

<b>Report Title</b>	<b>Mental health support for young people</b>
<b>Organisation</b>	<b>Bolton Foundation Trust Child and Adolescent Mental Health Service (CAMHS)</b>
<b>Dates:</b>	<b>16<sup>th</sup> and 21<sup>st</sup> March 2016</b>
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### **Acknowledgements**

Healthwatch Bolton would like to thank service users and staff at the Bolton Child and Adolescent Mental Health Service (CAMHS) for sharing their views and experiences.

### **Disclaimer**

This report relates verbatim comments gathered during the time of our visit. All comments recorded by Healthwatch Bolton have been added to Healthwatch Bolton's databank of patient comment.

### **Background**

Healthwatch Bolton runs an ongoing series of 'Corridor Events' at Bolton Royal Foundation Trust Hospital sites with the view of talking to current patients and service users about their experiences of health care. The CAMHS corridor event was part of this series. This report gives the views and experiences of CAMHS service users and their carers and staff within the CAMHS service.

### **Strategic drivers**

- CCG Transformation Plan for CAMHS recently published.
- Forthcoming CQC inspections of both Bolton Foundation Trust and GMW mental Health Trust.

### **Who we spoke to**

A total of 52 comments were gathered from young people (who were receiving treatment from CAMHS, family members and carers, and 2 staff members.

## Method

Healthwatch Engagement Officers, Gail Gregory and Karen Wilson attended CAMHS clinics over two days and invited service users and carers to come and discuss their experiences. A semi-structured interview method was used.

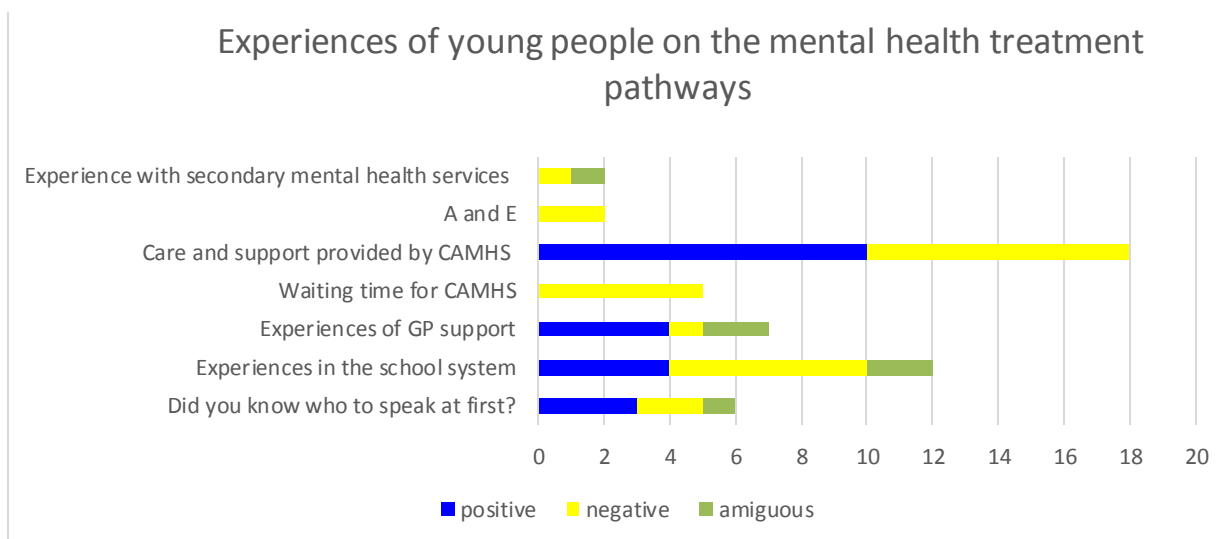
Since the young people were already under treatment in CAMHS they have experienced the early intervention and referrals phases of treatment. Some had also been in treatment for some time and had experienced both young people's and adults secondary mental health services. Some of the young people and their carers had experienced crisis services. Others have not.

The comments were grouped into experiences of different parts of the mental health pathway to give an indication of how the whole pathway is experienced by young people. Different coloured text is used to represent the views of young people (orange), the views of parents or carers (green) and the views of staff (blue).

## Topics/Themes

Young People: Mental Health: GPs: Schools: CAMHS: Accident and Emergency: Junction 17: IAPT services: home based treatment services: referrals: waiting times: transition from young peoples to adult services: self-harm: suicide: bullying

## The Comments



### Did you know who to speak to when you first had problems? (6)

Young people and their carers appear to have mixed levels of understanding/awareness about mental health issues at the first onset of their illness. A number of parents/carers

did know who to speak to get help, the young people themselves were, perhaps understandably, more fearful, withdrawn and/or confused.

- *I felt alone and didn't know who to speak to*
- *I had my friends but they had their own problems. I had that in my head but now I'm working to get myself better because I know that has to come before my friends problems*
- *I have contact with other parents in other areas through organisations working with Autism. From what I hear this CAMHS seems to be working better than services in other areas.*
- *I did know who to speak to and went to my GP.*
- *The first thing I did was going to see the GP.*
- *(Retreated) Into her bedroom.*

### Experiences of support in the school system (12)

There were mixed experiences within the school system and a feeling that understanding of mental health problems in this arena is patchy. A number of the young people had experienced bullying and exclusions and some were being supported by specialist provision. A number of parents/carers described the school/family relationship as being problematic with several stating that they felt a 'lack of understanding' on the part of the school/s. Young people also raised the issue of 'understanding' where they had mixed experiences at different times and in schools.

- *Primary School put the issues down to my child being disruptive, silly or naughty. It was when he went onto secondary school that when he had some further issues that the SENCO picked up signs that were concerning. Before my child's diagnosis there appeared a total lack of understanding by the school and he ended up being excluded for 4 days. We tried another school but that didn't work out. It looks more positive now that the Home Hospital School is involved. My child gets transport there and although it's early days it seems to be more positive environment after having his confidence completely robbed and feeling like a total failure. If anyone seems a little different in the main school system they struggle to cope.*
- *My child is a target for bullies - I was in the school literally every other day. School weren't as supportive as they could have been. I would have liked more support from the school; now they know he comes here they are more understanding. I had to go into school about a nurturing group that they had suggested but initially it didn't happen. You feel like you are banging your head against a brick wall. I don't feel bullying is being addressed in the school. Now I ring every lunchtime to ask them how he is and when he comes home I check with him if he is ok. I'm on top of it with school now. The nurturing group is helping him now and talking to the doctor here at CAMHS is helping too.*
- *I went into school and spoke with my child's year leader. The school nurse had also been on the case. It's at school (they) noticed how slim my child looked when she*

*had an inoculation and mentioned to the year leader. Because I had spoken to the year leader they told the school nurse.*

- They don't really know understand what it's like to have a child with mental health issues - bullying is heart-breaking. Sometimes when I go into school I feel they are saying "it's her again" I'd like them to be more understanding.*
- With my eldest child who was in the 6th form they weren't good at all. They did want to meet with us when my child took a knife into school and then they were very keen to talk to us. Prior to that incident no allowances were made even after disclosing the difficulties my son faced - they didn't respond to his emotional needs. Their answer was for my son to leave college. With my younger son his school was supportive both to him and to me. They weren't good at following any processes though. I later found out that that he could have been 'statemented'. He had not challenges academically so wasn't 'statemented' or assessed. He spent a lot of time out of school although we did have regular conversations over a 2 year period. To me some early help flags were missed.*
- My child has been a target for bullies - I was in school literally every other day. School weren't as supportive as they could have been.*
- School picked up a couple of issues and the SENCO thought it best if we spoke to our GP. The GP referred us to CAMHS.*
- The Head of Year said I could always go and chat anytime about my feelings*
- Teachers definitely understand how I feel at school - there is the 'Sunshine Room' - other children can go in there so I don't feel different about going there. I feel fine about school; I've no worries about going to high school. I'm not sure if the new school will have a quiet room. I have been told there is a lady who will look after me if I feel somewhere to go.*
- I stopped going to mainstream school which I found was very hard. Now I'm going to Park School - I've had a look and it seems ok. At first I will be starting on two days a week and then it will increase. Although I've talked to teachers in the past but they didn't seem to understand they said I was distracted!*
- I feel it helps me to come here. I was excluded a lot from school before I came here - I couldn't talk to my Mum as she was involved in some of the issues. I had counselling here.*
- I struggled at school so it was a relief to come here and find out what was happening. It was difficult at first because I didn't know anyone.*

### **Experiences of GP support (7 comments)**

The general view seems to be that working through GPs as prime referrer is working OK though there remain some issues with GPs as prescribers for some medications. Staff in the service report some initiatives to support the GP referrals process which probably also has other positive impact on long term management (via the GP) of young people who are under the care of CAMHS.

- Our GP is brilliant - she really understands him. It's (name of practitioner) at Burnside surgery.*
- Once I got on the case, and talking with the GP, school and CAMHS I felt a great weight had been lifted. Everything seems to be working together. Initially I felt*

alone and upset it's good to be able to share how you are feeling. I talk to my family and we work together. I don't want to crack. It's my job to hold things together.

- We were referred here by our GP. The first referral was refused by the CAMHS. After a second referral they have seen us.
- My GP isn't prepared to prescribe the medication my child receives, they don't believe in it. Because of that I have to come here for the prescriptions - that's the part that could be better.
- I had to go to see my GP after I was in 'Junction 17' as they took me off my medication. When I was home I had to go back on my tablets so had to see the GP about it. They seemed to understand me and it was alright.
- Child/YP - I have been coming here since I was 4. I was very unhappy with myself even then. Mum took me to see the GP and I ended up being referred here within 2 weeks. I was discharged when I was 7 and came back when I was 11.
- We try to get GPs to ring us if there is a query about whether to refer. It helps if the GP listens to and identifies what the problem is rather than describing a cluster of symptoms. We try to work with the GPs and we offer a telephone contact should GPs, School Nurses, Behaviour Support or Social Workers want advice about referral.

### Waiting times for CAMHS (5 Comments)

Waiting times are cited as a problem by parents and carers and staff. Waiting for a referral to convert to an appointment may be especially problematic for those who have already experienced many years of problems without achieving mental health assessment or support.

- Initially we were told there was a 16 week waiting list. They gave me then the telephone number of CAMHS. When things weren't going well I was able to contact them and they did see us before then.
- Once we've got into CAMHS is been good. We waited a couple of months to be seen which I thought was too long. If he is unwell I can ring and be seen sooner or even the same week.
- Went to see the Nurse Practitioner and GP who referred us to Breightmet Health Centre. My child saw the CAMHS counsellor there and then we waited for an appointment to come here. My child's first appointment was September, they were seen at school last week and we've come here again today (March). They try to work around you wherever you are seen.
- I took my son the GP as there were so many things happening to him like not sleeping, not eating and refusing to go to school. It's over two years ago now and the GP referred him to CAMHS for the insomnia. CAMHS rejected the referral but referred him again with more detail. We were told at that point there was a waiting list of 5 months. 7 weeks later we were very worried about his weight loss but found out this wasn't classed as an emergency. We had rung because we were told to contact them if things became worse. We were told that emergencies were self-harm or suicide related. We were actually seen earlier; my son's appointment was moved and he was seen within a month.
- We do feel waiting times can be initially lengthy but always give individuals our contact number to use if they feel things are changing.

## Positive perspectives on the care and support provided by CAMHS (10 Comments)

A number of young people and parents carers praised the attitude and commitment of CAMHS staff and clearly felt well supported. The service was seen to have an approach that is both practical and supportive in terms of communications and flexibility.

- *It's helping me to see (name of practitioner) about things I can do to get to sleep.*
- *I feel safe - I feel I can talk to (name of practitioner) - I like coming to do things I like the group. I used to do counselling with (name of practitioner) which was good - they were really good - they didn't judge me. I felt they were kind and I still do. I've been coming here a couple of years. I hope I can still come here when I go onto secondary school.*
- *Going to see my Dr here - about once a week - helps. It's ok for me to get here.*
- *Nothing could be better. They send you text alerts and are prepared to work around you.*
- *Once you get to see the psychiatrist or psychologist care is good, (name of practitioner), he's brilliant. He's gone above and beyond - fabulous care. He really hasn't wanted to give up on my son - he's tried different angles and has given him time. I feel if I rang him he would take my call, be helpful to me and give me some guidance. There's a difference at CAMHS to the clinical staff in Adult Services.*
- *My son has struggled with his diagnosis but really likes the doctor and the therapist he sees. He feels reassured that he will get the help he needs. When he hasn't been well at home he has asked me to ring CAMHS and there has always been someone on call to speak to. If the doctor isn't available she will make time to ring us back as soon as she can. I haven't tried to ring 'Out of Hours' or at the weekend but I suppose I would take him to A&E if I was worried.*
- *CAMHS are really good at working around what we need and anything is not problem. They are really helpful.*
- *We were originally seen in June last year and we got a diagnosis just before Christmas. They've gone above and beyond in the care we've been given. From reception through to all the staff they are really helpful.*
- *Initially we came for depression but the doctor here has picked up signs of Asperger's on the Autistic spectrum. So we've seen the Educational Psychologist as well. Dr (practitioner's name) has been absolutely amazing.*
- *We do try to be as flexible as we can be around the needs of our patients in terms of location. I've been into schools, individual's homes or places like Brightmet Health Centre. Sometimes it helps to ask patients to come here - therapy is based here.*

## Less positive perspectives on the care and support provided by CAMHS (8 comments)

On the less positive side several young people and carers felt Out of Hours provision to be inadequate and communication between appointments problematic.

Communication/coordination between CAMHS and adult mental health service was also identified as an area that needs much more attention. More awareness raising about



**CAMHS, more talking therapy approaches and more support for carers, friends and schools were also mentioned as gaps.**

- *Things could do better in terms of more effort in telling what CAMHS is and how it can help other children. I don't like speaking about it and my problems; if children found out about it I would worry that they would treat me differently.*
- *'Out of Hours' help would be good - someone to talk to or somewhere to go. I don't like talking to my Mum - it needs to be someone other than Mum.*
- *Once or twice it's happened where I can't get an appointment the following week - I found that quite hard. They always say ring up if you are struggling but tell my Mum to go up to A&E if she is worried - there doesn't seem to be a back-up plan.*
- *Autism has been diagnosed now. It's the first time in 2 years that they are seeing a psychologist; most of the care has been about medication. She needs that space to talk.*
- *Sharing information between Greater Manchester West Mental Health Trust and CAMHS is difficult because they are different service providers. In my opinion 'Case Managers' didn't appear to case manage. They didn't appear to engage with other providers because their caseloads are too big. It's possibly a resource issue - they can't meet the demands. I think previously the commission may not have been clear - it might be different now.*
- *It needs more support for families - perhaps a discussion group at school or a carers group.*
- *The Case Manager at CAMHS didn't usually ring back. Your initial call to CAMHS goes through to reception. They ask you if there is any 'risk' and then refer you to the duty manager who may or may not be available. If not, someone will ring you back. That doesn't always help because they don't know you the information you give them doesn't have a context of their situation. I understand the system and would circumvent it but other people wouldn't be in that position.*

#### **Accident and Emergency (2 comments)**

**Young people do not like going to A and E and neither does A and E seem either well placed or well equipped to manage CAMHS out of hours case load.**

- *There's school or college and here of course. There is someone here between 9 and 5pm. Outside of these hours parents have to take you to A&E and you end up waiting a long time; I don't like going.*
- *At A&E it can take a long time for the on-call Dr to come from, I think its Manchester, and usually it's just to sleep over night.*

#### **Secondary mental health services (2 comments)**

**Two people we spoke to had had experience of secondary care one at Junction 17 and one within adult services. Neither experience was good.**

- *I had to go into 'Junction 17' at Prestwich. It wasn't nice, I didn't have any freedom. I had 9 days without going out. I wasn't allowed out even with my*

*parents. I couldn't go out without staff and if staff were busy it didn't happen. There are no clocks either so the days are long. I felt imprisoned.*

- We had previously been seen by CAMHS at Wigan and then discharged. There was no continuing care just assessments and discharge. The way into CAMHS for us now has been through self-referral to Primary Care Psychological Therapies (IAPT) where my son has seen the CBT worker who referred him to CAMHS for assessment and medication. In the interim he attempted suicide which he shared with the CBT practitioner and ended up being sent to the Rivington Unit for assessment. We felt that he was caught between Adult Services and CAMHS seeing three services in that he had contact with the Key Worker from Home Based Treatment Services, CBT practitioner and CAMHS. It's because crisis care sits with the Greater Manchester West Mental Health Trust. He didn't have a care plan until I intervened. At his case review we saw the psychiatrist but the Home Based Treatment Service worker didn't attend saying he was "Tied up with something" - I guess it was a resource issue. The STR worker from the Home Based Treatment Service was excellent and really engaged with him.*

### **Would you know how to raise a concern with the service if you needed to? (4 comments)**

We asked the people we spoke to if they would know how to raise a concern or make a complaint if they felt it necessary. No one we spoke to had a clear idea of the process in this respect.

- No I don't know.*
- If I know there is something wrong my job is to be taking it to a professional and getting on top of it.*
- I wouldn't know who to speak to but I suppose I would ask at reception. I don't have a problem though.*
- I wouldn't know who to speak to but I would raise it.*

## **Recommendations**

### **Recommendations for Schools**

- 1. Embedding awareness raising (and perhaps resilience) programmes in schools would support, self-awareness, early identification (and perhaps prevention).**
- 2. Young people's experiences in schools is of concern. Specific and concrete training among the young people's workforce is required to highlight good practice improve skills and knowledge.**
- 3. A clear statement of schools responsibilities in respect of training, support and policy regarding young people with mental health problems is needed to underpin good practice and create consistency throughout the school journey.**

### **Recommendations for the GPs, the GP Federation and the CCG**

- 4. Some further consultation /engagement work among GPs would help to better understand their experiences of referring to CAMHs and supporting young**



people with mental health problems in the community. This work might lead to useful recommendations about obtaining advice from, referring into and working alongside CAMHS service for example, whilst young people are waiting to be seen or on issues around medication.

#### Recommendations for the CAMHS Service and the CCG

5. Proper 'Out of Hours' arrangements for CAMHS service users are needed. The default position of using A and E is not helping anyone.
6. Young People want to be able to speak to practitioners who know them if they need to call in for advice. A review of the 'case coordinator' arrangements might yield some opportunities for improvement.
7. Clear public facing information about the CAMHS service would be welcome.
8. Information about how to raise a concern / make a complaint should be given to all service users and clearly displayed at sites used by CAMHS staff and service users.
9. The continuing efforts to improve waiting times are welcome however some formal arrangements need to be made with regards to interim support for young people and their parents and carers during the period between referral and first appointment.

#### Recommendations for the CCG and voluntary/community providers

10. There is an expressed need for support for parents/carers/friends and family with regards to how best to work with their young people. Consideration should be given to commissioning some community-based activity in this area.

#### Recommendations for all commissioners and providers of CAMHS and Adult Mental Health Services

11. Junction 17 needs to share information regarding what improvements have been /are being made there.
12. Young people who are being treated and their parents and carers at Junction 17 need clear information about what they can expect.
13. A clear programme of work regarding interagency working between Adults and Children's mental health services is needed. Such a programme of work should be shared with all stakeholders.