, theory of mind, working memory, independence, ability to access training, education, and employment. More details.*

Which CAMHS: Brighton & Hove
Your experience: This, to me, is one of the biggest scandals of the way that CAMHS has been allowed to operate. Children who are autistic or who had ADHD receive very little if any adapted therapies, despite their neurodiverse conditions in themselves meaning that they require adaptations in education etc.

I have lost count of how many times I have been told 'CAMHS are not commissioned to work with autism' - no, autism is not treatable, nor SHOULD it be treatable. But CAMHS ARE commissioned to work with mental health conditions, and to the statement seems to be a 'get out of jail free' card to explain lack of adaptation.

They (ND kids) simply cannot access the 'standard' therapies delivered at CAMHS in any meaningful way. The children are being 'fitted' to standard care and if that doesn't work, then the children are seen to not be engaging etc. This is outrageous.

Additionally, the structure itself of CAMHS with the 'pathways' in itself is prejudicial to Neurodiverse young people. The therapies are siloed into different teams, with very little interaction or note sharing between them. The therapies are for specific timeframes, preventing traumatised and ND young people from having the time to build trust with yet another practitioner.

Our child has Disordered Eating, so doesn't fit on the FEDS pathway as they are actually NOT commissioned to work with ARFID (Avoidant Restrictive Food Intake Disorder).

Our child has OCD and GAD - but the CBT offered was not adapted to their needs - I believe that this should have been the anxiety pathway but have never been told.

Our child is autistic but has never met anyone from the autism pathway.

Our child self-harms and has attempted suicide more than once, but the DBT (was not adapted for autistic or ND young people and therefore couldn't be accessed effectively.

Our child has suffered severe and known trauma but needed to complete the (unadapted) DBT before they could have EMDR on the trauma pathway - so this hasn't happened.

Our child hears dangerous voices which tell them to hurt themselves, but there is no one in CAMHS who works with voice so………

Our child is situationally mute when in crisis but the DARST and CRISIS teams don't work with text so our child cannot access those services.

Our child's ADHD team have been fantastic so far, but this is with regard to medication titration and management and is not therapeutic.

I believe that this approach to siloing care by CAMHS is dangerous and detrimental to our young people and is in contravention to the Disability Discrimination Act. I feel that it should face legal challenge.
Our extremely unwell child has had to meet so many different people in CAMHS, has had to retell their story so many times which is immensely triggering, and no one is responsible for their holistic care other than me.

How to improve things: *An ND child who has co-occurring mental health conditions should be allocated ONE practitioner who is skilled at working with their needs, however, diverse they might be. This person should be able to call in on expertise from other teams and adapt approaches to the individual needs of the child in consultation with their parents/carers - this will vary from child to child. The number of different adults that the child is expected to work with should be kept to a minimum.*

Regular reviews should happen, with child and separately with parents, and CRISIS teams should have a core of regular staff who can engage with ND young people in a method that suits them.

Young people and carers should have the chance to explain when things aren't working, and approaches should be adapted.

If CAMHS are not able to find someone to work with the child in question, parents/carers should be enabled to find someone themselves, and CAMHS should share care.

Which CAMHS: Brighton & Hove
Your experience: We last saw CAMHS between 2016 and 2017. We had had concerns that our child had ADHD. In fact, our child was referred to the sleep clinic at the Evalina Hospital, by Seaside view, due to our child's inability to sleep. Evalina suggested that it wasn't my child's night-time behaviour that was contributing to his inability to sleep, but his daytime behaviour. The doctor we saw at Evalina suggested that our child might have ADHD, and it was the ADHD that was potentially contributing to his inability to

sleep. CAMHS came and observed our son at school, for one hour, and based upon that singular observation (in that singular environment), they said he did not have ADHD. They observed him one time, for one hour, in one setting, and dismissed ADHD as a potential diagnosis. Still, they were willing to prescribe ADHD medication. However, the medication they were willing to prescribe only came in capsule form, and my child can't swallow a capsule. We explained this to CAMHS, and CAMHS said that if our child couldn't swallow a capsule, there was nothing they could do, said there was no other alternative. I found this shocking, especially given how many ADHD medications are available. Still, no alternative was sought. In the meantime, I sought help elsewhere. I took my child to London, where he was assessed by London CAMHS, and my child was subsequently diagnosed with ADHD, among other things. The ADHD assessment that was conducted in London was far more rigorous than the assessment that was conducted locally, which, again, consisted of a single observation (four years later, I still find it shocking--not to mention negligent and irresponsible).

Prior to this, my child was referred to CAMHS, in 2014/2015. At that time, our child's paperwork was lost, LOST. I was in the process of completing DLA paperwork at the time, so it was fortunate that I had my child's records to hand, because CAMHS had lost them. We left CAMHS after that, and only returned later for an ADHD assessment. My child is now being seen by a team of professionals in London, and we will never return to our local CAMHS here in Brighton and Hove, as they are dangerously incompetent.

How to improve things: *They could have actually taken the ADHD diagnosis seriously. They could have performed more than a singular investigation in a singular environment. My child had all the hallmarks of ADHD and was subsequently assessed and diagnosed with ADHD by another CAMHS team, outside of Brighton and Hove. They are completely unprofessional, and my first impression of them (after they lost all of my child's paperwork) has been a lasting one. Again, they are dangerously incompetent, and my family has no trust and no confidence in their service. Our relationship with them began in 2014, and it has continued to erode ever since.*

Which CAMHS: Brighton & Hove
Your experience: My 12yr old daughter was diagnosed in September 2020 with ASC by a private clinical psychologist. She was self-harming and threatening suicide. The GP referred her to CAMHS, but they passed her back to the Wellbeing Service. I kept having to call as nobody was helping or getting back to me. Eventually she was assessed by the Wellbeing Service and put on a waiting list for counselling with an ASC trained counsellor. S
he is still waiting. She has not been in School since December and spends all her time in her bedroom with no friends. I've finally got her into a new school, and she is refusing to go. She has been abandoned and absolutely anything could have happened to her, and nobody would have known.

How to improve things: *CAMHS should have contacted me. They should have spoken to my daughter. She should have been allocated support as soon as possible before things got as bad as they are now. She's 13.*

Which CAMHS: Brighton & Hove
Your experience: CAMHS have a poor knowledge of how autism presents in girls. They also declined to support my daughter on multiple occasions because she is autistic. She has mental health needs additional

to her autism, but their default is diagnostic overshadowing and attributing all needs to autism and refusing to provide additional MH support.

Their anxiety group for autistic young people is not autistic friendly. It was far too wordy, and not adapted from standard CBT for a neurodiverse group at all. They use measures to assess anxiety that are not normed on an autistic population, and which don't capture the autistic experiences of MH issues. Their response is the CCG requires them to.do this, but that doesn't explain why they can't use an additional measure that IS designed for autistic young people.

CAMHS are like an impenetrable fortress. I found staff didn't understand autism very well and don't have a current knowledge e.g. around Masking in girls. This makes it even harder to get support.

My daughter said there was no point ever going back to CAMHS as they don't understand her, how to communicate but most important, they never offer help after an assessment. They just write a discharge letter and don't even explain to the young person why they aren't offering help.

I found I only got an appointment after making multiple complaints over a period of years. Parents need to be incredibly forceful and push for support at a time when they are being pushed to their limits in trying to support their young person. Not everyone can do that. CAMHS are failing our autistic young people time and time again.

How to improve things: Stop the diagnostic overshadowing, further training of staff to understand how autism presents in girls, much better communication around clinical decision making.