healthwatch

What did people tell us about children's mental health services during the pandemic?

April 2021 – March 2022

Are the goals of the Long Term Plan being met?

In 2019, the NHS Long Term Plan outlined a number of goals in order to improve children and young people's access to and experiences of mental health support. It highlighted the need for increased funding for child and adolescent mental health services, and reduced waiting times. It also aimed to improve the transition from child to adult services and improve NHS staff's understanding of the needs of people with learning disabilities and autism.

The goals of the Long Term Plan match what people have told us about what needs improving about their experiences. We heard stories of children and young people waiting months (and, sometimes, years) for diagnoses and then waiting longer for treatment. This includes young people with eating disorders, where fast treatment is paramount for recovery. We also heard that young people felt staff were dismissive of their symptoms and that support offered was not helpful. People shared that they were discharged from services once they turned eighteen, despite not receiving care and the Long Term Plan outlining that support for young people continues until age twenty-five. Finally, we heard concerning stories of young people with autism and ADHD not being offered appropriate support, and LGBTQ+ young people being at increased risk of mental ill-health.

The fact that this feedback was shared with us after the Long Term Plan was published indicates that its goals are, so far, not being met. Increased demand – likely due to the pandemic – has increased pressure on already stretched and underfunded services, so children are going without necessary support for their mental health. More work is needed to implement the goals of the plan effectively, and direct funding to services themselves, to ensure children and young people receive timely, high-quality care.

Why are we looking at this issue?

In 2019, Healthwatch engaged over 40,000 people across England to find out what people wanted from the next ten years of the NHS. People told us that ensuring better support for children and young people's mental health was a priority. The NHS Long Term Plan reflected this, with ambitious targets for improving mental health services so that 70,000 more children and young people would access treatment each year by 2020/21.

The 2019 Long Term Plan aims to:

- Boost funding for child and adolescent mental health services, growing the services and increasing support available

- Reduce waiting times for treatment for young people with eating disorders
- Improve the transition from child to adult services, extending services and reducing gaps so that services are cohesive across ages 0 – 25
- Improve the understanding of NHS staff about the needs of people with learning disabilities and autism, reduce the waiting times for assessments and diagnosis, and ensure that all care from the NHS will meet Learning Disability Improvement Standards

From what we have heard, none of the goals set out in the 2019 Long Term Plan are being consistently met. Between April 2021 and March 2022, we heard directly from 129 young people and their families about their experiences accessing mental health support. The vast majority of this direct feedback shared with local Healthwatch was negative; 80% of people who spoke to us felt negatively about their experience using child and adolescent mental health services, and just ten people (8%) had a positive experience.

Many people told us that waiting times for services, including eating disorder services, were long, with little support given to children waiting for care in the meantime. We heard from many people that, once they turned 18, they were abruptly cut off from support. And we also heard from people with autism and their families that waiting times for assessments and support were years-long, impacting their ability to access mental health care. Care for people with autism was often not appropriate; we heard concerning stories that some practitioners refused to treat people with autism and learning disabilities or offered inappropriate care. We also heard that LGBTQ+ young people were more vulnerable to mental ill-health but less likely to access support than their peers.

Key findings from this research:

- Children and young people have a good understanding of mental health. But they have a mixed awareness of what support is available and confidence in services is low.
- Children and young people face long waiting times for diagnosis and treatment.
- Experiences of care are generally poor, with young people feeling like their symptoms are not taken seriously and increased demand on services limiting what support is available.
- People aren’t always offered follow-up support once discharged from services, including discharge from inpatient services.
- Young people continue to face difficult transitions to adult services, often being cut off from support once they turn eighteen.
- Neurodivergent children, including children with autism and ADHD, struggle to access appropriate support for their mental health.
- LGBTQ+ young people more likely to experience poor wellbeing and self-esteem and report self-harm compared to others.

Themes from across our research

Young people have mixed awareness of support available

Generally, children and young people had a good understanding of mental health, but a mixed awareness of what support was available.

Healthwatch County Durham heard from 989 children and young people and found that all of them had a clear understanding of what mental health is. Younger children were able to describe when they felt sad or when something made them seek out someone they trusted. Older children had a deeper understanding of mental health and were able to articulate what this meant to them and their peers. Healthwatch Haringey found that nearly 70% of the young people they spoke to in their research were able to articulate what mental health was and identify their needs for healthy mindset and positive wellbeing.

But many children and young people felt that they were not taken seriously by their GP and other mental health practitioners. Healthwatch Gloucestershire heard from young people that they felt dismissed by GPs, which made them less likely to reach out for help. They felt that they would only receive help when in crisis. Information provided on CAMHS websites was also felt to be patronising towards young adults by young people who took part in a mystery shopping exercise for Healthwatch East Sussex.

> ‘I remember there was a long wait before I saw someone, and I almost gave up. I think professionals think because we are young, we don’t understand as much’ – Healthwatch Telford and Wrekin

Despite a good understanding of mental health, many young people were not aware of what support was available for mental ill-health. Only one in three young people surveyed by Healthwatch Central London had heard of CAMHS, and for those who had heard of it, knowledge of what support they offered was mixed.

Not knowing how to access support, and reluctance to speak to professionals, is a major barrier to young people seeking help that they need.

Young people face long waiting times for diagnosis

We heard from parents/carers and young people that long waiting times to be assessed by CAMHS were one of the main problems with the service and were having a significant impact on their health.

> Three months after a referral for a psychological assessment, I am still waiting for an appointment. The system cannot cope with the demand. – Healthwatch Birmingham

Parents and carers told us that they had reached out to CAMHS for help when their child was displaying symptoms of mental ill health but were not contacted by CAMHS, even in cases where children had attempted suicide. Parents and carers consequently felt uninformed about their child's care and unable to support them. They also didn't know how to access formal support for their children.

> Caller is trying to get someone in CAMHS to talk to about his daughter. They keep promising to ring back but never do. – Healthwatch Oxfordshire

People shared that they were waiting months for initial assessments from CAMHS, without which they are unable to access support. We also heard that these assessments were inappropriate, with multiple people sharing that they were short, uninformative, and that practitioners did not listen to their concerns.

We also heard multiple issues with referrals which were delaying assessments and treatment. Healthwatch Central West London surveyed 200 young people about their mental health, and found that information on referrals, specifically self-referrals, was unclear. Young people and their families want clear outlines of how to be referred to CAMHS for support.

People shared that their GP had referred them to mental health services, but these referrals were denied. We heard of referrals being lost, and that people were not given information on how long the wait would be or what care they could offer in the meantime. Finally, we heard from people who went to their GP with severe symptoms of mental ill-health, including self-injury, suicidal thoughts, and auditory hallucinations, but were unable to be referred to urgent treatment without an assessment by CAMHS.

> Since coming to Cambridge 5 years ago I can't get my child into the healthcare system. Twice CAMHS have refused a referral from my GP. List of requirements to even get on the list will take months to obtain - I don't believe these requirements are consistent with NICE guidelines and only serve to delay access/diagnosis and treatment. – Healthwatch Cambridge and Peterborough

An assessment by CAMHS is the first hurdle people need to clear in order to access care. Long waiting times for this assessment, followed by long waiting times for care, mean that vulnerable children are going months without support. We heard from people whose symptoms worsened significantly while waiting for initial assessment appointments.

> The mental health team have taken too long to do assessments which have been detrimental to the wellbeing of my daughter, who has bipolar but it took over 2 years for her to be seen, she was told her mental health was to do with her age and life circumstances for a long time and they would not prescribe medication due to her being a teenager. – Healthwatch Cornwall

Many people told us they understood that practitioners were doing their best but were overloaded; people felt the problem lies with a confusing and disjointed system that makes it confusing and complicated to access care.

Once diagnosed, waiting times for treatment are long

We heard from many people who had waited over 3 months for an initial assessment, and then had to wait longer to actually be treated.

> Our experience of CAMHS has been absolutely awful. We have waited for over 1.5 years on the waiting list and this has been when my child has self-harmed and had suicidal thoughts and been to A&E after self-harming. The service manager is very slow to reply to emails of complaint and even then, does nothing to resolve issues! We have been promised a clinician within a certain timeframe and then it has been withdrawn and denied. Communication is dreadful, the telephone is rarely picked up and you just have to leave a voicemail and are lucky to get a response within an acceptable time. – Healthwatch Milton Keynes

Many people told us that their children were waiting years to be seen by a clinician. We heard from parents of children with personality disorders, eating disorders, severe depression, and psychosis, who were waiting 1 – 3 years without treatment. This is especially concerning for children with eating disorders, where early intervention is key and mortality rates are high.

We also heard that services were not integrated, and this affected waiting times. Parents told us that they had moved while waiting for their child to get care, and then were put at the end of the waiting list in their new area. We also heard from people who had turned 18 while waiting for care and transferred to adult services without receiving any support.

Experiences of care are generally poor

We received some positive reports of care from CAMHS and other mental health services for children. Listening to children and young people, and tailoring care to their specific needs, was central to having a positive experience of care.

> I had therapy and had a fantastic therapist. She really made me feel validated and helped my symptoms. – Healthwatch Sunderland

On the other hand, we heard many more stories of medical professionals not listening to the children they were caring for. People shared that they were prescribed medication that did not alleviate symptoms, or had severe side-effects, but when they raised this with staff they were ignored. Some people told us they were only offered medication despite recommended treatment for their condition including talking therapies. Others shared that they requested medication but were only offered therapies which they felt were inappropriate. Ultimately, children and parents wanted to be involved in the decisions around their care but often we heard that, instead, their concerns and wishes were ignored.

People also shared mixed experiences of virtual appointments during the pandemic. Some people told us that they found them useful, but others said they felt impersonal. People were also concerned that their privacy could not be assured over virtual appointments. Again, people want the choice between face to face and virtual appointments, but feel they aren't being given this choice. Healthwatch Lewisham found that the majority of young people they spoke to felt that face to face communication was their preferred way of engaging with mental health services.

Many of the problems with care we heard about stem from poor staff attitude. People shared with us that clinicians were dismissive of patients' symptoms, spoke to patients rudely, and appeared to have a limited understanding of mental health conditions. Children also told us they felt talked down to and patronised by healthcare staff, and that written information that was available didn't meet their needs. People also told us that they felt communication could have been improved; clinicians didn't offer enough information about medication or self-care techniques, and parents often felt left in the dark about their children's care.

We also heard from children who had poor experiences of inpatient care, including for eating disorders. Services felt stretched and care felt impersonal; children were not given the care that they needed. We also heard that parents did not hear from services or their children for long periods of time, and consequently felt anxious about their children when they were away from home.

> The client's child had been at [inpatient services] around 6 months due to anorexia …. The client stated that they used to get regular updates from key staff about their child's condition, however, over the last 3 months nobody was communicating with them about their child's care at all. They advised that they were also getting no feedback from the review meetings and often found out about plans after the event and via their child. The client stated that they had attempted to ask for more feedback and communication in an informal way, but this had been met with no response. They also had concerns about the treatment that was being provided for their child and restraint being used. They advised that they had already made two complaints about inappropriate restraint and were waiting for the outcome of the second complaint. The client said they were also considering taking their concerns further as they no longer felt that their child was being appropriately cared for and their health had deteriorated. – Healthwatch Hertfordshire

Ultimately, we heard many more poor experiences of care than positive experiences. Healthwatch Birmingham, for instance, heard from 416 children and young people about their experiences of mental health treatment in Birmingham. All the children and young people, and 90% of their parents/carers, were dissatisfied with the treatment offered.

Poor experiences of care meant that children and young people may be reluctant to reach out to services for support. We heard from children who, following poor experiences of care, did not want to speak to any healthcare professional because their trust had been damaged. Healthwatch Haringey surveyed 95 young people about their mental health during the pandemic and found that just 6% would speak to CAMHS or a mental health provider if they experienced symptoms of mental illness.

However, when care was compassionate and children and young people are listened to, children and their families have trust in their practitioner and have better experiences of care.

> “I must say though the care and compassion from CAMHS for my child and my family has been excellent. I cannot imagine where we would be without them.” – Healthwatch Cambridge and Peterborough

The demand on services means that support is rationed

In May 2022, it was reported that the latest NHS figures show that the highest number of children and young people are being treated by mental health services since records began in 2016.[1] The latest Mental Health Services Monthly Statistics published by NHS Digital show that 420,314 children and young people were undergoing treatment or awaiting care in February. This is more than double the number from February 2020.

We heard many stories of children and young people with severe symptoms of mental ill-health – including self-harm, suicidal ideation, psychosis, and auditory hallucinations – unable to access treatment because of the increasing burden on services. If they were offered treatment, often it was inappropriate, because services were only able to offer more intensive treatment to the severest of cases.

Often, this meant that children were offered short courses of therapies such as CBT or medication, which did little to alleviate their symptoms. Once discharged, their symptoms continued to worsen, and mental health services did not have the resources to help them.

> I wish to make a formal complaint about the service my son has received from CAMHS. He has been put on fluoxetine without any other intervention. We were offered family therapy which we undertook for a few months but … I don’t feel it was handled well, … [and] it felt like my son wasn’t offered anything on an individual basis. He has continually expressed he wants to kill himself, I called CAMHS … who said that they were unable to do anything if he hadn’t actually hurt himself. Does it really have to be at this level before my son can receive intervention? – Healthwatch Oxfordshire

Support following discharge isn’t always there

We heard from a number of people who had been discharged from child and young peoples’ mental health services, and often people felt they were discharged from care before they were ready. Some people left inpatient services without their mental health improving, and others

---

[1] The Guardian - https://www.theguardian.com/society/2022/may/22/record-420000-children-in-england-treated-for-mental-health-problems

finished courses of talking therapies without improvement in their symptoms and were unable to access further care.

Families also felt that their children were often discharged without adequate follow-up support in place, especially from inpatient services. Families of children with eating disorders didn’t know how to support them once they have left inpatient care and sometimes saw deterioration of symptoms after discharge.

> Daughter in [mental health] hospital … following an acute stress reaction. She is due to come home, however [parents] have no idea of what support will be provided (if any) and ideally, she would need to go to a step-down hospital closer to home first. She has had no contact from discharge team who advised a plan would be put in place. – Healthwatch Torbay

Young people face difficult transitions to adult services

Despite the Long Term Plan pledging to extend young people’s mental health services to cover anyone under the age of 25, we heard from a number of young adults who were discharged from children’s services once they turned eighteen, with no adult care put in place. In many cases, people had been waiting for months or years for care and were removed from CAMHS waiting lists without receiving any care or even a diagnosis. They then faced longer waits for adult services and had to begin the referral process again.

> There was a one year wait to be seen by CAMHS and due to being under 18 years of age the service informed that they couldn't give a diagnosis … They told the patient that they had to 'self soothe'. When the young person turned 18 instead of transferring straight into adult mental health the case was closed. There was therefore another wait for adult mental health services and the young person had to re-tell their story. In the end the young person went private. It took 3 years for a diagnosis… – Healthwatch North Tyneside

We heard from many people that, even if they were offered adult care, the move to adult services was difficult and poorly managed. Case notes were lost or not passed on to new clinicians, and people found it difficult to navigate a new system with limited support.

> My daughter has been waiting for well over three years for help from the STT Team since being diagnosed with Borderline Personality Disorder. Initially promised to be admitted on a therapy programme in Nov 2020. - this was a two year wait from when she was told and longer given the hurdles we had to go through to get that far. She was with CAMHS but was lost from the system when she turned 18, and we effectively had to start again. After

> numerous calls in Dec last year, we were told she was … on the waiting list and would be seen within 3-months. 3 months later, she is still [waiting]. She is suicidal at increasingly frequent times, feeling she is being ignored by those who should be helping her. – Healthwatch Milton Keynes

The impact of these problems is high

Many of the stories we heard told us about the impact that waiting times for care and poor experiences of care has had, both on children and their parents.

We heard from children who had been unable to attend school, sometimes for years. Symptoms worsened in many cases while children waited for assessments or treatment, often leading to emergency treatment. Distressingly, we heard from several families whose child had taken their own life or passed away while waiting for care from mental health services.

> Her daughter took her own life in January this year and feels her daughter didn't get the support she needed from mental health services. – Healthwatch Northumberland

We also heard that the stress, uncertainty, and fear felt by many parents had an impact on their own mental health and on their families.

> 'As a parent you feel powerless to support a child who is experiencing mental health issues and not having expert support on hand when it is needed has an impact on the whole family. The wait for support was a few months following referral by the GP when my [child] was in a time of crisis and once accessed, there was no consistent worker - appointments were cancelled, the practitioner moved on and the support ended.' – Healthwatch Shropshire & Healthwatch Telford and Wrekin

Health inequalities

Experiences of neurodivergent children

We heard that the issues discussed in this report are compounded for people with Autism and ADHD, because services are unwilling or unable to offer adequate support for children with additional needs.

Many people told us that their child was unable to access support for their mental health symptoms because they were waiting for a diagnosis of, for example, Autism or ADHD. However, waiting lists for assessments for these conditions are years-long, and support is not put in place for parents or children while they are waiting. Consequently, people are unsupported while dealing with both untreated mental illness and undiagnosed conditions.

We also heard from people who told us that their child's referral to CAMHS was denied because they were diagnosed with a condition such as Autism or ADHD. Practitioners often stated that they were unable to treat neurodivergent children but did not offer alternative support, or the alternative support offered was focused on symptoms of neurodivergence and not on mental illness.

> Trying to get support for over three years about the suicidal thoughts my son was having. After a circus of jumping through hoops of assessments and being passed between services and on waiting lists, he was seen by someone … …. We have got an appointment with a psychiatrist, but I've given up to be honest now, too. No one takes him seriously about being depressed as he's been diagnosed with ASD. The support is not appropriate to need, not timely, not validating of the child's experience and there is no continuity of care. All his experience of CAMHS has done is teach him to mistrust NHS workers to the point I struggle to get him to the GP now too. – Healthwatch Leicester

When neurodivergent children were able to access support, we heard concerning reports of practitioners not understanding the interaction between conditions such as Autism and mental illness, and in many cases refusing to treat children because of this. We heard of practitioners stating that symptoms of depression, anxiety, psychosis and eating disorders were Autistic traits, as well as practitioners who believed therapies such as CBT wouldn't work for people with Autism. In most of these cases, parents felt that their child was being discriminated against because of their neurodivergence.

> "She [an NHS paediatrician] then told me (in front of my son) that autistic people are unable to empathise and therefore can't be offered CBT" – Healthwatch Milton Keynes

Finally, we heard from many people that reasonable adjustments were not put in place for either their child or themselves. Children were offered virtual support that was inappropriate for them, in some cases worsening symptoms of anxiety. We also heard from autistic parents who requested communications take place in their preferred format who were ignored.

As with offering mental health support to neurotypical children, it is important to listen to the needs of children and their families and tailor support to meet these needs. When treating neurodivergent children, it is also important for practitioners not to assume that mental health symptoms are a result of their neurodivergence.

> After some really bad experiences in the past I can only sing praises for the service we have received for our 2 teenagers. They have been listened to, plans have been changed and they are both now getting the help they so desperately needed. My son is

making real progress with EMDR therapy and my daughter has been prioritised to start psychotherapy in the new year after a CNT assessment appointment where all of the issues were discussed and alternative therapy as a result. It is the first time any service has properly recognised them as part of a family where their difficulties impact on each other and it is also the first time everything hasn't been out down to their autism and thus discharged. I hope all families are now getting this much improved service it is a real breath of fresh air. – Healthwatch Warwickshire

Experiences of LGTBQ+ young people

Healthwatch Suffolk run a regular survey each year, hearing from young people about their wellbeing, mental health, and self-esteem. In 2020, they heard from nearly 40,000 young people in Suffolk, including 830 LGBTQ+ and gender non-conforming young people.

The LGBTQ+ young people they heard from were more likely to experience poor wellbeing and self-esteem and report self-harm compared to other students in the sample. They were nearly twice as likely to report they were struggling when compared to male students and were more vulnerable to self-harm. One quarter of LGBTQ+ young people said they currently self-harmed, compared to just 5% of their peers.

But this group were less likely to seek help for their mental health than their peers. Reasons for this were that they were afraid of being judged, anxious about what would happen next, and that they didn’t want their parents to find out.

Appendix – Methodolgy

Where is our data from?

The Long Term Plan states that one in nine young people between the ages of 5 and 15 experiences mental ill-health. Our sample reflects the experiences of over a thousand young people and their families from across England, who shared detailed experiences of every stage of child and adolescent mental health services. This sample comes from:

- Local Healthwatch feedback and signposting data – between April 2021 and March 2022, we heard from over 50,000 people via our CRM. These data come from local Healthwatch hearing individual stories and signposting people to services.
- In 2021/22, 1,443 people shared their experiences of mental health services with us. This briefing is based on a dip sample of 129 young people and their families' detailed experiences of mental health services drawn from this larger sample. Our briefing on adult mental health is based on a dip sample of 579 adults drawn from this larger sample.
- Local Healthwatch reports – local Healthwatch conduct individual research projects throughout the year, engaging with specific groups about their experiences of services. Fourteen local Healthwatch completed work on young people's experiences of mental health services between April 2021 and March 2022 and this briefing includes their specific findings as well as drawing on larger themes. Local Healthwatch research covers the experiences of 1,960 young people and their families.

It is important to note that many of the experiences shared with us in this period come from the parents of young people rather than directly from young people themselves.

This briefing is informed by:

The experiences of **129 young people and their families**, shared with 58 local Healthwatch across England, between April 2021 and March 2022.

Research completed by **14 local Healthwatch**, including the experiences of over 1,900 people and their families.

2,089

How did we reach our conclusions?

We conducted a thematic analysis on our feedback and signposting data, reading through each individual story and categorising it based on overall sentiment, services involved, and overarching themes. We were able to calculate how much of the feedback was negative, positive, or neutral, and indicate common issues people experienced, based on this coding. We also included supporting figures from local Healthwatch research. Quotes are anonymised and used to illustrate wider themes.

We compared our findings to those from work completed in 2019 by Healthwatch England to inform the development of the Long Term Plan. We also used wider work by Healthwatch England and other organisations to support our conclusions.

healthwatch

Healthwatch England
National Customer Service Centre
Citygate
Gallowgate
Newcastle upon Tyne
NE1 4PA

www.healthwatch.co.uk
t: 03000 683 000
e: enquiries@healthwatch.co.uk
@HealthwatchE
Facebook.com/HealthwatchE