

# Healthwatch East Sussex

Navigating Mental Health Support in East Sussex:  
Identifying the Road Blocks

August  
2015

For children and  
young people using  
Child and Adolescent  
Mental Health  
Services (CAMHS)



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# 1. Executive Summary

1.1. **Between April and May 2015, East Sussex Community Voice, through its Healthwatch East Sussex functions carried out a piece of work to investigate access to Children and Adolescent Mental Health Services (CAMHS)<sup>1</sup> for children, young people, their carer's and other relevant organisations.**

1.2. The aim was to seek the views of children and young people on CAMHS and to identify any problems they may have had in accessing the service. Areas of good practice have also been sought.

1.3. This report is a summary of the key findings, priority areas and actions for Healthwatch East Sussex (HWES) and local partners to consider developing.

## Stakeholder feedback

1.4. Stakeholders receiving this document are requested to work with HWES to explore any issues raised in the research, and to:

- Comment on the key findings; and
- Identify potential next steps for collaborative working, and / or service change.

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<sup>1</sup> Services provided by Sussex Partnership NHS Foundation Trust and other stakeholders identified to seek the wider patient Voice



## 2. Background

**In recent months there has been increased coverage in the media about the lack of inpatient facilities for young people, with many having to be placed far from their homes. This is both a national issue and one that has affected East Sussex. The aim of this project is to seek the views of children and young people on the Child and Adolescent Mental Health Service (CAMHS) and to identify any problems they may have had in accessing the service. Areas of good practice have also been sought.**

2.1. The Department of Health produced a report entitled 'Future in Mind - Promoting, protecting and improving our children and young people's mental health and well-being'. This was to report on the work of 'The Children and Young People's Mental Health and Wellbeing Taskforce' set up by the Government in September 2014. Some key themes and issues were identified from this study. These included difficulties in accessing services with increase in referrals and waiting times, access to services at times of crisis and issues around the appropriateness of the tier system (as outlined below). One of the recommendations states "in every part of the country, children and young people having timely access to clinically effective mental health support when they need it" with this being delivered through a "five year programme to develop a set of access and waiting times standards".

2.2. The Care Quality Commission (CQC), the regulators of health and social care, produced an inspection report, dated 28 May 2015, on the services provided by Sussex Partnership Foundation Trust. It included a separate report entitled 'specialist community mental health services for children and young people'. CQC now rate all services. The overall rating for SPFT services is 'requires improvement'.

2.3. The overall summary states "Overall we found that these services require improvement because we evidence that people were waiting<sup>2</sup> too long for assessments to happen. We also found that there were not always adequate risk assessments and an inconsistent approach to physical health monitoring, particularly for young people on psychotropic medication. In some areas staffing levels did not always ensure that people in need of these services received a timely response. However, it is positive to see that in the caring domain these services were rated as outstanding. There was good evidence of very positive approaches to involving people and consulting with families and carers. We saw that the user engagement agenda was well

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<sup>2</sup> Children & young people in East Sussex are offered an initial appointment within 4 weeks for assessment. This is a Key Performance Indicator for Sussex Partnership NHS Foundation Trust to rep in East Sussex we use SDQ and have been part of the national Children & Young People's IAPT which has introduced a suite of additional measures which are currently being rolled out.

This is a KPI which we report to Commissioners and over achieve the 95% target. (Comment by Sussex Partnership

developed and embedded across these services and staff were highly committed and passionate about their work. Outcome<sup>3</sup> measures for children and young people were not routinely used to monitor the effectiveness of care treatment.”

2.4. The report also stated “Staffing levels did not ensure that young people in need of CAMHS received a timely service for their needs, which could put young people at risk. The risks to young people on the waiting list were not monitored, which put young people at risk of harm to themselves or others”.

2.5. A discussion was had with a team leader in a local CAMHS office to ascertain the process of referral and setting up support. About 60-70% of referrals come through GPs. The local office will have daily screening of referrals to decide which will be accepted and which will not. Those not accepted as appropriate for CAMHS will be redirected to other services. Young people and their families and carers are asked to complete a ‘strengths and difficulties’ questionnaire. Young people are also sent other information such as the download groups (local support groups for young people) and the ‘Getting to Know You’ leaflet.

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<sup>3</sup> In East Sussex we use SDQ and have been part of the national Children & Young People’s IAPT which has introduced a suite of additional measures which are currently being rolled out. (Statistic provided by Sussex Partnership NHS Foundation Trust)

2.6. Sussex Partnership Foundation Trust (SPFT) has produced a document entitled ‘Your Guide to Child and Adolescent Mental Health Services (CAMHS) in Sussex’. This document states that “We try to see people within 4 weeks of receiving the referral”.

2.7. If a referral is accepted the person will be invited to a ‘choice’ appointment. If the mutually agreed decision is that CAMHS can provide further support the person will be offered a ‘Partnership’ appointment. The document states “we typically help people over an average of 7-8 meetings”. The document also states “if you are offered Partnership sessions we will give you an appointment within 18 weeks of your referral”.

2.8. CAMHS also works to a tier system:<sup>4</sup>

Tier 1: consists of non-specialist primary care workers such as school nurses and health visitors.

Tier 2: specialist primary mental health workers who offer support to other professionals and organisations

Tier 3: specialist multi-disciplinary mental health teams (i.e. CAMHS) who deal with more complex situations, which cannot be dealt with at tier 1 or 2.

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<sup>4</sup> This is SPFT contribution to Tier 2 other stakeholders will include e.g. counsellors i.e. in schools & GP surgeries, paediatric professionals, youth workers, Youth Offending Services and many of those listed below. (Comment provided by Sussex Partnership NHS Foundation Trust)

Tier 4: specialist day and inpatient units for people with more severe mental health issues.



## 3. Methodology

**A number of means to seek young people's views were used. Information was also sought from carers and from organisations that support young people and their carers related to mental health needs. As a result, the following organisations were either met with or contacted by phone:**

- Care for the Carers
- Clued Up
- Families and Children (COPEs)
- Home works
- Sussex Oakleaf
- My Time
- Xtrax Young Peoples Centre
- Ice Project
- BEAT (Beating Eating Disorders)
- Counselling Plus
- Targeted Youth Support Services

3.1. Attempts were made to contact a range of other organisations, in both the statutory and voluntary sectors, but without success. Messages were left for people to make contact, but they failed to respond.

3.2. Assistance was also sought from SPFT. Meetings were held with several people including head office staff and those who manage local CAMHS services.

3.3. Arrangements were made to meet young people who were inpatients at

Chalkhill, a hospital run by SPFT, and at Ticehurst Hospital, who also run an inpatient unit for young people. In addition, a group of young people were met with at a support group run by SPFT.

3.4. A questionnaire and introductory leaflet were circulated, to seek young people's views. About 500 surveys were circulated through the above mentioned organisations. A freepost envelope was given with all surveys, so that there was no cost to people completing the form, to encourage as good a response as possible.

3.5. Some problems were identified during this project in terms of support from CAMHS. Whilst some sections of CAMHS engaged very well and positively with the project, others did not. For example, the timescale for completing the survey was originally mid-April. However, very few survey forms had been returned. As a result arrangements were made to spend time in various CAMHS offices. The purpose was to meet people in the waiting areas, explain about the survey and encourage people to complete the form. At a visit to one office it was noted that the survey forms had been left by the reception desk. However, of the 75 sent to this office, none had been given out. At another CAMHS office, the manager stated that not one of the survey forms had been given out as they were unsure what the survey was for or knew anything about it. It was very disappointing that some personnel appeared to have a negative attitude to this piece of work.



- 3.6. Soon into the project it became apparent that one issue identified by a range of people was that there can be a delay in getting an initial<sup>5</sup> appointment and a long delay before any service starts. As a result, a request was made to CAMHS for some relevant statistics on timescales for when people are offered their initial appointment and when the service actually starts. A copy of the template used to inform young people and their carers of any delays in an appointment or a service was also requested. None of this information was sent, despite a reminder.
- 3.7. Having said this, some CAMHS staff were very supportive and assisted in arranging visits to groups and offices and one office had been very proactive in encouraging young people and their carers to complete the survey forms.

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<sup>5</sup> All children & young people offered an initial/choice appointment within 4 weeks. East Sussex offers an extended assessment/treatment of up to 3 appointments to all. (Comment provided by Sussex Partnership NHS Foundation Trust)



## 4. Observations and findings

**A range of voluntary organisations were either met with or contacted by phone to seek their views. Key issues raised include:-**

- One worker stated that they felt there is a good relationship with CAMHS and generally there is a good response. Due to the high threshold before CAMHS will provide support to a young person and their family / carers, they can feel in the middle with CAMHS stating that the person does not meet their criteria, but the voluntary organisation cannot meet their needs as it cannot provide the level of support they require. They can support young people who are deemed to be in tier 1 and 2, but not tier 3, and they thought CAMHS tend to only work with those young people assessed as being in tier 4. The issue is; where do these young people assessed as tier 3 go for their support and help<sup>6</sup>? This person thought there is a lack of one-to-one counselling for young people, particularly in the Hastings area.
- One worker stated that they thought the CAMHS staff can be flexible and have seen young people at their establishment rather than in the office. They said that they tend to know what referrals will be accepted by CAMHS and so only refer those with a high chance of receiving a service. They stated that there is a waiting list

at CAMHS and, although the initial assessment can be undertaken fairly quickly, there can be a wait of about 10 weeks before the work and interventions can commence. The organisation this person works for tends to support those who are deemed to be in tier 1 and 2. They also thought that there is a lack of counselling for young people and their view is that CAMHS is not a counselling service.

- One worker stated that it is very hard to ever get a referral to CAMHS and this takes up a great deal of time, effort and continual pushing. This person also recognised the positive side to CAMHS. They stated “I have worked alongside CAMHS supporting other families and that has been a brilliant resource”. They also stated that the criteria before CAMHS provides a service is way too high and as a result young people are not getting the support and help they need, as they are deemed to be coping.

### **4.1. One worker for a voluntary organisation identified a few issues:-**

- One family they were working with was assessed and was given play therapy sessions. However, this was at Crowborough and the family live in Uckfield and so they had to get the child to Crowborough. This was not easy as it had to be by bus, which is not so efficient in rural areas.
- A child was assessed by CAMHS, not offered support but suggested that the

<sup>6</sup> Young people assessed as requiring a specialist (T3) service will be seen by CAMHS. Tier 4 would be inpatient which is provided at Chalkhill or other national services. (comment provided by Sussex Partnership NHS Foundation Trust)



family be referred to Children's Services. This the worker did, but they were also not able to assist.

- Another child was assessed by CAMHS who concluded that they needed "2-3 sessions" but had to wait 6-8 months for the appointment, by which time the issues had moved on.
- The assessment questionnaire for parents is very lengthy, time consuming and assumes parent has good enough level of comprehension and writing ability.
- Assessments are undertaken in a clinical setting and are lengthy. This can cause families and children to become quite anxious, which may exacerbate the situation.
- On the positive side, this person stated "I like the new booklet for children to complete in preparation for their assessment / appointment".
- Finally, they thought a referral form would be useful, so that everyone would be clear about the criteria and process.

*4.2. A group of young people who currently receive a service from CAMHS were met with. They had been receiving a service from CAMHS for varying lengths of time from about a year to about 6 / 7 years. Key issues they raised were:*

- Choice. They stated that they had not been given a choice of the type of intervention. For example, one young person had several sessions with a CAMHS worker and was asked to spend time drawing. The young person thought this was "boring" but felt unable to state this to the worker. They stated that appointments were

usually in Hailsham and so they have to travel there rather than appointments being local. However, one person did state that they had been seen more locally on occasions. One young person said that they had to see the therapist with their family and was not offered the choice of seeing the therapist on their own, which they may have appreciated.

- As a result of the above, there was a sense that the young people had little or no control over their support or the interventions. One young person had been an inpatient. He stated that he was told one day that he was being discharged. They were told that they could write down the reason why they did not think they should be discharged. The young person did not find this helpful or supportive.
- Communication. The young people felt that some workers were better than others on this. For example the young person who was assessed to do art therapy stated that they were not given a reason why they were asked to do this or an explanation at the end what it had achieved. This left the young person thinking it was pointless.
- There was general agreement that you had to deteriorate before getting the help and support you need. This was linked with their view that there is a delay in getting a service, unless it is deemed to be very urgent.
- One young person was told that they were too old for some therapies, such as play therapy.



*4.3. Arrangements were made with Ticehurst Hospital to visit the two inpatient units to try to meet young people there. Three young people agreed to meet with us. Each told a different story:*

- The first person had been receiving a service from CAMHS for about 2-3 years. They felt they had received a quick response and thought this was due to her GP and Head Teacher knowing how the system worked and so made the right referral at the right time. She was positive about the service. She stated that she had been offered choices of what support she wanted and also been involved in choosing which worker she wanted to support her. She stated that she had a good rapport with one particular CAMHS worker and so it was agreed that this person would continue to support and work with her, even though she should have moved to another worker. She had spoken with other young people who had not had such a positive experience as her, so she thought it “depended who you got”.
- The second young person was not so positive in explaining her experiences of CAMHS. She had met her key worker from CAMHS a couple of times, once before she was admitted to Ticehurst Hospital and once at a Care Programme Approach (CPA) meeting. She could not recall the worker’s name and the worker had spent no individual time with her, even prior or after attending the CPA meeting. The young person explained that she had been admitted to Ticehurst Hospital from a general hospital. She explained that the original plan was for her to go to Chalkhill Hospital at Haywards Heath,

but this had changed and she came to Ticehurst Hospital. She could not remember whether anyone gave her an explanation for this change, but she accepts that she was in crisis at the time and so this period is a bit vague for her.

- The third young person met with had been at Ticehurst Hospital for over a year. She stated that she wants no contact with her CAMHS worker because she thought she did not listen to her as they had made assumptions about her rather than asking her. She also stated that, as a result of this, she chooses not to go to her CPA meetings. She stated that she has received good support from the Ticehurst Hospital staff. She also stated that another patient’s discharge had been delayed by three weeks as her support services in the community had not been set up.

*4.4. A visit was made to Chalkhill to meet with as many young people as possible receiving an inpatient service.*

The meeting was facilitated by the MIND Advocate. Three young people agreed to meet with us. Being inpatients at Chalkhill, they often had long experience of the CAMHS services and were able to reflect on their pathway to being an inpatient. Key issues they raised included:

- One person said there had been many delays in her getting to Chalkhill. She had been admitted to a general hospital on four occasions, during which a referral had been made to CAMHS but there had been delays in the service starting. This person had been told that she would be found a



place at Chalkhill but this had been cancelled a number of occasions and at one point she had been told she may go to a hospital in Worcester or London. Finally a bed was found for her at Chalkhill. She had been given a couple of days' notice of the placement. She explained that her situation had to get really bad before they would help. She also stated that she did not feel supported by CAMHS.

- All three young people felt they had little control over what happened to them and felt uninvolved.
- They stated that meetings are held to discuss their progress but these are held with numerous people attending, most of whom they do not know or know why they are there i.e. do not know their role. They stated that no one tells them or forewarns them, unless at the very last minute as they are going into the room, that there will be so many people there.
- Nobody had explained to them about these meetings, their purpose or who would be there. They found attending these meetings was very difficult and one stated that she looked down during the meeting and could not face anyone.
- One person stated that she had been given about an hour's notice that she would be going to Chalkhill.
- Another person said that she was brought to the hospital with no

planning or involvement and she had not had time to pack. She wondered if they had done this in case she had refused to go. She stated that she felt like they had "tricked" her.

- One person felt that you had to be 'really bad' before you could get a service from CAMHS.
- It was not clear whether the young people had copies of their care plans or minutes / notes of the planning meetings.
- The impression gained was that things were done to, rather with, the young people and so they felt a lack of empowerment.
- The professionals met before they arrived to meetings and the young people explained that it felt like the decisions had already been made before they got to the meetings.
- One person explained the whole process was 'very confusing'
- One person thought she was attending a routine appointment, but it was only when she arrived and just before she went in, she was told that there would be other professionals attending. No one informed her who they were and what their purpose at the meeting was.
- They all reported that they received no information prior to meetings and no one met with them to explain what would happen.



## *A case study*

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A lengthy conversation was had with a parent of a child who is receiving support from CAMHS. Her opening comment was that “CAMHS are useless”. Her child was referred to CAMHS by the primary school head teacher due to his behaviour. A CAMHS worker spent about 20 minutes observing the child in school and concluded that he may have mild ADHD but offered no further support. This was approximately 18-20 months ago. A further assessment was arranged and took place at the school. The conclusion of the assessment was that art therapy would be offered. No timescale was given for when this would start. If she contacted CAMHS she was told that she was “just on the list”.

In the end the parent gained support from a voluntary organisation, who met with her regularly and also contacted CAMHS to find out what was happening and when the art therapy would commence. The worker was informed by CAMHS that the art therapist had left and so this service was no longer available. CAMHS had made no attempt to contact the parent and she would not have found out that there would be no art therapy unless the worker from the voluntary organisation had not chased this up. The parent would have expected CAMHS to have informed her that no art therapy would be available. The young person has now been offered a counselling session and told that there would be three sessions. The parent’s key issue is that the counselling service has taken over 18 months before commencing and that there was no contact from CAMHS during this period to explain what was going on or even inform her that the art therapist had left.



## 5. Analysis of survey forms

Due to the challenges of obtaining feedback directly from young people and their families and carers, the survey is a key source of the views and experiences of young people on the CAMHS service they have and are receiving.

5.1. Approximately 500 survey forms were distributed to a variety of organisations, both statutory and voluntary. The latter included; Clued Up, in Crowborough, My Time, based in St Leonards, Care for the Carers and COPEs. These accounted for about 130 survey forms. The rest of the forms were distributed through various CAMHS services with the majority (about 300) being through the CAMHS local offices. As stated above, some offices were very slow in starting to encourage people to complete the surveys and so it is likely that only a relatively small proportion of the 300 survey forms were actually given out to people.

5.2. Despite this, 43 survey forms were returned. It will be useful to provide an analysis of each of the questions asked, as well as any of the additional comments made.

### Question 1. Please circle the part of Sussex you live in:

Lewes	Wealden	Eastbourne	Hastings	Bexhill	Rother
5	10	15	9	3	1

Visits were made to the offices of both the Hastings CAMHS and in Hailsham to meet people in the waiting area and explain about the survey and its purpose. The Hailsham office covers both Eastbourne and parts of Wealden. This could explain the higher number of returned forms from these areas.

### Question 2. How long have you been receiving a service from CAMHS?

0-3 months	3-12 months	Over one year
18	11	14

There were high numbers of people who were fairly recent to CAMHS, but also some who had been with them for many years. One person said her family had been receiving a service for about 17 years. One person met with at a local office was attending their first appointment.



Question 3. What kind of help is this?

The vast majority stated that they were receiving 1:1 counselling. A few were also attending groups and five young people were either inpatients or had been in the past.

Question 4. How often do you receive such help?

20 people stated that they receive support at least weekly if not twice weekly. Nine stated fortnightly and the other respondents either did not state the frequency or else it was monthly or above. Therefore the vast majority receive a service very frequently.

Question 5. Was it easy to start to get help from CAMHS or were there any delays? If there was a delay, why was this? If you were refused help from CAMHS, please say why this was.

No delays	Yes, there were delays	Did not say
19	21	3

As can be seen, there was a split fairly much 50-50. Some people simply replied “yes” and “easy”. Other positive comments included:-

- Yes, my daughter was referred by her GP and received an appointment.
- No delays or refusal.
- Easy - referred by nurse at doctor’s surgery.
- No delay once referral had gone through.
- I got help quickly.
- Never refused help.
- I’m happy.
- Yes - good.
- Very easy and have been supportive.

Those people who stated that it was not so easy included the following comments:-

- It took a long time to get an introduction to CAMHS. Initial therapy was slow and had too many gaps.
- There was a delay of five weeks after the doctor informed them. I am not sure / was not informed as to why this is.



- Delays of 6 months - moving schools and waiting list.
- 12 week wait due to lack of appointments / overworked staff.
- Delay from first coming here to actually seeing the doctors.
- Lots of delays due to schools and social workers.
- Waiting list.
- Two months because of staff shortages.
- Long waiting list.
- Had to wait for appointment.
- Delays felt like forever to get somewhere, don't know why.
- Took approx 3 months.

Some comments made were mixed, some not indicating any delays or else a delay in one part but not another. Comments included:-

- There were lots of changes to begin with then finally I got the right help after 2 years.
- It took us two attempts via our doctor.
- It was hard at first but then it got easier.
- We waited five weeks for an appointment.
- No delays. Did have to use other methods in conjunction with CAMHS (urgent help) due to appointments not being frequent enough.
- First appointment was within timeframe. 2<sup>nd</sup> took a lot longer and we have now been waiting an awful long time for an ASD assessment with my son really struggling at school.
- Originally refused as thought my daughter didn't need help until a month later ended up in A & E on a drip.

For some people the process of getting access to CAMHS was easy and there were no reported delays. Other people said there is a waiting list and so need to wait for an appointment. Some indicated this was for months. A few respondents said that there can be a delay between the first meeting / appointment and any subsequent support. One person received support following an admission to hospital.

Question 6. If you have been in crisis, did you get help quickly? If there was a delay, why was this?

Over 20 respondents made no comment to this question, or stated not applicable, and so it has to be assumed that for these people they had not been in crisis. Of the 20 people who made a comment, 14 stated that there had been no problem. For example, one person



stated “Yes, very quickly after daughter admitted to A & E”. Another stated “no delays and help came quickly”

Those people, who were not so positive, did not raise any specific issues about the crisis service but more general ones about CAMHS. However, one person did state “short delay in seeing someone” and another stated “delay due to unknown severity of situation”.

Therefore, no issues were identified about how CAMHS responds to crisis situations and so this is seen as working well for people. This was illustrated by the positive comments about how quickly they received support when in a crisis.

### Question 7. Do you get the right sort of help and when you need it?

Yes	No	No comment
30	8	5

The vast majority simply replied “yes”. A number of people made comments, some indicating that they got the right help, but there were some issues along the way:-

- This is only our 3<sup>rd</sup> meeting but so far it’s been great.
- Yes, but would have liked help sooner.
- Took a while to get right help.
- It appears so; difficult at times to see developments however we have always been offered support.
- Yes, help - diagnosis and ongoing support.
- Not initially - change of therapist instigated by parent helped.
- Yes, I did receive a quality service; however it was quite a delayed start.
- Not originally but seems now as if we are.
- I don’t like having help.

### Question 8. How helpful is the support you receive? Please score it from 1-5, with 1 being poor and 5 being excellent.

1	2	3	4	5
0	2	8	16	13



29 people (67%) rated the service in the top two scores. This illustrates that the vast majority of people have positive views about the support they receive from CAMHS.

Positive comments included:-

- Excellent support.
- 5 - All my concerns and issues faced were excellently tackled.
- When we have been seen the staff have been great.
- Originally 1, now 5.
- (From a parent), difficult to score but for us being heard it is a 5. Unsure about the young person.
- 3 - so far it is really helping my son get everything out in the open.

Less favourable comments included:-

- 3 - slow to see behaviour changes over a year.
- 2 - I feel my child gets the wrong type of therapy and feedback is non-existent.

### Question 9. What is the best thing about the CAMHS service and the help and support you get?

Just about every person was able to make a positive comment about CAMHS:-

- My son is finally getting some help and support.
- Having contact with someone that isn't family.
- Weekly meetings and 1:1 time, as well as group time.
- It helps.
- Important to be able to be in touch when needed.
- Very understanding and helpful, especially helping support us with other services.
- Being able to talk. Not judged.
- Having someone independent to talk to.
- Most of the staff will see you as long as needed.
- They listen.
- First appointment therapist put us at ease, very understanding.
- Everything gets sorted.
- I don't feel so alone.
- Helping my son to get a diagnosis.



- It'll help me in the future too.
- Someone listening to me who is not my mum.
- They help you talk and sort out problems.
- They listen and understand; they listen and give advice easily.
- My daughter feels comfortable discussing personal issues at CAMHS.
- Easy to access and quite flexible.
- The people are understanding.
- Listening and having a good understanding of our challenges.
- Very active and wanting help.
- Friendly staff, calm environment, someone to listen.
- Knowing you are not alone and there is help and support out there.
- Expert advice from someone who understands what we are going through.
- You can talk to them.
- It is inclusive of all relevant family members.
- Knowing my daughter will get the help she needs to overcome her problems and be happier.
- The nurse I am seeing knows and is an expert in the area I am struggling with and so I can rely and trust in her opinion.
- Seeing my psychologist because she has helped me a lot.
- It's help! Might not be good or right but its help!
- Receptionists are nice (Wealden).
- Everything! When ball was rolling at beginning it was all done quickly.

Key and regular words include “understanding”, “listen”, “trust”, “help” and “support”. Some commented that it is good to get support from an independent person rather than your family. There was also a sense of moving forward, of making things better and improving.

#### Question 10. How can the CAMHS service and the help you receive be improved?

Again, it will be important to list all the comments to reflect the views of all those who responded:-

- None.
- More services and time available.
- Make access easier.
- Clinic closer to where I live [lives in Bexhill and so office is in St Leonards].
- CBT.



- More doctors so you get seen quicker.
- I don't know.
- I would like closer connections between school and CAMHS. Mental health is not taken seriously in East Sussex.
- Be seen sooner.
- Some staff want to get you in and out within 6 sessions.
- Location and no delay.
- Regular review of service input with daughter to see if the sessions are effective and tailored to meet individualised needs.
- More feedback from therapists.
- Initial appointment needs to be quicker as took a lot of hard work and effort to get one.
- I would prefer a female counsellor.
- Listen rather than dictate.
- No improvements on the actual service however it would have helped to receive it quicker.
- Better access; the service is obviously severely underfunded.
- More funding, so that a 'case' doesn't need to be so severe before help is offered. Please stop turning people away before it becomes severe.
- Due to progression, for future sessions to be targeted outside of school hours, weekends and nearer where we live.
- It would have been much better if we could have seen someone sooner.
- Go more in depth with mental health issues (cognitive behavioural therapy).
- I feel as though I should go private.
- Communication internally needs improvement, i.e. complaints should be responded to.
- Less waiting time to be seen.
- Quicker access to CBT.

### Question 11. Any other comments

As above, it is important to record what each person said on the survey form, to enable their views to be made known. These were:-

- Without CAMHS my daughter was bottling things up i.e. bereavement, as she didn't want to upset me. This was causing anxiety and panic attacks which are now under control.
- Very good service.
- Very pleased with the support ADCAMHS has provided us so far and that they were willing to assess our son.
- Realistic "distractions" should be offered. I was always handed a list of things to do when down (i.e. paint nails) that helped in the short term but never dealt with the



root. I had to find out for myself that such things like relaxation techniques, yoga; and meditation works so well for me.

- Building could be updated (looks very old school).
- I'm pleased that there is help for children so close to home.
- It would be good to be able to call someone up between appointments when we are experiencing difficulties.
- Poor security. Procedures unknown by staff.
- Very happy with everything now, thanks.
- I feel CAMHS do not have enough resources to provide a full service. They have many children who need their help and have not been seen yet.
- Parking and driving out of CAMHS.
- The ADCAMHS team have been very supportive to us as a family. As specialist in their field we feel that they totally understand our issues and act as a voice to other services on our behalf.
- Very helpful service and staff. Thank you.
- Parking at Conquest.
- Good team I have though.
- All carers should have access to therapeutic parenting courses.
- I have found CAMHS of great help to my son and myself.
- Should offer hot beverage (preferable hot chocolate).



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## 6. Conclusions

There are a number of key themes arising from the views and experiences of young people and their families and carers and from the views expressed by a range of organisations.

### 6.1 *Waiting time for services*

Although 19 of the 43 people who responded to the survey stated that they had experienced no delays in obtain a service, there were many examples of people having to wait. Timescales given by people on the survey forms include 6 months, 12 weeks, two months and 3 months. Many of the comments in the section entitled '*How can the CAMHS services and the help you receive be improved?*' related to a delay in getting a service. Words such as "sooner" and "quicker" were used by a number of people. From discussions with other organisations, workers also supported the view that there can be a delay in obtaining an appointment. One worker gave the example of having to wait 6-8 months before the 'participation' appointment.

### 6.2 *Threshold for services and pressures on the service*

Some young people thought that to get a service you had to be "bad" or deteriorating. This was supported by some workers in voluntary organisations. One had identified the nature of what would be an acceptable referral and so only made these referrals. This could leave young people without a service and needing help, but due to the demands on the service, the threshold has to be high. Some respondents to the survey also thought that staff were over worked and not enough of them to provide a service. The case study identifies that art therapy was assessed as being needed but there were no art therapist available. The pressure on the service is linked with the waiting times.

### 6.3 *Communication*

The case study provides a good example. The parent only found out that there would be no art therapy when the worker from a voluntary organisation made contact with CAMHS. No letter or phone call had been made to the parent directly. Some young people also made reference to this. For example, one young person in hospital stated that there was some confusion about which hospital she was going to and she felt that communication should have been better. Some young people who were inpatients thought communication could be improved about the CPA and other meetings. For example, one young person was told at the last minute, as she was about to go into the room, that a number of other people would be there who she did not know. This caused her additional stress.



#### *6.4 Choice and involvement*

A number of young people met with felt they had little or no control over what happens to them and lacked involvement. One young person thought she had been “tricked” into being admitted to a hospital. Another young person stated that they were told that they were to have art therapy, but this was not their choice and no one explained the purpose of the meetings. He was pleased when it ended.

#### *6.5 Location*

A few people thought a more local office would be beneficial. The nearest office for people from Eastbourne is Hailsham. One young person stated this was difficult as he may have to miss school to attend meeting.

#### *6.6 Very helpful therapy sessions*

The overwhelming view was that the service, once you get it, is very good. This was most clearly evidenced from the scores given to the quality of the support in the survey form. 67% rated it in one of the top two scores. Words such as “listen”, “understanding” and “friendly” were used to describe the sessions and the workers. The majority of people stated that they had benefited from the support provided by CAMHS and saw real positives to their lives as a result of their interventions.

#### *6.7 Quality of staff*

Many people made positive comments about the quality of the staff, including reception staff. For example one person stated that the therapist had put them at ease.

#### *6.8 Crisis support*

The overwhelming view from those who had been in crisis was that they received a very quick and efficient response.

### **Overall conclusion:**

The journey is very difficult, but it’s good when you get there.



## 7. Recommendations

Whilst many of the issues identified by those receiving a service and the carers and workers in voluntary organisations, could be resolved by additional funding, this may not be realistic in the current economic climate. Therefore, the recommendations made in this report have little or no financial implications and so are achievable and realistic.

1. Healthwatch East Sussex need to formally request from CAMHS key statistics including; the number of initial appointments not made within the four week timeframe and the number of partnership appointments not made within the 18 week timeframe.
2. Healthwatch East Sussex need to request information on when a 'holding letter' would be sent if any of the above timescales have been breached as well as what factors are used to decide who is seen more quickly than others, i.e. what is deemed to be urgent and what can wait for the 18 week period.
3. If no holding letter is used, CAMHS needs to consider introducing such a letter, so that young people and their families and carers are not simply left without updated information, waiting weeks for a letter to arrive inviting them to an appointment.
4. CAMHS needs to consider how it can improve the waiting times, as for most people, 18 weeks is far too long.
5. CAMHS needs to review its engagement with young people in terms of keeping them informed and involved in their care and support, including an explanation why something did not occur as originally intended.
6. CAMHS could consider utilising facilities for appointments in other locations such as Eastbourne and Crowborough, to reduce the incidents of young people and their families and carers having to travel for their appointments. This is an issue for some due to transport not being easy, particularly in rural areas.
7. Consideration could be given to a referral form being introduced, so that all referrers are clear on what information is required and when to make a referral.
8. A review of CPA meetings, particularly when an inpatient, could be carried out in the light of the views expressed by those young people currently an inpatient.



## 8. Response from Sussex Partnership NHS Foundation Trust

We welcome this report from East Sussex Healthwatch, we are delighted that there are a number of areas where those who have used our services have had positive experiences. The report highlights the recent CQC inspection report and we are pleased to report the services being rated as “outstanding” for Caring and “good” for well led. This report picks up a number of themes which are reflected in the CQC report and where we are required to improve which are included in our action plan. We will therefore use our current CQC action plan to address the issues raised.

- 8.1 This report will be shared with the Sussex Senior Leadership Team, East Sussex Leadership Team, the East Sussex Participation Worker, Chalkhill Leadership Team and MIND Advocate to pick up the local themes to further inform service improvement and development. East Sussex CAMHS has a participation worker and Chalkhill has a MIND Advocate - both support children, young people and their families and carers to give us feedback and work in partnership with us when making service improvements. We have a number of initiatives that we would be happy to share with you.
- 8.2 Children and young people of East Sussex do not experience the same level of wait for services as in other areas. We agree that waiting at a time of difficulty can be challenging for families. This is one of the areas included in our CQC action plan. We currently are meeting all our KPI's with regards to waiting times. We are experiencing increasing demands for CAMHS services and will be working further with our commissioners and partner agencies to develop service transformation plans as recommended and required by NHSE for all CAMHS services.
- 8.3 The report highlights the national pressure on inpatient bed availability, we will always aim to provide a service at Chalkhill for all Sussex young people however, there are times when this is either not available or a more specialist hospital placement is required e.g. psychiatric intensive care, specialist eating disorder service, secure hospital. In these instances we will aim to locate an admission to the most appropriate hospital as close as possible to the young person's home and community. We recognise the importance of family and community to support a young person's recovery and will work with our colleagues to ensure that the young person returns to local services as soon as possible.
- 8.4 As a service we aim to provide evidence based assessments and treatments as locally as possible to those accessing the service however there will be occasions when families may need to travel, we aim to keep this to a minimum.



8.5 We were delighted to have supported and been involved in this review and to have worked with Phil Hale the researcher, we would apologise for any lack of clarity with staff regarding provision of information in our waiting rooms to children and young people.



## 9. Disclaimer

Please note that this report relates to findings observed on the specific dates set out in the report. Our report is not a representative portrayal of the experiences of all service users and staff, only an account of what was observed and contributed at the time.



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