

We asked members to share their experiences of:

What service and therapy adaptations and accommodations do CAMHS SPFT offer if a child has difficulties in engaging due to their ASC or/and ADHD and neurodiverse conditions (for example, home visits, individual rather than group therapy sessions)

- Numerous times CAMHS have closed the case on my son as he refuses to engage. I've taken him to several appointments where he refuses to get out the car. I've asked the person to come say hi to him through the window to ease his anxiety etc... But they wouldn't do it. I bribed him to get to an appointment. He refused to talk to her and sat with his head down the whole time. She said there is no point in her referring him to any kind of CAMHS service as she could see he'd refuse to go. Whilst he was still in school, I suggested they see him there, as he will engage at school. They refused to do that as well. He's now been out of school so long and all services have failed him.
- Yes, my son was diagnosed with PTSD (Post Traumatic Stress Disorder) and struggled to engage so they said they couldn't help him.
- Yes, closed case with no engagement more than once.
- Sporadic engagement linked to MH presentation. Reasonable adjustments made after TCAT (Transforming Care Autism Team) involvement and a CTR (Care and Treatment Reviews) taking place.
- Yes. They tried to get rid of us when my daughter was unable to attend the appointments, I went mad at them to be honest.
- After calling CAMHS duty several times during crisis we were offered an emergency appointment, we were asked if we thought our son would attend as he was refusing to go to school or see anyone. I asked if they could visit at home, they declined said due to capacity and COVID we would need to attend. It wasn't said but it felt like the undertone was if he didn't attend, they wouldn't see him. He wouldn't attend the appointment, we did, and that was the last we heard until I complained via PALS (Patient advice and liaison service)
- Refused to offer any other way to help or support because "he refuses to engage" and then when he was evaluated 3.5m after his breakdown, they signed him off saying he refused treatment and support, basically because he didn't trust them to help him as they weren't there when he needed them and kept us waiting for literally years. Also lost his file for 12 months between primary and secondary. His MH would not have gotten this bad had a diagnosis happened when he was 8, he is now 13. Still no further on. He's self-healed, as are we all as a family together, and finding other

ways than CAMHS to do so!

- ... CAMHS sent worker to our home as son refused to go there yet when the worker arrived half hour late it escalated child's anxiety so he locked him in the kitchen and put a timer on him and when he was able to leave his words were "Child obviously cannot engage with our services so no point in continuing" Arrgh. !!
- We have had CAMHS close a case for my 16-year-old when he was 9 because he was unable to access group therapy for anxiety and then again recently when he could not/would not engage with Zoom workshops for anxiety, so he has been discharged again.
- It was the insistence of the camera being on and him needing to be in view of it that was the difficulty for my son. CAMHS said it was to ensure his safety, (despite me sitting next to him throughout) and so because he finds communication difficult, even more so in view of a camera, he would not engage as a result and so he was discharged. CAMHS said you could not take part unless you had the camera switched on.

Can I add a positive, My 10-year-old is currently receiving support via a Senior Clinical Psychologist from the CAMHS LD team, and this has been via Zoom. She has managed to engage with him whilst he is jumping on the bed doing flips and cavorting around the room with the dog. She has spent the time allowing him to be, with no pressure of time or focus on her goals. As he can't engage long term, she speaks with me when he cannot and this has been ongoing, every week and then every two weeks since February. The two home visits, one including a full IQ assessment were successful because of the relationship she managed to foster with him via zoom. She speaks with me for about one hour every two weeks to find out how he is and to discuss management of his OCD and anxiety and coaches me on different approaches and sends lots of information and workbooks to use. if he can, he is involved, but this is not a prerequisite. She has been acting as a fantastic advocate with regards to his difficulties at school, liaising with the school staff and other professionals and now she is invested in trying to find a suitable provision as he is without a placement.

- Yes, told me unless daughter engages and gives consent, they will not continue with assessment.
- It wasn't explained to me how CAMHS worked, and both my twins were discharged at the same time when I turned down what they were offering...they offered my ASC son group anxiety sessions (after our initial assessment where we had discussed how my child has quite clearly has severe trauma from starting secondary school resulting in severe fear of teenagers and walking into a room with other people) I was so angry at how inappropriate this was and was told this was all they could offer! Then for my selfharming daughter, who was having suicidal thoughts, we were offered 'family

therapy' and occupational therapy but it wasn't explained to me what the hell that was, she needed counselling ... I've then unsuccessfully been trying to get CAMHS to take my daughter back on their books as the initial woman we saw felt there was enough indicators for my daughter to be assessed for ASC (especially as her twin brother was late diagnosed) schools have tried, doctor has tried but 'computer says no'. So, infuriating. I managed to fight for and was successful in securing an EHCP for my daughter based on her obvious, but undiagnosed SEMH needs....no thanks to CAMHS.

- Only ever been offered 'group therapy' which is not going to work for a highly anxious young person! I find it bizarre and very wrong that NT kids have access to free INDIVIDUAL counselling from various sources in the city but there is no equivalent for ND kids!
- Worthing CAMHS wouldn't offer any alternative when my son struggled massively to engage in therapy sessions at Worthing Hospital. I asked if they would consider in school sessions, they said no. I then later find out they were supporting another child in the very same school ... It all ended up causing even more trauma!
- Similar happened to us when they lied and said there's no community outreach service to see people at home when in fact there was, but they just refused to come! 13 referrals asked them to engage as our son could not and yet they still refused. The damage was done, and no other services could then engage or help as CAMHS were the gatekeepers. It's very very damaging.
- I had a CAMHS community appointment today. They offered to see him at home, in a cafe or anywhere I suggested. That's new! But alas my son's response when I told him 'f**k off, I'm not seeing any of those c**ts ever again!'. The damage has already been done. They've should've seen him at home/school a long time ago when he would've engaged.
- Refused to accept my child couldn't engage speaking in crisis on the phone to urgent support so was refused even though was actively suicidal. So not accepted by that service. Refused 1:1 DBT when my child found it tough to engage in video group with new and unknown and ASC unaware practitioner who was supposed to be the personal support. Emergency 1:1 post crisis appointment - practitioner was unaware of clear notes about my child when said wouldn't engage properly with unknown person and would say anything to get out of the room. ... My child isn't the only child who 'doesn't fit NT boxes" CAMHS need to buck up and recognize the needs of their client group which are of course stipulated in diagnostic criteria about difficulties in social engagement.
- I explained that child can't talk or cope with being eyeballed but responds well to creative shared activities. After 10 mins the psychologist came out and said she won't talk to me. No surprise. Why not try an activity next time then? Next time there was some printer paper, 2 crappy pencils and 3

stubby wax crayons. Psychologist sat opposite her and attempted a ... little picture. 10 mins later same thing, she won't talk to me.... end of brief talking interventions.

- It's like these mental health experts haven't done the basic work to connect ASD, Alexithymia, demand avoidance, social communication difficulties and anxiety. It's basic stuff if this is your profession. I get that this might be unfamiliar information for a mainstream school or even GP but CAMHS ASD staff?
- I had to call our 'specialist' and suggest she provided some arts and crafts and got to know my daughter before launching into the bear cards and feelings pyramid and firing questions at her. "Oh" she said..."ok...that's a good idea..."....
- It's seriously left us all traumatized and unfortunately left my son untrusting of most professionals. I'm honestly glad they're in our past and wish I'd never fought as hard as I did to get support. It was useless, damaging and we've now all got a whole lot of healing to do.