

## Proposed changes to the service specification for Tier 4 Child and Adolescent Mental Health Services – General Children’s Services

Healthwatch Birmingham welcomes the opportunity to respond to NHS England’s consultation on ‘*changes to the service specification for Tier 4 Child and Adolescent Mental Health Services - General Children’s Services*. Our key role is to make sure that patients, the public, service users, and carers (PPSuC) are at the heart of service improvement in health and social care. In line with our role, we have focused our comments on:

- The involvement of patients, the public, service users and carers (PPSuCs);
- whether the proposals will improve the quality of care and lead to services that are responsive to the needs of patients and service users; and
- Whether proposed changes may address or lead to health inequality

We welcome NHS England’s plans to further shape and refine proposals for the delivery of safe and effective high quality CAMHS tier 4 children’s services that are easy for Children and Young people to access and meet their needs. The proposals being consulted on are relevant for Birmingham where 46% of its population is under 30 years of age representing more than 500,000 people. Almost 250,000 of Birmingham’s residents are under the age of 15 and at least 28,000 children and young people aged between 5 - 16 have a clinically diagnosed mental disorder.

In the West Midlands, there has been a rise in the number of children and young people that have been treated for mental health problems. According to NHS Digital, there were 13,510 active referrals to children and young people’s mental health services in the West Midlands in April 2018. This represents an increase of 6.5% on last year’s (April 2017) figure of 12,685. Around 2,000 under 18 years old are referred to a mental health treatment in the west midlands every month covering illnesses such as depression, psychosis and eating disorders.

It is positive to see that an increasing number of children and young people in West Midlands are accessing mental health services. However, we know some are not receiving the support they need or have concerns when they have accessed these services. Over 2017 and 2018 period, Healthwatch Birmingham has heard from children, young people and their carers about their experiences of accessing mental health services. The main issues across the experiences received relate to the integration of services for young people with mental health problems. In particular, around *who will accept responsibility for patients in crisis and actually provide the care, support and joined-up treatment needed?* Other experiences have been around the lack of awareness by staff of age related services, the length of time service users have been on the waiting list, referral delays, out of area care, changes to services leading to poorer care and lack of training and support for carers to enable them to support children and young people when discharged.

Below are some of the experiences:



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- *I went through Birmingham Healthy Minds but they referred me to something I wasn't comfortable with. I went to the Pause in Birmingham City, where it's a walk in but you would see someone different every time. This gave me a choice to when I can talk and see someone when I really need to*
- *I did a self-referral in February and heard back within a few weeks that I was on the waiting list for an appointment. It is now June and haven't heard anything further.*
- *Dr x [redacted], Forward Thinking Birmingham (FTB), Sutton Coldfield CAMHS site: "Dr x of FTB is very unapproachable, many parents have refused to allow their children to be seen by him. He turns up to appointments late or not at all. He is intimidating and does not listen to the child or parent insisting as a professional he knows best. He has given advice going against other professional's opinions. He caused my son incredible stress and anxiety making him feel belittled/unworthy/anxious/bullied (all words used by my son). The doctor's training and knowledge around my son's conditions is very poor (e.g he suggested increasing implementation of boundaries whereas the son's conditions advises not placing boundaries). He is patronising, doesn't turn up for meetings. I attended my son's school support meeting with the doctor, and the school support teacher told me afterwards that it was the worst CAMHS meeting they had ever been to".*
- *My experience was horrible. You wait two months for appointments - how are you meant to access quick help when appointments are not regular? How can you have a diagnosis and then be told it isn't right but still not get the right support even on medication? If it isn't working you still have to wait two months plus to ask for different medication or help to solve the problem.*
- *If I'm having a bad day I can't wait to be seen. Where do I go in an emergency? I've called them in an emergency and they say there are no doctors and they don't give me other places to go. I don't like my male doctor but if I want another male doctor I need to travel across the City. I am questioning my sexuality and have never told anyone as I can't talk to my doctor.*
- *I didn't get any help filling in the personal income payments (PIP) form even though I am autistic. I asked my Mental Health Team to refer me to anger management and they didn't. Mental Health told me I needed a social worker but I've never had any contact since.*
- *A Caller expressed serious concerns about their child whose care cannot be given in Birmingham due to bed shortages. Caller is worried that the child is not receiving the best care and has been misdiagnosed.*
- *A father called as his daughters were told that they needed an urgent appointment with CHAMS team and that a referral had been made. Three weeks later when the father called to chase the appointment he was told that there is a waiting list and that it wasn't considered urgent.*
- *A bit of all right. I was referred late Nov, seen on 12 Dec, seen 18 Jan, diagnosed. Report received last Friday. Am Pleased.*



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- *Caller rang as she has a young relative that attempted suicide a week ago. The family are concerned she has not had enough follow up care from the adolescent mental health services following her discharge from hospital and are scared she is at risk of another attempt.*
- *Family were not given the support or training to care for their child upon leaving inpatient care for mental health issue. Family were fearful of child getting worse and being readmitted to hospital following discharge due to not being given the skills, equipment or training to care for their child. No help and support was offered.*
- *Failure to respond and follow up referral. 20 months on told to go to drop in centre!*
- *My initial counsellor was great but then the service changed my counsellor and she doesn't keep up with my medication*

Other service users and carers stated that they feared reprisals for making a complaint. One carer who called Healthwatch Birmingham to share their experience asked to remain anonymous, worried that care would get worse for her son if the provider found out. She expressed concerns about her sons care and treatment and needed to prepare for his discharge, saying:

- *Family and staff at hospital are concerned that a hospital environment is actually making his condition worse. And for him to receive care at home by family and community services. But for this to happen I require training to meet my son's treatment needs (feeding); nobody will take responsibility for her training or preparing her son for this.*

Some service users found that their needs fall between services and it is difficult to find someone who will offer the timely support needed - without being made to feel they are being offered 'a favour'. Without support patients and carers say they feel they or the person they care for have 'been forgotten', they also call for better record keeping. The case below is outside the age remit covered by the proposals in this consultation. However, it highlights some key issues around the integration of services and how this impacts service users.

- *My daughter was given medication and the following day her crisis started. Phoned Forward Thinking Birmingham and the locum psychiatrist told me to phone the crisis team. They told me to phone Birmingham Solihull Mental Health Foundation Trust (BSMHFT), as she is over 25. The operator was adamant that I contact BSMHFT as she cannot have a referral to the crisis team. So I contacted BSMHFT and they said even though BSMHFT had referred her to FTB in the past they have no referral papers and no handover papers and could not help. Bsmhft told me they will contact FTB to advise them on my behalf. I phoned the Fwd thinking Crisis team and they said BSMHFT was wrong. A couple of hours later I phoned FTB crisis team and they stated that they will do this "as a one off "because they do not usually do this'...*
- *I have made sure [my daughter] is safe by phoning around for her medication/treatment. As **no one took responsibility**. Eventually [my daughter] was seen and was prescribed medication for the weekend (which did not help) by the*

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CPN (which I collected). She was told the team would come out on Monday. I chased up on Monday as she was running out of medication. I have collected medication from the clinic twice while [my daughter] was in crisis (This is the job of home treatment). **I believe she has been forgotten in the system.**

- The Psychiatrist who did a home visit told her she would have a visit every week to see if the new medication is working. This never happened. A CPN was to see [my daughter] every 2 days. This did not happen. I chased up after a week. CPN came out and assessed [my daughter] and she was told to get the Medication from the GP and to make an appt. with GP. He stated that the GP will have her medical notes from forward thinking. She went to the GP the following day with her mother and the GP said 'we have no medical records from Forward Thinking and cannot give her any new medications'. I had to Phone Forward thinking as it was near the weekend. They came out with a Prescription which we had to take to the Pharmacy. Medication helps to calm her suicidal voices (in crisis her voices increase and tell her to kill herself which she acts upon), again if I did not make the phone call to Forward Thinking she would not have any medication over the weekend, and why didn't the CPN chase it up. The CPN just did a visual check and said I have no notes. This has happened on three occasions in past and she has been sectioned and placed on home treatment with BSMHFT.
- The BSMHFT psychiatrist is angry as he had no referral papers sent to him and did not know she was on home treatment and in crisis, or of her history with forward thinking and he has now requested this from FWD thinking. On the same day we had a call from Forward Thinking a care worker to make a visit with [my daughter]. He asked where she was living because on he wanted to do a check-up and was going to [address] again the notes are not up dated As I have told the crisis Team that She is living with me temporarily for over 2 months due to her crisis. Please note the team have come to my address and not [address]. Steve states he has no record of my address!
- Seen both by Forward thinking for home support and BSMHFT for her medication. **No one has full responsibility and it looks like [my daughter] is lost in Transit.**

Healthwatch Birmingham believes that for service users and their families to experience the full benefits outlined in the service specification, some of the issues raised in the feedback we receive need to be addressed. We therefore welcome the response times outlined for referrals, completion of an initial risk assessment and the drawing up of care plans. In particular that there is clear guidance in the specification on carrying out CETR<sup>1</sup> for young people with a learning disability or autism. Should these timelines be implemented effectively, then children and young people are more likely to access services that meet their needs. However, as a Healthwatch Birmingham report<sup>2</sup> found, not all people diagnosed with a serious mental illness have a care plan in place despite stated policy. Therefore,

<sup>1</sup> CETR- Care, Education and Treatment Review

<sup>2</sup><https://healthwatchbirmingham.co.uk/news/is-every-person-in-birmingham-who-is-diagnosed-with-a-serious-mental-illness-provided-with-a-care-plan/>



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ensuring that the specifications outlined in the guide are actually implemented and actually address the stated objectives will be the real test.

Healthwatch Birmingham is pleased to see that the specifications include the involvement of service users, carers and their families in drawing up care plans, deciding appropriate treatment and discharge. Based on the feedback that we have received, it is important that service users, carers and family members are involved in reviews and that discharge planning should include the support carers and families need in order to better support the child.

On page 20 on the outcomes indicators, we suggest that there is an indicator on the percentage of service users whose CPA has been reviewed, and the percentage of patients, carers and family members involved in planning, treatment and discharge. In addition, we suggest that the patient experience questionnaire should include questions around how well service users, carers and family members feel involved in various aspects of care and treatment.

Generally, we agree with the service specifications outlined in the consultation, however based on the experiences we receive, there are issues that need to be addressed for these specifications to benefit service users and their carers. Other key issues are:

- The costs involved in ensuring that Tier 4 Children's services are located with other mental health services or acute paediatric services.
- The impact of moving services on the ability of children and young people to access services in an area close to them. Especially in cases where services are moving to a different location. How does this impact different groups in particular those young people with a learning disability or autism.
- Poor coordination between CAMHS and community services including failure to share service user records effectively. In particular, how does this impact their ability to plan well especially around issues of discharge or transition arrangements?
- The impact of cuts to local services on the ability of CAMHS to ensure the provision of services in the community are available.

Yours Sincerely,



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