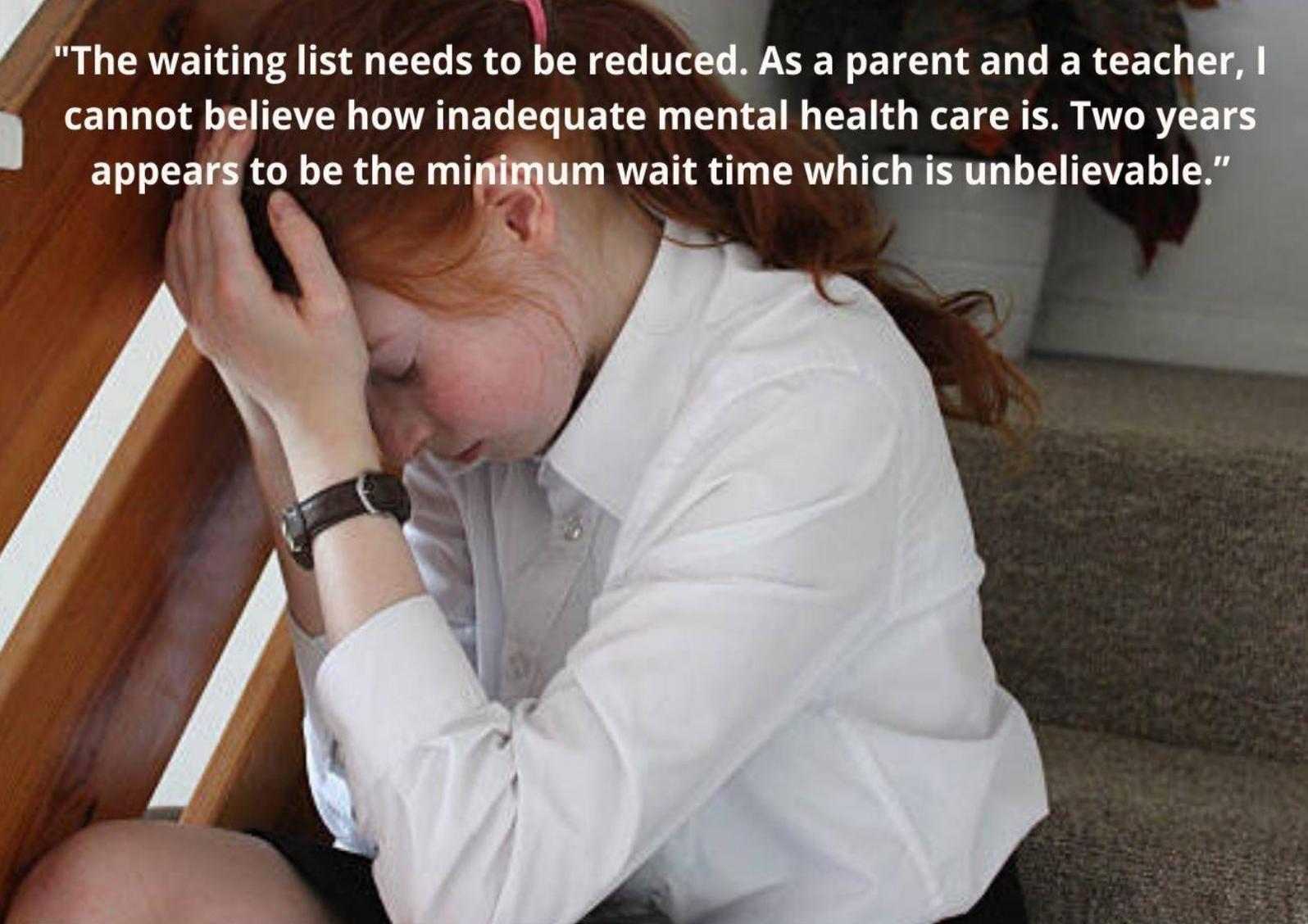


"The waiting list needs to be reduced. As a parent and a teacher, I cannot believe how inadequate mental health care is. Two years appears to be the minimum wait time which is unbelievable."



Child and Adolescent Mental Health Services (CAMHS) Survey Feedback Report February 2021

Contents

Introduction	3
Executive Summary	4
Recommendations	6
Survey Findings	7
Thanks	12
Acronyms Buster	13

“these are the adults of the future and you are letting them down”

Introduction

According to the BMJ report 10th March 2021, [Mental health of children and young people during pandemic](#)

“The mental health of the UK’s children and young people was deteriorating before the pandemic, while health, educational, and social outcomes for children with mental health conditions are worse than for previous cohorts.⁴⁵⁶ Between 2004 and 2017 anxiety, depression, and self-harm increased, particularly among teenage girls.” ⁽¹⁾

In February 2021 Healthwatch West Berkshire undertook an online survey exploring the views and perceptions of the parents/guardians of children who were currently using the local CAMHS. The survey was a follow-up to a focus group run by Healthwatch in July 2019. Due to covid the survey was available only online and was shared on the West Berkshire Healthwatch website and on social media. The survey ran from February to the middle of March 2021. This preliminary report explores the responses and presents some early recommendations for the way forward.

The key finding on extensive waiting times is of great concern especially given Berkshire West was found to be one the 10 CCGs nationwide with the largest increases in average waiting time from 2017/18 to 2019/20 in The Children’s Commissioner’s fourth annual report on the state of children’s mental health services in England 2020/21 ⁽²⁾

It is evident from the 128 respondents who took part in the survey that changes are urgently needed, however the recommendations are by no means exhaustive at this stage and involve far more than just the CAMHS service. Only a totally integrated approach will succeed in improving outcomes for the burgeoning numbers of post pandemic young people with Mental Health and other emotional issues.

While acknowledging the workload of those in managing and delivering the service, we hope this report will be a springboard for root and branch transformations that will improve the mental health and emotional wellbeing of our children and young people in West Berkshire. ensuring parity of care with physical health and indeed with other places in mental health.

1. Sadler K, Vizard T, Ford T, Goodman A, Goodman R, McManus S. The mental health of children and young people in England 2017: trends and characteristics. Health and Social Care Information Centre, 2018. <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>

2. The Children’s Commissioner’s fourth annual report on the state of children’s mental health services in England 2020/21 - <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2021/01/cco-the-state-of-childrens-mental-health-services-2020-21-tech-report.pdf>

Executive Summary

The online survey undertaken by Healthwatch West Berkshire of views and perceptions of CAMHS users locally in February/March 2021 had 128 responses. The responders were the parents and guardians of young people who were seeking help for their children or had sought help in the past. 93% of the children and young people concerned were of school age (11-18 years).

Many of the responses within the survey highlighted the issue of very long waiting times for help, with 50% of the responders waiting between one to three years to be given a diagnosis for their child. In addition, over half had waited between one to three years to access CAMHS for any reason. Some parents and guardians said that their child's condition worsened due to long waiting times, others believed their child's education had suffered and that the mental health and wellbeing of other family members had been adversely affected. A considerable number resorted to paying for private treatment and diagnoses. Three quarters believed that earlier access to CAMHS would have made a difference to their child.

In response to questions about the effectiveness of CAMHS, there was an overall feeling that the service was not satisfactory. 61% of respondents said the service had not made a real difference to their child. 70% were unhappy with the information received on discharge with 8 out of 10 stating they would have liked more information about where to get help.

Additional comments/requests supported the urgent need to decrease CAMHS waiting times and support parents/guardians and the children and young people at all stages including waiting to be seen and after discharge. Many responders felt there needed to be better communication between the CAMHS team and the families and there was a general plea for more staff and more experienced staff, better able to help the children and young people with complex and challenging mental health problems.

It is important to note that there has been a recognition by Commissioners of the need to improve CAMHS provision locally and a Local Transformation Plan was developed to this end in 2015. The *Future In Mind Local Transformation Plan (LTP) For Children and Young People's Mental Health and Wellbeing* has been regularly refreshed and in January 2020 a report was taken to West Berkshire Health and Wellbeing Board of the refreshed version of October 2019. The LTP provided an update on service development and improvement across the comprehensive Child and Adolescent Mental Health Service (CAMHS) system.

The refreshed LTP can be found here:

https://www.berkshirewestccg.nhs.uk/media/5486/children-and-young-people-s-mental-health-and-emotional-wellbeing-ltp_final.pdf

The backdrop driving activity and improvement in this area included a continued increase in demand for children's mental health services and thus increased waiting times; difficulty recruiting the CAMHS workforce, despite additional resources for specialist CAMHS teams across Berkshire West; concerns about the self-harm rates in all three Local

Authorities for people aged 10-24 and self-harm rates for 15- to 19-year-olds across all three areas that were higher than the national average.

The LTP listed 7 priorities for action, the majority of which relate strongly to the Healthwatch West Berkshire CAMHS survey, in particular priorities 1,3,5,6 and 7:

Priority 1 - Ensure that we embed and expand the Mental Health Support Teams in Berkshire West

Priority 3: Continue to build a 24/7 Urgent care/Crisis support offer for Children and Young People (CYP)

Priority 5: Improve the Waiting times & Access to support, with particular this year on access to Autistic Spectrum Disorder (ASD) and Attention-deficit/hyperactivity disorder (ADHD) assessments and support.

Priority 6: To improve the Equalities, Diversity and Inclusion offer and access for Children and Young People in Berkshire West

Priority 7: Building a Berkshire West 0 - 25-year-old comprehensive mental health offer.

The foreword to the LTP was signed by the Directors of Children's Services for the Berkshire West 3 Local Authorities plus the Director of Joint Commissioning for Berkshire West Clinical Commissioning Group. The following statement was made:

'We must and we will work together to find creative solutions to get the right help, at the right time, in the right place for our children and young people, and their parents or carers. We are committed to listening and responding to what children and families tell us they need. We will review and learn from what's working well and agree together what we need to do to continue to improve.'

Since January 2020 we have suffered a Coronavirus pandemic which has taken the lives of over 127,000 people nationwide. Many NHS service developments have had to be put on hold in order to deal with this pandemic. It is evident that there has been commitment at the highest levels locally in Berkshire West CCG and the 3 Local Authorities to improve CAMHS and address the mental and emotional health and wellbeing needs of children and young people. However, this survey demonstrates that the CAMHS in West Berkshire is still not meeting these needs and the service users are unhappy with many aspects of the service.

The recommendations listed in this report undoubtedly will dovetail with the action plans that have been developed as part of the LTP to improve the mental and emotional wellbeing services for our children and young people. Healthwatch West Berkshire believes that these recommendations should be urgently addressed.

Recommendations

1. Decrease the waiting times for children and young people to receive a diagnosis having been referred to CAMHS, to a level that is acceptable and reasonable.
2. Decrease the amount of time taken for a child/young person and their parents/guardians to be seen by CAMHS for any reason following referral.
3. Initiate an internal review as to why parents and guardians of young people who have been seen by CAMHS do not believe that it made any difference to their child. Develop an action plan to improve outcomes of the service.
4. Improve the quality of information and advice that all children and young people and their families receive from CAMHS when they are discharged from the service.
5. Ensure that all children and young people and their parents and guardians are signposted to other mental and emotional health and wellbeing services as appropriate.
6. Increase the support given to children and young people and their parents/guardians throughout the whole CAMHS journey from referral, diagnosis and treatment through to discharge or referral to another service.
7. Improve communication between the CAMHS team and parents/guardians and children and young people being referred to the service at every stage of their CAMHS experience.
8. Increase the number and quality of staff working within the CAMHS team to meet the needs of the children and young people and their families.
9. Ensure the most up to date Local Transformation Plan for Children and Young People's Mental Health in Berkshire West is fully implemented and all aims and objectives in any accompanying plans are fulfilled and reported to the Health and Wellbeing Board.
10. Ensure that all Public Health data relating to the ongoing mental health and wellbeing of children and young people in West Berkshire is regularly reported to the West Berkshire Health and Wellbeing Board and local service commissioners.
11. Improve the preventative and early intervention services available to all children in West Berkshire in order to improve and maintain their mental health and wellbeing and help to prevent the number of referrals to CAMHS.
12. Improve communication and liaison between mental health services in schools and CAMHS to help ensure that children and young peoples' needs are met and there is clear and logical continuity of care across settings.

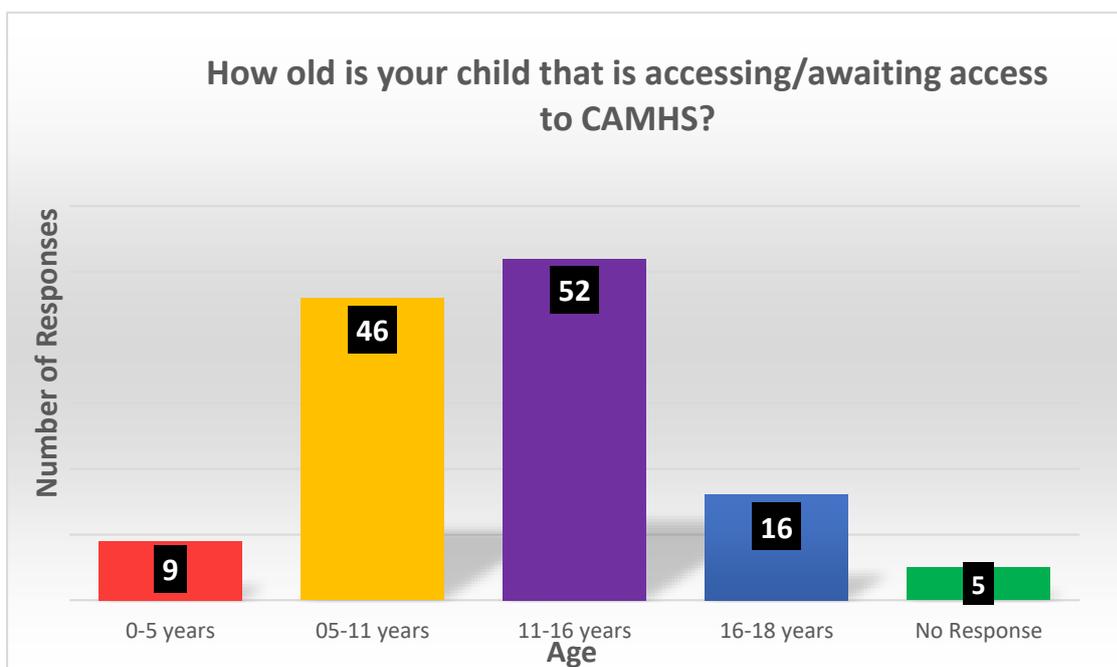
“Post diagnosis my child's mental health has not been good, and she has been self-harming. I contacted CAMHS and was told she didn't meet their criteria for referral, and they closed the case. They told me to wait for the Emotional Health Academy to get back to me, even though the EHA's triage form says if your child is high risk of self-harm, you should contact CAMHS.”

“Triage kids earlier! By the time we get seen, it may be too late to effectively help.”

“Impossible to access because of the ever-changing goal posts Remember these are the adults of the future and you are letting them down. They are thus starting adulthood on the back foot. Constantly changing staff who never read the notes means that the whole story has to be retold every time”.

Survey Findings

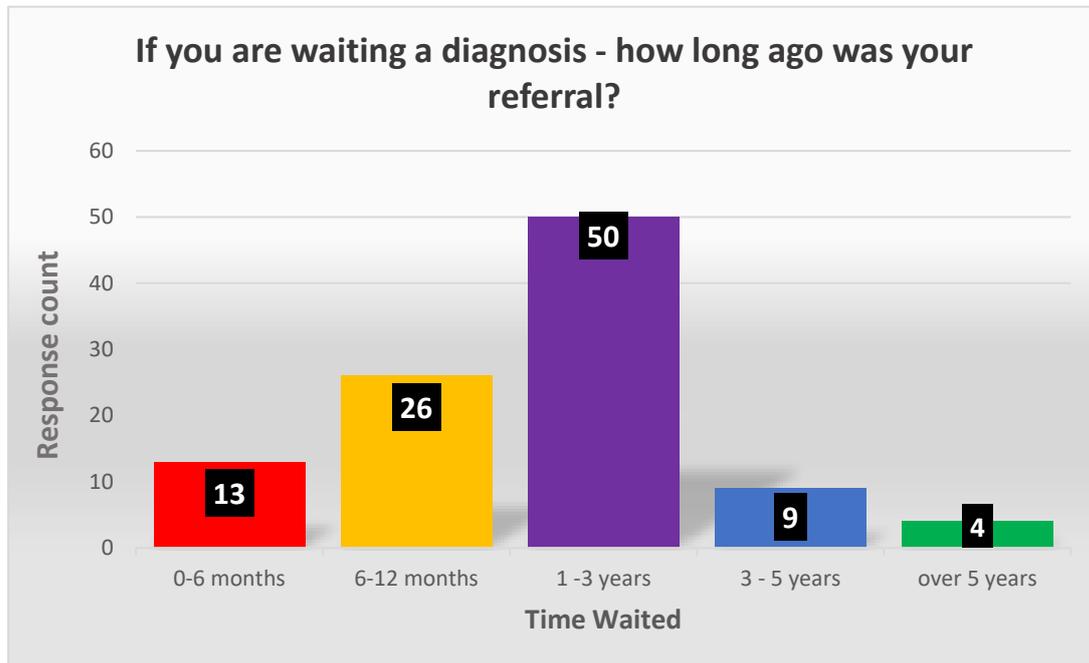
Question 1 - Parents/guardians were asked the age of their child who accessing/awaiting access to CAMHS was.



Out of 123 responses, 43% of children were 11-16 years old and 37% were 5-11 years old. Thus 80% (98 out of 123) were from ages 5 to 16 years. 13% were 16-18 years old, and 7% were in the 0-5-year age group. (5 non responders). For future reference 93% of the children and young people who were accessing CAMHS were of school age.

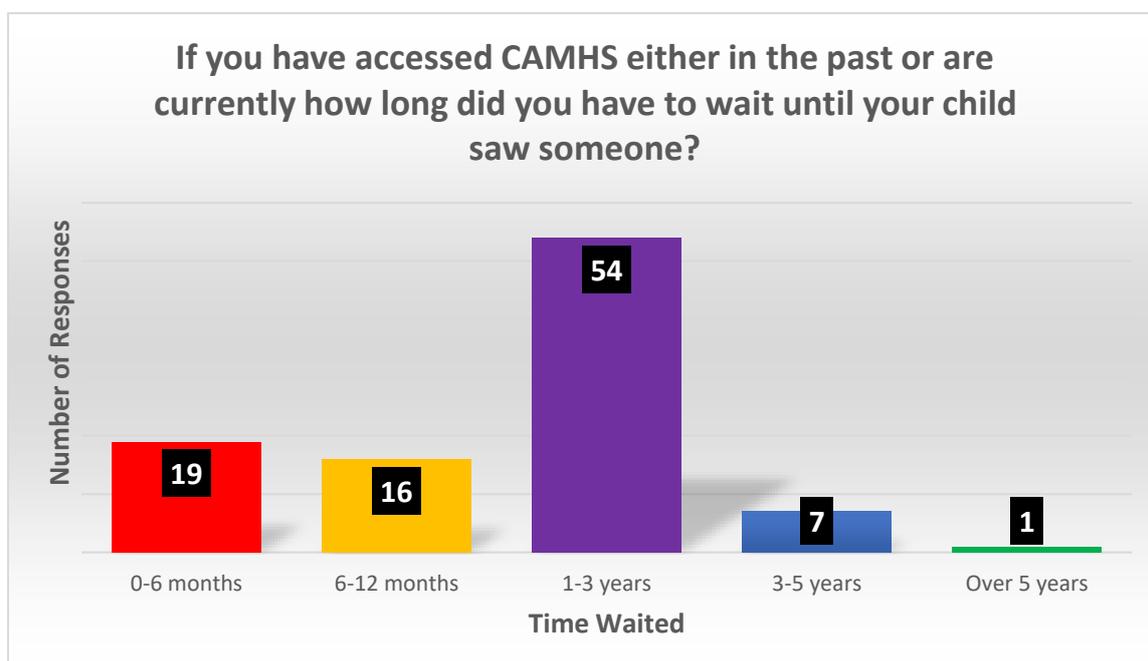
“More funding and more staff. Their waiting times are awful and to offer no help for a self-harming primary school aged child is negligent”.

Question 2 - This question examined the length of time a parent/guardian had to wait for a diagnosis if their child was referred for a diagnosis.



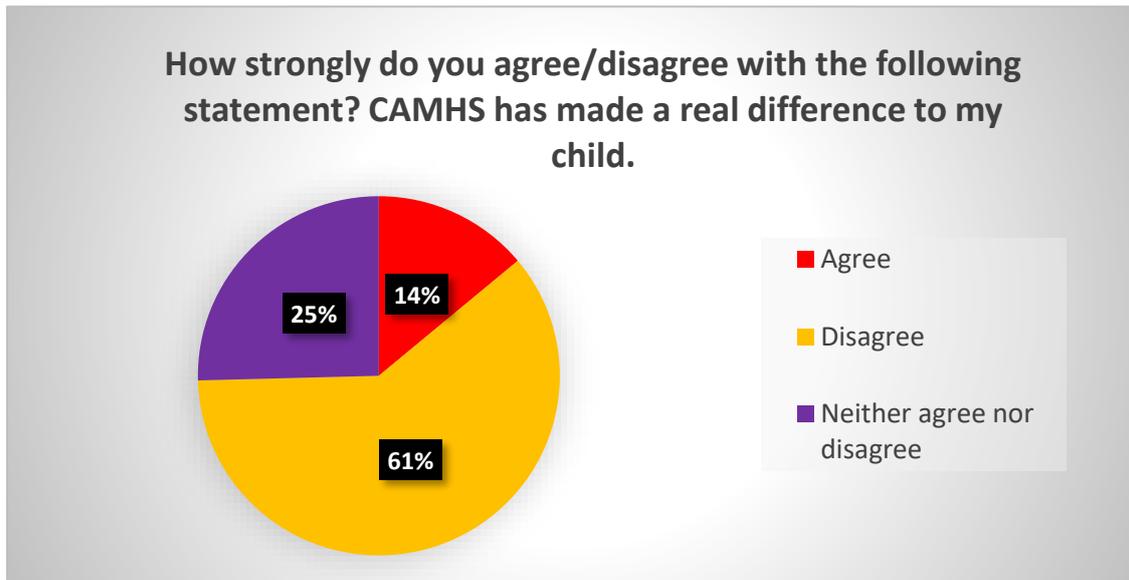
Out of 102 responses, almost half (49%) reported waiting between 1 and 3 years from their referral to CAMHS for a diagnosis. Only 13% said their referral to CAMHS was 0-6 months ago while another 25% waited 6-12 months. A disturbing 9% said their referral was 3-5 years ago, with a further 4% reporting a gap of over 5 years. (26 non responders). (Recommendation 1)

Question 3 - This question referred to waiting times in particular to be seen for any reason: 'If you have accessed CAMHS either in the past or are currently, how long did you have to wait until your child saw someone?'



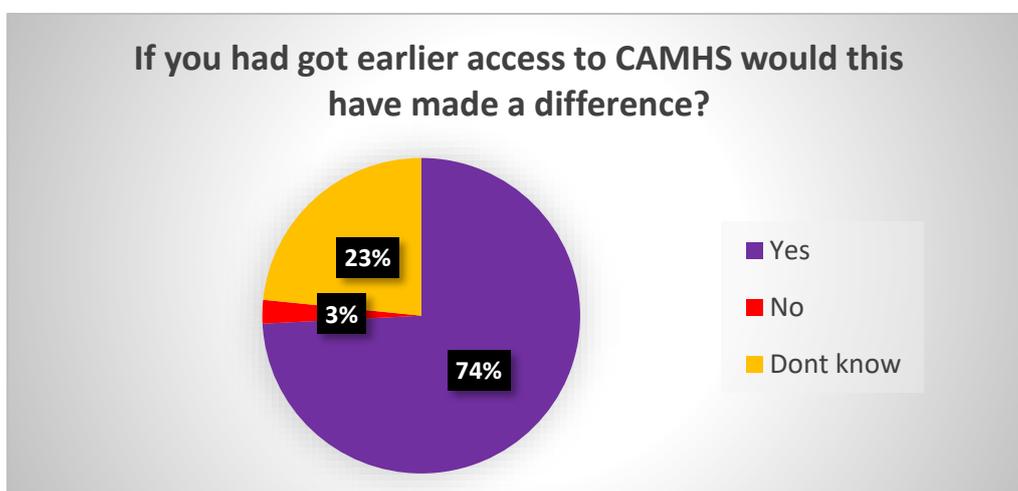
Out of 97 responses, over half (56%) said the wait for CAMHS to see their child was between 1-3 years. Only 20% said the wait for their child to be seen was between 0-6 months while a further 16% waited between 6 to 12 months. 7% of respondents said they waited 3-5 years for CAMHS to see their child with 1% reporting a wait of over 5 years. (31 non responders) (recommendation 2)

Question 4 - Parents/guardians were asked to agree or disagree with the statement 'CAMHS has made a real difference to my child'.



Of 122 who responded (6 non responders), a majority of 61% disagreed or strongly disagreed that CAMHS had made a real difference to their child. Only 14% agreed that CAMHS had made a difference, and 25% of respondents neither agreed nor disagreed. (Recommendation 3)

Question 5 - Parents/guardians were asked the following question: 'If you had got earlier access to CAMHS would this have made a difference?'

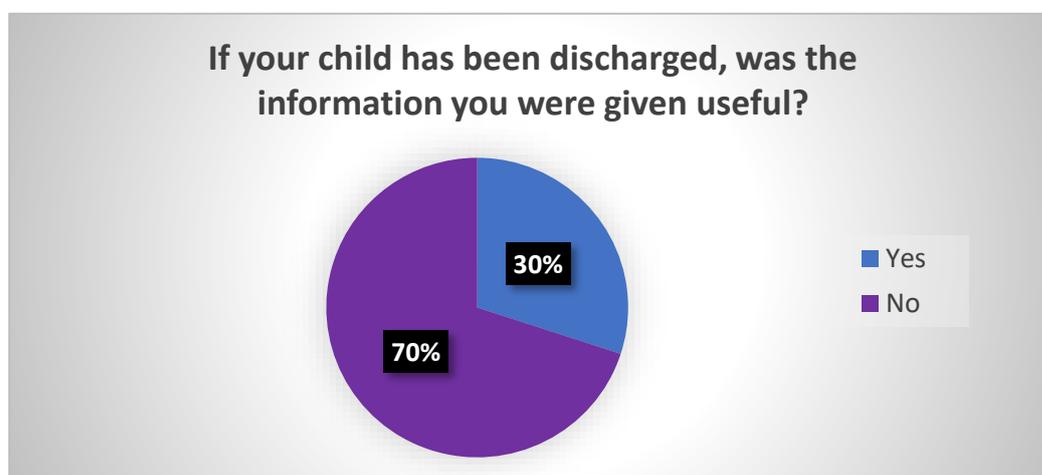


Out of 124 responses, around three quarters (74%) believed that if they had got earlier access to CAMHS this would have made a difference to their child's mental health. 23% reported they did not know whether earlier access would have made a difference while a small percentage (3%) did not believe earlier access would have made a difference. (4 non responders) (recommendations 1 and 2)

Question 6 - Respondents were asked to elaborate on this question and 84 shared their views which have been thematically analysed below. This is not an all-inclusive list but some of the more frequent answers have been grouped and included.

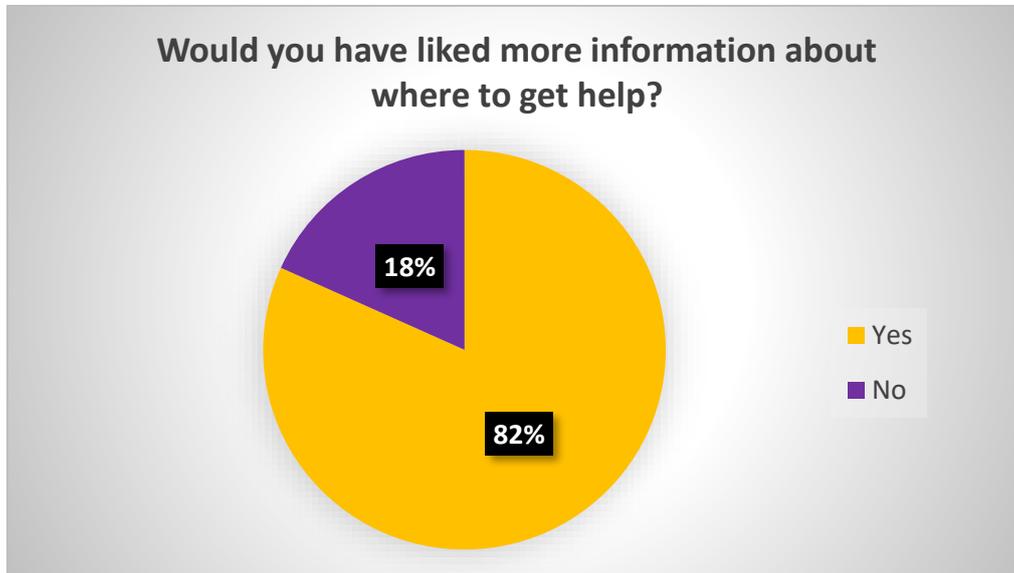
- 62% of responders (52/84) were dissatisfied with the time it took for their child to be seen by CAMHS. This included time taken to be seen, be assessed, be given a diagnosis or to receive treatment (recommendation 1 and 2)
- 20% or 1 in 5 (17/84) were unhappy with the treatment their child did receive from CAMHS (recommendation 3)
- 17% (14/84) believed the condition of their child worsened due to the delay in being seen by CAMHS (recommendation 1 and 2)
- 13% (11/84) believed that their child's education had suffered significantly because they had not received the help they needed from CAMHS in a timely fashion.
- 9 respondents stated that they were forced to pay privately for their child to receive help.
- 7 respondents reported that as a result of their child having to wait to receive the help they needed from CAMHS it had affected other family members.

Question 7 - Parents/guardians were asked the following question: 'If your child has been discharged was the information you were given useful?'



70% (49/70) did not believe the information given to them when discharged was useful, and only 30% (21/70) felt the information given was useful. 58 respondents did not answer this question. (Recommendation 4)

Question 8 - Parents/guardians were asked if they would have liked more information about where to get help?



Of 104 responses, around 4 out of 5, or 82% (85 respondents), said would have liked more information about where to get help from CAMHS. 18% (19 respondents) said they would not have liked more information. 24 people did not respond to this question. (Recommendation 5)

Question 9 - In this question parents/guardians were given the opportunity to elaborate on what recommendations they would make to improve CAMHS locally.

94 people shared their thoughts with 34 non responders. Again, these comments, many of which were emotional, and heartfelt have been clustered to demonstrate the most common recommendations. Further analysis could be undertaken to identify more suggestions.

- 55% (52/94) of respondents urged that waiting times be significantly reduced. (Recommendations 1 and 2)
- 20% (19/94) recommended more support be made available for both children and families while the child was waiting to be seen, from referral, during diagnosis and treatment, and after treatment. (Recommendation 6)
- 22% (21/94) recommended that there was better communication between the CAMHS team, the child/young person and the families at every stage of the process. (Recommendation 7)
- 23% (22/94) wanted to see more staff and more experienced staff within CAMHS. (Recommendation 8)
- 9 responders suggested increased funding was needed to bring down the waiting times and increase the number of staff.

Question 10 - A final section asked parents/guardians to share any other ideas and thoughts they had.

79 parents/guardians shared additional thoughts. Many showed a high level of frustration and dissatisfaction.

- Just over a quarter (21/79) of the comments were critical and negative. Typical phrases included ‘appalling service’, ‘disappointed with the service’, ‘feel let down’, ‘awful experience’, ‘an absolute disgrace’.
 - Only 8 respondents, or around 10%, made any positive comments. Some of these comments mentioned ‘practical advice’, ‘excellent clinician who got to the bottom of our problem’, ‘amazing course of therapy’ and ‘very thorough and diligent professionals’.
 - Waiting times again featured with 18 respondents, or 22%, mentioning this was a problem in their child’s diagnosis and treatment. (Recommendations 1 and 2)
-

THANK YOU

Healthwatch West Berkshire would like to thank all the members of the public who took the time to fill out the survey and everyone who has been in touch to give feedback around the CAMHS services in West Berkshire.

Thanks to Board Member Lesley Wyman for co-authoring the report, placement student Abbie Rickard and all of our amazing volunteers and board members for their help.

Acronym Buster

CAMHS - Child and Adolescent Mental Health Services

BMJ - British Medical Journal

LTP - Local Transformation Plan

CYP - Children and Young People

ASD - Autism Spectrum Disorder

ADHD - Attention Deficit Hyperactivity Disorder

CCG - Clinical Commissioning Group