

Spotlight On

Bee U,

the 0 - 25 Emotional Health & Wellbeing Service in Shropshire

March 2018 and September/October 2018

Who is Healthwatch Shropshire?

Healthwatch Shropshire is the independent consumer champion for health and social care in Shropshire. We aim to ensure that people from across the county have an opportunity to voice their opinion on the health and social care services affecting them. We are one of many local Healthwatch across England.

What we do

We listen to peoples' experiences, look for trends and influence commissioning, provision and scrutiny of local health and social care services. We also provide an information and signposting service. We are not individual case workers but can signpost people to the right service.

Project Background

Through our contacts with local groups such as Jigsaw ([Link](#)) we became aware in early 2018 that some families were feeling let down by the Children and Adolescent Mental Health Service (CAMHS) in Shropshire. The service was provided by South Staffordshire & Shropshire Foundation Trust (SSSFT) and formed part of the recently set up 0-25 Emotional Health & Wellbeing Service (EH&WB) jointly commissioned by Shropshire and Telford & Wrekin Clinical Commissioning Groups (CCGs). The 0-25 EH&WB service started in May 2017 and includes online services (Healios & Kooth) and Beam, the outreach support from the Children's Society. At this time there was a back drop of national concern being expressed about mental health services for young people.

We wanted to try and get a picture of the patient experience in Shropshire and in March 2018 sought feedback from families. Our Engagement Officer met with carer groups and we publicised the call for information through social media and the local press and community groups.

What people told us

We received 42 comments that raised 110 negative issues across 18 themes. We received two comments that gave positive feedback.

The main themes where feedback was negative were:

- Service delivery, organisation, staffing and access (59.5%)*
- Staffing levels (31%)*
- Continuity of care (26.2%)*
- Waiting times following referral (26.2%)*
- Cancellations (19%)*
- Communication (16.7%)*
- Diagnosis (16.7%)*
- Medication (16.7%)*

* Percent of comments that raised the issue

Our findings were shared with Shropshire CCG so that the patient voice would be included in the conversations that were taking place with SSSFT about the Remedial Action Plan that had been set up in January 2108. As part of that conversation we understood that SSSFT were working to address some service issues that had not been fully apparent at the time that CAMHS was incorporated into the 0-25 EH&WB service.

It was agreed by the HWS Board and Team that later in the year we needed to follow up the initial feedback to establish what changes, if any, were occurring in the patient experience as a result of the Remedial Action Plan.

During this time the service was branded as Bee U Emotional Health and Wellbeing (www.beeu.org.uk) and SSSFT merged with Staffordshire and Stoke on Trent Partnership NHS Trust to become Midland Partnership Foundation Trust (MPFT).

What we did

We decided it would be useful to try and get a clearer picture of the patient experience of the whole Bee U service and see how it was changing as the service developed; so we programmed a 'Hot Topic' into our calendar for Autumn 2018.

As we were planning for the Hot Topic it came to our attention that Healthwatch England was seeking patient experiences in perinatal mental health services across the country.

“Around one in five women will experience a mental health problem during pregnancy or in the year after giving birth. This might be a new mental health problem or another episode of a mental health problem you've experienced before. These are known as perinatal mental health problems.” www.mind.org.uk

To start our Hot Topic we decided to focus on perinatal mental health in Shropshire. We were aware that the [Maternal Mental Health Alliance](#) has published data which showed that the level of specialist support given to Shropshire women and their families is “extremely basic” and “falls short of national standards”.

We planned to follow up this work on perinatal services and will report separately on what we heard.

Following the initial focus on perinatal mental health we focused on services for school children.

We put the call out for feedback through our contacts in health, education and community groups across the county. Publicity was circulated through the local press and social media.

What we found out

Our Hot Topic ran through September and October 2018 and we received 47 comments that raised 93 issues across 20 themes. We received no positive feedback about the service.

The main themes of the negative feedback were:

- Service delivery, organisation, staffing and access (40.4%)*
- Waiting times following referral (36.2%)*
- Information providing (23.4%)*

- Diagnosis (12.8%)*
- Communication (12.8%)*
- Continuity of care (10.6%)*
- Quality of treatment (10.6%)*

* Percent of comments that raised the issue

Themes

Service delivery, organisation, staffing and access

Similar issues in this area featured in both sets of feedback although the comments we received in the Spring of 2018 included more general assessments of the service;

- “absolutely appalling”, “CAMHS are an absolute joke”, “It’s just a big shambles”

Concerns were raised about the accessibility of the BEAM drop in service

- “the only face to face session you can access is BEAM. But the drop in is in Shrewsbury. This is not a ‘drop in’ if you live in Whitchurch. You would need to drive there and get your parents to take you. If they work you wouldn’t get there in time for the drop in. it would also stop people from going who didn’t want their parents to know they wanted to get some support.”
- “People in Oswestry cannot go to the BEAM service in Shrewsbury. It is too far away and the timings aren’t any good around school times. BEAM is only a service for people who live in Shrewsbury. What about the children who live in the rest of Shropshire? Why do we matter less?”

There were issues about the support available to people who have been referred to the service but are on the waiting list;

- “Following referral while waiting for first CAMHS appointment there is no help or crisis support”

A lot of the feedback indicated that children and families did not feel that online services were an adequate replacement for face to face contact.

- “They told us to use KOOH but our child did not want to”
- “Children and Young People want face to face help, not from online services.”
- “Hopes are dashed when people are being given Healios as a solution when they think they will be getting an intervention that is person based and what they need.”
- “the Bee U service was supposedly designed by children and young people but there needs to be options for everyone.”

Waiting times

Waiting times of up to 2 years were reported.

- “One family I support were on the waiting list for CAMHS for 2 years, they received a letter from the service discharging them. They had never even had a first appointment. They then had to start the process all over again.”
- “Child was referred to CAMHS in November 2016 ... initial assessment appointment in June 2017. In September ... child’s case was referred to the neuro-development team to consider if further investigations were required. They decided at the beginning of November 2017 that he should be accepted onto the waiting list for further neuro developmental assessment. I called in February [2018] ... and was very apologetically told to call back in a month to get a feel of the waiting time left!!!”
- “Family waiting for an appointment with their consultant. It was cancelled and the one set for 3 months later was also cancelled. We are another 3 months in and still no appointment.”
- “Caller has been waiting 20 weeks so far for their autistic child to access CAMHS. Child has been excluded 24 times from school this year [2018] as there is no support available there.”
- “We’re now almost three months in an urgent waiting list for psychology as my child ended up in hospital seriously ill ... But its fine as BEAM has referred us to the library to read a book. Until my child attempts, and pray fails, to kill themselves we’ll never reach the top of that urgent waiting list will we.”

Staffing levels

This features significantly in the spring feedback where it appeared that several Doctors were leaving and families who were in the service felt no reassurance that their replacements would be in place in a timely manner.

Continuity of care

This featured more significantly in the spring feedback where more of the comments were from families with children already being seen by CAMHS. Most was linked to the high turnover of Doctors and how it was having a negative impact on children’s treatment.

- “my child ... will soon be on his 12th locum doctor in 5 years”
- “So far on her ELEVENTH locum.”
- “But all these people he has seen it's no wonder he now refuses to go hence doesn't get the help he needs!!”
- “It’s distressing to have to explain difficult stuff over and over again to different people”

The team approach to talking therapies also raised concerns around continuity of care, having appointments with several staff prevented the building of relationships and trust leading to children disengaging with the service.

Cancellations

Concerns about appointment cancellations appeared significantly in the spring feedback but very much less so in the autumn. It appeared to be linked to the issues around staffing levels.

- “At the moment people keep having [medication review] appointments cancelled. This can happen 3 or 4 times and then this means that child is going 9 months without a review of their meds.”
- “We’ve had our appointment cancelled for the 2nd time, overdue a review and on medication. Struggling with school, feels like no support from school or health services #childrenlost”

Information Provision

This theme came through strongly in the autumn feedback although it was commented on in the spring. A common feature from both sets of feedback was a lack of explanation for a decision.

- “Recently we have seen a big rise in people receiving discharge letters. This happens with no explanation and it is not understood if the discharge is appropriate.”
- “Parents have been finding out [about 2 doctors leaving] through support groups but were not informed directly by CAMHS. They just received appointment cancellation letters.”
- “After waiting 2 years, my child was meant to be starting his clinical assessment in school this week but it got cancelled last week "until further notice". CAMHS never gave an explanation as to why, in fact they never told me as the parent, they just told school.”

A lack of information while children were waiting to be seen was also apparent.

- “We knew we’d have a long wait, but didn’t expect to have the experience we have had, with lack of communication. The only updates we have received have been in response to hard chasing”
- “I activated a referral to CAMHS in May 2016 and the process is still ongoing today [Oct. 2018]. The parents said they have not heard from the service since then, no communication and no feedback. The service should keep parents up to date.”

In the autumn feedback there were concerns raised that the information surrounding the different services was inadequate and difficult to find.

- “It’s hard to understand what the commissioned services do let alone finding information about non-commissioned things in the area. The MPFT website is not very good either.”
- “Children and young people are being referred to KOOH and HEALIOS but are not being told what these services do, there needs to be better communication about the aims and objectives of these services.”

Communication

In addition to the lack of information families raised concerns about difficulties in achieving timely conversations with staff

- “You cannot get hold of anyone at CAMHS you can be on the phone all day.”
- “The parent has contacted the duty mental health team to pass on their concerns and ask for somebody to see the child, duty team promised to get back to the parent. The child ended up in A&E for the second time recently so parent, who had not heard from the duty team, rang them again but could not get through on the phone. The parent also rang PALS but they did not answer either.”

One comment raised the issue of feeding back to the service:

- “Adult service at SSSFT have involvement reps and groups to contribute to. Children’s services have nothing. There is no way to feedback concerns CAMHS do not have this, so there is no way to raise concerns or share issue.”

Recommendations

- Consider how to provide equitable access across the county to face to face services, in particular BEAM drop-in sessions
- Ensure patients and family are aware of the type of help available through each service within Bee U
- Consider how to provide timely responses to young people and families who are needing interim help while on the waiting list.
- Setting up family and patient involvement groups to improve feedback channels.

Service Provider Response

This report was shared with the provider prior to publication and we have received the following response from the Managing Director (Shropshire, Telford & Wrekin Care Group), Midlands Partnership NHS Foundation Trust:

“Midlands Partnership NHS Foundation Trust (MPFT) started to provide the 0-25 emotional & wellbeing service, called BeeU, in May 2017. We were asked to change the existing Child & Adolescent Mental Health Service to one that could care for children and young people up to the age of 25 years old and we were asked to provide an autism diagnostic service. Since receiving the service, many changes and improvements have been made, such as the development of drop-in sessions, on-line

cognitive behavioural therapy, the introduction of new posts and skills to the teams, a phlebotomy and ECG service for those on certain medicines, and a review of care to ‘looked after children’¹.

However, there has been no significant progress on the autism diagnostic service. This is for a number of reasons including a high demand for diagnosis. A diagnosis of autism can only be made by a multi-disciplinary group of staff with specialist skills. Such people are difficult to recruit into a diagnostic service. The demand is partly driven by general misunderstanding that a diagnosis is needed in order for additional support to be provided in schools. This is not the case. Even with a diagnosis there is no simple treatment for the condition. These issues are now better understood, and it is unlikely that any one organisation in Shropshire can improve the current situation. It requires further planning and commissioners are starting to consider how this can best be done and how to involve children, young people and their families in these plans.

We are keen for Healthwatch to follow the BeeU service as our improvement work embeds.”

The Mental Health Programme Director for the Sustainability and Transformation Partnership working across Shropshire, Telford & Wrekin shared his view of the feedback:

“Following the visit of the Intensive Support Team² in the summer of 2018 there have been some positive improvements in the BeeU service and in the partnership working with local authorities and across schools. A new model of care based on national recommended best practice (Thrive) has been developed and is being implemented.

The long waiting times remain a challenge but the service is working hard to resolve them. A particular area which is a priority is the availability of services for children and young people requiring assessment for suspected autistic spectrum disorder which commissioners and MPFT are working closely together to resolve.”

¹ A child who has been in the care of their local authority for more than 24 hours is known as a looked after child.

² The Intensive Support team was made up of specialist practitioners from other Trusts and from regional clinical networks.