

Children and Adolescent Mental Health Services (CAMHS)

Experiences of CAMHS



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Executive Summary

- 1. At the March 2021 Healthwatch Manchester board meeting, members agreed to an investigation, beginning in June 2021, looking at access to CAMHS.
- 2. A survey was designed by Healthwatch Manchester staff and volunteers that would allow citizens to fully outline their experiences of CAMHS. The survey had 9 questions (excluding demographic questions) and took an average of 15 minutes to complete. In total, 8 people completed the survey and 1 person agreed to an online meeting to discuss their experiences further. The survey results were analysed and all the responses are included within this report.
- 3. The research showed a disparity between the information we received in our FOI requests and the experiences outlined by our respondents, particularly around waiting times.
- 4. Respondents' overall sentiment towards the service was negative. One area that received a lot of negative feedback was the transition process out of the service, with a number of respondents feeling that they were simply dropped by the system once they reached the age limit.
- 5. We encountered difficulties in securing support from local schools when we attempted to engage them on this issue. Apart from one teacher, who told us anonymously that most referrals into CAMHS, which can include safeguarding referrals, are made by people who are not qualified to do this, we were unable to get any information from teachers or schools.
- 6. Despite a promotional and outreach campaign, we found it difficult to drive up the number of responses to the survey. Whilst those who did engage with us expressed very strong opinions about the issue, we were nevertheless unable to secure the number of responses we were aiming for in order for this project to carry sufficient weight.



Recommendations

- 1. When reviewing the findings of this report, consideration should also be given to a report produced by Healthwatch colleagues from a number of Greater Manchester localities, titled 'Healthy Young Minds', which can be found in appendix 1. There are a number of similarities between the findings of this report and the findings of our report, and it is important to view access to CAMHS in the wider Greater Manchester context.
- 2. Review the findings of the Greater Manchester Mental Health (GMMH) engagement project titled 'Enhancing the CAMHS Referral Process Have your Say' when the results are published. We understand that engagement sessions were scheduled to take place in December 2021 and the outcome of this work will provide a greater level of intelligence to the decision-making process.
- 3. Dialogue should be opened with the Royal Manchester Children's Hospital, the current provider of CAMHS, in order to see if any further support or assistance can be given to help reduce the current waiting time.



1. Introduction

- 1.1 At the March 2021 meeting, members agreed to an investigation, beginning in June 2021, into access to CAMHS.
- 1.2 The report aims to present the findings of a three-month investigation into the experiences of children and young people accessing CAMHS.
- 1.3 The report also includes provides information regarding the attempt by Healthwatch Manchester to gain similar information from teachers and parents.

2. Background & Rationale

2.1 At the March 2021 meeting, Healthwatch Manchester's board identified access to CAMHS as an area of work for 2021/22.

3. Methodology

- 3.1 A survey was designed by Healthwatch Manchester staff and volunteers that would allow citizens to fully outline their experiences of CAMHS. The survey had 9 questions (excluding demographic questions) and took an average of 15 minutes to complete. In total, 8 people completed the survey.
- 3.2 We promoted the survey through our social media channels and our monthly bulletin, and we also contacted relevant local voluntary-sector organisations to ask if they could promote it to their members and service users. Due to the low initial take-up, we also paid for targeted advertising on Facebook to try and increase exposure of the survey and improve the number of respondents.
- 3.3 One of the final questions on the survey asked participants if they would like to speak with us to discuss their experiences further. One person agreed to this, and their experience is outlined below. This interview was conducted by two members of staff through an online meeting.
- 3.4 As part of the research we submitted two Freedom of Information (FOI) requests to the Manchester University Foundation Trust (MFT) in order to obtain information regarding access to CAHMS. The responses we received can be found in appendices 1 and 2.
- 3.5 All of our participants consented to their experiences being used in this report. A demographic breakdown of our participants is as follows:
 - Gender: Men (2), Women (6)
 - Age (when accessed the service): 7 (1), 9 (1), 12 (1), 13 (1), 14 (2), 15 (1), 16 (1)

4. Results

4.1 First, we asked our participants who had referred them to the service.



- GP 3 participants said they were referred by their GP
- School 2 participants said they were referred by their school
- GP + school 1 participant said they were referred by a combination of their GP and school
- Paediatric consultant 1 participant said they were referred by their paediatric consultant
- No answer given 1 participant chose not to provide us with an answer
- 4.2 We then asked participants if their referral had ever been rejected.
 - 1 participant said that a referral into the service had been rejected
 - 6 participants said that their referral into the service had not been rejected
 - 1 participant said that they did not know if they had had a referral into the service rejected
- 4.3 We then asked participants how long they had waited to access their first CAMHS appointment. All of the answers are recorded below:
 - "few months"
 - "not sure"
 - "months"
 - "1 year"
 - "about 3 months even though an urgent referral had been made"
 - "didn't wait"
 - "8 weeks"
 - "think about a month or two"
- 4.4 Following the previous question, we asked our participants if they felt that this was an acceptable waiting time to access the service. All of the answers are recorded below:
 - "in the current climate I can understand"
 - "N/A"
 - "no"
 - "no"
 - "no"
 - "yeah"
 - "yes"
 - "no, they are long and I believe they are longer now"
- 4.3 We then wanted to know how this had affected them and the people around them, such as family and friends. All of the responses are recorded below:
 - "it was hard"
 - "put my mum under a lot of stress. I got excluded from school"
 - "I was unnecessarily suffering"
 - "My daughter is now 11 and has been referred back to them for a second ADOS
 assessment. This has had a massive detrimental effect on my daughter and our family,
 my daughter's has dived recently due to the lack of services offered."
 - "My condition deteriorated very badly by the time CAMHS did see me they admitted me to hospital the very next day where I stayed for 10 months"
 - "I don't know"
 - "It was hard, but we thought we would get the help I needed at the time."



- "Struggling with how to help me. It was all very new to my family and it was confusing for them how they could help me"
- 4.4 We asked our participants to rate their satisfaction with the service.
 - 0 participants reported being 'Very Satisfied'
 - 1 participant reported being 'Satisfied'
 - 3 participants reported being 'neither satisfied or dissatisfied'
 - 1 participant reported being 'Dissatisfied'
 - 3 participants reported being 'Very Dissatisfied'
- 4.4 We then asked our participants what they would change about the service. All of the answers are recorded below:
 - "For it to be continued as soon as I was 16 I was classed as an adult although I was still at school until the following June."
 - "To continue support to an older age. I feel like once I reached 17-18 I didn't matter"
 - "Nice staff, nice building. Scrap it and start again"
 - "Less waiting time, listen to parents and their concerns without dismissing them. More training on autism."
 - "Earlier appointment may have prevented hospital admissions. Better community support would have prevented subsequent admissions"
 - "Abolish it"
 - "To stop cancelling appointments. To make sure it's a warm, welcoming environment. To keep with the same counsellor rather than different counsellors who service users don't have the trust or confidence in. And counsellors who don't have a professional therapeutic relationship with the service user, this can be more damaging towards the service user. For instance, I was abused by a male and was given a male counsellor because my female counsellor wasn't in work, this upset me, raised my anxiety and I couldn't understand why I was given a male counsellor to talk about the abuse when I preferred to talk to females. The groups they had on wasn't age appropriate for me, I was 17 and yet in a group with 13-15 year olds. I began to experience symptoms of psychosis and was told I'm due to be discharged anyway so they won't look into this and to refer me to Early Intervention Team. To have person centred care in mind when delivering a service for young people."
 - "To carry on post 18+ would love to see my old psychologist again! The long term bond you build with your therapist and comfort can't be found in short term IAPT services. There isn't the time for gradual growth long term too."
- 4.5 For those participants who had transitioned out of the service, we asked them to describe their experience. All of the responses are recorded below:
 - "I was just dropped. If I needed help I was to go to A and E. I had to see the raid team then as an adult which was not a pleasant experience for me or my mum."
 - "Not good. I found it difficult to attend a couple of appointments when I reached 18 because I struggle with anxiety and they said they could not see me and adult services take years to get support"
 - "Very bad. CAMHS just wait until you're nearing 16 so they can get rid"
 - "Yes to thrive where interventions we put in place"
 - "sucked"
 - "I was discharged from this service and referred to Early Intervention Team due to being 18. My experience was atrocious, I began to have experience of systems of psychosis at 17 and was told that CAMHS wouldn't look into this as I'm due to be discharged in a few month time. I felt like I was lost, not important, I felt my parent



who came with me every week for my appointments wasn't being listened to with her concerns regarding the service they provided. This also put pressure onto me as it was making my family member unhappy, with being unhappy, confused with the systems and depressed myself I felt this added to my worries that I would never become happy again. This did make an impact on my self-harming."

- "Not great, poor communication between teams
- 4.6 As referenced above, we ended the survey by asking participants if they would like to speak with us confidentially to share their experience in more detail. Only one of our participants indicated that they would like to do this, and we conducted an online interview with that individual.
- 4.7 This participant told us that their experience with CAMHS began in 2014 when they were referred into the service by their GP, and they used the service intermittently between 2014 and 2015. During this period, they used the service for approximately 7 months, then at the end of 2014 decided that they did not want to keep accessing the service. However, in 2017 their mental health condition deteriorated and so they self-referred back into the service and continued to access support until the summer of 2018.

This participant told us that the first referral in 2014 involved a wait of between 1-2 months for the first appointment, but she was unable to remember how long they waited when they went back to the service in 2017. Following her referral to the service by her GP, she said that she found the waiting period before her first appointment to be very difficult, not just for her but also for her family. She told us that her mental health condition made her feel depressed and extremely upset, and her family struggled with this because they did not know if there was anything that they could do to help. Whilst our participant stated that she found the service to be very beneficial once she accessed it, this waiting period was a real struggle for her and her close family and friends.

Our participant also spoke about her transition out of the service once she had reached 18. She stated that she had developed a good relationship with the person who had been treating her and that she wanted to be able to continue seeing the same person. She described the process as leaving this person as 'very hard', given the trust that had developed between them.

5. Key Findings

- 1. There was a disparity between the information we received in our FOI requests and what we had heard from our respondents. This disparity was particularly clear around waiting times for entry into CAMHS service.
- 2. Respondents' overall sentiment towards the service was negative. One area that received a lot of negative feedback was the transition process out of the service, with a number of respondents feeling that they were simply dropped by the system once they reached the age limit.
- 3. We encountered difficulties in securing support from local schools when we attempted to engage them on this issue. Apart from one teacher, who told us anonymously that most referrals into CAMHS, which can include safeguarding referrals, are made by people who are not qualified to do this, we were unable to get any information from teachers or schools.



4. Despite a promotional and outreach campaign, we found it difficult to drive up the number of responses to the survey. Whilst those who did engage with us expressed very strong opinions about the issue, we nevertheless were unable to secure the number of responses we were aiming for in order for this project to carry sufficient weight.



Appendices

- 1. <u>'Healthy Young Minds'</u> (2019) report by Healthwatch Oldham, Healthwatch Bury, Healthwatch Trafford and Healthwatch Rochdale.
- 2. Freedom of Information request (5 August 2021)
- 3. Freedom of Information request (9 November 2021)



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