WARWICKSHIRE
PARENT CARER VOICE

Children and Young People's Mental Health and Emotional Wellbeing Services

Background

Warwickshire Parent Carer Voice (WPCV) was asked by the Commissioners to find out families' experiences of Child and Young People's Mental Health and Emotional Wellbeing Services in Autumn 2024.

Data has been collected through a mixture of online and face to face parent carer focus sessions along with an online survey.

We have also included the information relating to CAMHS from the Warwickshire Parent Carer Voice SEND Survey 2024.

We recognise that the Community Autism Support Service is not a Child and Adolescent Mental Health and Wellbeing Service however we have included the feedback here as parents see the service as linked especially as RISE / CAMHS often refer children there when they have sought mental health support for their autistic children and young people.

What's Good?

Feedback suggests that some staff members have had a positive relationship with parent carers and that parent carers appreciate good communication and 1-1 support. Feedback also highlights that more general support such as talks, workshops and being able to access advice after diagnosis is valuable.

One parent that had a positive experience shared that the '*detailed report i received from clinical partners was useful and the number i could phone as a parent after autism diagnosis was great*'.

A further response was '*the person we saw for his assessment was really nice and welcoming, my son felt comfortable talking to her*'.

One comment discussed the positive relationship they had with a care coordinator and shared that they had '*access to a highly specialist family therapist who was an advocate. Sits partly in the eating disorder service and is our care coordinator. She was great*'.

Another parent carer mentioned '*amazing consultant - regular meetings, good communication*'.

Another response to feedback discussed that their two daughters had accessed MHST and one of their daughters had a positive experience.

The parent carer shared that '*both of my teenage daughters accessed MHST. I was just so grateful to get some support for them and I knew this meant we accessed support much quicker than if we'd been in a general CAMHS waitlist'.*

The same response also shared that *'one daughters counselor identified autistic traits and within a year we were able to get diagnosis through rise referred to problem shared*' and that '*overall MHST were absolute lifesavers for us and I can not praise my younger daughter's counselor enough for the exceptional care and support that she offered not just to my daughter but also to me as my mental health was at rock bottom by the time and possibly neurodiverse myself so she gave excellent feedback for my daughters counseling session in terms of supporting my youngest daughter in the most practical and effective way*'.

A further parent carer discussed their son's experience with the Early Intervention in Psychosis team, highlighting that the process went smoothly, with professionals responding quickly to their child's mental health difficulties. It was shared that '*my* *eldest was sent to A&E at Walsgrave by the GP, he was admitted immediately and given medication the next day and then provided with regular outpatient appointments for monitoring until the community CAMHS accepted his referral. The Early Intervention in Psychosis team did a thorough screening and reassured him that it wasn't likely to be a psychotic illness. The emergency autism assessment (within 3 months) of the hospital admission through a joined up approach between CAMHS and the neurodevelopment service gave him the reassuring diagnosis he needed*'.

It was also highlighted that '*1-1 support from CASS was a good offer for the community*'.

What's Not Good?

Parent carers highlighted several issues they have come across within their experience of using Children and Young People's Mental Health and Emotional Wellbeing Services, which are detailed below.

One of these issues is having a long waiting period to access services. Comments discussed that wait times are long, such as '*long wait to access ED service even though child in hospital very unwell*'. Another comment noted a '*year long wait for 1-1 with CASS. A new referral pathway was started and my daughter's referral was lost. Daughter had 12 weeks with CASS and it then ended with no communication to us. Felt a waste of time*'.

A parent also discussed that their child or young person '*last saw psych in October 2022 and then a gap until February 2024 with no communication in between*'.

Along with the lengthy waiting times for services, some parent carers have had to pay privately for Autism assessments.

A lack of continuity was another of the issues highlighted within the feedback. An example of this is a parent carer sharing that her daughter '*told her story to fourteen different people*'.

Some parent carer feedback also indicates that parents, children and young people may find CAMHS advice repetitive and unhelpful such as ‘*my daughter told CAMHS she knew they were going to tell her to have a bath and a hot drink*’. Parent carers also found new staff observing to be ‘*unhelpful*’.

Several comments highlighted a negative experience of therapy. Some of these comments also highlight that CBT was offered despite being unsuitable for their autistic child, with no alternative available.

One of the comments is ‘*she struggled to engage with the counselor and type of counseling that they gave. There was no adaptability to try a different method or counselor. Since then has struggled more than before. Also took over three years to get any support*’.

Another comment shared ‘*with my son, who is also autistic, he was self harming at school. The CAMHS clinician said that CBT was unsuitable for him due to his autistic presentation. However they only do CBT so he was discharged’. We tried to access the autism service but nothing came of it*’.

Additional comments around therapy are ‘*a complete lack of therapy (despite hearing a voice/being heavily medicated) because ‘he wasn't mentally unwell he just needed to understand being autistic’ was unhelpful*’ and ‘*no support after meeting. Only offered CBT which isn't great for autistics, no understanding of PDA*’ (pathological demand avoidance).

Experiencing barriers when accessing support is another issue shared by parent carers.

An example of this is ‘*There are so many barriers put in place to prevent a child from accessing mental health support. My daughter has been referred on a regular basis, approximately 5 times now and there's always an excuse why she can't access support. This means that year on year her mental health is worsening because there's nothing in place to help her. We waited 5 months for an assessment, then it’s an online assessment which my daughter struggled to engage with (she's 7) meaning that I needed to talk for her. Then the second they hear she's autistic they try and pass her* *onto another service even though it's very clear my daughter has symptoms of trauma and several anxiety disorders diagnosed by an educational psychologist. The service they want us to use instead, CASS, also has barriers, e.g. they want a specific professional referral and my daughter isn't registered with a school due to LA failures or under any other professionals meaning she can't access CASS either. There is no website for ARFID so we were just given a website address info*'.

Feedback has also found that some parent carers feel support offered has led to no clear outcomes or support. Services have been described as '*quick to discharge and pass the buck to someone else*'.

Further to this one parent carer discussed that '*my daughter has had three mental health crisis' that have required hospital care. Each Time we were discharged into the care of the crisis team at Camhs. Each time, the crisis team has stated that my daughter didn't need mental health support but instead support for her autism. However, in one report it stated she didn't have mental health issues, it was just her autism. The school then refused to accept that she was anxious and refused to help me get her to school. Therefore CAMHS actually made the matter worse. I have been left to deal with my daughter's mental health needs on my own because the autism service say she is too complex and she no longer has access to the neurodevelopment team*'.

It was also shared that '*the lady doing the video call ws asking questions about suicidal thoughts and then at the end if the call she said it was down to his autism and that was the only outcome*' another comment is '*we received no support from the original assessment, other than a referral to CASS. he is still struggling with his mental health and anxiety but has no support*'.

Another issue highlighted is that children receiving support offered by Children and Young People Mental Health and Emotional Wellbeing services can have vastly different experiences. One parent carer gave feedback about the experience of her two daughters. Despite one daughter having a positive experience with MHST, their other daughter experienced some difficulties with the support provided and did not have the same outcomes as her sister. The parent carer shared that '*for my other daughter the counsellor was very good but he did not grasp the underlying neurodivergence factors*

I raised and so the CBT based work wasn't so effective for her. I was frustrated as I felt some uncertainty on the counsellors' part in what to do (in terms of referrals) delayed the whole process which I would have pushed to get underway much sooner, just as the counselling started. She's been referred onto further online counseling now which is very CBT based and again I think it is a shame as it overlooks potential neurodivergence issues meaning it's not so effective. I'm unsure if it's okay to suggest not fiddling and being told to make eye contact etc as social anxiety is how things are being framed and the uncertainty without a diagnosis is a strange place to be'.

Feedback given also suggests that parent carers struggle with the processes around referrals. A parent carer discussed that '*a number of referrals were declined on technicalities, it took a long time*'. It was also discussed that '*the system is very complicated and frustrating*' and '*there seems to be gatekeeping of appointments*'.

Additionally some comments highlighted that there is a lack of transparency and communication from services. One comment highlighted that '*there is no indication of timescale for appointments*' and that '*processes are not clear*'. A comment also shared was '*I feel fobbed off*'.

Various comments shared also highlight that a more holistic approach is needed for children and young people with mental health needs who are also autistic. Two examples of this are '*with my son, who is also autistic, he was self harming at school. The CAMHS clinician said that CBT was unsuitable for him due to his autistic presentation. However they only do CBT so he was discharged*'

and '*my daughter has had three mental health crisis' that have required hospital care. Each Time we were discharged into the care of the crisis team at CAMHS . Each time, the crisis team has stated that my daughter didn't need mental health support but instead support for her autism. However, in one report it stated she didn't have mental health issues, it was just her autism. The school then refused to accept that she was anxious and refused to help me get her to school. Therefore CAMHS actually made the matter worse. I have been left to deal with my daughter's mental health needs on my own because the autism service say she is too complex and she no longer has access to the neurodevelopment team*'.

Where services are delivered?

Feedback suggests that children and young people would benefit from a tailored approach to where services are delivered such as offering choices such as online, at a venue, in school or a home visit. Comments also shared ideas for how venues could be more welcoming, such as a relaxed environment and specific rooms.

One parent carer shared '*I think face to face is far more effective for younger children (I'm a therapist who specialises in online therapy so I'm absolutely not anti online therapy at all). Community venues and clinics such as Crown Way Clinic, basically places that are accessible, not too imposing and with parking nearby so disabled children can access, staff need to actually be able to engage with children, we've met so many professionals in children's services who don't seem to have a clue how to adapt things for children or relate to them*'.

It was also highlighted that some children may prefer appointments in school whereas others would not, with one parent carer sharing '*for my son, having access to mental health support at school would probably be better. For my daughter, having access to mental health support at home would be better but taking her into the clinic would work too*'.

Further comments shared were '*transporting my distressed daughter is unhelpful*' and '*my preference would be the child's preference. With autism the biggest thing is who is that person? What do they look like? So an initial home visit would help then my child would be happy to travel*'.

Additionally, some parent carers have found that travelling to appointments has been difficult due to appointments not being local. An example of this is '*local venue (we had to go to Coventry from Nuneaton and that is not an easy journey, even more so when you don't have your own transport). Face to face and online would be good. Out of school hours if possible so they don't miss out on school and parents don't miss work*'.

A further comment was '*more in south Warwickshire please : we are based in Alcester and there are few services locally, it would be great to have an upper KS2/ lower KS2* *wellbeing group who meet and do fun activities and talk about their own mental wellbeing*'.

Feedback also indicated that children and young people would prefer a relaxed friendly environment as opposed to a clinical setting. One example is '*in a relaxed children's centre that is specifically for children, not shared with adult services meaning they can still feel like children and more sensory activities. Also maybe have dedicated rooms that are suitable for different age ranges to make it more fun, not so regimented and prevent it feeling like an interrogation*'. Another comment was '*maybe in an area more friendly rather than a blanket office with two chairs*'.

When discussing specific settings, Orchard house, Whitestone and The Railings were mentioned. Orchard house was described as '*a bit better*', Whitestone was felt to need an '*uplift*'. In regards to The Railings, a parent shared '*The Railings in Rugby is horrible, really oppressive, unfriendly, feels like a prison, not trauma informed or welcoming*'. A further comment shares that '*a more flexible, welcoming setting is needed, that feels safe*'.

When?

Feedback suggests that some children and young people can struggle with appointments being offered during the school day and with appointments not running on time.

One parent carer commented '*please try to avoid school hours as my children hate having their day interrupted*'. It is also commented that '*after 8pm at night, need a children's crisis service' and a further comment suggests 'not just school based services*'.

Further comments made suggest that the appointments do not run as smoothly and professionally as parent carers and their children and young people would like. Examples of this are '*the psychiatrist told my daughter she needs to get used to appointments running late as that happens in the real world*'. It was also shared that '*CAMHS team are always late to turn up which needs to stop happening*'

How?

Feedback around how services are delivered also suggests a more tailored approach, with a choice between face to face and online services.

Some parent carers suggested that they prefer face to face appointments, for example '*definitely face to face, my daughter does not want to do zoom*' and '*Not on Teams*' However it is noted that some people found an online assessment / sessions helpful so that young people can engage without having to leave their house / bedroom. Additional comments shared were '*home visits due to anxiety and PDA*' and '*initially online and then face to face*'.

Gaps?

Parent Carer feedback suggests that there are various gaps within the services available to them. These gaps are detailed below.

One comment shared is '*are there not any gaps? What a stupid question, the gaps are massive and children are falling between them all the time for example autism assessments'*.

Another comment highlighted that support to prevent a child reaching a crisis point is not available. The comment shared was '*everything needs to get to crisis point before support kicks in*'.

Staff shortages are also mentioned with the parent carer feedback being '*the gaps are huge, staff shortages are a problem, not joined up*'.

Some comments discussed the waiting times with one parent carer stating '*how to support families who are on waiting lists for years*'. A further comment from a parent carer was '*there needs to be investments made into waitlists*'. Some parents commented that they were told that if their child's school was part of Mental Health in School Teams they could be seen quicker.

The eating disorder service is described as '*inaccessible, slow with high staff turnover*'. It is highlighted by a parent carer that hospital environments are not suitable environments and exacerbate issues.

Feedback around autism awareness within services was also given. One parent carer shared that 'nobody ever mentioned autism until my daughters were in crisis. Autism needs to be embedded in CAMHS and in schools. The early identification is lacking'.

Some feedback highlighted that parent carers find it difficult to access information about what support is available, with one comment being '*parents don't know what services are available - we need a comprehensive directory of services*'.

Parent carers also had various ideas of how to close gaps in the support for children and young people's mental health and emotional wellbeing.

One parent carer suggested '*more lived experience in every area of CAMHS would be beneficial, parent groups to help other parents who have lived experience*'.

It was also suggested that there could be '*better support when young people are transferred home to the community*'.

Some comments around therapy suggested '*animal therapy*' and '*there needs to be art and play therapies for children who cannot access CBT*'.

Parent carers also discussed the process for support, with comments such as '*follow up on people who have accessed the service to check in, the service could learn alot from them*' and '*there is no clear pathway from CAMHS to other available services. There is Mind but not available for my child as I was told to go to IAPT first which closed the door to mind youth service. NHS does not collaborate with other outside services in our area*'.

Other Feedback?

Some of the further feedback shared by parent carers expressed disappointment with the services available to them and frustration with the impact this is having on their lives.

One parent carer discussed their child's experience of being in a crisis situation and shared that they are ‘*disgusted with the health professional’s attitudes towards us as families and feel we are truly being let down and feel it’s just an ‘if your face fits’ depends on level of respect and support you receive. Too many people getting paid too much for doing too little. My son is now in crisis situation and has affected my youngest now as well, just truly disgusted and extremely exhausted in the whole sector for children, it's a disgrace and feel all the feedback taken isn't really ever implemented as the same issues seem to always arise, especially for us as a family. Had nothing but a negative experience and lack of support when it is so desperately needed*’.

Another parent carer, with multiple children accessing services, shared *‘I feel very disappointed by the lack of support for my neurotypical child as well as my two autistic children’*.

A further comment highlights that accessing services can be tiring, with the parent carer stating ‘*parents are worn out and deflated by services so not keen to engage with feedback sessions such as these’*.

There was also some focus on the secondary effect to parent carers themselves with one comment stating ‘*parental trauma due to having to constantly fight and watch their children struggling with their mental health*’.

There was also feedback regarding the ADHD assessment process. One parent carer commented ‘*please can someone review the ridiculous process that requires people to have an ASD assessment before ADHD assessment*’. An additional comment made was ‘*open and honest conversations around the challenges of the ADHD assessment waitlist so people can make choices around right to choose and private services*’.

Another parent carer shared that ‘*it impacts our lives waiting for a meds appointment’* and that *‘the system isn't good enough*’.

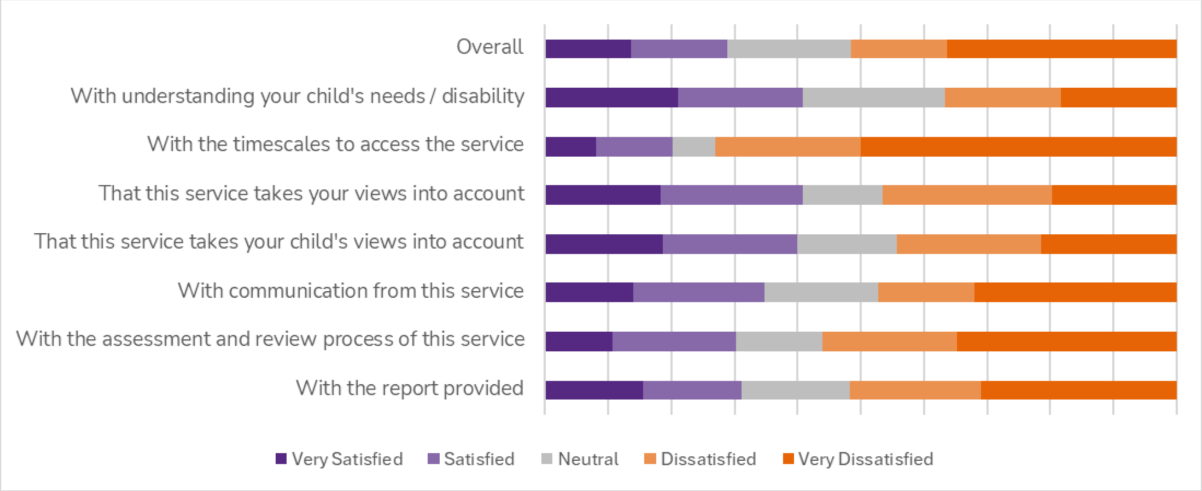
Children and Young People’s Mental Health Stories

Parent carers sharing their child and/or young persons mental health story highlighted that they have faced various challenges.

An example of this is ‘*my neurotypical child was seen briefly at age 14 by CAMHS and discharged quickly. There was a lot of impatience shown by the therapist. School then referred to the school mental health team at age 15. The support that was given was meant for low level anxiety and discharged my child for being too complex. No other pathway was shared and when I voiced my concerns they said she can be referred back in. But how is that possible when she was too complex for the service?. They recommended IAPT as was due to turn 16. I was told that CAMHS didn’t accept new referrals after 16 even though they state up to 18 years. My child went to IAPT but they weren’t experienced in talking to a young person with trust issues. My child struggled to make a therapeutic connection with the therapist and was discharged. We contacted MIND regarding support for youths that were aging out of CAMHS but because my child was not told of the correct pathway, she didn't meet the requirements because she accessed IAPT before MIND. I paid for counselling privately and part of the therapeutic relationship was to go for a walk. This allowed my child to open up and really get to know the therapist well. Unfortunately financially this couldn't be kept up. My child has a lot of mistrust regarding NHS. Generally speaking she has had very negative experiences including trauma from the NHS including physical health as well as mental health services. She feels abandoned and not listened to. Unfortunately I feel this has made such an impression that she may take these negative thoughts into adulthood. I have three children and all three have had negative experiences from services that should know better. They have all been traumatised by clinicians/therapists narrow minded views and refusal to be flexible in their approach. Overall, very poor service*’

Data from the 2024 SEND Survey

72 parent carers feedback on their experiences of Child and Adolescent Mental Health Services in the 2023/2024 academic year (September 2023 to August 2024).



The themes relating to CAMHS (including autism / ADHD support) are:

- Waiting times

  "Still waiting to see psychiatry, crisis team accessed for an assessment but didn't offer any further support"

  "*A referral has been made for mental health support, from school, but we've no feedback on where this is in the system*"

  "*Massive delays post urgent Camhs referral*"

- Waiting for ADHD assessments

  "*Still on waiting list for AdHd, had help to chase but have not had communication unless I have chased*"

  "*We have so far been waiting 5 1/2 years for an Adhd assessment, with no camhs support or access to medication in the meantime*"

- Therapy offered not being responsive to individuals' needs

  "*was told by CAMHS that they would not be able to provide support for CYP via chat function. They would only provide face-to-face support that CYP is currently unable to engage with, due to ASD*"

  "*CAHMS did not provide an individual plan but a generic CBT programme that wasn't suited to an autistic teen*"

“*Camhs only provide pills for my child I’ve been asking for the last 10 years for any tones of therapist for my son, but there is nothing just tablets*”

“*Referred for EMDR, offered anger management. Not what is required from trauma based incidents. YP left unsupported*”

“*The only support offered by CAMHS was CBT (which has been outsourced and online) not great for an autistic teenager (and it's taken eight months since I went to the GP concerned with burnout to get this offer)*”

- Autism and mental health
  “*Mental health services put child's issues down to autism and recommended autism assessment which was helpful but autism diagnosis doesn't then solve child's anxiety.*”

  “*My daughter was referred to CAMHS due to her mental health. CAMHS said that they could not help my daughter due to her autism.*”

- Lack of a service for Tourettes
  “*Tourettes and signs of other moment disorders, there is no local support*”

- Autism post-diagnosis support (both negative and positive)
  “*Discharged after autism assessment without ongoing support*”

  “*We’ve used the CASS* [Community Autism Support Service] *service by CW Mind. Really helpful toolboxes and WhatsApp support*”

Suggestions

1. Clear pathways so that the provision of support does not feel like a lottery
2. Waiting areas at clinics that allow children and young people to remain anonymous
3. Greater accessibility to mental health services, especially in the home for children who are unable to attend a setting or engage online
4. A range of therapy options available rather than CBT as a ‘one size fits all’. Families should understand what the options are and the decision of which route to pursue be made collaboratively
5. Better understanding of the interactions between mental health conditions and neurodivergence and the development of a service for neurodivergent young people to plug the gap between the neurodevelopmental service (just assess) and CAMHS (‘it’s part of the autism’) and the service needs to be able to support the complex cases
6. All staff working for CAMHS (including psychiatrists) need to have training and understanding of autistic burnout from those with lived experience
7. A pathway for Children and Young People struggling with Avoidant / Restrictive Food Intake Disorder (ARFID)
8. All schools to have access to Mental Health in Schools Teams
9. A 16-25 service so that young people are not left with a transition to adult services at a key point in their education
10. Better links between CAMHS services and education and social care so that children and young people gain holistic support
11. Reducing the ADHD waiting list

12. Continued engagement with Warwickshire Parent Carer Voice and IMPACT and appropriate funding to ensure that service developments are coproduced with children and young people and parent carers