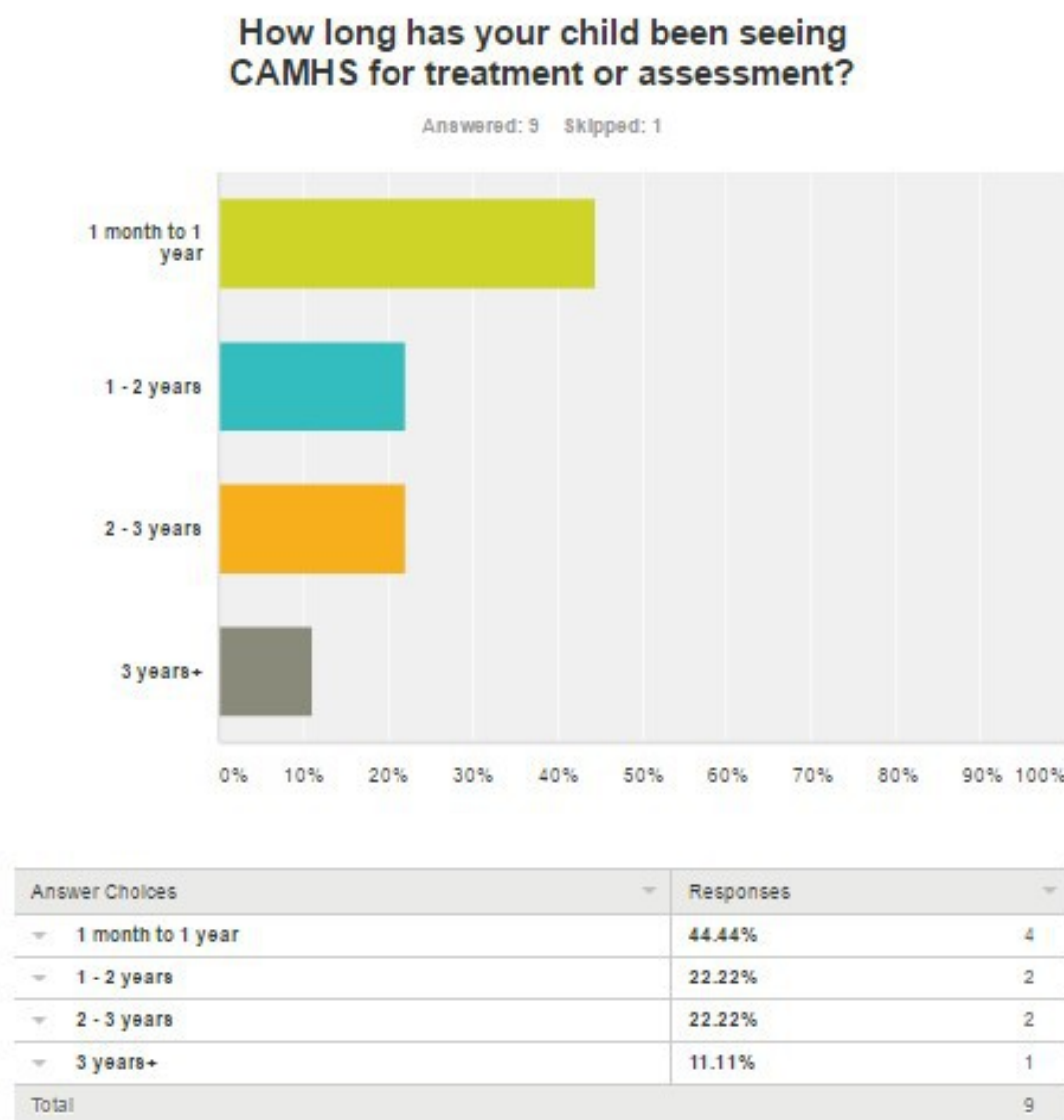


REPORT ON CAMHS AND AUTISM BRIGHTON & HOVE (running since 4.9.16)

Question 1



Significant Comments

"It would have been longer but they upset child at autism assessment and failed to engage child as a result. This left parent being sole supporter of child's emotional and mental health for over a year and having to pay for private services."

"Following 3 years of failure to support, urgent referral resulted in file being closed!"

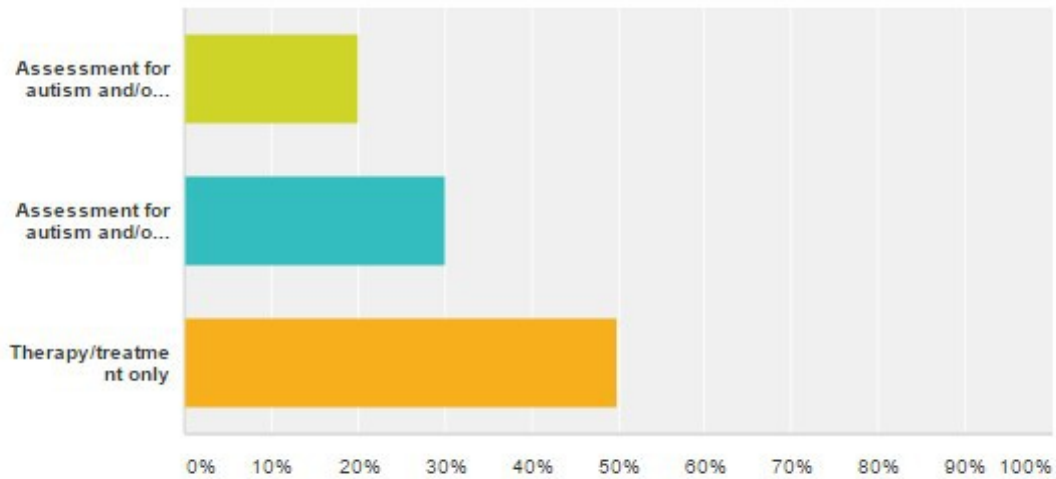
"Was referred when my daughter was first diagnosed June 2013 but only just started to receive any help August 2016." (A common complaint from parents is that their children wait inordinate amounts of time to receive CAMHS support.)

"My son was not given access to CAMHS as I was coping (apparently), despite him having high anxiety and meltdowns at school in infant years (he is now 10), still has anxiety but is learning to recognise how he feels and what to do." (Another common complaint is that CAMHS sets the bar too high, which is reactive, not providing the early intervention the Government states should happen and contributes to people reaching crisis.)

Question 2

What has your child seen CAMHS for?

Answered: 10 Skipped: 0



Answer Choices	Responses
Assessment for autism and/or ADHD	20.00% 2
Assessment for autism and/or ADHD & therapy/treatment	30.00% 3
Therapy/treatment only	50.00% 5
Total	10

Significant Comments

"CAMHS has been singularly unsuccessful at both."

"So far medication has been the only option as child too anxious to access therapy. Perhaps had 3 years of failure to support not occurred the anxiety would not have become so entrenched to result in this."

"Anxiety, depression, behavioural problems." (The vast majority of autistics (well over 70%) have co-morbid mental health problems. A significant amount of these mental health problems develop because they are unsupported and struggling (especially in schools). This goes back to the lack of early intervention, to improve outcomes. The figures for autistics being unemployed are very high, the figures for "high-functioning" autistics developing mental health problems and poor outcomes are also very high. **CAMHS has to do something about this.**)

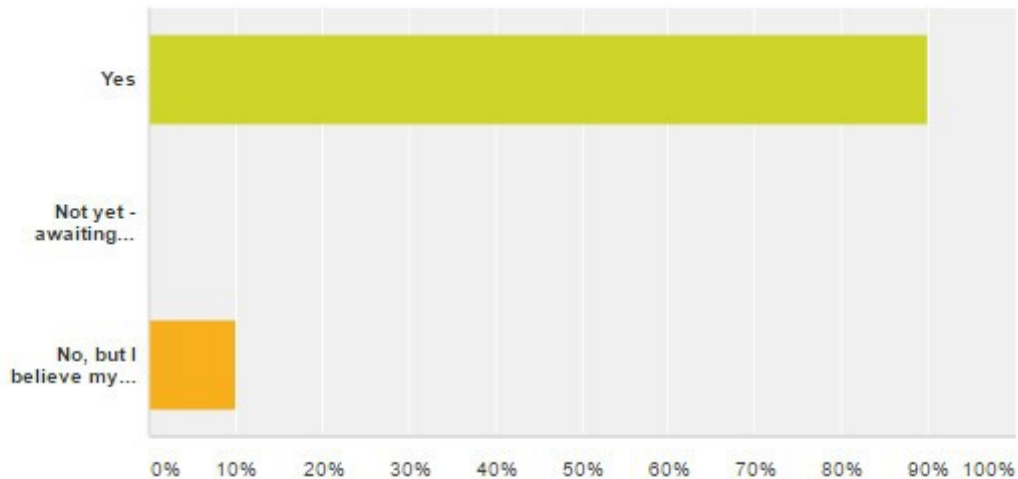
"First for assessment and now for therapy and further assessment."

"None, I was told CAMHS don't see children for autism, I was referred to Seaside View. I also don't understand the different tier levels." (A common complaint is chaotic communication and processes. Why are parents not more informed of how things work and who does what? **Clearly this person was misinformed!**)

Question 3

Has your child been diagnosed with autism and/or ADHD yet?

Answered: 10 Skipped: 0



Answer Choices	Responses
Yes	90.00% 9
Not yet - awaiting assessment	0.00% 0
No, but I believe my child has autism and/or ADHD and this has been a diagnostic failure	10.00% 1
Total	10

Significant Comments

"Diagnosed with autism [at Seaside View] but CAMHS diagnostic failures regarding PDA dual diagnosis and ADHD."

"But they failed to diagnose her autism. It was diagnosed through a 2nd opinion out-of-area which I pushed for. They relied totally on the ADOS-2 (only 77% clinically reliable in high-functioning individuals as it was researched and developed on prototypical autism cases and likely even less so in females and PDA). They disregarded the wealth of information I gave them on her and tried to brush off her high score on the ADOS-2 (missed cut-off by 2-3 points) to OCD and anxiety (both of which are frequently co-morbid to or intertwined with autism incidentally). Even when child diagnosed, we received nothing from CAMHS. They didn't even notify ASCSS, I was the one to do that."

"Yes - ASD with Demand Avoidance (PDA), not diagnosed by anyone in Brighton obviously as it doesn't exist here does it?!" (There is a big problem with lack of recognition of PDA locally as well as elsewhere in the UK. There is a postcode lottery. Research on PDA exists, it is an ASD and must be diagnosed as such. The NAS and other organisations run professional training workshops on PDA. CAMHS has to step up regarding PDA and get their staff trained in recognising it.)

"My son has had stage 2 assessment and has "traits" but no full diagnosis. I felt this was a box ticking exercise and one size fits all. My son has also seen the OT team at Seaside View (who were very understanding and listened) and was diagnosed as tactile defensive." (You cannot be a little bit autistic. Not meeting the diagnostic criteria, simply means that certain boxes are not ticked, which is often due to the child's learned masking and mimicking neurotypical peers, which CAMHS seem unable to recognise. There is a huge gap in CAMHS clinicians being able to recognise high-functioning, female and PDA presentations.)

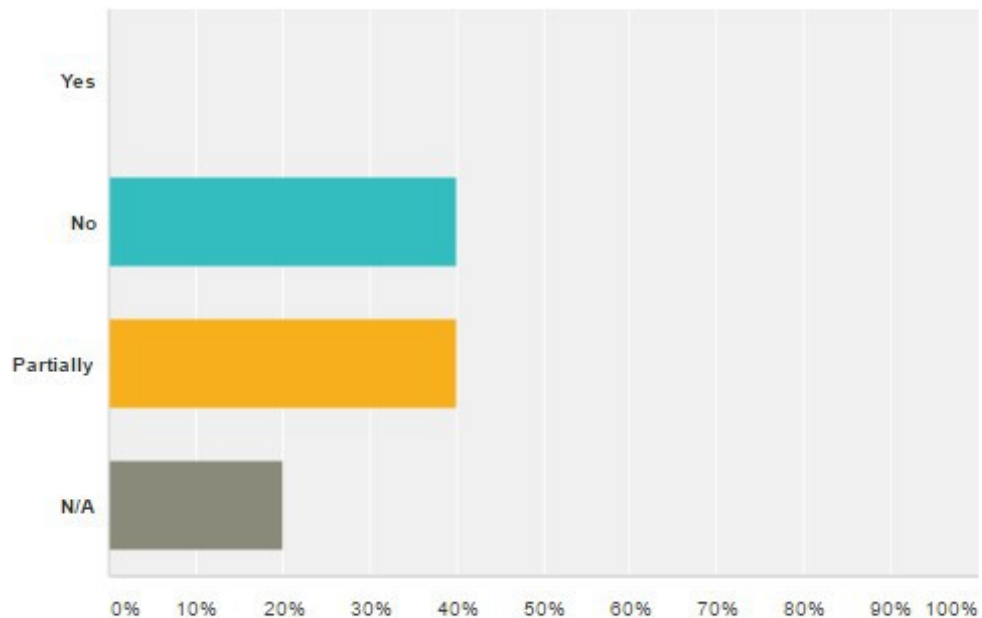
"Yes, but this is disputed by Seaside View and CAMHS." (Only the most incompetent clinician would diagnose autism where it did not exist so why are diagnoses made elsewhere being disrespected? It is possible this family obtained a private diagnosis. It is not acceptable to refuse to recognise private or out-of-area diagnoses. NHS NICE does not state that to receive support a diagnosis must be a local NHS one!)

40% of the 90% of respondents' diagnosed children were clearly not diagnosed by CAMHS however, judging by individual comments, would CAMHS have diagnosed that 40%?

Question 4

If your child has been receiving therapy or other treatment from CAMHS has it been successful?

Answered: 10 Skipped: 0



Answer Choices	Responses
Yes	0.00% 0
No	40.00% 4
Partially	40.00% 4
N/A	20.00% 2
Total	10

Significant Comments

"Well over a year of useless therapy then medication (suggested very late down the line to a child who had already suffered co-morbid depression and anxiety for well over a year by the time she agreed to see them) which has not worked so far. One counsellor who would make the most appalling comments and leave her in tears, one psychologist who has been offended by being told by the child she isn't helping her!"

"Medication has not worked. Now tapering off to try another one."

"Practitioner did not see child on initial appointment due to anxiety and behavioural problems. Did not bother trying again but just interviewed both parents." (CAMHS are supposed to be the specialist service for those exact problems! Where is the flexibility and thinking outside of the box? Home visits and other options should be offered.)

"They have openly admitted they don't know what they are doing with an autistic child with mental health issues so the ASCSS have been giving a lot of guidance how to help." (This comment says it all. Many parents experience that CAMHS have no autism expertise.)

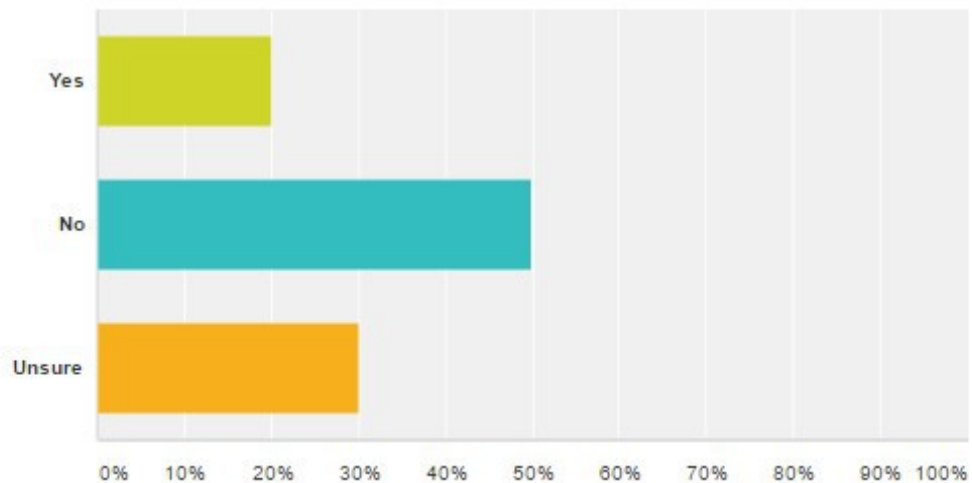
"Seen variety of therapists Tier 1 much more helpful than Tier 3 And specific therapist e.g. for spider therapy more useful."

No respondents said CAMHS therapy for their autistic child has been successful!

Question 5

In your experience, have CAMHS staff that your child/you have seen, had autism expertise and experience?

Answered: 10 Skipped: 0



Answer Choices	Responses
Yes	20.00% 2
No	50.00% 5
Unsure	30.00% 3
Total	10

Significant Comments

"There are not words to explain how inexperienced they are regarding autism and yet how they still have a level of apathy about learning more and utilising parental expertise in their children, that staggers. They follow those tick-boxes come what may, no matter how evident it is to be inappropriate for an autistic child."

"Complete lack of autism expertise, despite a likely considerable experience of seeing autistic children. 1 in 10 children seeing CAMHS are autistic so it's wholly unacceptable that there is no expertise there. Psychiatrist has failed to make an SEN recommendation in her report which has resulted in child school-refusing and ending in losing school placement (which was fought at SENDIST for single-handedly by parent) and now child has no school placement. CAMHS staff don't read child's file."

"Seemed minimal, was prepared to simply quote basic standard autism parenting practice and blame us for the issues." (This parent blame culture simply has to go. Inadequate parenting does not make a child appear autistic anyway!)

"They need more experience with atypical autism." (I would extend that and say they need a lot more experience with all autism subtypes.)

"None, my daughter's key worker has never worked with an autistic person or had any training." (Shocking. Autism means any co-morbid mental health conditions are likely to present differently because of the autism, the techniques required may need to be different and some therapies can be completely inappropriate or even harmful for some autistics.)

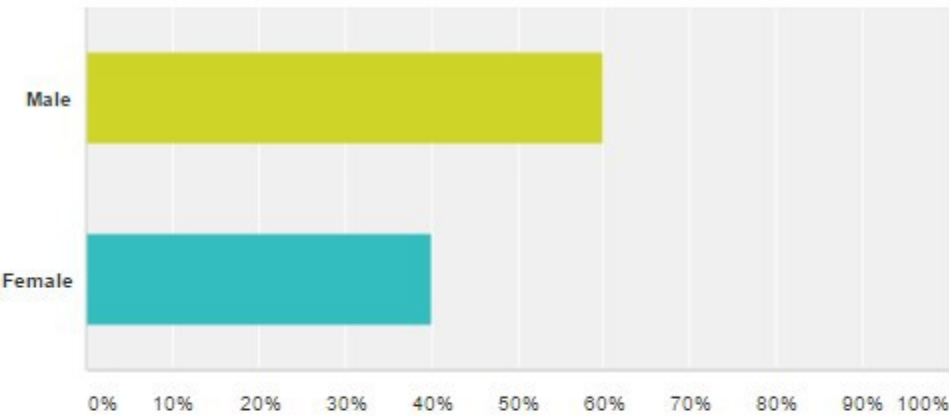
"I would say no from what I have heard from other parents."

Only 20% experience that CAMHS have autism expertise, that is shocking.

Question 6

Is your child male or female?

Answered: 10 Skipped: 0

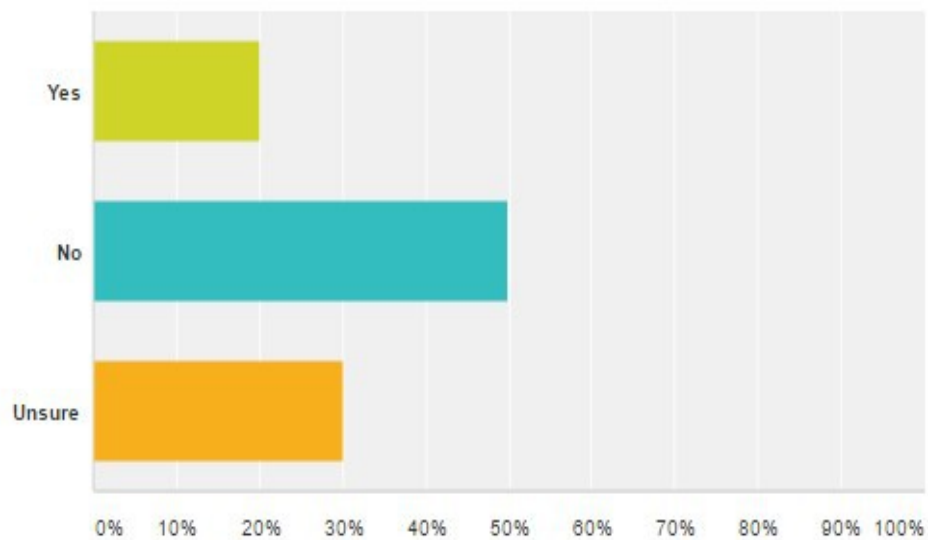


Answer Choices	Responses	
Male	60.00%	6
Female	40.00%	4
Total	10	

Question 7

Do you think the gender of your child has had any bearing on the treatment or diagnosis your child has received?

Answered: 10 Skipped: 0



Significant Comments

"Because as a female, she masks in school. If she was disrupting classes like boys are more inclined to do, school would put pressure on CAMHS to do something and perhaps then they'd listen."

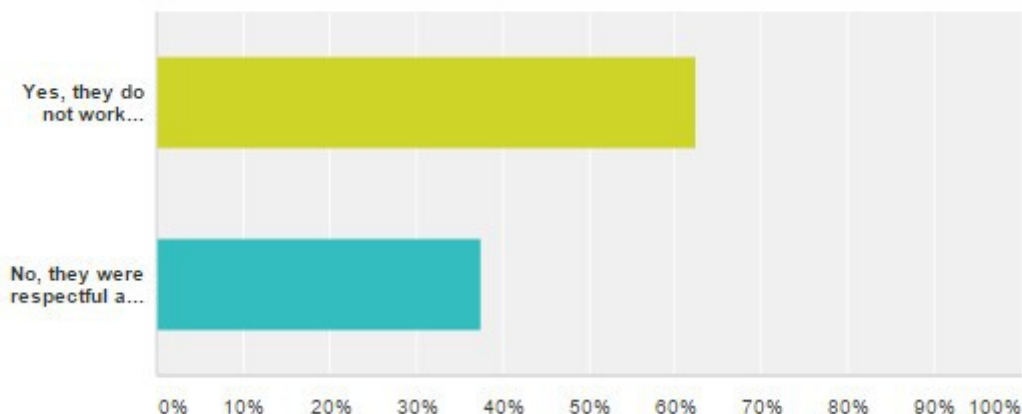
"I believe CAMHS' total lack of understanding of female presentation heavily contributed to their fearful (deliberate?) reliance on the ADOS-2."

Only half of respondents said no.

Question 8

Have you experienced a parent-blame culture from CAMHS staff and has this caused delays to diagnosis or treatment?

Answered: 8 Skipped: 2



Answer Choices	Responses
Yes, they do not work respectfully or in partnership with parents and were fault-finding to explain away my child's difficulties and falsely attributing blame to home-life or parenting (if this caused diagnostic or other delays please explain in comments)	62.50% 5
No, they were respectful and recognised my child's difficulties were due to their condition or mental health	37.50% 3
Total	8

Significant Comments

"Amazing what an SAR can uncover. The most appalling lies and fabricated gossip by CAMHS staff as an exercise in parent blame. Total discrimination against autistic traits of parent, total disrespect (written admission of ignoring valuable parental evidence on child's autistic difficulties sent to help assessment process). Diagnostic failure heavily contributed to by this parent blame attitude and unwillingness to listen to parent at any level. How much money is wasted by such gossip and useless meetings? And all the while children suffer."

"The parent blame culture in CAMHS ensures lack of respect for parental evidence and information on their own child. I have been discriminated against by CAMHS staff (including the GM) and they don't even understand their own basic legal duties towards equality. CAMHS also failed to listen to parental evidence regarding PDA and ADHD and therefore diagnostic failure has occurred."

"Went through so many procedures of referrals, for family therapy, plus Triple P groups, before reaching diagnosis criteria. (Another shocking problem, is that CAMHS have a history of diverting parents seeking assessment for neurodevelopmental conditions, to parenting courses. Most parents are decent parents. Most will have tried everything already by the time they realise their child has an underlying medical cause for their behaviours. To delay assessing ND conditions is unethical, prevents early intervention (by the time a child is CAMHS age, they are already a late diagnosis), leaves families floundering without answers or support and may condemn a child to struggle unnecessarily in school and other areas and develop serious mental ill health. Clearly this is a deliberate tactic to avoid providing access to resources!)

"I would like to point out the only person I found who understands autism and has held some fab causes is [T2 practitioner]. I found out about her through a parent group, I was not referred by CAMHS, doors are closed when you do not have a full diagnosis." (Leaving families struggling with an undiagnosed autistic child is unacceptable.)

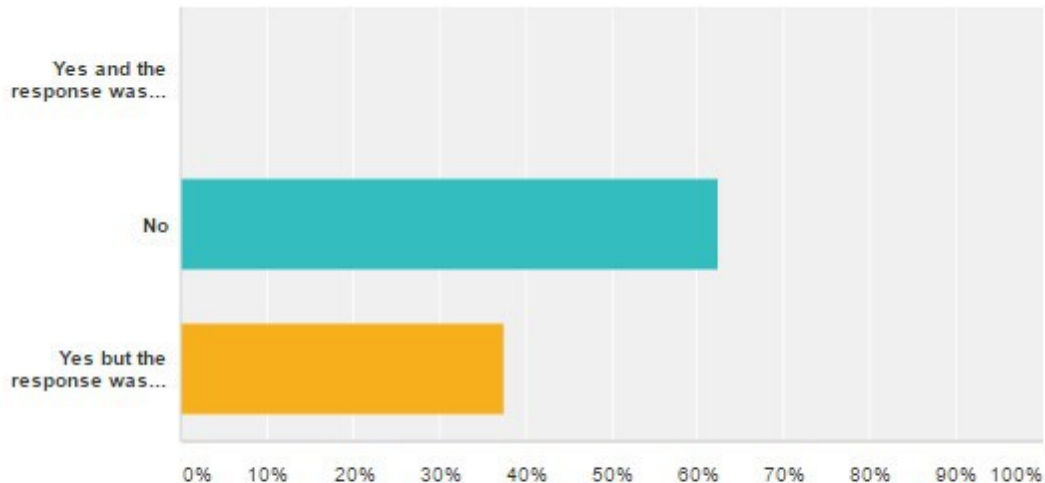
"So far they have not either mentioned parental blame or child's condition but rather "external issues"." (Another diversionary tactic!)

The majority of parents experience this parent blame culture from CAMHS! IT HAS TO STOP!

Question 9

Have you had cause to formally complain about CAMHS and if so, was the response satisfactory?

Answered: 8 Skipped: 2



Answer Choices	Responses
Yes and the response was satisfactory	0.00% 0
No	62.50% 5
Yes but the response was unsatisfactory	37.50% 3
Total	8

Significant Comments

"They may as well throw complaints in the bin for all the gravity and diligence applied to dealing with them."

"Response didn't answer many points of complaint, completed response letter was not sent to me until I chased it a month or more after it's production and subsequent reply to unacceptable complaint response is unanswered - despite chasing. They simply don't care! The arrogance is astounding."

"I am considering going back and demanding a further diagnostic appt as now we have serious issues simply trying to get her into school."

CAMHS have a history of diagnostic failure with autistic children, this is due to a tick-box approach, lack of expertise, parent blame culture and denial of resources.

"Would have, but hardly heard from them in the time we were with them, before being passed back to Seaside View who were equally as useless."

Clearly there is great dissatisfaction from families towards the CAMHS service, even when they don't complain.

"Complained twice and received no formal reply let-alone a response."

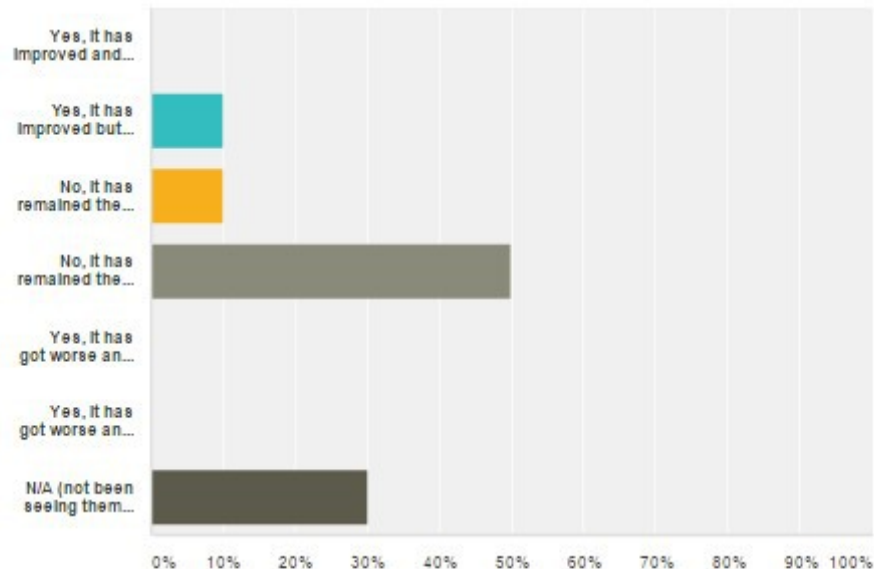
This author can vouch for non-response being an issue, it is absolutely unacceptable for this to happen. Not only is a response expected but resolution!

Complaints are gold dust for CAMHS, an opportunity to improve and learn – so why?

Question 10

Have you noticed any difference in the last year or so in the quality of service received by CAMHS and have they sought service-user feedback?

Answered: 10 Skipped: 0



Answer Choices	Responses
Yes, it has improved and we HAVE been asked for feedback	0.00% 0
Yes, it has improved but we have NOT been asked for feedback	10.00% 1
No, it has remained the same and it is unsatisfactory, we HAVE been asked for feedback	10.00% 1
No, it has remained the same and it is unsatisfactory, we have NOT been asked for feedback	50.00% 5
Yes, it has got worse and we HAVE been asked for feedback	0.00% 0
Yes, it has got worse and we have NOT been asked for feedback	0.00% 0
N/A (not been seeing them that long)	30.00% 3
Total	10

Significant Comments

"Could it get any worse?"

"It may have got worse, but we went from complete diagnostic failure and failure to engage one child, as well as failure to support other child, to more diagnostic failures, chaotic and extremely tardy prescription issuing, failure to prescribe other child until 2nd opinion and ineffective/harmful therapy - how do you quantify which is worse? Perhaps when the next bout of therapy starts with different clinicians I will have more of an idea!"

Only 1 person out of 10 says it has improved (10%).

5 people (50%) say it is the same as it was before the 5 year plan was implemented. As the baseline was **known to be inadequate from the outset**, even though nobody has said it has got worse, this is not good enough because it has remained unsatisfactory.

3 people (30%) have not been seeing them long enough to judge, but it is likely that they have not been asked for feedback anyway, in view of overall inadequacy of the service it is reasonable to say, that likely most of these people would develop dissatisfaction due to the inherent lack of autism expertise in CAMHS. Lack of adequate feedback seeking was noted in the 2013 LA scrutiny, in which it was stated that CAMHS must improve seeking feedback from service users, as there is no way for CAMHS to gauge how they are doing without it! We are 3 years down the line and **CAMHS have done nothing**.