



Feedback on Calderdale Child and Adolescent Mental Health Service (CAMHS) from families of children displaying signs of autistic spectrum condition (ASC), attention deficit hyperactivity disorder (ADHD), or attention deficit disorder (ADD)

November 2019

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Abbreviations

Attention deficit hyperactivity disorder (ADHD)
Attention deficit disorder (ADD)
Autistic Spectrum Conditions (ASC)
Care Quality Commission (CQC)
Child and Adolescent Mental Health Services (CAMHS)
Healthwatch Calderdale (HWC)

Message to the commissioners/service providers:

We appreciate the number of people receiving a service via CAMHS umbrella organisations is greater than the number of people we engaged with here, so this feedback is not representative of all service users. A number of people, mainly those who said they had received a service in under 6 months, did not leave comments. Those who left comments were those who had been waiting for more than 6 months. While we sought all views - positive and negative - the majority of feedback was negative. We would like the opportunity to meet with commissioners and service providers to speak further about this and discuss the impact of the progress already made.

Our work at a glance:

What was the issue?

Since 2016 we have heard from people through Healthwatch Calderdale's NHS Complaints Advocacy and Information and Signposting services in relation to their experiences of Child and Adolescent Mental Health Services (CAMHS). The number of calls and complaints we received in relation to the service increased in early 2019, specifically with regard to children with symptoms of Autistic Spectrum Condition (ASC), attention deficit hyperactivity disorder (ADHD) attention deficit disorder (ADD) along with mental health concerns.

What did we do?

As well as supporting patients and parents/carers on a one-to-one basis, Healthwatch Calderdale decided to engage collectively with children, young people and their families to understand more about the issues these families are facing. We compiled a case study template and an online survey to obtain experiences, feedback and ideas from participants with regard to what would improve the current service.

What did we find out?

Around the same time, an Ofsted and Care Quality Commission (CQC) inspection report was published for Calderdale Children's Services, entitled 'Joint local area SEND (Special Educational Needs and Disabilities) inspection in Calderdale', which touched on themes we were hearing negative feedback about.

In the report, dated May 20, 2019, the Inspector says: *"Long waits for autism spectrum disorder (ASD) assessments... are areas for improvement. Several parents told inspectors that they are disappointed by these long waits and the variability in the support their children receive in some local schools."*

It adds: *"Parents and carers, education professionals and health practitioners have different perceptions of child and adolescent mental health services and the effectiveness of pre-diagnosis and post-diagnosis support for ASD. Knowledge about what support is available, how to access it and the expectations about its quality and timeliness are not communicated clearly."*

Our own findings

Our research highlights some worrying issues, namely:

- Some children are missing out or falling behind in their education because of the lack of support available while they wait for assessments under CAMHS umbrella services.
- Patients continue to face long waiting times.
- Those with mental health needs and ASC are left without the support they need for both conditions, due to omissions in mental health care for people with ASC.
- Carers experience a lack of support.
- Parents cite communication concerns when dealing with CAMHS, including calls not being returned.
- The health and employment of parents/carers was negatively impacted because of dealing with their child's health and care needs and lack of support.
- All of the above gives people a negative perception of the CAMHS service locally.

How we will use the feedback

Our findings will be presented to the service providers, commissioners and those with responsibility for children and young people (for example parents and carers) affected by this service and local groups with an interest. It will also go to local politicians, both councillors and MPs, once the 2019 general election is complete. We will ask service providers and commissioners how our feedback will be used to ensure that CAMHS is improved

for the benefit of all. We will make our findings public via our website and our social media channels after the outcome of the 2019 general election.

Background

In July 2017 Healthwatch Calderdale produced a report entitled 'CAMHS Tier 3 Calderdale' after receiving negative reviews of the service on our website. After publication we met with commissioners and service providers to obtain feedback.

It is clear from the Ofsted and CQC Inspector's comments, and from current feedback to us, that the following remain challenging:

- Obtaining a referral;
- waiting times;
- early intervention support;
- support for people with autistic spectrum condition (ASC) who also have mental health needs
- staffing;
- the level of expectation from parents/carers and their children;
- communication between CAMHS and parents/carers.

We have mapped this report against the main themes of our 2017 report and this demonstrates that some of the issues raised in 2017 remain.

What did we do to investigate?

In total we have engaged with 50 people as part of this project, as follows:

Direct contact:

We sent emails to clients who had previously contacted us about CAMHS in relation to ASC, ADHD, or ADD, to ask them for more in-depth feedback in the form of a case study. We contacted 11 people and received 5 case studies; a mother's journal of making a crisis call, and a young person's view. We received 1 unsolicited case study from a family previously unknown to us but who had links with another client, and 1 respondent to the online survey contacted us for one-to-one assistance with their case.

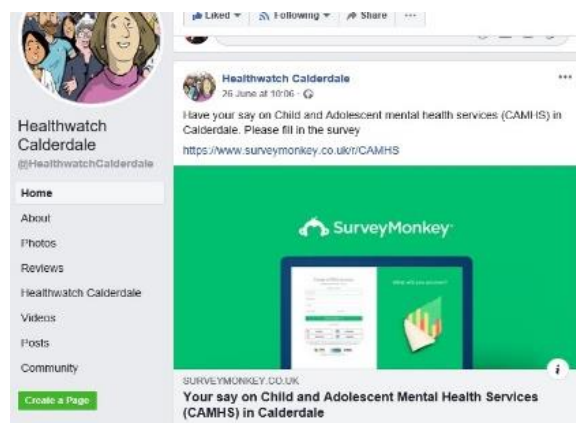
Online survey & engagement:

We compiled an online survey and shared it with relevant groups including the Calderdale National Autistic Society support group. It was promoted on our website, Facebook and Twitter feeds, with local schools and voluntary organisations. There were 43 responses to our survey.

A Healthwatch Calderdale staff member promoted the survey on her own Twitter feed and the posts achieved the following reach: (dated 22.7.2019)

- Engagement (people who clicked links, liked or retweeted): 74
- Impressions (i.e. total number of people who saw the post): 4118.
- HWC Facebook: Reach from the 1st post: 579; engagement: 50; shares: 12.

(Pictured, the HWC Facebook post)



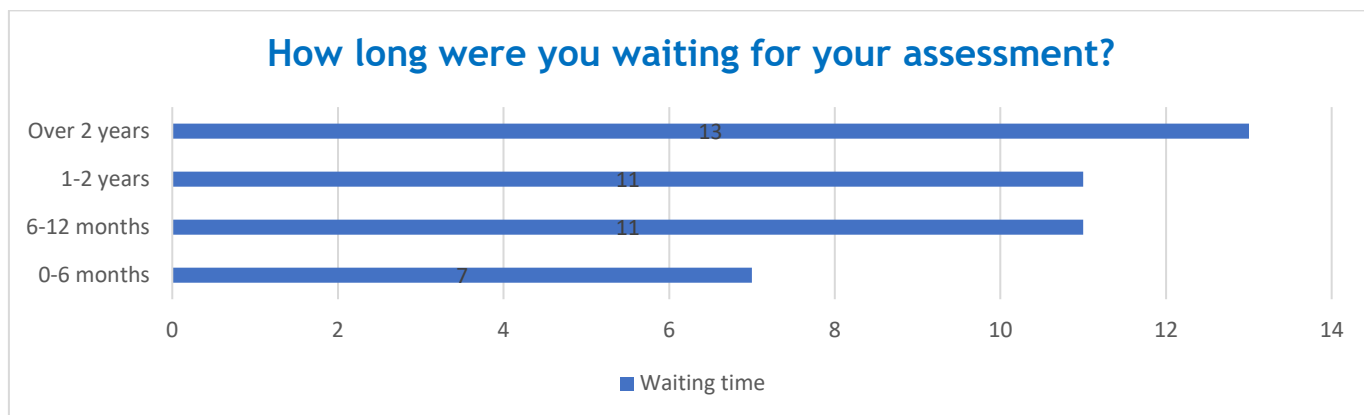
What did we find?

We looked at Northpoint and South West Yorkshire Partnership NHS Foundation Trust services in our survey and case studies.

Here is an overview of the key themes.

a) Long waits for CAMHS assessments and support:

As in 2017, more than half of respondents to our 2019 online survey and all respondents to our case studies request mentioned long waiting times as a concern. Just over half, 22 people (51.16%), said they were not told how long they may be waiting for an assessment, whilst 21 (48.84%) were given an idea of a waiting time.



One mother told us it took 2 years for her child to be accepted onto the waiting list, and that came after 3 previous requests for referral failed. She believes it will be 3 years before an assessment - meaning a possible 5 year wait. The mother said she was worried about the further impact on her child’s education without the right support in place.



A small number of people told us they paid for private assessments and/or support therapies due to the delays, in some cases putting financial pressure on the family. One parent said: *“I dread to think where we would be if we were unable to afford private services.”* Another parent asked why it was unclear if service providers and commissioners would accept the outcome of a privately-funded assessment, or an assessment out of area, and if local support therapies would be provided if the outcome of a private assessment suggested some were needed.

b) Access to mental health services for those with/suspected to have ASC:

We have heard that mental health support for young people with autism is not readily available in Calderdale. Parents and young people told us when they sought mental health support, they were told because their child also has ASC it is not available for them. This has an impact on their child/them while they waited for an assessment or after a diagnosis confirming autism. One mother told us CAMHS organisations need to *“Understand that while autism affects mental health it’s not part of the autism, leaving the person with a poor service for mental health.”*

“Adapt mental health therapies to enable children on the spectrum to receive care. My child is selective mute and couldn’t speak to the therapist but might have communicated in written form if the opportunity was given.”

One young person asked for: *“Mental health support for people like me with suspected Asperger’s.”*

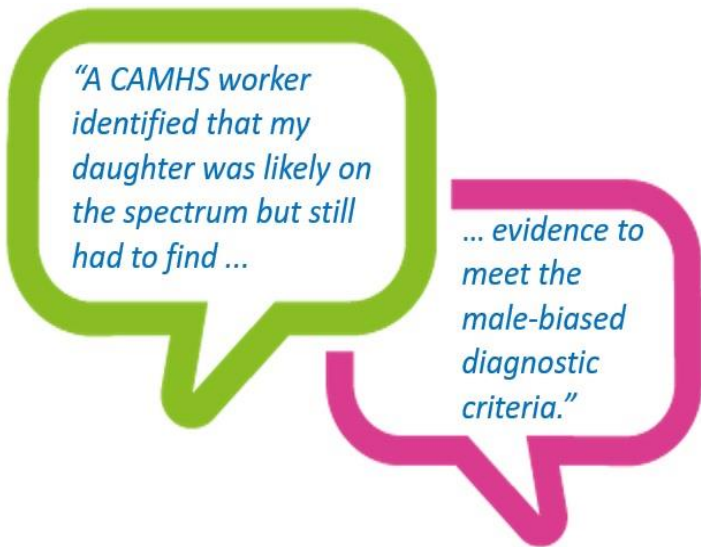
One idea proposed was: *“Preventative interventions promoting mental well-being for all children at point of autism diagnosis. (e.g. the Resilience Hub support offered to children and families by CAMHS in Manchester).”*

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

In our 2017 report we noted that parents seeking ASC assessments and diagnosis raised concerns about the use of a dated diagnostic mode. They also said they requested an assessment because they are experiencing an ongoing struggle and need support to meet their child’s needs. Parents then told us that even without a diagnosis of ASC, their children need support but they were not receiving it.

In our latest survey over half of the respondents - 28 people (65.11%) - commented on the assessments for ASC, ADHD/ADD, telling us:

- The diagnostic criteria used for assessments is dated;
- The waiting rooms and venues are unsuitable for older age groups;
- There is a need for quicker assessments so education support can be made available;
- Parents feel that their children are passed from one NHS department to another and remain without a diagnosis and/or support.

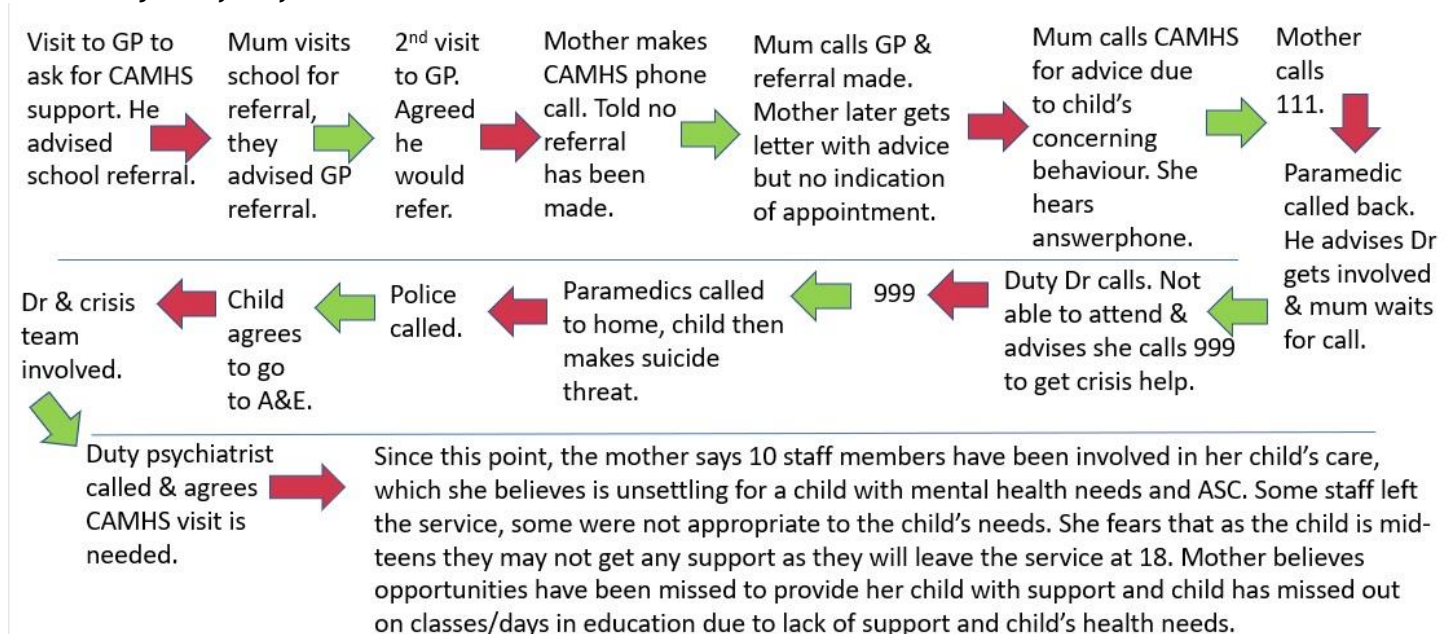


“Assessments should be longer than sitting 15 minutes with the child. How sitting with a child for 15 minutes can decide whether or not they have ADHD is beyond me, especially when other medical professions who’ve known him a lot longer say he had it.”

“We had psychologist reports from specialist at (another hospital) making recommendations and these were sent to CAMHS with the note from them that our child needed to be seen urgently. We then had to reapply and be rereferred and go back to the beginning of a waiting list.”

d) Response to reports of young people in crisis, suicidal thoughts and/or self-harm & high thresholds for intervention:

Parents reported that often feel they have to be in a state of crisis before being accepted as needing support. Of comments relating to this theme, we feel sharing a section of a mother’s journal highlights what service-users and their parents/carers told us. One crisis led to the mother calling for help which secured a CAMHS appointment. This is the journey they followed:



e) Limited access to support whilst waiting for a diagnosis:

In 2017 people told us they felt unsupported whilst they were trying to interact with CAMHS. Some said they received a diagnosis but were then left without support, even if that was indicated through the assessment. Similar comments have emerged once again, with more comments on the lack of early intervention support.

In our latest survey, of those who commented on support received, 25 said they had received **'none'** or **'nothing'**; 1 was sent on a Parenting Course; 4 were signposted to other agencies such as support groups or were given leaflets; 3 said they had 'interim' support by the way of a phone conversation/discussion with staff; 2 received support via a school. Speech and Language Therapy (SALT), Cognitive Behavioural Therapy (CBT), Occupational Therapy (OT) and Single Point of Access (SPA) were mentioned by 1 respondent to each; 3 further comments were excluded from the data as they did not fit the question.

"Absolutely no support whatsoever."

"Nothing until I started bugging them!"

"We have been on the waiting list for assessment since April 2018 and we have been advised it will be at least another year till we are seen and no support has been offered while we wait."

Some people told us that by the time they were referred to the service they had explored and exhausted other options and felt in a state of crisis. They felt facing a long wait for an assessment, with little support offered from the outset, further impacted on their child and the wider family.

One respondent asked for *"more support before, during & after diagnosis/assessment rather than being sent on your way."*



Another respondent told us they had to wait 1 year after an ASC diagnosis for training on anger management as the course was full. They told us: *"By the time we were able to attend various thing we're ingrained in family life and are taking a long time to eradicate."*

One mother questioned why parents are dismissed so early on and another spoke of being told her child was too young for an assessment, adding: *"they're not too young if they are displaying signs (of autism)"*.

Another mother said she felt professionals blamed her, urging staff to *"try not to blame parents at Tier 1 in an attempt to refuse assessment for children that have obvious needs"*.

f) Communication:

Communication issues were raised by over half of our respondents, including:

- Lack of updates and confusion over waiting times;
- Uncertainty regarding the level of support that can be provided by CAMHS;
- Poor communication after an assessment;
- Delays in responding to patients'/families' questions;
- Getting a diagnosis then feeling unsure of where to get the support they need.

"Took them 6 months to write to me to tell me results of tests they did."

“The latest delay (from Nov 2018) has broken the continuity and trust as things were promised and didn't happen. It takes a lot for someone to open up and be reassured that things will happen and then nothing does.”

“Got an information pack then nothing for 2 years, despite contacting them.”

As the Ofsted and CQC Inspector noted that “expectations about its quality and timeliness are not communicated clearly”, it could be that poor communication about waiting times may lead to unreasonable levels of expectation of the service that cannot currently be met. With some patients experiencing limited support while they wait, many families told us poor communication experiences exacerbated their anxieties and led to negative views of CAMHS.

“Clear explanation of what to expect and when. Designated support worker to ask questions. Quicker assessments, knowing what happens after. Seems lack of communication between health, school, family & it leaves family running around like headless chickens to get answers. I don't want to criticise staff, but the service isn't set up good enough.”

“Once the service user has been accepted and attends sessions, details of what is going to happen and what is required of them and their family so that their expectations can be managed. This should be in writing with contact details to call should things go wrong.”

g) Administration processes

A number of respondents raised concerns about:

- Inaccurate notes;
- Notes going missing;
- Calls not being logged;
- A patient's history not being known to practitioner at meetings.

One respondent told us a child had an assessment but they never received the report. They chased it for months only to discover that, if it has been written, it had gone missing. It meant the young person, who struggled to open up originally, lost trust in the system. One respondent says notes indicate a child is receiving treatment when that is inaccurate, while notes from a clinician at a CAMHS service elsewhere were not acted upon locally.

“Explain why the different assessment meetings have to be so spaced out, rather than once someone is seen for the first time getting on with the rest of the assessments within a few weeks - it would save the risk of misplacing notes and having to ask the same questions again.”

“Frustration with people at CAMHS who take details and don't call back. No records kept or reports recorded... having chased this through children's disabled team, paediatrician, neurologist and personally to the CAMHS team several times, we are now at the end of June 2019 and no-one has got back to us. This has been escalated by the person answering the phone at CAMHS at 2 separate occasions yet no response.”

Impact of CAMHS delays on children, young person and wider family:

All 50 respondents were asked to tell us the impact of their child's needs. The feedback shows that the lack of support for their child's needs or delay in assessment has a significant life impact, not just on the young person themselves but on their wider caring network.

Our findings reveal:

- Some children are missing out or falling behind in their education,
- Some parents have lost jobs due to their child's health and care needs.

Impact on child:

Education needs: 18 respondents told us that their child's medical and/or behavioural needs had directly affected their education; either their children had to be taken out of school or they needed/were asking for extra support in school and were not receiving it. Some felt that without a diagnosis the level of support that could be provided was not sufficient.

Mental health: 8 spoke of their child self-harming or expressing suicidal thoughts, highlighting the need for improved mental health services for those also with ASC.

“Unable to attend school. Continuing anxiety, toileting, eating, self-harm issues.”

“We 1st requested an assessment 4-years-ago but were told it wasn't necessary, there is now likely to be no support before high school and without support I think we will struggle.”

“Harder to access other help i.e. education, health and care plan (EHCP), other assessments, short breaks etc.”

“My child is now out of school due to lack of support and awaiting EHC plan so she can possibly go into an Autism spectrum disorder (ASD) unit or special school.”

“No progress in the first 2 years of primary school due to lack of support available.”

A young person's view in their own words:



Child A: waiting 6-12 months for assessment and was not given an idea of waiting time.

Support received: “Not much, college gave some support with extensions when I could prove I had a breakdown. I was told to contact single access point but found when I did that I was too far gone & A&E was quickest option for my mum to call & get quicker medical help.”

Impact: “Impacted on education, missed 2 Exams GCSE & I've missed college classes & am falling behind. Then feel pressured to catch up & anxiety grows.”

Impact on family: “I know my mental health impacts on my parents, I feel the need to hide it from them which means it's near crisis when I do alert them. Feel trapped in a system I don't understand, contacting people for help who don't know me, feel like I have to be quick in appointments as I know how many patients they have to see.”

Ideas: “More facilities in the community to access, maybe a drop-in where staff can access our history. Mental health support for people like me with suspected Aspergers.”

*Service user told us they had contact with Northpoint.

Impact on parents & the wider family:

Employment: Of the 50 responses, 14 people told us that the delay in their child obtaining support/an assessment from CAMHS had affected their employment; some having to reduce hours worked, change jobs and some having to leave employment altogether to care for their child if they are out of education, affecting them financially.

“I have to leave my job due to my daughter not coping in school.”

“Had to stop working full time due to constant appointments, school meetings so on. Emotionally draining & huge stress to whole family.”

“I left my job, he was always in trouble at school. Now at 17 he suffers terrible anxiety.”

“Without proper childcare, our working hours are restricted (we) found it difficult to put sufficient energy into planning and running a business. But the greatest blow to our finances has been to (parents') employment, which they gave up as they was forced to take (child) to school every morning when Calderdale MBC refused to supply appropriate home to school transport for two years.”

Relationships: 6 other people spoke of relationship breakdowns as a result of the pressure the family faced; 7 spoke of the effect on their other children, some feeling guilty that their other children were overlooked in the family as so much focus was on the service-users' needs.

“It was such a strain on the whole family, my husband and I worked opposite shifts to try support our son but in the process of being swamped with the emotional and difficult behaviour displayed by our son...”

...our other children unfortunately suffered at no fault of ours, as did our relationship.”

Health: 11 people told us their child's health had an impact on their own health, resulting in a wider pressure on services within the NHS, specifically on adult mental health services.

Finance: 3 people told us they had paid privately for their child's assessments as they believed the waiting time was too long or they could not cope with their child's needs in the meantime. 1 person was considering a private assessment.

7 people told us their experience left them with a view that CAMHS was “unfit for purpose”, 1 other questioned the management structure, processes and systems.

“I have been blamed as a parent. I had my own mental health scrutinised rather than the needs of (my child).”

“I had to give up to work to care for him. The family dynamics are at an all-time low. Little or no help despite trying everywhere I can think of.”

“Family life is not good, school struggle, he has no real friends, lack of sleep, stress, can't work full time.”

“Impact on my mental health - no-one ever asked if I was ok. Impact on siblings, he takes so much attention they get ignored while we deal with him.”

Participants ideas & feedback:

We asked children, young people and their parents/carers for their ideas that could improve their experience of CAMHS. We ask that their feedback is viewed constructively. We understand some of these may already be in place or are being considered, and hope by including the ideas it may highlight a need for service providers to share the information more widely with patients/carers.

Waiting times and assessment

- Quicker process for assessments.
- Reduce waiting times.
- A time frame would be useful.
- Where parents are voicing concerns over care, especially when CAMHS colleagues are also concerned about other clinicians' formulations, rapid assessment of those concerns takes place.
- Consider active diagnosis and not just trying to manage risk.
- Appointment times: a short meeting/15 minutes is not acceptable.
- If a service user is moving through stages and moves from one organisation within CAMHS umbrella to another, records and reports must be handed over. Ideally, they should share a central database so that files can be stored and referred to.
- To not just dismiss a child without even seeing them.
- Make it easier to self-refer.
- Arrange appointments in suitable place for client: traveling and new places can be very difficult and create more stress.
- Rooms are very clinical and the waiting room had a very annoying clock and nothing to interest a teenager in it (only younger children's toys and drawings).
- Improve the crisis point of access. People currently using A&E unnecessarily.

Treatment:

- Follow NICE and best practice advice e.g. appointment of care coordinator to support parents, not to discuss historical events with suspected ASC patients except in accordance with Royal College of Physicians advice.
- Adapt mental health therapies to be suitable for children on the spectrum.
- Consider multi-technology for young people to respond to clinician if they feel unable to talk.
- Awareness of masking & awareness of different presentations (i.e. typically female presentation is missed).
- Change of diagnostic criteria to fit current knowledge i.e. a male-biased diagnostic criterion is used.
- Consider also using Diagnostic Interview for Social and Communication Disorders (DISCO) and assess dyspraxia and pathological demand avoidance (PDA).
- More understanding of autism and co-morbid conditions (mental health)
- Engage autistic people in their therapy beyond 6 weeks.
- A person-centered approach, it's about the person and their needs not CAMHS' needs and practices.

Support:

- Consider a drop-in where staff can access medical history, sign-posting, help and support before assessment.
- Consider social prescribing.
- People who answer phone need to be able to help then & there, not direct to online resources.
- Enable parents to attend training before a diagnosis.
- Help with transition to adulthood.
- Offer to liaise with school to advise mental/emotional health breaks when necessary.
- Preventative interventions promoting mental well-being for all children at point of autism diagnosis.
- Telephone/email advice in short term.
- Mental health support for people with ASC.

- More joined up working with community services, education and others, under a Care Education Treatment plan.
- More therapy to be conducted in the community.
- Flow chart to person needing the service explaining what the process is and when each stage is likely to be.

Staffing:

- More trained, qualified staff.
- Regular updates by staff, including while on the waiting list.
- Single point of contact/lead professional/named keyworker.
- Less change of staff whilst in therapy (being autistic makes change difficult).
- Note-keeping, records and supervision of case load is needed.
- Implement management structures so that staff are supervised effectively.
- Quicker times to see the Psychiatrist/other medic/support after diagnosis.

Communication:

- Improve access to supportive workshops/leaflets/information early on.
- Listen to the family & have respect for the parent's point of view and be less dismissive of parents' opinions.
- Email correspondence (or live chat): it's not always convenient to talk with a child around.
- Better communication about services/courses while going through a traumatic period.
- Clear communication process and contact numbers with name of person that the service uses can contact for progress upon their case.
- Clear information about waiting times and delays to manage expectations.
- Respond when people have called and left messages.
- Once the service user has been accepted and attends sessions, details of what is going to happen and what is required of them and their family so that their expectations can be managed. This should be in writing with contact details to call should things go wrong.
- Information needs to be joined up and the service user communicated with in person before discharge.

Conclusion & recommendations:

Our aim was to understand people's experiences of accessing this area of the NHS, the impact of the conditions they/their children have and their ideas for positive change. We also wanted it to be constructive for service providers and commissioners after the Ofsted and CQC report earlier this year raised a number of concerns. We hope that in asking for ideas and ways to address future changes, the voices of the service users who have taken part can lead to positive changes.

Healthwatch Calderdale would like to meet with CAMHS commissioners and providers to help shape change and bring about any improvements to benefit those who have taken part in this work, plus all others.

This report is being sent to the following people and organisations, with suggested actions for them to take.

Organisation or name	What action is to be taken:
Calderdale Clinical Commissioning Group: Matt Walsh, Rhona Radley	Please respond to Healthwatch Calderdale as follows: <ul style="list-style-type: none"> • Arrange a meeting to discuss this report in further detail; • Respond to participants' comments, ideas and feedback; • Discuss issues raised and advise on future plans for improving services for children and young people with autism and mental health concerns. Please respond by Friday December 20.
Northpoint: Jon Davies	Please respond to Healthwatch Calderdale as follows: <ul style="list-style-type: none"> • Arrange a meeting to discuss this report in further detail; • Respond to participants' comments, ideas and feedback; • Discuss issues raised and advise on future plans for improving services for children and young people with autism and mental health concerns Please respond by Friday December 20.

South West Yorkshire Partnership Trust (SWYFT): David Ramsey, Linda Moon	<p>Please respond to Healthwatch Calderdale as follows:</p> <ul style="list-style-type: none"> • Arrange a meeting to discuss this report in further detail; • Respond to participants' comments, ideas and feedback; • Discuss issues raised and advise on future plans for improving services for children and young people with autism and mental health concerns <p>Please respond by Friday December 20.</p>
Ofsted & CQC Inspector: Gina White	To acknowledge this report by Friday December 20.
Calderdale Council: Julie Jenkins and Lynn Powell	<p>Please respond to Healthwatch Calderdale to discuss ideas and feedback by participants to this report that fall within the service area including:</p> <ul style="list-style-type: none"> • Consider this for an agenda item for the Emotional Health and Wellbeing Board where Healthwatch Calderdale can attend and offer further context behind the stories. <p>Please respond by Friday December 20.</p>
MPs and Councillors	This report will be sent to MPs after the 2019 general election. It will also be sent to councillors with a relevant portfolio at the same time.

Appendices & further information:

This section contains further details of our work, including a copy of our survey; online reviews of CAMHS and news stories & statistics.

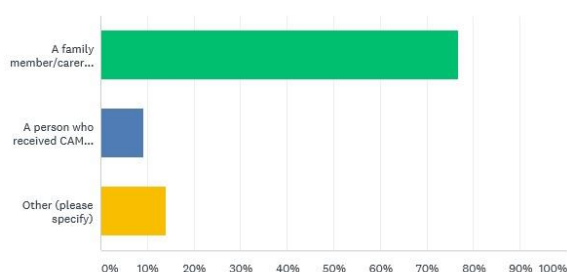
Results of our online survey:

The survey was open for 4 weeks and we received 43 responses.

Here is an overview of the responses:

Are you?

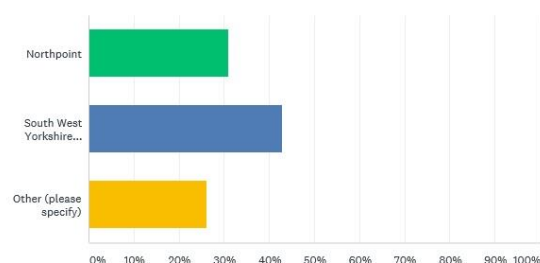
Answered: 43 Skipped: 0



33 respondents identified as a family/carer of a person who received CAMHS care; 4 were from people who had received the care; 6 selected the 'other' box and they identify themselves as follows: a worker from a charity that works in mental health intervention; a parent of child with attachment disorder; a parent of child with special needs (who sought mental health but was turned down); a parent of someone unable to access CAMHS; 1 aunt.

Which service were you accessing?

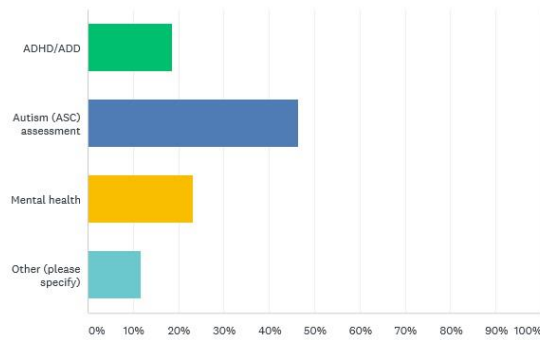
Answered: 42 Skipped: 1



Of the 11 'other' responses they include: Don't know; Refused to see; Tier 3 not sure who' CHFT; Halifax; Unable to access; Tier 2.

What was the reason for your referral to CAMHS?

Answered: 43 Skipped: 0

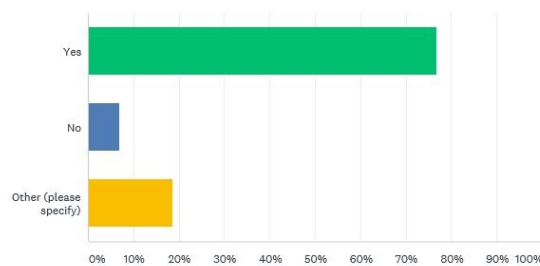


Of the 5 'other' they are as follows:

ASC and mental health;
Foetal alcohol syndrome (FAS), attachment disorder, behaviour and social difficulty;
Several health service providers including consultant, psychologist etc;
Mental health and ASC assessment;
Chose a £3k private autism assessment due to lack of provision. Chose private CBT therapy due to lack of CAMHS provision.

Have you been referred for an assessment?

Answered: 43 Skipped: 0



Of the 8 'other' they respond as follows: Tried self-referral; Children we work with have had assessments; Discharged from CAMHS. ASD diagnosis given; Currently on ASD waiting list; we have been assessed and treatment began - we have been forgotten about; done; Chose private CBT as no response following school referral. Chose £3k private assessment as waits over 4 years at the time; Yes but wasn't done as too young.

Analysing the data: Where we asked open questions i.e. a comment box, we gathered all the feedback together and grouped it into key themes: waiting times; support; communication and so on, to find those with the greatest volume for our 'key themes' section. We also mapped the comments from our case studies against this to obtain the statistics presented below.

Online reviews: In addition to our direct engagement, Healthwatch Calderdale continues to receive reviews on our website in relation to CAMHS. There are 31 CAMHS reviews in total, each can choose a star rating and the average is 1.5 stars. Here's an example of the reviews left since our last report in 2017:



Calderdale Child and Adolescent Mental Health Service (CAMHS) Tier 3 - South West Yorkshire Partnership NHS Foundation Trust



Rated by Dawn
25th June 2018

Underfunded and inconsistent.

Due to poor funding my child with social anxiety cannot be treated due to the time it will take to gain her trust to enable her to engage well. Diagnosed social anxiety and agoraphobia only to change this during a meeting with school, then said my child is picking when she will/won't engage. No understanding of how anxiety fluctuates i. E good and bad days. Child discharged and cannot leave the house. She is signed off as unfit for school but isn't getting any help. Very poor service less -

Leave a pr



Rated by Anonymous
21st July 2019

Unhelpful and unsupportive

Our GP referred my daughter to CAMHS following a prolonged period of anxiety and self harming. We were told, over the phone, that the self harming was not serious enough to warrant support and that we should try accessing free support from a local charity for young carers. We then paid for our child to have private therapy for her anxiety. The therapist helped enormously, but recommend that our daughter be assessed for autism as she felt this was the route cause of her anxiety. The GP agreed and referred her to CAMHS for an assessment. This was rejected by CAMHS as her school did not see evidence of autism - against NICE guidelines recommendations on autism assessment. We are now awaiting a private assessment, but CAMHS would not recommend any private services or confirm whether they would offer any support based on the finding of this assessment. The team have been very unhelpful and unsupportive throughout this whole process and I am appalled that they are now claiming that their autism assessment process is much improved in the local press.



Rated by Anonymous
21st June 2018

Closed without assessing

I'm a professional and have made referrals for families I

Work with which have been closed without any assessment despite strong evidence that a mental health condition is present. It seems they just want to pass the cases into other services due to under funding and too many cases. Staff agreed full assessment was needed then senior staff closed the case. A year later another referral has been made asking for a full assessment less -



Rated by Julie Dent
30th December 2017

Same level of service I have come to expect

My ASD diagnosed son has been increasingly violent. In summer when he was diagnosed I told them this but was told they were discharging him as he "just" had ASD and no other MH conditions. The only other thing they would do was referred to ASD team at school. So now 6 months later it is worse, every day my partner and I get spat at, kicked and hit, hair pulled, verbally abused etc. In desperation I emailed "camhs first point of contact". It's several days later now and they haven't had the courtesy to email me back, not to sign post or anything, not even auto reply. I know it is the Christmas period but everyone knows that is one of the most stressful times of the year for people with MH issues. Absolutely disgusting. less -



Rated by Hayley
Midland
24th October 2018

2 and a half years wait for assessment

My son was referred by school to Camhs in may 2016 assessment took place September 2016 all good. They referred him to tier 3 finally got seen last wk October 2018 after several phone calls. Went back to have a review meeting after waiting for as hr no-one taking any notice I asked how much longer was we to wait, to find out the person we was seeing was off sick and wouldn't be in the rest of the wk, and she'd be hoping to sort appointments out for mid November. less -



Rated by nicholas
ivine
5th December 2018

don't offer the service that is needed

I have 3 kids with suicidal thoughts and self harm and CAMHS done a report saying help needed but didn't offer the help or ref to other places less -

Example of our survey:

Case study: Child and Adolescent Mental Health Service in Calderdale
2. About you (delete as appropriate) A family member of person who received CAMHS care: A person who received CAMHS care: Other:
Which service were you accessing? Northpoint South West Yorkshire Mental Health Trust Other (please specify)
What was the reason for your referral to CAMHS? ADHD/ADD Autism (ASD) assessment Other? (please specify)
Have you been referred for an assessment? Yes No
How long were you waiting for a 1st CAMHS appointment? 0-6 months 6-12 months 1-2 years Over 2 years
Did CAMHS give you an idea of the waiting time for an assessment??
What support were you given while you waited for an appointment?

What impact did the lack of CAMHS support or delay in assessment have on your child?
What impact did the lack of CAMHS support or delay in assessment have on you in terms of family life, health, employment and so on?
Please tell us your ideas to help improve the service:
Which part of Calderdale do you live in (delete as appropriate)? Halifax Central (Park, Skircoat , Sowerby Bridge and Town Wards); Halifax North and East (Illingworth & Mixenden , Northowram & Shelf, Ovenden, Warley); Lower Valley: (Brighouse, Elland, Gresland & Stainland , Hippobolme & Lightcliffe , Baistrick); Upper Valley: (Calder, Hebden Bridge, Sowerby Bridge, Luddendenfoot , Ryburn , Todmorden)

Information providing:

We did a simple search online to see how user-friendly the CAMHS website was in terms of people seeking access to help, support or information. The highest ranking website people see when Googling 'CAMHS Calderdale' is <https://calderdalecamhs.org.uk> & the 1st words on it say:

"Welcome to Calderdale CAMHS

This website has been produced by [Northpoint Wellbeing Limited](#)."

Are details of the website provider the best first message to send to those seeking information and support about CAMHS?

Further, young people are directed to Open Minds, but the information on that website under help and support sends people straight back to <https://calderdalecamhs.org.uk>

News stories:

Waiting times for all areas of the NHS have long made headlines news and it has already generated negative publicity for local health providers. The Halifax Courier, in August 2018, published two stories, plus a further in November 2019.

“School age kids face five year wait for autism tests in Calderdale”

“5 year wait - health chiefs say sorry”

“Calderdale young people and families finding access to mental health services difficult”

Source: <https://www.halifaxcourier.co.uk/news/health/school-age-kids-face-five-year-wait-for-autism-tests-in-calderdale-1-9309981> and <https://www.halifaxcourier.co.uk/news/health/health-chiefs-apologise-over-children-s-five-year-autism-test-wait-1-9311187> and <https://www.halifaxcourier.co.uk/health/calderdale-young-people-and-families-finding-access-to-mental-health-services-difficult-1-10093828>

Yorkshire Post: ‘Ten-year-old Leeds girl missed nine months of primary school after council failures’ -

https://www.yorkshirepost.co.uk/education/ten-year-old-leeds-girl-missed-nine-months-of-primary-school-after-council-failures-1-9922472?fbclid=IwAR3Rf9oLZ42CgRpggeoS3uQ3horrYu5X21ICz5FKTa2_xgHq2I7ypU4iSW0

We’ve included this link as the Local Government and Social Care Ombudsman recently ruled against Leeds City Council for failing to have a policy in place for children missing education because of ill health. Link to Ombudsman ruling: <https://www.lgo.org.uk/decisions/education/alternative-provision/18-011-706>

Reports to council meetings:

The basis for the initial story was a report to Calderdale Council’s Health and Wellbeing Board, the annual report for 2017-18, which says: “Waiting list numbers increased with pre-school children waiting 12 months for assessment. Meanwhile, school age children, can sometimes wait four or five years to achieve an outcome. This has led to parents and carers becoming very concerned about obtaining a timely diagnosis and access to support.”

Source: page 8: https://www.calderdale.gov.uk/nweb/COUNCIL.minutes_pkg.view_doc?p_Type=AR&p_ID=57313

More recent statistics provided by SWYPFT to Calderdale Council’s Mental Health Innovation Hub (April 2019) says: “...the waiting list for specialist treatment is around 4-6 weeks which is a reduction from 6 months, from July 2018; 16 ADHD assessments per month, which is an increase from 3-4 assessments per month in July 2018; 20 ASC assessments per month, which is an increase from around 4-5 assessments per month in July 2018; on track for our waiting list to be down to 1 year by March 2020.”

Source: https://www.calderdale.gov.uk/nweb/COUNCIL.minutes_pkg.view_doc?p_Type=AR&p_ID=66530

The Ofsted & QCQ Inspection report: <https://files.api.ofsted.gov.uk/v1/file/50080918CQC>