

What are Children's and Young People's Emotional Wellbeing and Mental Health needs, what are the challenges of meeting those needs and user experiences of the new service in Surrey?

October 2021

Healthwatch Surrey has been asked to attend the Children, Families, Lifelong Learning and Culture Select Committee as a witness to provide insight into children and young people's Emotional Wellbeing and Mental Health needs, the challenges of meeting those needs, and user experience of the new services.

One of the statutory duties of Healthwatch Surrey is to listen to the views of local people about their health and social care and to share these views with the organisations who make decisions about local services.

How do we listen to the views of local people?

Healthwatch Surrey receives feedback about children's mental health services via our agenda free listening and more targeted outreach. two routes: - through agenda-free listening, and targeted outreach.

When we hold agenda-free engagement our engagement team (staff and volunteers) visit GP surgeries, hospitals and we hold events on the high street/ shopping centres. We also gather insight by people pro-actively sharing their experiences with us, via our partnerships with Local Citizens Advice services, our telephone Helpdesk, our website and by post.

Over the course of the last 18 months, we have also attended online support groups, where we've gathered more issue-based insight, given the purpose of the groups. In addition, for this report, we used social media to ask parents/carers and young people to share their experiences. We also held a small focus group with some parents of children, recruited via Family Voice Surrey.

We also reached out to partner organisations for insight from their service users.

Introduction

The experiences included in this report have been gathered since April 2021. However, it is likely that most of the experiences come from service users who were in the system before the new service was launched, therefore they will not have benefited from the new approach.

We also hear from many families who have a child/children with ASD. They share many of the same needs as other families who are accessing EWMH services, however they do have some specific needs which are highlighted separately.

It is worth noting that often the people who reach out to us do so because they have had a negative experience. Therefore, the experiences below are not representative of all service users.

Our summary focusses on the first two questions posed: what are the needs of service users, and what are the barriers? We hope that this insight will continue to inform the service provision.

Where it is obvious, we have identified new service users, and their experiences of the new service. However, given the fact that the service was partially launched in April, and the second phase, including the new website was rolled out in September, we believe it is very early days for any form of evaluation. We would be delighted to have a further invitation to share insight with this committee in due course, once the new service is further embedded, and where it may be more possible to evaluate the difference that the new service is making.

Key Findings

What are the needs of service users? (and importantly, their families)

Families are desperate and begging for help, yet they feel there is no help for them. Many of the parents who have contacted us are desperate for help. Some have given up work to support their children through the process of accessing help for their needs. Some are then spending money that they can't always afford on help for their children, rather than waiting two years for help.

Parents need to feel listened to, and for this to make a difference. One parent told us:

"I get the feeling I keep going to events and giving a lot of info and suggestions and it goes into a black hole. Nobody listens and nobody cares. It needs to be tackled on a political level. Unless the government agree to provide funding, we are well and truly up the creek".

Parents want their wishes to be respected, for example, they would like to be able to have contact with CAMHS without the child being present.

"You cannot see CAMHS without your child, the child is traumatised, and why should they hear all the stuff we are saying is wrong with them?"

Families need help to navigate the system. The pathways are confusing, with a myriad of routes and professionals involved. They feel that all the responsibility lies with them in terms of working out how to find help.

“The whole world is very unclear; you need someone telling you this is what you need to do”.

Families need help earlier - if help could be provided earlier more serious issues could be avoided.

Families don't need to feel blamed. Some parents have been told that their child's problems stem from 'bad parenting.'

The impact on families is enormous. We have heard from many parents who are struggling with their own mental health issues. We've heard about families whose marriages have almost failed and another who told us this:

“It has become so serious we are now having to seriously consider splitting the family unit into 2 households so that her siblings physical and emotional well-being are protected. To have to split up a family unit purely because CAMHS are unable to deliver an adequate service to a child in need is disgraceful”.

What are the challenges of meeting these needs?

We have heard about long waiting **times** to be seen on an ongoing basis for many years. Recently we have heard several experiences that throw the long-term consequences of delayed ASD diagnoses into sharp relief.

“My child has been failed by CAMHS. He wasn't diagnosed with Autism until he was 15 by which point it was too late - he'd already missed 5 years of school and suffered lots of mental health problems as a result.”

The thresholds for access are confusing. Families are feeling let down when their child is rejected by the service, especially when they have waited so long to be seen.

“CAMHS said to my daughter that they can't do anything for her, you are not bad enough. So, we were offered a referral back to Learning Space, my daughter said it left her feeling worthless. She had called an adult suicide hotline in July.”

The family were left wondering at what point would their case be serious enough.

There are gaps in the service at transition stages. In the past we have heard about issues as older teenagers are referred, and what happens when they go up to adult services.

“Now he’s due to transition to adult services and I have no idea what will happen. It seems that he’ll just be expected to cope by himself. His social worker keeps saying she should discharge him, but we have no one else to turn to so we can’t lose her”.

However, we have also heard about issues at the younger age, when transitioning from paediatric to children’s services.

“My son was referred to have an Autism assessment, during this time he turned 6. After a year of waiting, I spoke to the paediatrician who confirmed they had done the CAMHS referral, CAMHS say they never received it. I literally cried at the paediatrician who ended up helping me get the assessment for ASD.”

High staff turnover -we have heard many times about staff leaving and the impact on continuity of care.

“In January a CAMHS clinician had discussed the possibility of medication for her. Sadly, the CAMHS Clinician left before this could be arranged and since January, we have been repeatedly told that CAMHS has no psychiatrist or prescriber that can assess and support her. It’s my understanding that my daughter has been discussed at several MDT meetings and these clinicians have decided medication or therapy will not be prescribed, however none of these clinicians has actually met with her or myself and fully discussed her needs. This has meant she has been completely unsupported and is now almost back at crisis point”.

“My daughter was diagnosed with autism when she was 9 years old - she is now 17. She was seen by various CAMHS “professionals” (11 in total), most of whom left, passed her case to colleagues or discharged her”.

High turnover means relationships need to be built afresh. We’ve heard frequently about situations when a child has met a professional, built some rapport, only for that person to leave. The consequences are huge for a child, when it often takes time for a child to build trust with a new person. N.B. we have discussed this with SABP in our regular meetings and they acknowledge that staff promotion and staff leaving is an issue not only in mental health services but across health and care in Surrey more generally.

“SABP seem to have a real challenge keeping staff as they are changing all the time. It takes such a long time for him to trust people but by the time he does, they just leave and we have to start all over again.”

Lack of staff - we have heard numerous times of people being told that *“there is no one here who can help you anymore”*, additionally we heard that there is no Ed Psych in some parts of Surrey.

“All we have asked for is a full mental health assessment to take place as a matter of urgency to ensure her well-being, however, are constantly told CAMHS don’t have the staff. Her mental health shouldn’t need to continually decline due to Surrey’s inability to recruit and retain staff”.

The service is fragmented - when a child presents with multiple conditions it is really difficult for parents:

“Why do we have to see so many different professionals, why can’t we have one contact that liaises with everyone- it is so stressful for us”.

Admin mistakes - we heard about mistakes in letters with the wrong child’s name and the wrong GP surgery. We heard about results being attributed to the wrong child.

Inaccurate reports - we heard that despite meetings with professionals, the final report was not a true reflection of what had been discussed.

“We saw a clinician via CAMHS on zoom. He was contracted in from [the] North. The conversation was totally rushed, he didn’t listen. We had to complete three questionnaires - one was a pre-assessment questionnaire. It was huge and could not be saved and returned to, it had to be done in one sitting. I put the contents in a word document and copied and paste. It was handy that I did this, as after submitting this, I got no receipt and subsequently the clinician said he never received it. I asked for a hard copy, completed it and sent back tracked so I knew it would reach them. The report then given to me showed inaccuracies and inconsistencies. I wrote to my GP and the clinician. I was told I had to raise another SAR - (Subject Access Request) this gave me evidence that the RCAD score (Revised Children’s Anxiety and Depression Scale) and results were not my daughter’s. I re-wrote the report with her RCADS- CAMHS reluctantly re-wrote and amended report”.

Families with Autism

We have heard many experiences from families with Autism, some of which are positive:

“My son had a good experience the first time round with CAMHS. We had a long triage call within 1 week, seen 5/6 weeks later. They displayed a real level of empathy. I was told it would be 2 years to wait for an Autism assessment, it took 18 months in the end. We then waited 9 months for therapy, and we got 12 sessions. The last few I attended alone as my son found it too much. We were also signposted to the psychiatrist who diagnosed him with depression and prescribed medication.”

However, on the whole, we generally hear more negative experiences from families with a child with Autism.

There is a lack of CAMHS support for children with a diagnosis of Autism once the diagnosis has been made- and then no signposting to support for the child's mental health issues

“The feedback in general from parents isn't good for parents of Autistic children. These children are in need and often in crisis, they are not signposted after a diagnosis (if they get one) and then their only option is to end up in A&E.”

There are delays in medication reviews.

“I called CAMHS in April 2021 to see what was happening about my son's medication review, they said they would get back to me. I phoned again in August, and heard nothing, Finally I have an appointment now in October.”

Professionals can't see beyond the Autism diagnosis. The child is just seen as Autistic and other mental health conditions are dismissed, as part of their Autism.

There is confusion about the pathway for ARFID - (avoidant restrictive food intake disorder).

“With the eating disorder (ARFID), it is directly linked to Autistic traits, but this is not recognised as an eating disorder. He is on the 1st percentile (for weight)! It is anxiety based, yet he did not meet criteria with the 'One Stop'. So does he have to present at A&E in crisis to get help? Specialist dietitians lay blame with parents. Feeding clinic won't see me as he has an ASD diagnosis.”

However, we have heard of someone who has accessed this clinic, but who has concerns about the transition to adult services.

“My son is 17 and has been under the CAMHS Surrey eating disorder clinic based in Epsom for a long time. He has Autism and ARFID avoidant restrictive food intake disorder. He is severely underweight, and his problems have been long term with eating. When he turns 18 he cannot be transferred to the adult eating disorder service because they are not commissioned to deal with ARFID. My son needs the expertise help and I am terrified what will happen when we no longer have the support from his current clinic.”

The new service

We have only heard one experience which is a definitely attributable to the new service.

“We have been pleased with the speed of referral so far. We contacted our GP in April, and we were contacted by a discovery officer from Eikon in June. She spoke to me and then to my daughter. Although my daughter and I are close, the discovery officer did find out some things about my daughter which I did not know, which she did disclose to me with my

daughter's permission. My daughter then had a series of zoom counselling sessions with someone from Eikon. After a while my daughter withdrew from them, feeling that they weren't helping her. However, she has been feeling much better in herself. As agreed with the person from Eikon, she contacted me in September to see how my daughter is doing. She suggested that the best route might be for her to see one of the new counsellors at school, she said that she would check as to when they will be in place. We have been pleased with the service so far".

We discussed the new service with some families. For many, it just sounded like a marketing exercise, they had not yet noticed any difference, and they wondered what difference it would make to them, and when.

The families also questioned how the new All Age Autism Strategy would fit in with the new service.

Finally, it is not obvious from the Mindworks website which age group is being served.

Questions from Healthwatch Surrey.

As we highlighted above, families need to feel listened to. It is essential that as the new service develops, really robust mechanisms are put in place to actively encourage feedback and complaints, to support people to share their feedback, to listen carefully to children and families, and to demonstrate that feedback is acted upon. We welcome the fact that a CYPF (Children Young People and Families) group has been set up who regularly attend alliance planning meetings. We would ask for reassurance that this is robust, easily accessed, and transparent for all.

We understand that a Children and Young People Alliance Board is in planning, which will sit alongside the Alliance Board. We would like to ask for clarification regarding how the members will be recruited/refreshed as they 'grow out' of the service? How will you ensure that they represent others' voices and not just their own?

We would like to thank colleagues at Surrey Youth Focus and Family Voice Surrey for their contributions to this report.

How do we share local views with decision-makers?

Healthwatch Surrey have been building relationships with Children's services organisations over the last couple of years. We have quarterly meetings with Surrey and Borders Partnership where we have shared CAMHS insight in the past.

Why does feedback matter?

Sharing the insight that local people report to us is an essential part of our remit and collaborating with colleagues at both third sector organisations such as Surrey Youth Focus and commissioned services such as Family Voice Surrey and the User Voice Participation team adds more power to the voices which we seek to amplify. A key challenge for a system which wants to improve is to actively encourage, listen to and act on this feedback.

With this in mind, we monitor our database on a weekly basis, and if we see any concerning cases, these are escalated to providers and commissioners. We see our relationship with commissioners as being a critical friend.