



Children's mental health

A Healthwatch York snapshot report, October 2022
In partnership with York Mind and York Carers Centre

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Background

Healthwatch was set up in 2013 to hear people's experiences of health and care services. Healthwatch is your health and social care champion. We make sure NHS leaders and other decision makers hear your voice and use your feedback to improve care. There is a local Healthwatch for every part of England. Healthwatch York covers the City of York area.

Healthwatch York at York CVS is based on a very simple idea – that the best people to help shape our health and care system are those who use (or struggle to use) health and care services.

Recently, we have committed to sharing more of what we hear in Snapshot reports. Unlike the reports where we investigate an issue and publish a report to share our findings, our Snapshot reports aim to encourage further conversations. We hope that by knowing what other people are saying about a service, more will come forward to share their experiences, good or bad. In light of the recent health and care system reforms, with renewed focus on user voice and coproduction, we also hope these reports will be useful to those who buy and provide services, providing insight into how people currently experience health and care in the city.

This year, one of our key areas of focus is mental health. We have heard from a number of people experiencing significant challenges in trying to access Child and Adolescent Mental Health Services (CAMHS.) From these accounts we're able to identify where services can focus their resources in order to improve service user outcomes. This report is a collation of these voices, highlighting the challenges people face when accessing care.

Child and Adolescent Mental Health Services (CAMHS)

CAMHS has been used predominantly in this report by parents and teachers as the name for NHS – provided services (across the UK) for children and young people who have difficulties with their emotional or behavioural

wellbeing. However, CAMHS in the wider system iThrive approach covers both specialist mental health services, local authority CAMHS teams and people working in children's mental health in schools and the voluntary and community sector.

The CAMHS workforce can include:

- psychiatrists, psychologists and paediatricians
- nurses, including health visitors, school nurses and specialist substance misuse and learning disability nurses
- social workers
- support workers, such as school counsellors and youth workers
- occupational therapists
- psychological therapists: this may include child psychotherapists, family psychotherapists, play therapists and creative art therapists
- primary mental health link workers

What is the iThrive model?¹

iThrive is a care framework that aims to replace the four tiered system of CAMHS provision, by grouping children and young people based on their needs. It reflects concerns that the current tiered model reinforces the belief that CAMHS is the ultimate destination. The framework was developed by charity the Anna Freud Centre and the Tavistock and Portman NHS Foundation Trust. It is a response to research suggesting specialist CAMHS is only be effective with 60% of cases and that alternative community based interventions may be more beneficial to some young people and families. The aim is for the whole children's workforce to be able to identify children for early intervention in schools

¹ [Implementing iThrive? Pick priorities and prepare, says commissioner \(acamh.org\)](https://www.acamh.org) January 2018

National picture

This report is being published at a time of extreme pressure within our health and care system. The latest Care Quality Commission State of Care Report² highlights a system in gridlock. They report that people in need of urgent care are at increased risk of harm due to:

- long delays in ambulance response times
- waiting in ambulances outside of hospital
- long waits for triage in Accident and Emergency

The report also spells out the workforce issues, with significant staff shortages across all health and care organisations, and struggles to recruit and retain staff.

When looking specifically at mental health, the CQC's Community mental health survey 2021³ showed that people consistently reported poor experiences of NHS community mental health services, with few positive results⁴ Many said that their mental health had deteriorated as a result of changes made to their care and treatment due to the pandemic. Across many areas of care, experience of using mental health services was at its lowest point since 2014.

The report also highlights specific concerns about children and young people's mental health.⁵ They found that:

² [State of Care - Care Quality Commission \(cqc.org.uk\)](https://www.cqc.org.uk)

³ [Community mental health survey 2021](#)

⁴ (based on feedback from 17,322 people who used NHS mental health services in England between 1 September 2020 and 30 November 2020).

⁵ [Provider collaboration review: Mental health care of children and young people during the COVID-19 pandemic - Care Quality Commission \(cqc.org.uk\)](#)

- Services struggled to meet demand, increasing the risk of children and young people’s symptoms worsening and reaching crisis point, and being cared for in unsuitable environments.
- While there were positive examples of systems working collaboratively together to ensure continued access to mental health support, there were some concerns around silo working.
- Communication – both between services and with families – was mixed, with some people not always aware of what support was available.
- The pandemic shone a light on, and exacerbated, health inequalities faced by some children and young people, in particular those living in deprived areas.
- Digital technology enabled services to adapt almost overnight, ensuring continuation of care. But we heard that this could lead to risks such as staff missing cues or issues that would have been picked up face-to-face.

The Local Government Association, January 2022⁶

In this report the Local Government Association confirm that at least one in six children and young people have a diagnosable mental health condition. This report also goes on to state:

- Children and young people are more likely to have poor mental health if they experience some form of adversity; living in poverty, parental separation or financial crisis, where there is a problem with the way their family functions or whose parents already have poor mental health.
- Young people who identify as LGBTQ+ are also more likely to suffer from a mental health condition.
- Looked after children are four times more likely to experience mental health issues than their peers.
- A third of people in the youth justice system are estimated to have a

⁶ [Children and young people's emotional wellbeing and mental health – facts and figures | Local Government Association January 2022](#)

mental health problem.

- Nearly three quarters of children with a mental health condition also have a physical health condition or developmental problem.

Further, their report states that demand has gone up, but funding has stagnated. This is leading to an overstretched service without the capacity to meet the mental health needs of their population.

BBC Data Request, August 2022

A BBC article published on the 9th August 2022⁷, following a data request identified 18 deaths of people aged 18 and under in CAMHS in-patient units since 2019, and a further 26 deaths of patients who had been discharged within a year in the same time period, amid claims of a lack of ongoing support. The article states that there has been a 77% rise in the number of children needing treatment for severe mental health. Within the article is a collation of first-hand accounts. It concludes that CAMHS units are failing to meet the needs of children and young people under their care. In particular, the article cites specific failures to respond effectively to self-harm attempts across some in patient services. It also suggests that over-reliance on temporary staff is leading to patients being put at risk.

The Times Education Supplement Magazine January 2019⁸

The challenges in providing good mental health support have been exacerbated by the pandemic. But even before the pandemic, the Times Educational Supplement magazine was reporting a record rise in the demand for CAMHS, and CAMHS' failure to meet the needs of the children and young people being referred into these services.

The article suggests that better public education is needed to make sure children are being referred to the right support for them, and that specialist CAMHS are not overwhelmed with inappropriate referrals. "Too

⁷ [Camhs deaths expose child mental health unit pressures](#) BBC News 9 August 2022

⁸ ['The state of Camhs is a national disgrace'](#) TES Magazine 15 January 2019

often CAMHS are dealing with cases that should never have made it to their waiting rooms.” However, it also makes it clear there are “severely troubled and vulnerable children being left without help because of how stretched these services have become.”

Local picture

City of York Council review of children and adolescent mental health referral systems May 2022⁹

In the City of York Council review, they found that young people in York feel that the wait time for CAMHS is too long and that it is causing further negative impact on their mental health.

This report also found that the provision of mental health services from various providers results in confusion and children being passed from one service to another without explanation.

YorMind Young People’s Experiences podcast¹⁰

You can hear from those who have been directly impacted on the Chat Chit podcast produced by YorMind (a project of York Mind)

Mental Health Services Data Set¹¹

Data regarding specialist mental health services (secondary care) for the former NHS Vale of York CCG footprint is available from the NHS Digital Mental Health Services Data Set, or MHSDS. This is now shown as NHS Humber and North Yorkshire ICB – 03Q – 03Q¹².

This visualisation shows data categorised as:

⁹ [Review of Referral System](#) City of York Council, May 2022

¹⁰ [Young people's experiences podcast](#) YorMind, various date

¹¹ [Mental Health Services Data Set \(MHSDS\) - NHS Digital](#)

¹² [CCG to ICB listing - NHS SBS](#)

- people in contact with mental health services (CYP01) – the number of people known to be in contact with children and young people mental health services
- open ward stays in mental health services (CYP21) – the number of open ward stays in children and young people mental health services
- open referrals in mental health services (CYP23) – the number of open referrals in children and young people mental health services

This tells us that at the end of May 2020 there were 1,925 children and young people in contact with CAMHS. By the end of June 2022 there were 2,765 children and young people in contact with CAMHS, and 2,870 open referrals to CAMHS. The data covers all providers, not just TEWV.

Decommissioning of Kooth

Kooth is an online mental health support service for children and young people. It was commissioned across Humber and North Yorkshire during the lockdown period to provide additional support during the pandemic.¹³ It was then decommissioned at the end of the last financial year. Access to the service across North Yorkshire and Humber ended on 30 April 2022 having closed to new registrations on 1 March. NHS Vale of York CCG advised partners:

“We are currently issuing communications to advise partners and signpost to Childline. An engagement process with children and young people is being set up to consider next steps.”

North Yorkshire County Council, Young People’s Overview and Scrutiny Committee, February 2022¹⁴

in their consideration by the county council’s young people overview and scrutiny committee, give 2021 and 2022 figures on measures such as

¹³ [Partnership Newsletter July2020_v9_ \(humberandnorthyorkshire.org.uk\)](https://www.humberandnorthyorkshire.org.uk/partnership-newsletter-july2020-v9/)

¹⁴ [County Council's Young People Overview and Scrutiny Committee](#) North Yorkshire County Council Children's Mental Health 25th February 2022

waiting times and numbers of referrals into CAMHS. The report shows an increasing demand for CAMHS over the last two years and suggests that some services are unable to meet these demands, with increasing wait times for specific services. This report does not contain any user stories or explain the impact of poor access on the population.

Healthwatch North Yorkshire, May 2022¹⁵

Healthwatch North Yorkshire report that in their sample of young people (aged 16-24) across North Yorkshire, as much as 72% reported having experienced mental health issues.

They also found that 50% of their sample did not seek help for their mental health issues. They suggest that the barriers to seeking support are due to; long wait times, reluctance to ask for help, stigma surrounding mental health (embarrassment), feeling a burden and/or not knowing where to go for support.

The report concludes that there needs to be an increased awareness on how to access support as well as further work to reduce stigma around mental health. They also recommend that wait times for services needs to be reduced significantly.

¹⁵ [Young people's experiences of mental health and well-being report](#)

Healthwatch North Yorkshire 12 May 2022

Key Findings

A summary of our findings:

- The current process lacks the flexibility to recognise the individual needs of parents and children; for example some families struggle with appointments being given during school drop off and pick up times.
- There is a need for better awareness of training and resources available to teachers, schools and those involved in the initial referral
- The pathway through the referral process is unclear, and the reliance on forms prior to, or instead of, conversations can leave parents and professionals ill-informed on how best to assist moving the referral process forward
- There is a clear need for better administration processes
- There is heavy reliance on self-advocacy or parental advocacy to make sure the child can access the care they need
- It is unclear to parents what triggers a CAMHS diagnosis and in which circumstances you should be signposted to other services
- There is a need for more effective partnership working between organisations working to support children's mental wellbeing

Recommendations are made at the end of this report.

What people are telling us

What we have heard: April 2021 to September 2022

Comments from our signposting, information and advice work; including comments from our online feedback centre. These comments are in people's own words wherever possible. Where this hasn't been possible, these are shown as a story, though all names used have been changed.

Positives

“Since we have been referred back to CAMHS from private psychiatrist, they have been really responsive to adjusting meds, they listened to parental feedback when the increased dose affected his appetite and returned to the original level. We have had regular checks for both height and weight with HCA as well as 3 monthly zoom calls with psychiatrist.”

“Now the clinical psychologist has actually met him (after 18 months wait) things seem to be moving quite quickly with additional appointments / assessments etc.”

“Once I was in with CAMHS I had a worker allocated to me. I saw her regularly so I was able to build a relationship with her which helped. When I turned 18 and left CAMHS, I didn't see her again and support wasn't as regular. I felt a bit left on my own.”

Negatives

June 2022 – Woman stated that mental health services “practically do not exist in York”. She works with teenagers and young adults that are struggling to access any support.

May 2022 – Woman expressed concern about her friend's young daughter who is showing signs of autism and complex needs. She can't seem to get a diagnosis without going private and paying lots of money.

February 2022 – Child of a military family referred for an autism assessment when based in Northallerton. The family were transferred to York in the summer of 2021, and the child was removed from the waiting list. They later received a letter from CAMHS in York stating that they would receive an assessment, but not immediately, and eventually received a date in April 2022 for that assessment. They feel they have been treated unfairly due to being a military family and are requesting an earlier date for assessment.

February 2022

Woman shared that her 14-year-old son has had significant learning and behavioural difficulties over the past few years. With the guidance and support of his school they sought a diagnosis privately. They decided to pay as they were told by the school that diagnosis would take a minimum of three years. This was confirmed by the CAMHS team and his GP. Her son received a firm diagnosis of ADHD (Attention Deficit and Hyperactivity Disorder – Combined Type) classed as moderate to severe from EBOR Psychology Group in York. There has been a long delay since their GP contacted CAMHS of around two months.

They have since had conflicting advice after speaking to two different members of staff. Firstly, somebody phoned for a telephone meeting – after speaking to him and explaining that they had received a diagnosis privately, he advised them to call back after a few days to make sure that their son was put onto the ‘ADHD Pathway.’ They asked how long it would be for him to see somebody who was able to talk through possible medications. He suggested that this should not be a problem and her son should be seen within a few weeks given that he has already been professionally assessed.

As advised, she phoned CAMHS and spoke to a manager who told them that the private assessment/diagnosis would not be taken into consideration. They would need to wait to speak to somebody who will then put them on a waiting list to go through the entire process again.

Their consultant's response was:

"Hi, I am sorry to hear that and surprised. I have just spoken to a former colleague who still works at York CAMHS who thought this may be happening but there was still some flexibility depending on the quality of the private assessment. We have completed a number of ADHD and ASD assessments for CAMHS in the last few years and so they are happy with our assessment process. They have also recently contracted some assessments out to The Retreat and so obviously still work with independent services. You could ask to speak to the service manager and question their position (to see how accurate it is)."

She confirmed her concern is that as it was the Service Manager who said a fresh assessment was needed, they will not get any further with this. If the wait is as long as advised, it will carry through into his GCSEs.

What teachers have told us

July – August 2022

Teacher reports that CAMHS regularly lose paperwork and that it's common for him to have to fill out the same assessment forms for the same children several times.

Personal stories 1: Concerns over accessing professional help when needed



[Accessing SEND support] is definitely an issue in state schools. Absolute nightmare trying to get support / help when you know a child has a difficulty and the paperwork / hoops you have to jump through is ridiculous. I

don't notice it as much in private [school]. Most parents will pay to go private when they have concerns as they get seen quicker. But they're lucky to be in a position to be able to afford to do that.



Personal stories 2: Concerns over SEND provision in schools



*“ My main concerns are the following-
-very slow identification of SEND needs in schools. Often because class sizes are huge and schools are underfunded!
The slow identification leads to low self-esteem for the kids and potentially, problems that are much greater when they are finally identified than they need to be! Added to this when they are identified, the waiting list at CAMHS is massive, and help just doesn't arrive!
- a lack of training for teachers, I have had almost no formal SEND training (that I haven't sought out and funded myself) in my 20 years of teaching, this means that not only are teachers unable to identify needs but also are unsure how to manage them in busy classrooms.*

- a lack of TA support. This speaks for itself. For example, [a well-thought of York Primary School] is allowed class sizes of 34, very few classes have a TA more than a few afternoons a week! Kids with SEND often need tailored materials and support - this is NOT available despite very hard working (exhausted) teachers!"

- the York offer for secondary SEND provision is almost all focused on young people with autism, there is basically nothing for anyone else (Danesgate is the only option, it is not suitable for most kids with SEND and also is oversubscribed)! The autism support is needed but so are the others! Mainstream schools can't manage complex needs (again I cite my 20th year teaching experience here) so kids either 'manage' or they don't!!



Personal Stories 3: Feedback from Ellie*, a teacher in the York system working with students potentially experiencing disadvantage:



A girl I referred in year 9 is now in year 11 and still hasn't had a full assessment, only the initial one. I am concerned she will age out of the system before we can get her a diagnosis.

The paperwork for school is often sent to family homes even though we've described their situation to CAMHS as chaotic. Then the paperwork doesn't reach us and the case is closed as a result of failure to submit paperwork.

One case I referred was closed, because they ring from a withheld number. This meant the parents didn't answer it, and then we're told the case is closed. If you've got parents who are in financial difficulties, getting calls from bailiffs, you won't get them answering withheld numbers. I re-referred it and told the parents they had to answer. And in fairness they did, but they told CAMHS there was nothing wrong with him, he's just a naughty boy. I've been told that the case has been closed again, with no direct contact with the child.

A new pupil moved to the school part way through the CAMHS process. They have the clearest case of ADHD I have ever seen. They've had an initial assessment where CAMHS explained they'd lost the paperwork from the previous school. This meant I had to recomplete that paperwork.

I phone regularly to check on young people and where things have got to with their assessments. I am often on hold for 45 minutes. But I will dedicate that time as I know if I reach the right person CAMHS can make things better.

One young person I work with, he got a diagnosis 18 months ago. I became really concerned about his mental health. He was hearing voices. I had a really good conversation with his CAMHS doctor. She gave me her direct contact details. If you can get these, and the doctor is good, everything changes. She was extremely helpful, gave me great advice that allowed me to feel his mental health was being looked after properly. It's so reassuring when I know he's so vulnerable. I felt like I wasn't the only one in his corner.

I did a referral, and I know I spelt her name right. When the paperwork eventually came her name was misspelt. I alerted CAMHS and changed it on all the paperwork I sent back. When I called to follow up after the initial assessment, they had no record of her on the system. This horrified me. How could that be? But I stuck with it, insisted she had to be there. I asked them to search by date of birth and address. Eventually they found her - under yet another version of her name.

When I think about the situations those kids are in, I could just cry. They are in households where parents either respect or mistrust authority to the point where they won't question or challenge it. There are low levels of literacy and numeracy. I'm not downplaying the problems middle class children and their parents are experiencing, but this is a whole different ballpark. So who is advocating for these kids? I just don't feel the current CAMHS system recognises or takes seriously these inequalities. Also, when we talk about ADHD running in families, the harder we make it, the less likely we'll address these issues. We're building opportunities into the system to whittle down waiting lists by timing people out.



What parents are telling us

What we have heard: July 2022 to date

Personal stories 1: A parent to a child aged 15



“My child has experienced anxiety and panic attacks for a number of years, has self-harmed and had an eating disorder for the last three years. They were referred to CAMHS a couple of years ago and received video support calls which finished with no improvement to their symptoms. They were discharged with a list of support apps.

My child was experiencing regular panic attacks at school throughout this period and missing a significant amount of lesson time. School were generally supportive, and on at least two occasions phoned the CAMHS crisis line for support, but there was no response on either occasion. My child has independently phoned the crisis line on at least one other occasion, and again, there was no response.

At the end of last year, the eating disorder had got much worse. My child was receiving group support from MIND, and the group leader suggested to my child they should refer back to CAMHS Eating Disorder Team for some support as they had noted their condition deteriorating. MIND helped my child with the self-referral and 6 months later, we went to Orca House for an assessment. Whilst the CAMHS team noted the eating disorder, they were unable to offer any support as they stated that it was a form of self-harm due to anxiety, and therefore the wrong kind of eating disorder for their service. They suggested that we get in touch with MIND (having missed that the referral came from MIND) and signposted us to IAPT, whilst

acknowledging that my child would probably be too young to access their support.

We put in a self-referral to IAPT and have never received either an acknowledgement or an appointment.

Following this, we went back to our GP for advice, and as part of this agreed that we should request an autism assessment, as this had never been considered previously. We phoned the Single Point of Access number and were given a time for a clinician call three weeks later.

On the day of the call, a Friday, we were given a time slot between 12 noon and 5pm. CAMHS said they would endeavour to call after three as my child was at school, but if the clinician got through the list more quickly it could be earlier, and if we didn't answer the call we would be discharged from the service. My child took half a day off school, I rearranged two dental appointments and a music lesson and we waited all day without receiving a call. From 4.30pm I phoned CAMHS a number of times, but each time it went to answerphone. As my child was getting upset and agitated, we again tried the Crisis number, but no response. I also sent an email, to which I have never received a response.

Early the next week, I tried to call CAMHS again on the Monday and the Tuesday, but with no response. Eventually we received a letter on the Wednesday informing us that they had tried to call but the number appeared to be unobtainable. We had checked this number a few times, and it was correct and a working number. The letter suggested we contact them via the Single Point of Access number again if we wanted to continue. I immediately called and did manage to speak to the receptionist who was apologetic, and mentioned that there were

other calls that day that appeared to be unobtainable, suggesting an issue with the CAMHS phone system. We were called back by a clinician later that day, and given another appointment.

This telephone appointment went ahead and my child has now been given an appointment for an initial assessment by video. We received a bundle of forms to complete in advance of this appointment, however, were sent the wrong forms (for ADHD screening rather than ASD), I then had to email and phone twice to request the correct forms. As the school term has ended, the school forms may not be completed in time for this assessment, which is likely to delay things further.

We also phoned IAPT again to follow up the online referral, and they had no record of the referral. When I suggested that they should check their systems if the online referrals were not being received, I was told that there was nothing they could do about that and we should call next time.

The whole experience has been hugely frustrating and upsetting for my child. They have lost any hope that they will receive any useful support and the anxiety, panic attacks and eating disorder continue. We work hard to support in every way we can as a family, but without appropriate clinical support, I fear that this will have a long-term impact on my child's future.



Personal stories 2: A parent of a child in their last year of primary school



“They never answer the phone or acknowledge messages. This leads to more anxiety and stress for parents as you don't know if messages have been received or acted on, for example if you need to rearrange an appointment. This can lead to 'missed' appointments. Complete lack of empathy and understanding! Last week I did manage to speak to reception (once in 20 calls) and after I really pushed it, was told a clinician would call me. They rang 2 minutes later by which time I was dealing with war between the kids so missed it. They left a message saying if I still wanted to speak to someone I could call back but of course I haven't managed to speak to a person again. I left a message saying I really wanted to speak to a clinician so please call again, but of course no-one did. Assessment calls with parents – call between 12 and 5 no regard for school run etc. Miss call and discharged!



Personal stories 3: A parent of a child in year 4 of primary school



*“ My journey with CAMHS so far is as follows:
The SEND lead at school is fantastic – they sorted a referral the second day after he started there (March 2021).
The SEND stayed in contact with me and chased CAMHS for me to have a call back.*

I eventually received a call back from CAMHS. I shared my concerns regarding my child and was told I'd receive forms in the post (within 5 days) that would need to be completed by me and by the school – 1 for ADHD and 1 for Autism. I felt reassured.

A week later I'd not received any forms – I called every day for a week or more, didn't get through and so left a message every day.

I finally had them sent to me – the forms were completed by myself and the school and posted off together in 1 envelope.

Months passed and then I received a letter to say that if I didn't complete documents, my child would be discharge.

I called and spoke to someone about this. His ADHD paperwork had been lost, but the Autism document had been received (along with our change of address). My child had only been put into the admin system as needing assessment for Autism and not ADHD. Therefore it appears some of the documents had been lost. I was asked to complete documents again, and for the school to complete them again, and return them.

When I first spoke to someone regarding my concerns that my child's paperwork was floating about somewhere, they told me they couldn't have been completed. They lacked any understanding as to why I'd be annoyed. If anything, they were annoyed with me.

Had to chase for these to be sent out again. When I asked, they were able to confirm that they had received his change of last name and address (which was sent with the other documents) but that they could not find the assessment documents – the lady was lovely and even went to the archive room to look for them whilst I was on the phone. They couldn't be found.

Myself and the school completed the forms again and sent them on. I don't remember receiving any confirmation of receipt, but I did receive a letter to say how we could contact crisis line and other services if we

needed to. Following this letter, I heard nothing for months and months. My attitude after having shared my experience with others, was that was just how it was! And that I'd have to sort something out myself. Thankfully the school is amazing and implement additional support to meet his needs, despite lack of support from external agencies.

After a year of waiting to hear anything from them (hoping if I did it would be for an appointment!), I contacted our MP to raise my concerns. I was concerned for other Children in York and the lack of acknowledgement of the issues. Following this contact with the MPs Team (who promised to chase my son's case) I received the same letter with contact information about how to call for crisis support and information on other services, but nothing else. No date or information on next steps.

I know from speaking to others that it's at least a 2 year wait with around 4 'assessments' before diagnosis – we've had nothing other than the initial telephone conversation following the school's referral. I have in the last few days received a call from CAMHS asking why I hadn't attended an appointment on zoom that morning. I explained that I hadn't any knowledge of an appointment! She didn't seem surprised by this, and said she'd find out what happened and to get another sent to me for 2 days later. This has now been received.

I was surprised to hear her say that they had enough information on him to do a zoom assessment, but then be asked whether I had returned my assessment forms? How could they know about him if they've not yet seen the forms! This suggests to me that the practitioners don't have the time to fully prepare for their assessments with the children – very poor considering the experience is already reduced by providing only online zoom appointments.

My concerns are as follows:

- *How can primary schools provide effective provision if they don't have the support needed – practical, resources, training and financial?*
- *What happens to children moving from primary to secondary?*
- *There must be a growing number of children presenting with MH/LD/Autism/ADHD but with no diagnosis – how are schools being supported to prepare for this?*
- *Why are there SO MANY assessments and calls before formal diagnosis/final assessment? Surely this is a waste of resources.*
- *Also, with how long the whole process takes, how are children on the waiting list managed when they reach adulthood (before having a diagnosis under CAMHS) – do they go onto a list to access adult mental health services?*

I feel strongly that people have become complacent and feel that it's 'just how it is'. But I know from experience that there are great examples of care across the country! So why is this being so poorly managed in York?

Managing referral systems and overseeing administration is a very simple thing – losing paperwork is a serious breach of data regulations – it also wastes the trusts time and resources

It seems that at every step there is a waste of CAMHS staff time and resources, not tackling this now will put an expensive burden on adult services as these children grow up with their needs unmet”.



Personal stories 4: A parent to a child in year 4 with complex emotional needs

6 “[Our] CAMHS experience is no different to expectations. 18 months from referral to them starting the diagnosis assessment process. The issue is that his problems are severe and he nearly got excluded from school. Which made matters stressful. With their support, we have also only really addressed his ADHD. I think there are other underlying issues (maybe pathological demand avoidance type autism) – but despite having been in contact with CAMHS over the past 18 months, and despite his risk of being excluded from primary school, I haven’t even started to explore this with them. I haven’t found CAMHS very good at dealing with complex cases. But we are being seen, and in the meetings, they have seemed helpful. Hopefully, we might get there in a few years!”



What professionals are telling us

September 2022

Comments from those working with or within CAMHS services.



There is a lack of transparency internally. Staff aren't sure of what the pathway to accessing care is. Staff don't know how long an individual has been waiting.



It feels like a closed organisation. There is a lack of transparency. This is shown in their confusing reporting.



“From my experience, CAMHS support isn't effective for those considered ‘complex cases’. There is no joined-up working”.



Views from Contributors

York Carers Centre



The stories from parents are sadly very familiar. Examples include systems that do not take into account the individual needs of the family – for example, putting pressure on a parent to get their child to remain throughout a video call when they have Pathological Demand Avoidance – the very reason they need support!

One carer talks to us about issues getting through via the crisis line, which has been extremely tricky and only through sheer determination and 'pestering' have they managed to access some appropriate support. They worry about those who do not have the will to push for services.

We feel that eating disorder responses are far better than they used to be, with some assessments happening quickly and families able to access relevant advice and support in order to prevent further issues. Others still feel there is a long way to go, especially where there are complexities for example an eating disorder linked to OCD, Autism or other conditions.

In Response

We are currently running a 3-year National Lottery funded project offering CBT and whole family support to young carers. This project was developed in response to long waiting lists at CAMHs (6 months + for an assessment in many cases), and many young carers not even meeting the threshold support after this wait. This led to worsening mental health both during the wait and on being declined intervention. For those who have been eligible for support, many struggled to engage with the group CBT sessions offered, stating that they would prefer 1:1 work.

We had input into the bid from the CAMHS Whole Pathway Commissioning and we see this project as being complimentary to the work they do, and providing an early intervention approach.

More recently we have met with different areas of the CAMHS service (co-creation lead, Single Point of Access team, CBT group coordinator) who have been very supportive of the work, and where appropriate, shared resources and information.

We have spoken with the co-creation lead about being able to refer young carers who have completed NL funded CBT and require further services – for a ‘higher’ tier of support.

Additionally, should they need to continue their journey through referral to statutory services, we would also be applying early intervention support to help stop their condition from worsening.



York Mind



The following is from York Mind’s research into young people’s experience of accessing mental health services in York. This included a range of services which young people had either accessed or attempted to access and included statutory CAMHS.

As part of York Mind system change project, York Mind have captured the experiences of those aged 13 – 20 who access mental health services across York. A summary of our findings to date show:

No one size fits all when it comes to young people’s mental health services. But what we have concluded is that a holistic system is

needed. One that can offer a range of services based on the individual and their needs is of paramount importance.

What is apparent is that all of the experiences could have been improved with **earlier intervention**.

Whilst on waiting lists, and in-between counselling sessions, there was the feeling that there was a severe **lack of communication** with them, which resulted in an internal battle where the young person would question themselves about not being taken seriously enough or not being “bad enough” to get the help they felt they needed.

When they did receive communication and were signposted to another service, they felt like they were “**fobbed off**” rather than having it explained to them why they were directed to this alternative service.

A number of issues repeated themselves throughout the research. Both the **lack of support** outside of school coupled with a lack of awareness of what help and support was potentially available to them, led to their mental health deteriorating.

Additionally to this, it became apparent there was a lack of youth provision with no services and support available to those young people who weren't “bad enough” despite evidently needing support. One young person expressed stated that

“doctors just refer to CAMHS; what about other options, what about other places?”

In some people's experiences CAMHS had offered some good resources and coping mechanisms. But many felt, patronised, given lots of homework and summarised their experience of CAMHS as “not worth the wait”.



Responses to this report

Before publishing our reports, we ask key partners to fact check them. This also gives them the opportunity to respond.

We would like to thank all those who responded below.

Tees Esk and Wear Valleys NHS Trust (TEWV)

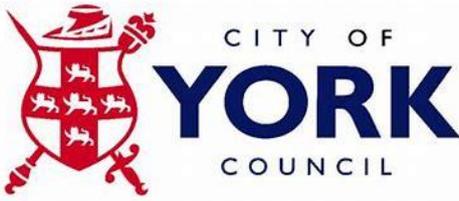


Tees, Esk and Wear Valleys
NHS Foundation Trust

TEWV confirmed “We use all parts of the working day so appointments will be offered during school drop off and pick up as well as other times of the day. We have to maximise the use of clinical time. What works for one family will not work for another, but there also needs to be a better understanding that for a specialist service, in the same way as for other specialist appointments in acute hospital settings, outpatient clinics have to run to maximise appointment time.”

They also questioned why there would be a lack of clarity as to what triggers a CAMHS diagnosis. They clarified that a diagnosis can only be provided following the assessment and information gathering process and provided by a qualified clinician.

In response to some concerns, we have made a number of changes to the report to better explain data and reflect the wider CAMHS workforce.



CAMHS is not the only support that is available for children and young people and families where there are concerns about mental health. The School Wellbeing Worker Service, which is jointly funded by City of York Council and health is a universal service working with all primary and secondary schools in York. The service provides a wide range of support including whole school training and individual casework and group work sessions in schools. The Wellbeing in Mind team (NHS funded Mental Health Support Team) works with 8 schools (primary and secondary) to provide interventions both in school and also with families. City of York Council have commissioned additional counselling support from York Mind and also commissioned York Mind to deliver the Department for Education Wellbeing for Education return resources to schools between 2020 and March 2023. All secondary schools in York have accessed the Department for Education Senior mental health leader training in the last year.

The case studies in the report do highlight a need to ensure that there is better communication about the different ways that children, young people and families and teachers can access support in York. In the case of teachers this is important as very often SENCos and pastoral leaders are aware of the support available but this information may not be as accessible for class teachers and subject staff in secondary schools.

York Health and Care Partnership

The comments in the report appear to relate solely to specialist CAMHS services, which are commissioned to treat children and young people with moderate to severe mental health difficulties. The report does not reference the wider and long standing CAMHS offer in York which is commissioned across the NHS and City of York Council. This includes

- School Well-Being Service

- Wellbeing in Mind Team
- The support service working with children with complex needs arising from autism
- The embedded mental health nurse working with the Youth Justice Service
- York Mind's counselling service.

The report should also reference within the definition of CAMHS the work of third sector organisations who support the emotional and mental well-being of children and young people, such as The Island or IDAS.

All the above have an important preventative as well as therapeutic role: the delivery model in York is iThrive, which focuses on what enables children and young people to manage their emotional ups and downs and know and be confident in seeking advice and help when they need it. Thus the approach, particularly in schools and fostered by the School Well-Being Service, is focused on what makes for a thriving and nurturing environment. Resource is put into other support, all with a role in prevention and early intervention: this includes the All About Autism Hub run by York Inspirational Kids, an autism social prescriber, and a mental health social prescriber due to work in primary care in an early advice and intervention role.

The Integrated Care Board, as successor to Vale of York Clinical Commissioning Group, has a firm commitment to children and young people's mental health and well-being, alongside the City of York Partnership of statutory and third sector agencies in the City.

Recommendations

Healthwatch York worked with York Minds Youth Group to review the experiences gathered within this report. The group have set recommendations based on these experiences. These recommendations come from young adults who have, or who are currently, using mental health services.

| Actions needed | By whom |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| Provide teachers with support when completing referral information on behalf of a child. Giving an understanding of what information is needed, why, and how this relates to special educational needs or disabilities, and educational health and care plan. | TEWV and CYC |
| Hold a conversation at the first point of contact with CAMHS outlining service options and the expected journey following referral. | TEWV |
| Provide information on 'who, what, why, when' as part of their journey to receiving support. E.g. who will you see, for what and why that decision has been made. | TEWV, CYC, YH&CP |
| Improve administration processes in accordance with current GDPR. | TEWV |
| Address staff capacity in order to support staff with answering parents', child's, and professionals' questions through the referral pathway. | TEWV |
| Better signposting support. On first contact with CAMHS, direct individuals to relevant training and information workshops available. | TEWV, CYC, YH&CP |

Glossary

| | Description |
|------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| CAMHS | Child and Adolescent Mental Health Services |
| Danesgate | York school that provides education and opportunities for children and young people who have Social, Emotional and Mental Health needs. |
| SEND | Special Educational Needs and Disabilities |
| SENCo | A SENCo, or Special Educational Needs Co-ordinator, is the school teacher who is responsible for assessing, planning and monitoring the progress of children with special educational needs and disabilities (SEND). |
| TEWV | Tees, Esk and Wear Valleys NHS Foundation Trust |
| Statutory | Services that are paid for and provided by the government e.g. National Health Service(NHS), school nursing, social services. |
| The Retreat | A Mental Health and Wellbeing provider for adults, children and adolescents. |
| TA | Teaching Assistant |
| ADHD | Attention Deficit Hyperactivity Disorder |
| ASD | Autism Spectrum Disorder |
| Orca House | The building that York CAMHS work from. |
| IAPT | Improving Access to Psychological Therapies provide services and therapies to people with anxiety disorders and depression. |
| Single point of access (SPA) | A team of clinicians who review your emotional and mental health concerns and help establish the best way to support you. |
| MH | Mental Health |
| LD | Learning Disability |

Conclusions

Snapshot reports are just that – a snapshot of what we are hearing. The aim is to make sure people know that everything they tell us is heard. Everything we share helps shape our future health and care services. We want this to be the beginning of a conversation, not the end.

We understand that with the current challenges facing our health and care system, there are no easy answers. Without additional investment in services, bringing down waiting times for assessment and diagnosis will be extremely difficult. However, what we can do is try and reduce some of the pain and anxiety in waiting. Better communication, and improving parent and teacher confidence in the admin processes could make the journey to diagnosis feel less adversarial.

Within this report there are also hints of further places to explore, and questions we haven't begun to answer. For example, one case study raises the possibility of a child being excluded from their primary school as a result of their mental health. What happens to those children excluded at such a young age? What support is provided to them? How are parents in this position supported to access the services needed and the education their child needs? There is also the feedback from teachers, suggesting either a lack of support available in schools, or a lack of information about how to access that support. The data also suggests particular groups with poorer outcomes, such as looked after children.

Through this report, we want to encourage more people to share their experiences of CAMHS with us and add to our local understanding. We also want to start a conversation with our colleagues in the local health and care system. We know there are no quick and easy solutions to these challenges. We believe that by really understanding what is happening for local people, we can help support those providing services to deliver better. Because ultimately, we are all on the same side – wanting the best health, the best possible future for all our city's children and young people.



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