



Child and Adolescent Mental Health Services in Oxfordshire

Report into Survey Findings 2020

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1. Executive Summary

This report summarises feedback gathered from 606 children, young people, parents, carers and professionals about their experiences accessing Child and Adolescent Mental Health Services (CAMHS) in Oxfordshire. Respondents completed an online survey at the start of 2020 about their experiences of accessing CAMHS in Oxfordshire. The report has been written by Oxfordshire Parent Carers Forum (OxPCF) and aims to present the results of this survey in a way that gives useful insights that may help shape service improvements.

The key messages from the survey responses are:

- **Communication is an issue for those who refer to or attempt to access the CAMHS service. Throughout the process from referral to discharge there seems to be a mismatch between user expectations of acceptable levels of communication and that received.**
- **Waiting times appear to be having a significant impact on young people, parents and schools with more than half waiting over 16 weeks and a significant proportion waiting for over 2 years for an initial appointment.**
- **Over half of those responding rated their overall experience as poor with nearly half indicating they would not recommend the service to family and friends.**
- **Many respondents supported the valuable work undertaken by the staff of CAMHS and recognise that many of the difficulties arise from the service being underfunded.**

In writing this report OxPCF are mindful of the many challenges facing Oxfordshire CAMHS and the dedication shown by those working for the service, who strive to do their very best for the children and young people of Oxfordshire. At the same time it is also inescapable that these challenges are having a significant and detrimental impact on the children and young people of this County. Their interests must always be paramount, and it is in this spirit that this report is written.

2. Background

OxPCF exists to support the development of parent carer participation, a process in which parents work together with professionals to make improvements to local services. OxPCF is run by and for parents and carers of children and young people with additional needs. OxPCF believes passionately that 'Every Child Matters' and that all disabled children and young people in Oxfordshire, should have access to the same opportunities, experiences and information as any other child.

Since OxPCF was relaunched in 2018 access to CAMHS has been a recurrent theme raised by parents and carers. OxPCF has endeavoured to capture this feedback and to share the concerns raised with those in a position to effect change. However much of this feedback has been anecdotal and in 2019 a suggestion was made to undertake a survey to gather more rigorous data to evidence these concerns.

In December 2019 a parent volunteer offered to produce a survey and drafted a version later shared with the Co-Chairs of OxPCF. This survey was then adopted by OxPCF and distributed widely through OxPCF's networks. Contained in this report is a summary and analysis of the responses to this survey. We would like to extend our heartfelt thanks to all the children, young people, parents, carers and professionals who took time to complete this survey. We know how precious their time

is and it is very much appreciated. We would also like to thank the Oxfordshire Clinical Commissioning Group, Oxfordshire County Council and Oxford Health NHS Foundation Trust for engaging with us on this report and exploring opportunities to address the feedback received.

3. Survey Respondents

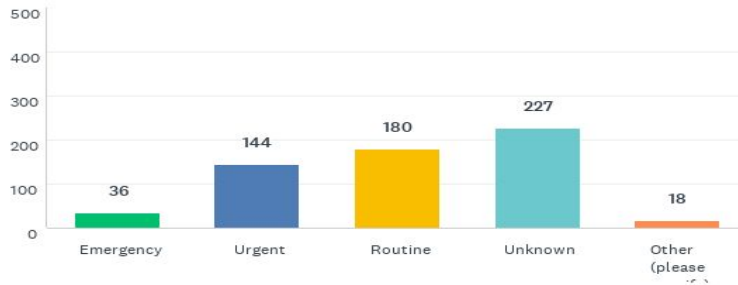
606 people responded to the survey asking for feedback on access to CAMHS. The profile of respondents was predominantly parents/carers (471). Most respondents were people whose CAMHS referral had been made since 2017 (85%). Notably 92 responses came from professionals and a further 16 responses from young people under 16, and 12 responses from young people over 16. 63% of all respondents knew their referral pathway, however, 227 respondents did not know their referral pathway (37%) or the priority given (31%) irrespective of whether or not their referral had been accepted.

Of those who knew their referral had been accepted: 192 respondents said that they did not know which pathway they had been referred to. 147 were on the NeuroDevelopmental Conditions pathway (e.g. Autism Spectrum Condition diagnosis).

Pathway	No.	%
Unknown	192	32%
Neuro Developmental Conditions (NDC)	147	24%
Getting Help (GH)	63	10%
Getting More Help (GMH)	43	7%
Learning Disability Service (LD CAMHS)	40	7%
Harmful Behaviour Service (CAHBS)	33	5%
Family Assessment & Safeguarding Service (FASS)	15	3%
Neuropsychiatry Service	13	2%
Eating Disorder Service	12	2%
Outreach Service (OSCA)	8	1%
Forensic CAMHS	Less than 5	Less than 1%
Specialist CAMHS Housing Pathway	Less than 5	Less than 1%
Horizon Service	Less than 5	Less than 1%
Inpatient Service (Highfield Unit)	Less than 5	Less than 1%

Of the 605 respondents, 227 did not know what category had been assigned to their referral. 180 confirmed that their referral was routine, 144 had an urgent referral and 36 had an emergency referral.

If known, what category was given to the most recent referral made to Oxfordshire CAMHS?

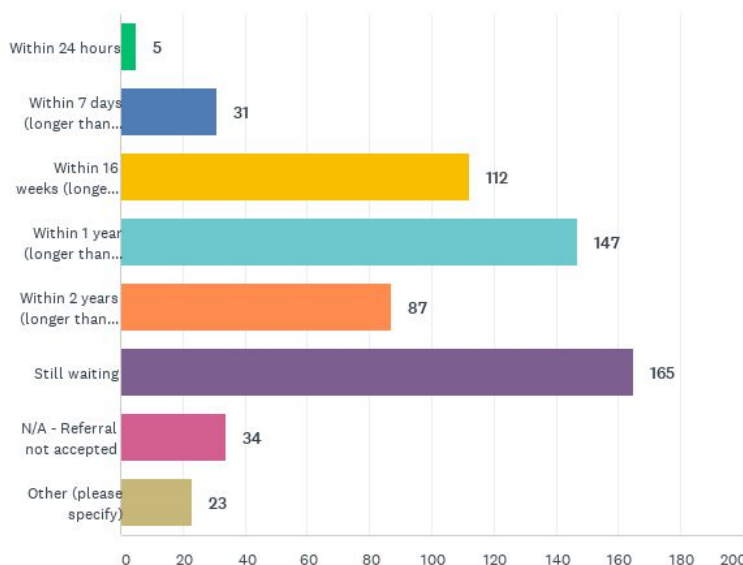


4. Survey Response: Waiting Times for CAMHS

Survey respondents were asked: ‘How long was the wait from when the referral was first made to Oxfordshire CAMHS, to the first appointment with a representative of Oxfordshire CAMHS (either in person or virtual)?’

604 people responded to this question. 87 of those individuals waited over 2 years for their appointment. 165 individuals are still waiting. 147 were seen within a year.

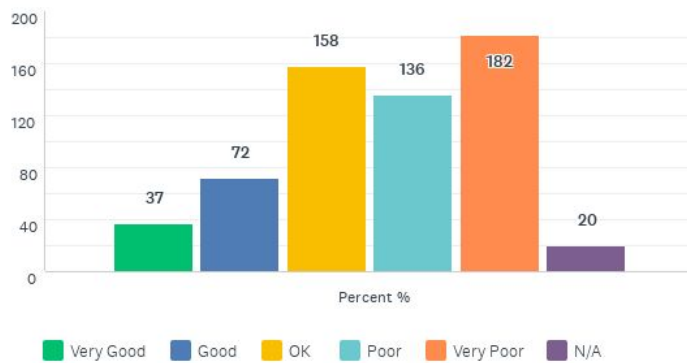
How long was the wait from when the referral was first made to Oxfordshire CAMHS, to the first appointment with a representative of Oxfordshire CAMHS (either in person or virtual)?



5. Survey Response: Overall experience of CAMHS

Survey respondents were asked: ‘How would you rate your experience of being referred to Oxfordshire CAMHS?’ The responses split by pathway were as follows:

How would you rate your experience of being referred to Oxfordshire CAMHS?



605 people responded to this question. Overall 318 people rated their experiences as either poor or very poor, compared to 267 who said that they either had an ok, good or very good experience. 20 people felt that it was not applicable to them.

The data shows that 417 responses were from people who identified themselves as a parent/parent carer, of those 243 rated a poor or very poor experience compared to 219 that rated an ok, good or very good experience.

For those that responded as a young person, 12 felt that they had an ok, good or very good experience compared to 14 that reported a poor or very poor experience.

How would you rate your experience of being referred to Oxfordshire CAMHS?

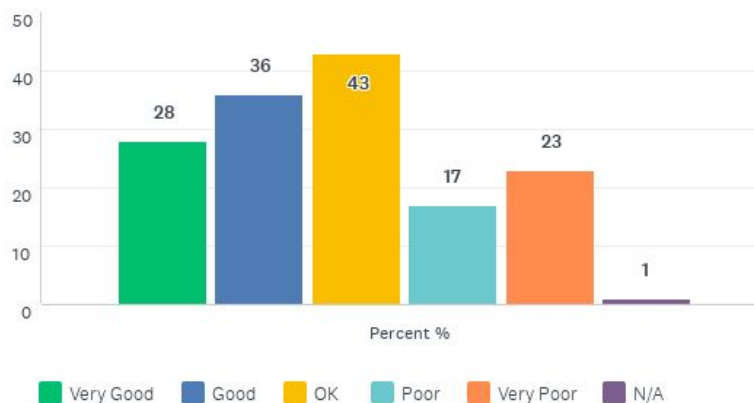


Chart 1: Data filtered by those that waited within 24hrs, 7 days and 16 weeks.

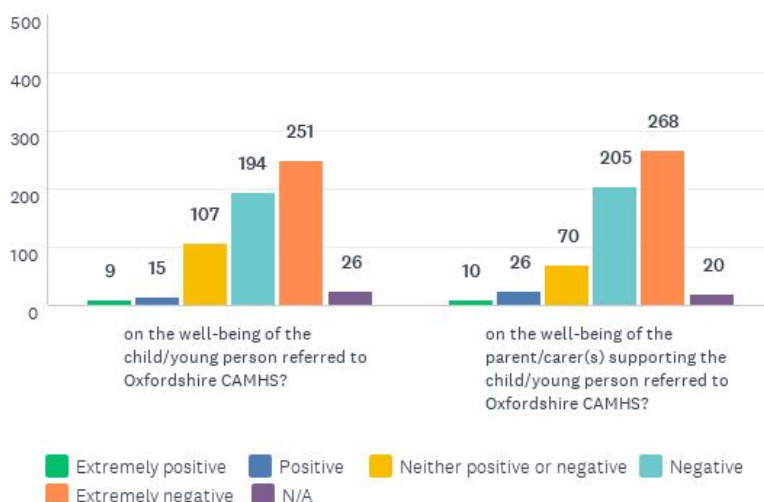
Further analysis of the data shows that for those that waited between 24hrs and 16 weeks, the satisfaction levels improved significantly with 107 people reporting an ok, good or very good experience, compared to 40 who reported a poor or very poor experience.

Further scrutiny of the waiting time data shows that 87 respondents have waited over 2 years for their first appointment. Notably 41 of those were referrals for Neuro Developmental Conditions, and 17 respondents did not know which pathway they were waiting for.

6. Impact of waiting for help

Survey respondents were asked: ‘What impact do you think the waiting experience had or is having on the well-being of the child/young person referred to Oxfordshire CAMHS?’ They were also asked the same question in respect of parents/carers.

What impact do you think the waiting experience had or is having?



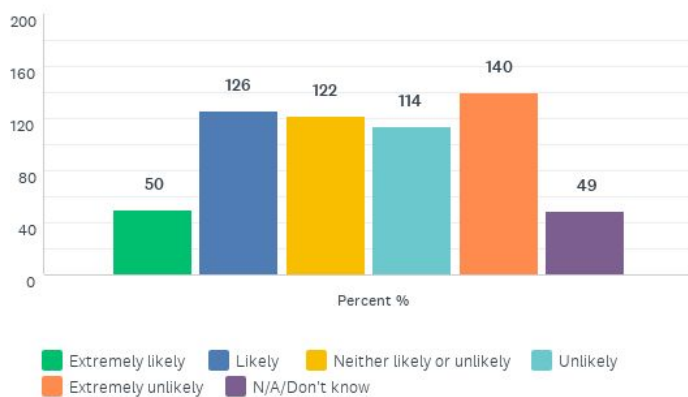
The chart above shows that waiting times, for the majority, have a negative or extremely negative impact on both the young person and the parent carer’s wellbeing. The data shows that even for those waiting between 24hrs and 16 weeks (147 people), the impact of that shorter wait, still resulted in 76 people feeling that the wait had either a negative or extremely negative impact on the young person, 47 felt that it had neither a negative or positive impact on the young person and 18 felt that it had a positive or extremely positive impact.

7. Friends and Family Test

The ‘Friends and Family Test’ is a question that has been used by the NHS since 2013. This question was included to enable comparison with benchmark data. Survey respondents were asked: ‘How

likely are you to recommend Oxfordshire CAMHS to friends and family if they needed similar care or treatment?’

How likely are you to recommend Oxfordshire CAMHS to friends and family if they needed similar care or treatment?



The chart shows that overall the majority of people would recommend CAMHS to friends and Family. A ‘child or young person’ is most ‘likely’ or ‘extremely likely’ to recommend Oxfordshire CAMHS, with a combined score of 34%. In contrast a ‘parent or carer’ is most ‘unlikely’ or ‘extremely unlikely’ to recommend with a combined score of 43%.

8. General feedback on Oxfordshire CAMHS

In total 416 people answered this question. Comments were received as follows:

- 10 young people over the age of 16
- 13 young people under the age of 16
- 327 comments from parent/parent carers
- 66 comments from professionals

Below we summarise the feedback received, further comments are shown in Appendix 1.

Young People told us:

Only one young person provided positive feedback. Other comments reflected the following themes:

- That while they accepted the service was busy, for some it meant that they were not getting the support they needed
- Difficulties in accessing the service/appointments
- Lack of support

Parents told us:

There were positive comments received, but these were caveated by the broad themes below:

- Waiting times, specifically
 - Delays to waiting times to access referral, initial assessment and treatment
 - Confusion about the referral processes and eligibility criteria
 - Impact of waiting times, describing loneliness and isolation for the family and child
- Communication and Administration, specifically:
 - Infrequency and difficulty of communication with the service
 - Quality of administration from the service: errors in personal identifiable information, difficulty getting through on the phone, lack of communication
- Experience of CAMHS once seen, including the attitude of professionals
 - Positive feedback, some families felt that accessing the service had a positive life changing impact on the family
 - Positive experience about the clinical input, but offset with concerns about the delay to access a professional
 - Concern about the attitude of staff
 - Concern that the length of treatment is not sufficient in some cases
 - Concern that there is insufficient ongoing support
 - Comments about the lack of facilities and the unwelcoming nature of the physical environment of CAMHS

Professionals told us:

There were positive comments received within the professional feedback, however these were often caveated around the broad themes below. Professionals also reflected an understanding of the pressures placed on the service due to insufficient funding and issues with staffing levels.

- Waiting times were mentioned in nearly all feedback responses, the remaining can be categorised into three main themes, communication, referral process and support.
 - Frustrations around issues with communication
 - Frustration caused by a complicated referral process
 - Confusion around which form should be used
 - Not having the capacity to chase referrals whilst supporting parents
 - Parents may also have self-referred through the single point of access, but remained unsure as to whether or not their referral had been accepted and if it had what action was being taken to progress that referral.
 - The amount of time it takes to process a referral
 - Lack of joined up support with other professionals once a case is open.
 - Specific concerns about the online referral form
- CAMHS Assessment and Diagnosis
 - Questionnaires for parents and staff are sent out immediately which puts parents into a false sense of security for how long the process will actually take.
 - When paperwork is sent out to families for them to complete, no one from CAMHS checks that the family have received and returned these forms.
 - If these referral forms have been misplaced it is often many months down the line before this mistake is found.
- Impact on young person or school, the impact on schools and settings cannot be underestimated
 - Schools find themselves in an exceptionally challenging position, where they are not only dealing with the young person in school and supporting them to the best of their ability, but they are also the only face-to-face contact that many families are having, during this very difficult time.

9. Recommendations

The Oxfordshire Parent Carers forum (OxPCF) welcomes the feedback from this survey. When a system that is meant to support children and young people with SEND results in increased stress for families already living with additional stresses, changes need to be made. As always, OxPCF would recommend listening to parents about how to provide the best service possible. We feel that there are a number of opportunities highlighted in this report to improve the experiences of parents, young people and professionals who are accessing the CAMHS service.

The recommendations/suggestions from professionals, specifically were:

- If at all possible families should seek support or diagnosis from a private provider.

- Improve jargon in care plans
- Feedback on service improvement should be more frequent with professionals allowed to input
- Manage parent expectations with clear timelines for appointments
- Greater information about eligibility criteria/thresholds
- Guidance on support available to families while they wait
- Contact number for professionals to call to get advice

10. Next Steps

Covid-19 has caused an unforeseen delay in producing this report; we are however, pleased to say that it is now complete and has been signed off by all members of the Oxfordshire Parent Carer Forum's steering group.

This report will initially be shared with the Service Manager and Service Director for Oxfordshire CAMHS at Oxford Health NHS Foundation Trust.

Following this we will share the report with the commissioners at Oxfordshire Clinical Commissioning Group.

We will publish this report on our website and share it with our parents via our newsletter and social media during the week commencing 17 August, ahead of the CAMHS Assurance Board in September.

We feel it is our responsibility to gather feedback on services to help aid service development.

It is our hope that alongside Oxford Health NHS Foundation Trust and Oxfordshire Clinical Commissioning Group that we will be able to work on an action plan for CAMHS, drawing from some of the very insightful feedback contained in the report findings.

Appendix 1: Analysis of feedback from Question: Is there anything else you would like to say about your experience with Oxfordshire CAMHS?

Young Persons Feedback

There were 12 young people over the age of sixteen and 16 young people under the age of sixteen that responded to the survey.

For those aged under sixteen, 13 chose to provide additional feedback. Overall the feedback related to accessing the CAMHS service and the accessibility of appointments.

'The problem is accessing any help from CAMHS, not the service we actually get'.

Again there was some acceptance that the service is busy, but for some respondents this meant that they were not getting the support they needed.

'I wait 2 years, I know they are busy'.

'They did too much talking and they need more different ways of describing what they are talking about. They didn't help school or me and School just got more difficult and nothing changed. I am still scared and I'm trying to get these things out of me, but they just keep coming back'.

For those aged over 16, there were 10 responses to this question. It is clear from those that responded that they remain feeling unsupported and are not reflecting a positive experience of CAMHS.

'Seemed to be unable to help me as I was not at immediate risk to myself but still was very very ill'.

'I was initially referred over a year ago and my initial referral was accepted and I had 6 virtual sessions with the Healios. This then ended and I wasn't under the impression I would move on to see the CAMHS team face-to-face but I was discharged and didn't not feel that I had been helped to any great extent as fabulous as the Healios team were. My mental health is now deteriorating and I don't have any support'.

'They told me I wasn't depressed <12 hours after a suicide attempt and that I just had 'extended low mood'.

One individual provided positive feedback.

'Was a great service as I did not know where to turn and how to deal with the situation'.

Parent/Parent Carer Feedback:

327 responses were received from people that identified themselves as parents/parent carers. The main themes raised by parent/parent carers related to:

- a. Waiting times
- b. Communication and Administration
- c. Experience of CAMHS once seen, including the attitude of professionals

Impact of Waiting Times:

This was by far the most frequently cited issue with **154** of the respondents raising this as an issue.

In addition to general comments on waiting times, the specific comments fell into three main areas: referral, the initial assessment and subsequent treatments.

Issues surrounding referral were cited by 27 respondents. The majority of the comments were on the **delay** in getting referrals:

'Her referral was accepted in July 2018!! We are now in January 2020!

'Even after taking an overdose her 'urgent' referral still took 6 months and 2 more overdoses'.

'My daughter was referred in December 2018...I subsequently chased in July 2019 when it became apparent that the referral had not been touched or processed'.

Within these responses eight indicated **confusion about the referral process and criteria:**

'Twice the referral was not accepted and deemed unnecessary. My daughter then attempted to take her own life and was then seen immediately by the crisis team'.

'The whole referral process seems mired in vocabulary and the referral pathways designed to confuse'.

The **wait for a first assessment** was cited 46 times. Many of these responses described the impact of the wait on their child and/or the family, describing the loneliness and frustration at lack of help and support available while waiting.

'I am waiting for an assessment for my 9-year old who is becoming increasingly violent'.

'We had a one year process just to get our son on to the waiting list for an appointment: since then we have been waiting 22 months for the ASD assessment he so desperately needs'.

'Other medical professionals won't help when a referral to CAMHS is in place. Even though the referral was very urgent... we still have no appointment or advice of who can use whilst waiting and are struggling alone'.

The **wait for treatment** to start after assessment was specifically cited 6 times

'Starting the actual therapy took months which made the problem worse'.

'We have been told that it will be another 24 months before anyone sees him'.

'The psychotherapy our son needs to treat the underlying causes of his anxiety has a ridiculous waiting list'.

Communication and Administration:

Comments fell into two broad areas from 21 of the respondents - the infrequency and difficulty of communication and the quality of the administration. Some of the examples cited, included errors in personal identifiable information, difficulty getting through on the phone, and in some cases a lack of communication at all.

'I understand they are busy but a simple letter explaining he had been transferred would have been appreciated'.

'Getting appointments, prescriptions and calls returned is absolutely appalling. I often sent emails which were never responded to apart from the reception to say it had been received'.

'I found it very hard to get in touch with CAMHS as the phone lines are so busy'.

Experience of Service Once Seen:

116 comments on the experience of the service once seen were the most varied. For 25 of the respondents CAMHS was a very positive, indeed life-changing, service of which the following responses are a sample:

'Always friendly and supportive. Massive help for my son'.

'My daughter was having a rough time and I am forever grateful for the help she received. She has made such great improvements.... Thank you'.

'I am impressed with the work done by this organisation'.

'Our experience with having two children on the autistic spectrum referred for diagnosis and support from CAMHS has been positive'.

'We were seen very quickly as my son had a crisis. The response we got was brilliant'.

'Everyone we saw was friendly and efficient. We were listened to and didn't feel rushed at our appointment. I had phone calls and letters sent and was kept updated'.

Another 33 respondents were positive about the clinical experience, but they raised other issues, chiefly delay.

'Our experience once we managed to get an appointment has been positive and we are very grateful. But the wait for the appointment was too long'.

'Our experience once we were seen by the NDC team was very prompt and professional. The waiting time for the assessment, however, is utterly unacceptable and of extreme detriment to the young person and their family'.

***'Great people with knowledge, just horrendous waiting time
A really good resource for diagnosis but were unable to provide any help or support after diagnosis'.***

'This service is excellent but there just isn't enough appointments available to support everyone who requires this intervention. The wait can be long and then you only get 6 appointments and then it stops!'

In contrast there were several responses which reflected a very negative experience of CAMHS in general.

'I felt we didn't matter. I felt my daughter didn't matter, the impact her anxiety and depression were having on her life didn't matter, and the impact this was having on us as a family didn't matter'.

'A complete waste of time. There is no help even when the child is screaming they want to die'

***'CAMHS is broken. Whilst I accept that funding levels and demand levels are not aligned, my personal experience of the completeness of the CAMHS service has been woefully inadequate...
This is not a professional service. It is at best triage. Shameful'.***

'What will it take for something to be done about this? Does a child need to die? Children in Oxfordshire are being failed by a service they can't access. And when they do access it, things have got so bad it's hard for them to find a way back. For the sake of our children, I really hope someone takes note of this survey'.

More specific comments fell into two main areas: the clinical experience and the length of treatment and support afterwards.

Some respondents felt the attitude of CAMHS staff was lacking:

'The original Dr was unhelpful and disinterested'.

'The Doctor I saw didn't even seem to have read up on my child before our initial appointment and kept looking at his watch!'

'I was surprised at how un-child centered the experience was – a box of half-broken toys and my son almost completely ignored for long stretches of the appointment'.

'Since moving from another authority, Oxfordshire's service has been less personal and detached. My child was seen by a doctor who was very cold in nature and a care-co-ordinator who was more nose-y, assuming and abrupt in her approach'.

'We had a mixed experience. Some practitioners were very good, listening carefully, trying to provide appropriate advice and support. Others are not very child friendly and are very scientific in their approach and see the answer in just getting a diagnosis and prescribing medication'.

The length of treatment and availability of ongoing support came up in 12 of responses.

'After our son's six week course we felt slightly abandoned and lost without on-going support. Felt short-changed and wondered how it could be expected that a 6 week course could fix my son's emotional mental health that had been present since he started school'.

'Getting good follow-up is difficult due to pressure on the service. I felt my daughter could have been offered more behavioural therapy'.

'The six-monthly check-ups never happen on time and requests for repeat prescriptions are sometimes ignored, meaning that my children are without their medication as the GP will not prescribe once the repeat is up'.

'When you have waited the tremendous waiting times and you finally get the help, the service is good. The treatments are very short. Waiting list shortened due to using locums and a lack of permanent staff. The person is often signed off before they really should be finished'.

Two comments were made on the physical environment of CAMHS

'The environments we visited were poor. Buildings were stark and unwelcoming and felt very temporary. It was clear that CAMHS was having to scabble around for space and use whichever rooms they could find. This gives a sense of the service being unimportant and underfunded and clearly adds complications for the excellent practioners who are trying to work within it. The experience of a CAMHS assessment is made less pleasant because of this'.

'Face to face meeting in horrible room that triggered child's ASD resulting in poor engagement'.

Professional Feedback:

Of the 92 respondents when asked, 'Is there anything else you would like to say about your experience with Oxfordshire CAMHS?', 66 provided additional comments, six left a single piece of feedback and 60 left multiple comments.

The issues which arose fell into the following main areas:

- Waiting times
- CAMHS Assessment and Diagnosis
- Impact on the young person and/or the school

Of the 66 responses there were positive comments contained within this feedback, but many were positive experiences with caveats attached.

'I find contact with the spa to be helpful.'

'I have had prompt delivery of information on young adults I need discharge letters and care plans for but this can be inconsistent'.

'I have been impressed with the support offered to young adults by the duty clinician'.

'Dr XXXX who acted immediately provided excellent advice and support for a very vulnerable child with critical mental health needs'.

In addition there were 14 comments relaying an understanding of the pressures placed on the service due to insufficient funding and issues with staffing levels.

'It is my experience as a fellow professional that the service is under extreme pressure and consequently is unable to function to meet the needs of the client base. This must be frustrating and demoralising for those working in the service as it is for those who need support. My responses are not a criticism of those trying to meet the demands placed upon them but an opinion that the service cannot cope and that young pupils are not receiving the necessary medical intervention'.

Waiting Times:

When considered in isolation this was the most frequently cited issue with 28 respondents raising this as a concern.

'The waiting list to be seen is increasingly getting bigger and therefore it is taking longer for children to be seen. During the wait time behaviour and well-being of the child and parent deteriorates'.

'The waiting time for an initial assessment is not always the issue. The issue is the waiting time following that assessment if a parent is investigating a potential diagnosis or has concern about an on diagnosed underlying issue having an early initial assessment followed by a two year wait is hopeless'.

'I cannot help but feel it is sad, that families are so accepting of the horrendously long wait for their child to receive support through CAMHS'.

While there were general comments around waiting time, mentioned in nearly all feedback responses, the remaining can be categorised into three main themes, communication, referral process and support.

14 comments related specifically to issues with communication and the frustration experienced by both professionals and families.

'I have had a phone conversation about six months after the referral to give some advice but the fact that we are still waiting for the actual appointment two years later is ridiculous'.

'The communication is very poor. Referrals are declined without clarification with the referrer meaning that you have to go back to square one'.

'When I met recently with a representative from CAMHS, they informed me they were a diagnostic service and didn't provide training or advice to help support pupils in school, I was very shocked. Perhaps an email communicating and explaining the service provided would be helpful in deciding whether to refer or not'.

'As a professional it is frustrating not to be kept up-to-date after making a referral so that we are aware of what is happening as a result also as a school we often need support in how to best support a child in the school setting but this is not provided'.

Referral process was cited in 10 responses put forward by professionals. These related to the frustration caused by a complicated referral process, confusion around which form should be used and not having the capacity to chase referrals whilst supporting parents, who may also have self-referred through the single point of access, but remained unsure as to whether or not their referral had been accepted and if it had what action was being taken to progress that referral.

'Schools have to complete numerous questionnaires regarding the child many of these questionnaires are duplicated. The school send the same information about the child several times. Even when the information requested is sent directly to CAMHS by the school the information is not recorded or saved and the parents are told that school has not sent the requested reports and questionnaires'.

In addition there was specific feedback about the amount of time it takes to process a referral and then the lack of joined up support with other professionals once open. This was highlighted as follows, and relates to the online referral form:

'You cannot save as you go so you have to do it all in one go'.

'You cannot print off a copy of the referral so I've been advised to contact the team to ask for it to be sent to me'.

'You cannot skip ahead to see what the questions are going to be, so the first time you fill in, this is challenging because you don't know what you're going to be asked'.

'You cannot add more information to it at a later date so you either need to send a new referral or a separate email. It should all be in one place'.

CAMHS Assessment/Diagnosis:

Professionals identified concerns that questionnaires for parents and staff are sent out immediately which puts parents into a false sense of security for how long the process will actually take. When paperwork is sent out to families for them to complete, no one from CAMHS checks that the family have received and returned these forms. If these referral forms have been misplaced it is often many months down the line before this mistake is found.

'Although I appreciate the huge caseload and need for the service I think it is so sad how many families we deal with that we refer and then wait for months and then years with cams claiming referrals have not been received despite us sending email evidence to the contrary'.

'For another family we work with that has been waiting in excess of a year since the original referral out of desperation we involve the school nurse through a TAF. The school nurse was made aware and so she was able to chase through the NHS links and we had an appointment allocated within weeks. Although we were relieved to see this family moving forward for some pupils and families we are struggling to keep them on board when CAMHSs appear to have lost referrals or not even attempted to contact them and it would be so helpful if this was not the case'.

Impact on the Young Person:

If you combine responses citing impact on young people and impact on schools, (18 for young people and 13 for schools), then professional concerns about impact are the highest cited issue.

'I am a SENCO and have referred a number of children invariably children are put on the neuro pathway and her on the waiting list for 18 months plus. A current child aged six years old has extreme behaviour and has been waiting more than a year. The family are desperate and the child is now at risk of permanent exclusion. This is a common experience for schools and families'.

'Thresholds are very specific which doesn't always help children with SEND. Many referrals that I make relating to crippling anxiety for a young person are not accepted as the anxiety is put down to being part of their ASD diagnosis and should therefore be accepted as part of their condition'.

'Any concerns raised by school around self-harm should be treated as urgent and supported promptly and thoroughly to prevent the situation deteriorating further and having potentially devastating consequences'.

'During the wait time behaviour and well-being of the child and parents deteriorates'.

There were positive comments from professionals and acknowledgement of the challenges that staff in CAMHS are facing.

'Thank you for what you do, many children when they finally receive your service are able to begin the long road to recovery'.

Impact on schools

The impact on schools and settings cannot be underestimated and 13 comments relate specifically to the impact that these delays can cause.

Schools find themselves in an exceptionally challenging position, where they are not only dealing with the young person in school and supporting them to the best of their ability, but they are also the only face-to-face contact that many families are having, during this very difficult time.

'Like all services the requirement for CAMHS is vastly oversubscribed and you underfunded and understaffed as a result. I write from the school perspective and we are ever more left with children with complex needs and there is nowhere to go to signpost them or to help their parents'.

'We understand that the child we referred was not showing significant signs of self harm but we still felt that it would have benefited their mental health, their parents well-being and life at school if they had been seen with a little more haste'.

'Referrals are now more quickly dealt with. It would be good to be able to save a copy of the referral forms completed online as currently I have to save each page as an HTML file otherwise I have no record of the referral made. This is time-consuming given that it takes nearly as long as the actual completion of the forms, although the referral process is quicker now, often the

outcome for our pupils is for the school to do an EHA and set up community TAF. Many of our children would benefit with talking therapies at that point particularly older primary pupils’.

Again despite the frustrations raised by professionals there was still acknowledgement that staff are working in challenging circumstances and recognition that staff are doing the best they can.

‘I believe cams staff are doing all they can with woefully in adequate resources and in an adequate support network surrounding them so complex issues are referred back to schools who are unable to provide appropriate support for pupils’.

5 comments relate specifically to the suggestion, that if at all possible families should seek support or diagnosis from a private provider.

‘I would only recommend cams if the parents could not afford private support. The cases I have referred to have taken more than seven months for a child to be seen and in most cases the child was at risk e.g. hearing voices telling the child to do bad things or self-harming’.

‘I have worked with a family that in the wait paid to go privately and received excellent support it is unfortunate that it puts families at a disadvantage if they cannot afford this support’

There is a very real shared frustration from the professionals providing these responses.

They are fully aware of the funding and staffing pressure on the CAMHS service and many shared their support and belief that in general the professionals working for CAMHS, are doing the very best they can.

8 comments contained possible suggestions to help improve the service and increase efficiency.

‘I sometimes find the technical jargon on care plans for young people difficult to interpret and we need to act promptly at times especially to bridge the gap between getting help and getting more help. Simplifying the language would be a big help’.

‘Feedback on developments and changes needs to be available on a regular basis and input through the year would be very helpful’.

‘It is very important to give families a realistic timeframe both from the initial referrals as well as from when they are accepted to the NDC. A clear expectation as to what to expect i.e. diagnostic only is important and needs to be given with the letter explaining the timeframe. Any stress

caused to parents is always going to be passed on to the children no matter how well they try to avoid this.'

'Can the spa team have more support to understand service thresholds prior to signposting families who do not meet threshold for getting more help'.

'Sometimes it would be really good to have a phone call or someone as a professional you could talk to about the case as it is hard to convey via paper when you feel something might need further exploration from professionals e.g. a parent who is really struggling and 1 who may be reliant on accessing a service.'

'More guidance from cams about useful support services that parents could engage with whilst waiting.'