

Feedback for South West Yorkshire Partnership NHS Foundation Trust, Calderdale Clinical Commissioning Group and the Care Quality Commission

Calderdale Child and Adolescent Mental Health Service (CAMHS) Tier 3

June 2017

Introduction

At the end of May 2017, Healthwatch Calderdale was approached by an individual who was having a poor experience trying to get access to CAMHS Tier 3 for their child, and indicated that their experience was similar to others.

As a result of this, we shared a post on our Healthwatch Calderdale Facebook and Twitter pages asking people who had experience of the CAMHS Tier 3 service in Calderdale to leave reviews of that service on our website - please click [here](#) to see the reviews on our website.

Healthwatch Calderdale
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<http://www.healthwatchcalderdale.co.uk/.../calderdale-child-a...>

Have you used the CAMHS service in Calderdale?

We want to hear your experiences.

Click the link above to leave an anonymous review on our website

healthwatch
Calderdale

1,382 people reached Boost Post

Within 48hrs, we received 25 reviews through our website.

The Facebook post requesting feedback had reached 1382 and had been shared by 12 people.

The Twitter post was seen by 263 people, but 5 actively interacted with the post.

Over 80% of the reviews we received were negative, with 17 of the reviewers rating CAMHS Tier 3 just 1 out of 5 stars.

3 of the reviews were very positive, and gave CAMHS Tier 3, 5 out of 5 stars.

We have read and thematically analysed the reviews. As there are only 25 reviews, we do not have a representative sample, but we think it's useful to understand the basis of what people are saying in their reviews.

These are the 10 key themes that we have picked out through analysing these reviews. They were stated by 5 or more of the 25 reviewers:

1. Long waits for CAMHS assessments and support
2. Lack of progress updates from CAMHS staff
3. Specific access issues for children with Autistic Spectrum Conditions (ASC) and Attention Deficit Hyperactivity Disorder (ADHD)
4. Limited access to ongoing support whilst waiting for and after diagnosis
5. Limited response to reports of suicidal thoughts and self-harm
6. High thresholds for intervention
7. Limited resources in CAMHS
8. Poor staff conduct
9. Poor quality care
10. Good quality support from staff

Call to action

We ask that you consider this feedback as part of your ongoing monitoring of CAMHS Tier 3 in Calderdale. We are aware that work is taking place to try to improve delivery of this service, so we ask that you provide us with some information about what you are doing as organisations to try to improve delivery of CAMHS in this area, and consider whether this is going far enough, given the experiences listed below. It is of specific concern to us to see parents and carers reporting that their children are suicidal, and that this does not result seem to result in their receiving additional support.

Key themes

1. Long waits for CAMHS assessments and support

Over half of the people who left reviews reported issues with long waits to access CAMHS. Most reviewers reported significant delays in receiving a CAMHS assessment for their child, with many specifically stating that this took well over 6months, and that they were not given any indication of when the assessment would be taking place across those months. In several cases the wait was over 12months.

"I expected a few months of waiting but once it was over 6 months - especially after being told by the Speech Therapist he had been "fast tracked"

"My child has been referred to the service in October 2016 and at the end of May 2017 I have no idea when he will be seen."

"Referred by GP in July 2016. Escalated to tier 3 in October 2016 and it is June 2017 tomorrow. That's nearly a year so far without seeing anyone from CAMHS at all. Disgusting treatment of a four/five year old."

A smaller number of people stated that they had delays in receiving care following an assessment, despite the acknowledgement from professionals that there was a need for support.

"Saw initially over 12 months ago. They promised to ring June last year. Heard nothing."

“Six months ago my daughter was once again assessed and we agreed on child psychotherapy. Told there would be a 5 month wait.”

Some concerns were raised about the need for early and effective intervention, in preventing the worsening of a young person’s mental health.

“Early intervention with any course of treatment proves higher success rates and this needs to be applied to this service.”

2. Lack of progress updates from CAMHS staff

Families report that they are not kept up to date by staff at CAMHS with regard to progress with arranging their child’s assessment, their position on the waiting list, or the wait for care or treatment. This is a significant cause of frustration, as parents and carers are left chasing the CAMH service for answers around progress with their child’s referral, and are asking for advice which is not forthcoming.

“Constant phone calls to chase referrals, lost referrals, no help.”

“Difficult to get hold of people directly, waited weeks for a call back.”

“Little information given on where we are in terms of what to expect or do in the meantime.”

Several reviewers report calling to request an update and being told someone will call them back, but this never actually taking place, or taking an excessive length of time.

“Managers never call back, staff never call back, emails are also ignored.”

“I ring regularly. They never ring back. Just waiting and waiting.”

3. Specific access issues for children with Autistic Spectrum Conditions (ASC) and Attention Deficit Hyperactivity Disorder (ADHD)

It’s unclear from the content of the reviews how many of the reviewers are parents and carers of children with ASC or ADHD, however 7 reviewers specifically identify that they are supporting a young person/young people with ASC or ADHD, or are awaiting a diagnosis.

Specifically, most of these reviewers indicate that they have waited significant periods of time for an assessment, which hasn’t had the result they were hoping for. For some, their child has not received a diagnosis of ASC. One person attributes this to a dated diagnostic model. These individuals have requested the assessment because they are experiencing an ongoing struggle and need support to meet their child’s needs. Even without a diagnosis of ASC, these children still needs some support, but they are being denied this.

“My children both display very obvious signs of ASD but they don’t fit the tick box criteria set out by CAMHS so we received no help after a very long wait to see CAMHS, we are back to square one with no help and same issues”

For others, the diagnosis has led to a reduction in care or has not led to appropriate support. One parent states that receiving a diagnosis of ASC meant that all existing

support for their child was stopped. Another reports that the long wait was not followed by good quality care.

Two reviewers report that CAMHS have identified ASC as a potential issue in initial assessments but have not put their children forward for an assessment until situations have become critical.

“At initial assessment we flagged up our belief that she probably had ASD but firstly they treated her for eating disorder”

For those who specifically mention ADHD, they against reference long delays in accessing specialist care. However, one person gave a very positive account of their experience of the ADHD service.

“Service was responsive from the initial referral being made by school and the Assessment was done quickly. The doctor we saw spoke honestly and openly about medications. My son had a good experience.”

4. Limited access to ongoing support whilst waiting for and after diagnosis

For some of the reviewers, they felt unsupported whilst they were trying to interact with CAMHS. Some state that they received a diagnosis but were then left without support, even if that was indicated through the assessment.

“I telephoned 3 times after diagnosis for support and was told we now had diagnosis so needed no support now!! We were/are desperate how can 5 years of support stop with a label?”

“Saw initially over 12 months ago. [...] They don't offer any other help whilst you wait.”

“Eldest child has ADHD hasn't been seen for 3years, no medication review or anything, they have forgotten about him again, not the first time either.”

“Too long of a wait between appointments.”

“Six months ago my daughter was once again assessed and we agreed on child psychotherapy. Told there would be a 5 month wait. I have called CAHMS 3 times in the last 2 months.”

“My child was referred urgently to the service, May 2016, we have seen one therapist who actioned further support. No further support has been actioned.”

5. Limited response to reports of young people in crisis, suicidal thoughts and self-harm

Some reviewers stated that, even though they felt their child's safety was in jeopardy, and their families were in crisis, they could not access support from CAMHS. In cases where young people were having suicidal thoughts or attempting suicide, this did not seem to result in an escalation of their support.

“Despite several self-harm attempts, suicide attempts and referrals from a variety of professionals. There is absolutely no care [...] I regularly stay up all night to prevent my child ending their life!”

“As my daughter had suicidal thoughts and self-harming she received 6 weeks CBT and was discharged but referred to a ADHD specialist and we are now in June and have heard nothing I've telephoned and been told it's a long process.”

“My child's treatment was delayed by 8 weeks and this time delay was significant in terms of keeping my child safe and other family members. This time delay caused our family into crisis mode.”

“Most recent call was last week to update them of my daughter wishing to be male and self-harming. I was told someone would be in touch by the end of last week to tell me where on the list my daughter is. Not heard from them.”

“Many families are at crisis point when they contact CAMHS only to be turned away.”

“When finally she had been hospitalised for a paracetamol overdose (having been hospitalised several times over 7 months for severe self-harm) and placed on suicide watch, she was assessed and diagnosed as autistic.”

6. High thresholds for intervention

Alongside those reviewers reporting that their children couldn't access support despite feeling suicidal or actively self-harming, other people felt that the threshold for intervention was too high, and that families had to be in crisis in order to access support, if that support was even there at all. There was felt to be very limited focus on intervening at an earlier stage to prevent crisis.

“The threshold for intervention is way too high.”

“CAMHS not interested in non-urgent cases”

“Getting CAMHS to see your child and accept a referral in the first place is a huge mountain to climb. So many children don't meet their criteria.”

7. Limited resources in CAMHS

A small number of the reviews indicate that parents and carers are being told that there is not enough resource in the CAMHS service to allow them to offer timely support.

“I have been told there is no money for preventing the above [self-harm and suicide attempts]”

“My son was referred for CAMHS through our GP and we never heard from them. Were told they were very busy.”

“People expect waiting times - we know services are stretched - but it would be helpful to have an idea about how long they will wait.”

“More investment needed.”

8. Poor staff conduct

Five reviewers specifically mentioned conduct of staff that they thought was inappropriate, although several more stated that they thought staff not calling back when messages had been left for them was poor conduct.

“There is no accountability for staff lies and cheats. Staff say whatever they want and won't write anything down, ever. Reports never match conversations.”

“The people you speak to on the phone are really rude and unhelpful.”

“My child struggling but they just say you have to wait and you're lucky it's not as long as other areas!!!!”

In one case, staff had told the reviewer to seek a diagnosis privately.

“I was then told "if I were you I would go private" and "to wait another year is optimistic”.

9. Poor quality care

There were some reviews which criticised the quality of care from the service as a whole.

“Even once you've endured waiting lists the service is poor and ineffectual.”

“This is a terrible service, it is supposed to help young people with mental health difficulties. I cannot believe all the hassle.”

“Don't they care about the kids who will grow to be the adult of this country?? So very sad.”

“After therapy not good enough”

10. Good quality support from staff

Some reviewers gave positive comments about their experiences with staff from the CAMHS service.

“Once we got through the system, the lady we saw for CBT therapy was very nice.”

“Her therapist was fantastic.”

“The lady we saw was brilliant I'm positive now that we are going to get the help we need to support our daughter.”

“Nicky in the OT team is amazing, so supportive and offers such good advice.”

“Service was responsive from the initial referral being made by school and the Assessment was done quickly. The doctor we saw spoke honestly and openly about medications. My son had a good experience.”

Additional themes

There were some issues that were only raised by 1 or 2 individuals, and those can be seen through reading through the full list of reviews (Appendix A). It's important to reflect that 2 people did state specifically that they had concerns about record sharing between Tier 2 and Tier 3 CAMHS; they were concerned that the organisations didn't share enough, so didn't know enough about the child coming in to their service.

Appendix A

No.	Title	Review	Rating	Likelihood they will recommend
1	<i>awful.long wait.no help) :</i>	My children both display very obvious signs of ASD but they dont fit the tick box criteria set out by CAMHS so we received no help after a very long wait to see CAMHS.We are back to square one with no help and same issues) :	1	Extremely unlikely
2	<i>Terrible</i>	Absolutely, astoundingly awful. Constant phone calls to chase referrals , lost referrals, no help. There is no accountability for staff lies and cheats. Staff say what ever they want and won't write anything down, ever. Reports never match conversations.	1	Extremely unlikely
3	<i>they don't care</i>	Eldest child has ADHD hasn't been seen for 3years , no medication review or anything, they have forgotten about him again, not the first time either. Second child had 6 sessions and that was it the phycologist was more interested in her pregnancy.	1	Extremely unlikely
4	<i>Waiting list is terrible</i>	My (then) 4 year old was referred last summer. I expected a few months of waiting but once it was over 6 months - especially after being told by the Speech Therapist he had been "fast tracked" - I became concerned and followed this up. I was then told "if I were you I would go private" and "to wait another year is optimistic". There seems to be no real structure to when people get seen. Another thing I was also told when I queried wait times was "you were not on the main pathway, you were on a different pathway that leads to this pathway, but now you are on the main pathway" . We need clear language and clear wait times from the onset. Still waiting for a response to my official complaint submitted in March but the South West Yorkshire Partnership NHS Foundation Trust who run CAMHS TIER 3 tell me they don't have a designated time to respond to complaints, although they "aim" for 40 days. This has now elapsed. Hopefully when I do get to see them it will	1	Extremely unlikely

		have been worth it and the trust will be able to justify their recent (April) CQC "Good" rating. This website asks about if we would recommend this organisation. Unfortunately if you live in Calderdale and don't have the money to go private, as far as I understand it, you are stuck with them regardless. Choice is a privilege.		
5	<i>Will see us if daughter tries suicide</i>	There is no preventive help, no therapy. Despite several self harm attempts, suicide attempts and referrals from a variety of professionals. There is absolutely no care , I have been told there is no money for preventing the above and only a crisis team available if the above happens again. I regularly stay up all night to prevent my child ending their life!	1	Extremely unlikely
6	<i>No good in a crisis</i>	The threshold for intervention is way too high. Even once you've endured waiting lists the service is poor and ineffectual.	1	Extremely unlikely
7	<i>Frustrating</i>	Difficult to get hold of people directly, waited weeks for a call back. Waited months for limited help.	1	Extremely unlikely
8	<i>Awful experience - made situation worse</i>	After being on waiting list for a long time (over 12 months) had initial referral to proceed with asc assessment - SALT cancelled two of three assessments and initial assessment resulted in no diagnosis. Upon asking for this to be reviewed this was done but despite providing comprehensive evidence to camhs to support asc, still no diagnosis given. Camhs use an outdated and widely-critised model of diagnosis, DSM 5, which is not fit for purpose and is unsuitable for diagnosis of autism in girls. I would rate zero stars if that were possible.	1	Extremely unlikely
9	<i>I would give minus stars if I could</i>	My child was referred urgently to the service, May 2016, we have seen one therapist who actioned further support. No further support has been actioned. Managers never call back, staff never call back , emails are also ignored. This is a terrible service, it is	1	Extremely unlikely

		supposed to help young people with mental health difficulties. I can not believe all the hassle, I was so pleased when we were referred and seen quickly that we were moving towards more help		
10	<i>Shocking and failed</i>	<p>We were refered when my child age 5/6 regular meetings her school setting failed and new setting ? asd so refered we waited from year 5 unril start yr 7 I telephoned 3 times after diagnosis for support and was told we now had diagnosis so needed no support now !! We were/are desperate how can 5 years of support stop with a label ?</p> <p>In December 17 we were refered to ADHD screening and mental health as my daughter had suicidal thoughts and self harming she received 6 weeks CBT and was discharged but refered to a adhd specialist and we are now in June and have heard nothing I've telephoned and been told it's and long process</p>	1	Extremely unlikely
11	<i>crisis mental health</i>	<p>My child experienced a severe bout of depression, the challenges and barriers we experienced to access CAMHS service was appalling and very worrying as a parent. Referral methods were limited to GP referral whereas any professional should of been able to do so. My child's treatment was delayed by 8 weeks and this time delay was significant in terms of keeping my child safe and other family members. This time delay caused our family into crisis mode. If my child had broken their leg, then health services would undertake a course of treatment immediately ,the same attitude needs to apply to mental health. Staff members rarely returned phone calls. The whole service needs to be reassessed cause it is failing young people and their families. Early intervention with any course of treatment proves higher success rates and this needs to be applied to this service.</p>	1	Extremely unlikely
12	<i>Long Waiting times</i>	<p>Long waiting lists and notes not shared effectively between tier 2 and tier 3</p>	1	Unlikely

13	<i>Waiting over 12 months!!!</i>	Saw initially over 12 months ago. They promised to ring June last year. Heard nothing. Paed chased twice. I ring regularly. They never ring back. Just waiting and waiting. They don't offer any other help whilst you wait. Don't they care about the kids who will grow to be the adult of this country?? So very sad. My child struggling but they just say you have to wait and you're lucky it's not as long as other areas!!!! Who really cares about our kids?	1	Unlikely
14	<i>CAMHS not interested in non urgent cases</i>	My son was referred for CAMHS through our GP and we never heard from them. Were told they were very busy.	1	Unlikely
15	<i>Still on waiting list for child psychotherapy</i>	Six months ago my daughter was once again assessed and we agreed on child psychotherapy. Told there would be a 5 month wait. I have called CAHMS 3 times in the last 2 months, most recent call was last week to update them of my daughter wishing to be male and self harming. I was told someone would be in touch by the end of last week to tell me where on the list my daughter is. Not heard from them	1	Neither
16	<i>Still no news about when my child will be see</i>	My child has been referred to the service in October 2016 and at the end of May 2017 I have no idea when he will be seen. People expect waiting times - we know services are stretched - but it would be helpful to have an idea about how long they will wait. His lack of assessment means other services won't get involved. It's not fair on him.	1	Neither
17	<i>The waiting game</i>	Referred by GP in July 2016. Escalated to tier 3 in October 2016 and it is June 2017 tomorrow. That's nearly a year so far without seeing anyone from CAMHS at all. Disgusting treatment of a four/five year old. Early intervention is key. This needs sorting for Calderdale. Oh and Tier 3 have no email address either which makes communication tricky with a highly strung child. I am sure the staff are very good when you finally get to see them. More investment needed.	1	Extremely likely

18	<i>Impossible to get into CAMHS!</i>	Getting CAMHS to see your child and accept a referral in the first place is a huge mountain to climb. So many children don't meet their criteria. Many families are at crisis point when they contact CAMHS only to be turned away. The people you speak to on the phone are really rude and unhelpful. Waiting times are really bad. Notes taken about my child at tier three could not be accessed by tier two which was ridiculous. Once we got through the system, the lady we saw fir cbt therapy was very nice.	2	Extremely unlikely
19	<i>Failure to listen to parents due to arrogance</i>	14 year old Daughter was referred to camhs tier 3 as a result of mental health issues including odd eating patterns, self harm and claims to undergoing psychotic events. At initial assessment we flagged up our belief that she probably had ASD but firstly they treated her for eating disorder, then when her self harming escalated, they blamed parents for causing this and digested attachment disorder was the problem. When finally she had been hospitalised for a paracetamol overdose (having been hospitalised several times over 7 months for severe self harm) and placed on suicide watch, she was assessed and diagnosed as autistic.	2	Unlikely
20	<i>Always having to contact them for updates etc</i>	Too long of a wait between appointments. Little information given on where we are in terms of what to expect or do in the meantime. Feeling lost on a difficult journey.	2	Neither
21	<i>there are no other options needs a no option</i>	Waiting times too long for ASD diagnosis, after therapy not good enough and CAMHS should be trained in spotting ASD but despite several years therapy there they missed it !!!	2	Extremely likely
22	<i>My daughter is ASD with depression and GAD</i>	She had art therapy then was ditched, then after a letter from my doctor she was picked up again and diagnosed with ASD at 16 years. The psychiatrist pushed medication at her eventhough she	3	Likely

		said no. He seemed more bothered about her weight and kept telling her that the anti depressants would curb her eating. My daughter was distraught at this and made it clear she was terrified of the side effects of the anti depressants but still he pushed...and pushed...so I ended up getting her a prescription just to shut him up. She never took them. She has anxiety and depression on top of the ASD - he was no help at all but her therapist was fantastic.		
23	<i>Excellent service</i>	the lady we saw was brilliant I'm positive now that we are going to get the help we need to support our daughter	5	Extremely likely
24	<i>Ot are amazing</i>	Nicky in the OT team is amazing, so supportive and offers such good advice.	5	Extremely likely
25	<i>Great experience on ADHD pathway</i>	Service was responsive from the initial referral being made by school and the Assessment was done quickly. The doctor we saw spoke honestly and openly about medications. My son had a good experience	5	Extremely likely