



Mental Health Crisis Services for Children and Young People in Shropshire, Telford & Wrekin

Survey Report

Engagement period:
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About Healthwatch



Healthwatch is the independent health and social care champion for local people

We work to make your voice count when it comes to shaping and improving services. We use a variety of methods to find out what people like about services, and what could be improved and we share these views with those with the power to make change happen. Our reports go to:

- the organisations who provide services
- the commissioners who pay for services (e.g. Shropshire, Telford & Wrekin Clinical Commissioning Group, Shropshire Council, Telford & Wrekin Council)
- service regulators (the Care Quality Commission, NHS England)
- our national body Healthwatch England to let them know how local services are working in Shropshire, Telford & Wrekin



We are not experts in health and social care and surveys are just one of the methods we use to put a spotlight on services and ask people to share their views with us. Usually our surveys are publicised and promoted through our engagement activities (e.g. talks and stands at events) as well as through online publicity and local press releases. Due to the pandemic we were unable to use face to face engagement for this topic.

Please note

Our survey was time limited but we continue to want to hear from people who are willing to share their experiences with us and we will share them with the providers, commissioners and regulators.

Executive Summary

- 'There has been a significant increase in poor mental health of children, with self-harm, taking tablets and watching social media harm sites. Low mood and lacking in self-esteem and self-confidence. Drug taking has increased which in itself brings increased concerns.' (Head of School in a Shropshire Secondary School)

Since local Healthwatch was established in 2013 we have received comments from people about their experiences of accessing Child and Adolescent Mental Health Services (CAMHS) and witnessed the development of the current service, BeeU, provided by Midlands Partnership Foundation Trust (MPFT).

The mental health needs of children and young people are met by a range of professionals and organisations, including GPs, schools and colleges, social services and specialist providers including CAMHS and inpatient services (e.g. hospitals and specialist eating disorder units). The service they receive depends on the severity of their problems. (See p.12)

It has been widely reported in the media over the recent months that the on-going Covid-19 pandemic has impacted the mental health of children and young people and this has led to a greater severity of need among many and an increased demand on services at a time when they have had to adapt to working under Government restrictions and increased staff shortages.

In Shropshire, Telford and Wrekin the issues were highlighted by the Care Quality Commission (CQC) inspection of the Shrewsbury and Telford Hospital NHS Trust (SaTH) in February 2021 and report which described the experiences of children and young people going into the Trust in crisis due to 'acute mental health needs and or learning disabilities' and the challenges faced by the Trust to meet their need including the staff's understanding of and ability to treat these conditions when not mental health specialists. The CQC explained the importance of organisations working together to provide these children with the appropriate care and treatment, including MPFT and the local authority.

- 'Taking them to A&E if there is no medical treatment need is not helpful.' (Mental Health Professional working in Telford & Wrekin).

However, the lack of 'Tier 4' beds (specialist inpatient beds for the most seriously unwell) in the county means that our children and young people will be admitted to either Royal Shrewsbury Hospital or Princess Royal Hospital, or The Redwoods

Centre (an adult mental health hospital) while waiting to be moved to a suitable hospital outside Shropshire.

Healthwatch Shropshire and Healthwatch Telford & Wrekin were asked to give these children and young people the opportunity to share their experiences and say what could have been done to improve the help they have received. We know that ideally Shropshire would have its own specialist inpatient provision but this is not expected to happen for a number of reasons, including funding and resources. Ideally no child or young person would need to go into hospital and for many, early support could prevent this happening.

Our approach

Due to the on-going Covid-19 pandemic Healthwatch were not able to speak to children and young people face-to-face so we decided to produce a short online survey that was promoted through a press release, on social media and by SaTH, MPFT, the local authorities and voluntary and community sector organisations. The survey ran from 1st October to 13th December 2021.

We knew that many children and young people would not want to or be able to comment themselves so we also asked parents/carers and professionals working with them to share their experiences of crisis mental health services for this age group and their views on how things could be improved.

67 people shared their views with us, including six young people.

Key findings

Children and young people

The five children and young people were aged 13–20. Two had received services from BeeU in the community, one had also had to go to A&E and three had been an inpatient in Shropshire or outside the county.

The main issues highlighted were:

- Access and waiting times
- Changes to staff
- Relationship with professionals

Sample comments:

- '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' (14 year old, Telford & Wrekin)
- 'The help I have been given since being on the waiting list has been so good I can't say anything that needs to be improved apart from the waiting list for the Psychiatrist because my suicidal thoughts had gotten worse.' (16 year-old, Shropshire)
- 'It would have helped me if I could speak to the same person. I always had too many different people and it's overwhelming.' (13 year old, Telford & Wrekin)
- 'I wasn't given any help. I was just lectured and talked about.' (14 year old, Shropshire)

Parents and carers

46 parents and carers described the experiences of 50 children and young people aged 10–26 years old with:

- Autism and/or a learning disability (16)
- Mental health, including anxiety, depression, refusing to go to school, self-harm and suicide ideation/attempts (24)
- Eating disorder/anorexia (6)

Positive comments related to professionals and the quality of support given, e.g.

- 'The support workers and nurses were good and talking things through with [them].' (Parent of 17 year old, Shropshire)
- '[They have] had excellent on-going support [through their GP]' (Parent of 19 year old, Shropshire)

The main issues highlighted were:

- Access and waiting times
- Assessment and diagnosis
- Communication and value placed on the parent/carers views
- Care plans, Personalisation and continuity of staff
- Discharge and on-going support
- Dual diagnosis (e.g. children with a learning disability and anxiety/depression)

- Staff training
- Multi-agency working

Sample comments:

- 'Currently under BeeU but after years of waiting, it took [them] wanting to commit suicide for them to actually see [them]! Not good enough' (Parent of 15 year old, Telford & Wrekin)
- 'It took a long time to receive an assessment [for ADHD], not much guidance for emergency help while waiting.' (Parent of 19 year old, Telford & Wrekin)
- 'They were excluded from mainstream mental health services because of their learning disabilities' (Parent of teenagers, Shropshire)
- 'Completely inadequate. Protocols regarding informing a parent and the assessment environment ignored. No joined up service between police, social services, mental health provider. No proactive discharge plan and no follow-up.' (Parent of 19 year-old, Shropshire)
- 'Been in the system from age of 7 and although have regular appointments no care plan or support given.' (Parent of 11 year old, Shropshire)
- 'The care has been a shambles with all the switching services, wards and transition from children's to adult services. It is wholly unacceptable.' 'Very little joined up services.' (Parent of 18 year old, Shropshire)

A number of parents/carers were concerned that their child's experience of mental health services had had a negative impact on them and added to their trauma.

- 'It triggered [them] but there was not support put in place to help [them]. It was a damaging process' (Parent of 10 year old, Shropshire)

Professionals

We heard from 16 people working in:

- The NHS (3)
- Education (5)
- Charity and the Voluntary Sector organisations supporting children and young people (7)
- The independent sector as a private counsellor (1)

The main issues highlighted were:

- The complex needs of children and young people
- Lack of time and appropriately trained staff
- Lack of services
- Lack of access to specialist services and training
- Challenges of multi-agency working, including communication and information sharing, criteria for accessing services and lack of shared definitions, e.g. 'crisis'

Sample comments:

- 'Prolonged hospital stays due to unavailability of Tier 4 beds creates a lot of issues with these young people. They spend many weeks and sometimes months waiting for a placement to implement the right support and care they need, [] We are a workforce of Paediatric trained Nurses and Doctors, we need additional training to help support these young people.' (SaTH)
- 'The Crisis Team are under immense pressure and work tirelessly to support young people in the community with the resources that they have. Step down from Crisis can be difficult, again due to lack of service provision in mental health.' (Mental Health Professional)
- 'The support is not available quickly enough. Early help support is not available to prevent children reaching crisis point. [] The huge rise in mental health needs is greatly outweighing the capacity in schools to support this.' (Primary Head Teacher)
- 'The MHST [Mental Health in Schools Team] do not have a clear criteria for schools to refer by.' (Primary School Inclusion Manager)
- 'Young people and their families struggle to get the support they need from BeeU - we have had some brilliant joint working with certain practitioners but there seems to be a barrier with accessing mental health support in the first place and other services are left to try and fill the gap. Understandable cuts to services nationally mean the BeeU service has lengthy wait lists - the turnover of staff can be difficult for young people too once they have built up a therapeutic relationship. [We] now have a joint working protocol with BeeU to try to best support young people with coexisting substance misuse and mental health issues.' (Substance Misuse Worker)
- 'Young people are dying waiting to be seen by mental health services, parents are unsupported and confused by the way teams do not communicate and the inconsistencies i.e., a young person might not see

the same social worker/counsellor or be passed between teams with no opportunity to build trust.’ (Private Counsellor)

Key messages for the Shropshire, Telford & Wrekin Integrate Care System

We asked everyone to tell us how things could be improved.

Many people understood the challenges being experienced by services who support children and young people who are in crisis and need specialist support, including a lack of funding, difficulty recruiting to specialist roles and the lack of Tier 4 beds.

The things that people told us would make a difference to these children and young people, their families and carers, and the professionals working to support them were:

1. Reduced waiting times and signposting to sources of information, advice and support while waiting for assessment, diagnosis and specialist services, to prevent reaching crisis (including out of hours)
2. Improved monitoring to see how the child or young person is getting on to decide if they need to be seen sooner or action taken to prevent them reaching crisis
3. Clearer criteria and definitions, e.g. of ‘crisis’, to support schools to make appropriate and timely referrals
4. Once services have received referrals they need to communicate with children, young people and families/carers promptly, e.g. about expected waiting times, to reduce pressure on the referrer
5. Efforts being made to ensure children and young people have access to the same person rather than seeing multiple workers
6. Re-introduction of face-to-face appointments as soon as possible and the offer of a virtual face-to-face appointment in the meantime where the technology is available
7. Greater access for children and young people with learning disabilities to mainstream mental health services, this is likely to require services to work in partnership

8. More training for professionals so that they understand the challenges being experienced by children and young people and can provide the right support and signposting, e.g. Autism Awareness, Attachment, Trauma
9. Post-diagnosis support for children, young people, their families and carers to help them to understand the condition including workshops and support groups, e.g. for children with Autism, ADHD, Anorexia
10. Improved communication between services and children, young people and their families, e.g. listening to concerns, valuing the information provided by young people and their parents, agreeing a care plan
11. Improved multi-agency working to make sure care is coordinated and transition between services is seamless, e.g. Post Adoption Team and BeeU, Child and Adult Services

Context

On 24th February 2021 the Care Quality Commission (CQC) carried out an unannounced focused inspection at Shrewsbury and Telford Hospital NHS Trust (SaTH) because they had:

‘received concerning information about the safety and quality of the provision of the assessment and treatment of children and young people who presented to the service with acute mental health needs and/or learning disabilities.’ (p.2)

Following this inspection, the CQC stated:

‘We have rated the service as inadequate and have taken enforcement action as a result of this inspection to promote patient safety.’ (p.3)

However, they also noted:

‘Staff coordinated the care of children and young people admitted with mental health needs and learning disabilities with other services and providers when required.’ (p.5)¹

¹ To download the full CQC report go to : <https://api.cqc.org.uk/public/v1/reports/5a3f65db-bd7a-44e6-80ff-5af756efac80?20210419070435>

In conclusion the CQC reported:

‘Staff told us they had seen an increase in the numbers of children and young people who presented with significant mental health issues, learning disabilities and behaviours that challenged over the past year. The trust had a formal agreement in place with the local mental health trust² that stated how they would work together to provide training and administration associated with the Mental Health Act. However, there was no formal contract in place that outlined the specific support required to ensure the needs of children and young people with significant mental health needs, learning disability of behaviours that challenged were met.

The contract for the provision of children and young people’s mental health services at the trust was commissioned by the clinical commissioning group (CCG) from the local mental health trust. However, despite the reported increase in admissions in this cohort of patients, the trust had not worked with the CCG and mental health trust to ensure effective plans were in place to meet the needs of children and young people with significant mental health needs, learning disability of behaviours that challenged.’

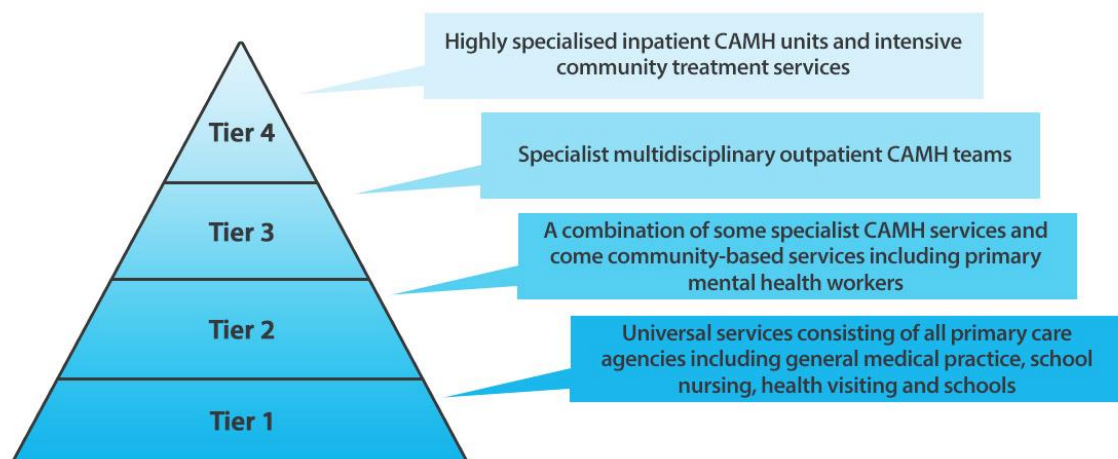
(p.13)

Before the report was published in April 2021 SaTH, the CCG and ‘mental health trust’ (Midlands Partnership Foundation Trust – MPFT) started working to improve how they were working together to make sure children and young people can receive the right care and treatment at the right time. This has included members of staff at MPFT being seconded to SaTH.

² Midlands Partnership Foundation Trust (MPFT)

The Children and young people's mental health service in England

The CAMHS tier system



Tier 1 (Universal services) These are services whose primary remit is not that of providing a mental health service, but as part of their duties they are involved in both assessing and/or supporting children and young people who have mental health problems. Universal services include GPs, health visitors, schools, early years' provision and others. Universal services are commissioned by CCGs and Local Authorities and schools themselves, and may be provided by a range of agencies.

Tier 2 (Targeted services) These include services for children and young people with milder problems which may be delivered by professionals who are based in schools or in children's centres. Targeted services also include those provided to specific groups of children and young people who are at increased risk of developing mental health problems (e.g. youth offending teams and looked after children's teams, paediatric psychologists based in acute care settings). Targeted services are commissioned by CCGs and Local Authorities and schools, and are provided by a range of agencies. Arrangements vary across the country and according to the nature of the service.

Tier 3 (Specialist services) These are multi-disciplinary teams of child and adolescent mental health professionals providing a range of interventions. Access to the team is often via referral from a GP, but referrals may also be accepted from schools and other agencies, and in some cases self-referral. These services are commissioned by CCGs although there may be a contribution from Local Authorities. The latter varies cross the country.

Tier 4 (Specialised CAMHS) These include day and inpatient services and some highly specialist outpatient services including services for children/young people with gender dysphoria ; CAMHS for children and young people who are deaf; highly specialised autism spectrum disorder (ASD) services; and highly specialised obsessive compulsive disorder services. These services have, since April 2013, been commissioned directly by NHS England. p.11

<https://www.england.nhs.uk/wp-content/uploads/2014/07/camhs-tier-4-rep.pdf>

At the time of writing this report there are no 'Tier 4' inpatient beds for children and young people in Shropshire, Telford & Wrekin. So, if they are very unwell these patients often go to A&E and are admitted to a ward in SaTH or The Redwoods Centre³ in Shrewsbury while waiting for a bed in a hospital outside the county.

The Midlands Partnership Foundation Trust (MPFT) provides specialist (Tier 3) CAMHS services:

'Bee U is the emotional health and wellbeing service for people, up to the age of 25, living in Shropshire and Telford & Wrekin.'

Services include:

- Kooth (an anonymous 24-hour online service offering peer support, self-help and counsellors) ↓
- Shropshire, Telford & Wrekin Beam (The Children's Society) (Emotional wellbeing support) ↓
- Healios (Online Specialist assessments, evidence-based psychological therapies, earlier intervention) ↓
- Mental Health Support Teams ↓
- Core Mental Health Service (e.g. psychologists, family therapists, MH nurses, social workers, etc) ↓
- Attention Deficit and Hyperactivity Disorder (ADHD) pathway ↓
- Autism Services ↓
- Learning Disability Pathway ↓
- Young People Community Eating Disorders Service ↓
- 24/7 Urgent Helpline ↓
- Crisis and Home Treatment Team ↓
- Resources and Self Support ↓

<https://camhs.mpft.nhs.uk/beeU>

MPFT have given us the following description of BeeU:

'BeeU comprises of several providers who are commissioned by the Shropshire & Telford Clinical Care Group (CCG) to provide a full range of services for children and young people (CYP). Most referrals for mental health support for CYP are made via GPs according to NICE guidance and they are filtered by the MPFT BeeU Access Team. The Access team triage all referrals and signpost the

³ The Redwoods Centre is run by MPFT 'for adults with acute mental health problems, dementia and rehabilitation needs'. <https://www.nhs.uk/Services/hospitals>

referral to the most appropriate service for that CYP. The most appropriate service might be provided by one of the other commissioned providers in the BeeU partnership, the local authorities and / or voluntary services. The treatment and support from all partner services is always CYP centred and is designed to provide the best opportunity for the CYP to learn how to recover. The specialist MPFT BeeU service is there to provide clinical services for Children and Young People (CYP) who have significant mental health issues, who cannot be treated by the other partners.'

Healthwatch are aware that children and adolescent mental health services (CAMHS) have traditionally been under funded nationally compared with adult services.

What we did

In June 2021 the Director of Nursing at SaTH approached Healthwatch Shropshire and Healthwatch Telford and Wrekin saying: 'I'm keen to explore how we can seek the voices of C&YP with Mental Health, I really want it to be a system piece.'

We then worked with members of staff at SaTH and MPFT to develop our approach. Due to the ongoing Covid-19 pandemic it was not possible for us to go out and speak to children and young people, their families/carers and professionals face-to-face so we decided to create an online survey which was put onto the website of both Healthwatch. The survey was promoted through a joint press release and social media messaging that was re-shared by service providers across the county. We also created posters that were placed in community halls and sent to GPs and Pharmacies.

'Over the last 12 months we have seen an increased number of children and young people presenting to Shrewsbury & Telford NHS Hospital Trust with mental health conditions and we are working alongside our system colleagues to ensure we are providing the best possible care. Your views are integral so that children and young people are at the centre of the future developments and improvement in our services.' – Director of Nursing at SaTH (Press release)

'There are times when a child or young person needs help quickly so we recently expanded the Crisis and Home Treatment service so that we can respond within 4 hours in the community, but we are keen to hear your experiences to help us understand how the service can be further developed.'
- Managing Director Shropshire, Telford & Wrekin Care Group at MPFT (Press release)

Our main aim was to hear from children and young people themselves and so we wanted to make it as easy as possible for them to share their views while also asking what suggestions they had for how services could be improved.

We asked them to tell us:

1. A bit about you and what led up to receiving the latest help
2. What things do you most remember about the help you received?
3. When did you receive this help?
4. How could the help be improved?
5. Where were you treated?



We knew that a lot of these young people would not want to or feel like talking to us, so we also asked for the views of their parents/carers and professionals/volunteers working with them and their families.

The survey ran from 1st October to 13th December 2021. For the full survey please see Appendix 1.

What we found out

We heard from:

	Shropshire	Telford & Wrekin
Children & young people	2	3
Parents/carers	36	10
Professionals: NHS	2	-
Professionals: Other support services	6	2
Professionals: Education	1	4
Professionals: Not given	-	1
Total responses	47	20

Please note: We did not ask the postcodes of people completing the survey and so people could have completed it on either Healthwatch website regardless of where they live.

The children and young people



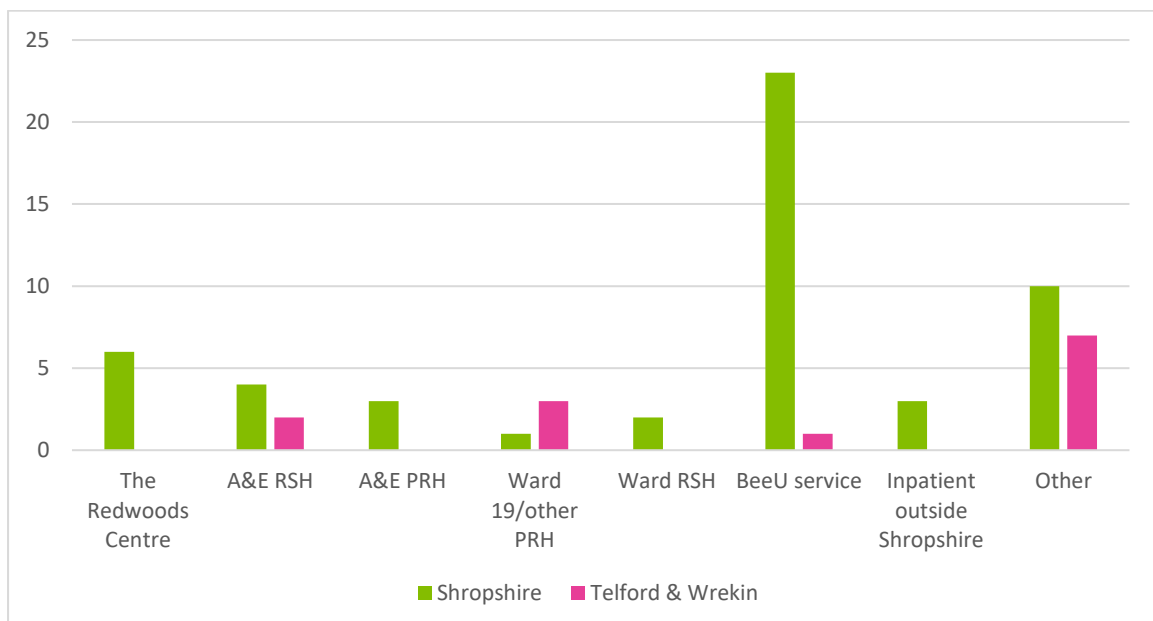
Chart 1: Age ranges



We also heard from the parent of a young person who is now 26 years old. They had been diagnosed as anorexic at 17 and discharged at 19. They had gone on to university.

- ‘Fabulous support, from the doctor’s receptionist who listened, to adult services discharge. Support was amazing’

Chart 2: Where the children and young people received services



Other includes:

- Adoption Support Team
- Adult Mental Health Service
- GP practice
- Private Counselling
- School

Due to the complex nature of the difficulties experienced by some of these young people they had accessed several services.

The issues experienced by the children and young people include:

- Abuse – domestic, emotional, sexual
- Adoption/attachment
- Attention Deficit Hyperactivity Disorder (ADHD)
- Anxiety
- Autism Spectrum Disorder (ASD)/Autism
- Bullying
- Depression/low mood
- Disability, e.g. learning disability, visual impairment
- Divorce/family breakdown
- Eating disorders – anorexia
- Health conditions
- Looked after child
- Pandemic
- Post traumatic stress disorder (PTSD)
- Self-harm
- School refusal
- Suicidal thoughts/ideation/attempts
- Transition, e.g. between schools and services

The experiences shared by children and young people and their parents/carers highlight that many young people experience multiple issues and some are triggered by their experiences of the services that are there to treat them or made worse by the delay in being seen.



What the young people told us:

I am 13 years old from Telford and Wrekin, I have always struggled with my mental health from being in care. I also struggle to make friends. I am currently receiving treatment. I first received treatment through the A&E department at RSH. I am now receiving treatment from another service.

What do you most remember about the help you received? 'I remember a lot of phone calls'

How could the help be improved? 'It would have helped me if I could speak to the same person. I always had too many different people and its overwhelming'

I am 14 years old from Shropshire and currently receiving treatment. I have been a patient at The Redwoods, A&E at RSH and PRH and been an inpatient outside Shropshire. I have been 'suffering with anorexia for nearly three years now also depression, anxiety and PTSD. I've been an inpatient [outside Shropshire] for six months and I was discharged with no help whatsoever.'

What do you most remember about the help you received? 'Nothing, I wasn't given any help. I was just lectured and talked about.'

How could the help be improved? 'Quicker in coming, contactable 24/7.'

I am 14 years old from Telford and Wrekin and I am currently receiving treatment for my eating disorder after I was admitted to Ward 19 in PRH.

What do you most remember about the help you received? 'I remember there was a long time to wait before I saw someone, and I almost gave up. I think professionals think because we are young, we don't understand as much'

How could the help be improved? 'Not having to wait so long before being treated'.

I am 20 years old from Telford and Wrekin and I have been receiving treatment for the last 6 months [*Didn't give name of service*]. I suffer with anxiety, low moods and struggle with isolation following a recent breakup.

What do you most remember about the help you received? 'I received a lot of over the phone support and I am currently waiting for high intensity therapy'

How could the help be improved? 'Not waiting until it gets so bad there's no choice but to treat'

I am 16 years old from Shropshire and started receiving treatment more than 18 months ago from BeeU. 'I have PWS (Prader-Willi Syndrome) and Autism I used to find it hard to deal with my emotions and understand other peoples. I then, after being on the waiting list for a long time, developed anxiety which led to being too anxious to go into school some days and then last year I started to have suicidal thoughts.'

What do you most remember about the help you received? 'After being on the waiting list for a long time I was given a Psychologist who helped me to learn other people's emotions and how to deal with mine after some time as it was felt it might be needed I was put on an waiting list to see a Psychiatrist to see about getting some medicine for my anxiety. [Both professionals] have really helped me and I feel I can be honest to them about things I find difficult to talk about and to be able to go into school every day again and to get a place at college.'

How could the help be improved? 'The help I have been given since being on the waiting list has been so good I can't say anything that needs to be improved apart from the waiting list for the Psychiatrist because my suicidal thoughts had gotten worse.'

What parents and carers told us

The main issues related to services identified by parents and carers were:



- Access and waiting times
- Care planning and personalisation
- Communication
- Continuity of care/staff
- Discharge
- Dual diagnosis (e.g. Autism and mental health)
- Impact of the intervention
- Impact of the pandemic (e.g. lack of face-to-face meetings)
- Multi-agency working and signposting
- Referrals, assessment and diagnosis

Healthwatch Shropshire heard from 36 parents/carers who described the experiences of 40 children and young people aged 10-26 years old:

- Fifteen parents/carers described the challenges young people experience as a result of having a learning disability and/or autism

- Sixteen experiences of children and young people with anxiety and depression as a result of poor mental health and trauma were shared
- Five parents/carers described the experiences of a child/young person with an eating disorder

Healthwatch Telford and Wrekin heard from 10 parents/carers who described the experiences of 10 children and young people aged 13-19 years old. Eight of these related to a child/young person with mental health problems, one described the challenges of an older teenager with ADHD, and one described a young person's experience of support for an eating disorder.

As well as sharing their experiences of services we also asked parents and carers to tell us how things could be improved.

Learning disability and autism

The comments from parents and carers of children and young people with a learning disability and/or autism highlight concerns around:

Assessment and diagnosis:

- 'They needed to do a more thorough assessment and then put [my child] on an appropriate pathway. In [their] case, the ASD pathway. Instead, they promised follow-up assessment (which never happened) and discharged []. They needed to identify there was an issue that needed supporting and either signpost us or refer us to the appropriate services.' (Parent of 10-year-old referred to BeeU end of 2020)
- It took a long time to receive an assessment, not much guidance for emergency help while waiting (Parent of a 19-year-old recently diagnosed with ADHD)

Case study: Autism Awareness

'The mental health nurse giving the Brief Intervention had no understanding or knowledge of autism, and when I suggested that the approach needed to be simplified, she said that my [child] perhaps needs a brain scan to find out what's wrong. This was said in front of my [child]. When [my child] struggled to understand her in the face-to-face sessions, she instead replaced them with check-up phone calls where she gave my [child] no space or encouragement to talk other than checking that [they] could recall the mental health worker's name and that [they were] not suicidal. After 8 "sessions" like this, she checked with the team if there was anything else available, and they confirmed that there was nothing until [my child had had their] ASD diagnosis. We were told that once [they have received their] ASD diagnosis, [they] will be eligible to go on a 2-year waiting list for psychology assessment. By this point [they] will be 16 and a half. [They have] waited for the diagnosis for 4 years and 3 months and has just received an ADOS (Autism Diagnostic Observation Schedule) appointment for next month; [they were] first referred when [they were] 10 years old.' (Parent of a 14-year-old with Autism.)

Context: 'Mental health crisis triggered by returning to school in Sept 2020 in the middle of the ongoing Covid pandemic. Autistic challenges with social interaction and communication were heightened beyond anything experienced before to the point of being unable to access school. Requested CAMHS support in Feb 2021. Started self-harming and expressing suicidal thoughts in May 2021.'

'You need to decide what to do about the BeeU service for folk with Autism. Either diagnose using NICE but don't wait for this to provide mental health support.'

Access to support / waiting times

- 'My [child] got to the point of trying to commit [themselves], I reported this to the social worker and school, it was ignored, and we have not received any help.' (Parent of a 10-year-old being assessed for ADHD, ADD and Autism in the last 12 months)
- 'The waiting list for support is so long.' (Parent of a 10-year-old struggling with anxiety and issues related to autism currently receiving support from BeeU)
- '[BeeU] didn't help. It triggered [them] but there was no support in place to help [them] it as a damaging process. Shropshire is a terrible place to live with neuro diversity. As a family we have been treated so badly and our [child] has been damaged and traumatized.' (Parent of 10-year-old who had a school related breakdown in late 2020 'Was referred to BeeU who did



a short online assessment and discharged without any further support. Has gone on to have a further two breakdowns and is not in school.’)

- ‘It was quick, but due to her learning difficulties they had to go down the medication route straight away.’ (Parent of a 14-year-old who accessed support in the last year due to depression and anxiety triggered by the move to Secondary School)
- ‘Not able to access support as struggles with social anxiety so struggles to engage.’ (Parent of 16-year-old with Autism)
- ‘All they got from crisis help was four home visits telling [them they] needed a sleep routine nothing more.’ ‘At the time, and many times since, needed sectioning and serious help. This didn’t happen. Still waiting for support from CAMHS. Been pushing for ten years!’ (Parent of an 18-year-old with ‘Autism and bad mental health problems, suicidal, etc.’ Accessing services in the last 6 months)
- ‘It failed. I was passed from crisis team to Shrop doc to GP – a very distressing 24hrs.’ ‘Crisis Team we’re approached for support several times – but kept telling us to phone back if things got worse.’ (Parent of 20-year-old diagnosed with ADHD and Asperger’s at 13 – most recent episode between 12 and 18 months ago).

Complex needs and access to the appropriate trained staff and treatment

- ‘Because [they are] under CAMHS for medication [they have] received little to no support.’ ‘After two overdose attempts my [child] still hasn’t had a mental health assessment and has had no mental health support. Crisis discharges after three visits because [they] wouldn’t engage.’ ‘If your child has additional needs the support is very poor there is little to no face-to-face. Children like [mine] are left to suffer until it’s at a point they can’t live within a family anymore.’ (Parent of 11-year-old with ASD and ADHD. Accesses BeeU).
- ‘They were excluded from mainstream mental health services because of their learning disabilities’ (Parent of teenagers with learning disabilities after trying to access help more than 18 months ago)

Discharge and multi-agency working

- ‘Was dismissed by CAMHS at age 18 with no onward referral to adult services – suffered very badly last three years with three suicide attempts, still no support. Been in Telford Hospital, still no support.’ ‘CAMHS didn’t

assess and just discharged at 18 saying nothing wrong since been placed under the eating disorder team and adult mental health Was in Telford Hospital twice after overdose and discharged with no support. Later diagnosed with BPD (Bipolar Disorder). 'Just a total and utter let down by ALL Shropshire mental health services BOTH hospitals and CAMHs.' (Parent of 21-year-old who has 'been under CAMHS for years with no help had to get diagnosed privately – Autism and ADHD'. Has been treated in A&E at RSH and PRH and Ward 19 at PRH)

Case study – Multi-agency working

'Completely inadequate. Protocols regarding informing a parent and the assessment environment ignored. No joined up service between the police, social services, mental health provider. No proactive discharge plan and no follow up.'

'This has been our first experience of mental health services and it's been a very frightening one. Realising there is no service out there that can/would help should concern everyone involved. We are left with the impression the authorities feel it is acceptable to just sit and wait for my [child] to seriously harm [themselves] or others.'

'There has been no mental health support while awaiting specialist services and we are still waiting for such service. Appalling lack of provision for a young person consistently showing in [their] actions that [they] need help urgently. Mental health is considerably worse than 12 months ago with no support/treatment offered. (Parent of 19-year-old with 'ASD and other associated learning difficulties and emotional regulation difficulties.')

Context: Deteriorated between 6 and 12 months ago. They have been an inpatient at The Redwoods

'People need to be assessed as individuals who need an individual treatment plan, currently as is our experience if you don't 'fit' the criteria of a pathway you are just bounced around the system with each pathway declaring it's not their responsibility.'

How the help could be improved:

Improved access and reduced waiting times

- 'Complete a 'thorough assessment' so that children and young people can be put on an 'appropriate pathway' and signposted/referred to 'appropriate services'.

- 'Quick access to appropriate therapy. Listening to and believing parents.'
- 'Immediate referral to a consultant psychiatrist experienced in OCD (Obsessive Compulsive Disorder) and (ASD) Autistic Spectrum Disorder. Even if this meant an out of area referral.' Don't keep referring to A&E.'
- 'Reasonable adjustments be made for young people with learning disabilities in mainstream mental health services and that young people with learning disabilities are not excluded from mental health services but that these services work in partnership with learning disability services.'
'People with learning disabilities need to be included when commissioning any mainstream health services.'
- 'To be able to provide medication during an acute crisis.'
- 'Try to engage with those that can be hard to engage with rather than discharging them.'

Support for children with autism and/or learning disabilities, families/carers and professionals

- 'Emotion workshops for children with Autism or special needs which their parents could attend with them to support would be so helpful.'
 - 'Autism awareness for the Brief intervention workers.'
 - 'Offering any kind of mental health support for autistic people, not just diagnosis, and not dependent on diagnosis – they are people with mental health needs too!'
 - 'More services and availability of support for young people with ASD who struggle to access mainstream services but don't meet criteria for disability services, huge gap in services.' 'Needs to be ASD specific service.'
 - 'Long term care – Provide better support to a young person following a diagnosis of ADHD or Autism to come to terms with what that means. It is a really big deal! Prescriptions are not the be all and end all.'
 - 'Emergency support signposting needed. Keeping parents in the loop even if over the age of 18. As my [child] is over 18 I was cut out of the loop, but [their] ADHD means [they] struggle with retaining information and organizing.'
-

Mental health (including depression, anxiety and trauma)

The sixteen experiences of children and young people with anxiety and depression as a result of poor mental health and trauma included some positive comments:

- 'One person on BeeU telephone line was nice and listened.'
- 'I cannot fault the school they are amazing organisizing nurture and CBT. [Their] Head of Year is very supportive to us all and will help with anything they can even having an open-door policy for [them].'
- 'We have tried BEAM which is an excellent resource but limiting.'
- 'The support workers and nurses [at The Redwoods] were good and talking things through with them'
- 'The guy [they] did speak to on the phone [at BeeU] was very understanding and helpful.'
- '[They have] had excellent on-going support [from their GP]'
- 'Prompt and so helpful for myself as a parent as well as my child. I was happy with all the support received [from BEAM].'

Two parents of adopted children reported very different experiences:

Case Study - Post-Adoption Support

Case A: 'Lack of care. Lengthy waiting list. Not prepared to listen - seen as just a parent who "obviously knows nothing". One person on BeeU telephone line was nice and listened, the other was just "doing his job" to see if my [child] needed to be hospitalised (didn't understand the complexity of attachment issues and frankly didn't care). When asked for someone more senior to call, was told 'ok', but no one has (this was in August 2021). When advised my [child's] records from before (2017/18) didn't appear to be on file, was told as a parent I had no need to worry about this, it was internal. I reminded them of GDPR and that these are my [child's] records - promised an update, still none received (again promised in August 2021). No help actually received from Mental Health services, one offer of a video consultation (pre-COVID) which was not at all accessible to my child at that point so case closed. Awaiting an appointment for one part of the service - 16.11.2021, The other part of the service I am told [child] is on a waiting list for a waiting list! Cannot talk to anyone about the appointment on 16.11.2021 to discuss concerns around this - cannot have my [child] with me and discuss issues or [their] life story - again lack of care and understanding of the difficulties adopted families have.'

Context: 11-year-old has received treatment in A&E at PRH and from BeeU (CAMHS) as the result of complex trauma as a very young child.

'Adopted Families should have specialist medical practitioners attached to them as the high majority of them will need support outside of that the Post Adoption Team can manage. If Post Adoption team advise CAHMS there is a child in their service needing support this should be looked at speedily and prioritised - these children have been through enough already (and some let down by the "system" massively so already!) More understanding from the "crisis" team as to what it means to have a child with attachment disorders.'

In contrast another parent of an adopted child was keen to tell us about their positive experience during the pandemic after the child disclosed abuse:

Case B: '[The help] is ongoing, is via Adoption Support Team, Adoption Support Fund [ASF] in the form of a clinical psychologist, yoga therapist and The Branch Project in Shrewsbury who deal with victims of sexual assaults.' 'It was amazingly quick, literally within weeks as I had already applied to the ASF for support with her change in mood and to discuss life story work.' 'I cannot express my relief and gratitude that the services were there for [them], [they were] self-harming and I suspect suicidal, [they have] had support that was timely and relevant and already [they are] getting back to the person [they were], confident, funny, cheeky, and looking and discussing future plans, [they] feel listened to and cared about.'

However, they also said: 'I worry that if [they were] not adopted [they] would not have had access to this support in such a timely manner and how this would have eventually panned out for [them] and the whole family, I had already given up my career in order to support [their] deteriorating mental health this has had financial implications which has a knock on effect in our relationship and adds other pressures which resulted in us moving house.'

The other comments from parents and carers of children and young people with mental health needs highlighted concerns around:

Assessment

- 'I feel [their] assessment has been rushed and not thorough enough and lots of assumptions were made without really looking into things. I suggested that we have been told many times that [they] may have autism but the consultant psychiatrist just dismissed it.' 'I find that when we used to go to local A&E because of self-harm, [they were] nearly always discharged very quickly even when we felt [they were] a risk to [themselves] and others. This includes [their] admissions to The Redwoods.' (Parent of 17-year-old with Emotionally Unstable Personality Disorder (EUPD) 'has had lots of crisis situations over the years. The last time we needed help was when [they] tried to hang [themselves] and [were] admitted to The Redwoods)
- 'From the school: being told not to worry [they have] no concerns [they are] not suicidal. Referral process: Hard to access even though consultant can see the traits and trends yet the referral process for assessment need evidence based from the school, not taking the word of a professional worries and concerns onboard. The whole process is long winded and waiting lists are months. Even though patient has already declared they have suicidal thoughts still no help received.' 'The whole system is failing young adults. This is from secondary school up.' (Parent of 15-year-old 'turned to self-harm after being informed in a PHSE lesson by the teacher, that self-harm is a normal coping mechanism for dealing with anxiety stresses and worries of day-to-day life. Currently under a neurological consultant who referred to Local mental health services for assessments which was first declined but chased by GP and Consultant again. This time was successful; however part of referral cannot be actioned without documentation /evidence from the school who say there are no issues.')

Access and paying privately:

- [They] received help through school when [they were] was in yr6 of Primary they arranged a counsellor for [them] who did some weekly CBT, it helped in parts. [They] moved to senior school and appeared to have found [their] own way of dealing



with [their] anxiety but then Covid happened and [their] anxiety spiraled out of control, to this day it is a daily battle for [them].

- I have taken [them] to the Doctors but other than patronising [them] have basically been told they can refer [them] but it can take weeks, which it did (9wks) to speak to anyone in which that time [they were] getting worse so we have hired a private counsellor. (Parent of a 13-year-old receiving help through a Private Counsellor, BeeU and school)
- 'Very little help. On waiting list for 10 months now for CBT. Have had to pay privately which is crippling financially. My child has been referred to IAPT as 17 but has received support elsewhere when in secondary school as we have been going through this for 5 years.' (Parent of a 17 year old accessing support from BeeU (CAMHS) for the last 6 to 12 months. 'Suffers with anxiety, stress and very low self esteem. Occasionally has panic attacks. Has made skin sore through anxiety.'
- 'It took too long to get it, it wasn't face to face as we would have liked but now [they have] received it, it has been helping. [They have] has been diagnosed with ADHD recently and the medication has helped.' (Parent of 19 year old who identifies as Transgender was already struggling with mental health issues, the pandemic led to [them] being furloughed and being very isolated. [They] self-harmed for the first time in several years and was, and still is presenting with more severe depression than before, anxiety also not eating enough leading me to wonder if [they were] anorexic and we tried to get counselling face to face for [them], we were prepared to pay but even paid services had long waiting lists. Currently receiving support from Psychological Wellbeing Services and Mental Health Team regards ADHD.)

Effective care planning and consistency of staff and care

- 'No help given. Been in the system from age of 7 and although have regular appointments no care plan or support is given.' 'I have lost count of the number of Doctors my [child] has seen as they come and go all the time so no continuity of care. Latest one lives in Ireland and can only provide appointments outside office hours via teams which means he is doing a day job too.' (Parent of 11 year old who has 'suffered anxiety for most of life due to abusive [parent]' and received support from BeeU.)
- 'Didn't find BEAM telephone service helped as seeing a different person each time so no rapport established with my [child].' (Parent of 12 year old

who has self-harmed and taken an overdose. Treated in A&E at RSH and currently receiving help from BeeU)

- 'I had to speak to someone first as [they were] 13 at the time. They couldn't guarantee same staff member would speak to [them] from Bee U which [they were] worried about. The guy [they] did speak to on the phone was very understanding and helpful.' (Parent of 14 year old first accessed support from BeeU (CAMHS) between 6 and 12 months ago. Self-harming. Suffered emotional and domestic abuse. Not sleeping, suffering from chronic stress and lack of self-esteem. Refuses to go to school)
- '[They were] referred by GP to CAMHS. After an initial appointment, there was a follow up. The next appointment was cancelled and then the practitioner left the service so the support came to an end. We then paid for private counselling sessions.' '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.' (Parent of 20 year old 'suffering with depression and self-harm)

Case Study – Consistency of staff and duty of care

Context: Between the ages of 16-18 this young person has been receiving support as an inpatient in and outside Shropshire and from BeeU. 'They took an overdose in the early stages of lockdown and were admitted to PRH. They had previous mental health difficulties which were being managed but the lockdown removed their coping mechanisms.'

'At the time we had a good CAMHS case worker, so we felt supported. [They] then retired and we have felt since then the services were extremely disjointed and under stress. [My child] was transferred from the PRH to [a hospital outside Shropshire], then in December 2020 to [another hospital outside Shropshire], and then in July 2021 on turning 18 to The Redwoods.

[They] are now being discharged from The Redwoods, Section 3 under the Mental Health Act. The last 18 months have damaged [them] in its mishandling at every stage and [they are] a shadow of [their] former self. [They have] not been rehabilitated in any way. The care has been a shambles with all the switching services, wards and transition from children to adult services. It is wholly unacceptable.'

'Very little 'joined up' services. Many services finally involved from BeeU (although no real jurisdiction/oversight), CCG, Social Workers etc but no one organisation/case worker that looked directly after [their] care.'

The role of parents:

- 'Doctor has been rude and dismissive of my concerns and even accused me of exaggerating my [child's] problems despite having never met [them] in real life.' (Parent of 11 year old – as above)
-

How the help could be improved:

Staff awareness, training and access to specialists

- 'Firstly, employ Doctors who want to help and not just want the money. Provide parents and the patient with support and not be dismissive. Employ Doctors who acknowledge that children behave differently in different settings and listen to parents concern.'
- 'More support for school pastoral care teams e.g. training, resources and sign posting. More group therapy available. Easier access to resources. Services available are stretched to breaking point causing staff shortages and children being missed.'
- 'Access to better services through school'

Consistent care/staff and face-to-face working

- 'Have a care plan in place after each appointment and also follow up notes explaining this plan.'
- 'Access to the same person to speak to, zoom call rather than phone I think [they] would have preferred ([as has] gone on to request zoom not phone now).'

Better communication and support, including signposting

- 'Better quality support, more effort to engage with young person, more timely response.'
 - 'Who we can turn to for help when we need it.'
 - 'Calls or emails to see how the patient is getting on (especially when they declared they have suicidal thoughts and have had a plan.) to see if they need to be seen sooner.'
 - 'Support whilst waiting would be great. Face to face services being implemented sooner. Support when the provider is on holiday would be useful, the gaps aren't helpful.'
-

Eating disorders

The main issues identified by the parents/carers of children and young people with eating disorders were:

Timely access and communication

- '10 suggested sessions only received four. Art therapy was suggested by CAMHS practitioner but not able to provide any, re-referred back into the service and haven't heard anything (since several months ago). Practitioner unable to talk on an appropriate level to the child, didn't feel like they listened to [them]. Very disappointed with the service, Covid used as a reason why [they] couldn't be seen. Service happy for a child with a BMI [Body Mass Index] on the 0.2 centile⁴ [low] to be sent to a further MDT [multi-disciplinary team meeting] with no follow-up provided.' 'Lost in the system' (Parent of 10 year old with 'high anxiety, refusal to eat, stopping participating in preferred activities)
- 'Too overwhelming. Too much information. Slow. Not enough urgency. Incorrect advice. Not fit for purpose. Not enough help is available.' (Parent of a 14 year old who has been an inpatient in and outside Shropshire and received treatment at both A&Es and through BeeU)
- 'Poor communication, lack of care plan, very little support' (Parent of 17 year old with an eating disorder. GP referred to BeeU in April 2021 assessment completed June 2021)

Lack of face-to-face appointments

- 'We have been told they have no capacity to do face to face appointments and have to use the internet. They do not speak to us directly but delegate communication to someone who does not have any information to answer questions but can only pass on messages.' (Parent of 17 year old diagnosed with Anorexia and currently trying to access help through BeeU)

Transition to adult services

- 'Felt abandoned when transferring from CAHMS to adult services. Transition did not feel planned and we're left in limbo between the 2 services for a couple of months when neither would take ownership of care, coincided with a suicide attempt and basically no support. Consultant blurting out

⁴ 'The BMI centile is a simple and reliable indicator of a healthy body weight in childhood.'
<https://www.rcpch.ac.uk/resources/body-mass-index-bmi-chart>

weight when [person] was being blind weighed. Very slow to add calories to food plan, learnt more from online support groups.’ (Parent of 21 year old with ‘anorexia, depression and anxiety’. Received support from BeeU more than 18 months ago and the adult eating disorder service.)

How the help could be improved:

Access and face-to-face appointments

- ‘Early help and intervention; to be supported at an earlier stage when problems were spotted.’
- ‘Not everyone needing care in Shropshire lives in Shrewsbury’
- ‘Remote sessions did not make the support accessible’
- ‘Please, please offer face to face appointments and named people to ensure continuity of care. This experience is making things more stressful not less.’

Family/carer support and planned transition to adult services

- ‘Shared experiences of other parents dealing with the same issues’
- ‘I belong to a Parent Support Group in Shropshire. It seems very evident that the amazing support [that was] available to us is not available. I was given the strength to challenge the anorexic beast.’ (Parent of 26 year old who was diagnosed as Anorexic at 17 and has since been discharged from Adult Services)
- ‘Planned transition between services. No limbo period.’

What professionals told us

We heard from 16 people working in:

- The NHS (3)
- Education (5)
- Charity and the Voluntary Sector organisations supporting children and young people (7)
- The independent sector as a private counsellor (1)



The NHS

We heard from two members of staff working at the Shrewsbury and Telford Hospital NHS Trust (SaTH) with children and young people with 'eating disorders (e.g. anorexia), deliberate self-harm, suicidal ideation and victims of child sexual exploitation and 'county lines'⁵ and a healthcare professional supporting young people's mental health.

The challenges

Complex needs and lack of time/staff

- 'These patients need a lot of patience and time to be spent with them to understand their individual needs. The patients presenting with eating disorders take a lot of time, encouragement and support and are probably amongst some of the most complex patients we care for with a mental health problem.' 'Many of these young people just want to feel listened to so it is imperative we can spend time with these patients.' (SaTH)
- 'It holds children back that short staffing means attention is split over larger than optimal groups of patients (8-10 patients rather than 4-5), and also that some staff deem mental health care "not their job" and don't proactively seek out resources to help them understand what the patients and their families are going through.' (SaTH)
- 'Taking [children and young people] to A&E if there is no medical treatment need is not helpful.' (Mental Health Professional)

Lack of access to specialist services and training

- 'Prolonged hospital stays due to unavailability of tier 4 beds creates a lot of issues with these young people. They spend many weeks and sometimes months waiting for a placement to implement the right support and care they need, being on the Paediatric ward a long time with minimal mental health support is incredibly difficult for patients and their families. We are a workforce of Paediatric trained Nurses and Doctors, we need additional training to help support these young people.' (SaTH)

⁵ County Lines is where illegal drugs are transported from one area to another, often across police and local authority boundaries (although not exclusively), usually by children or vulnerable people who are coerced into it by gangs. The 'County Line' is the mobile phone line used to take the orders of drugs. Importing areas (areas where the drugs are taken to) are reporting increased levels of violence and weapons-related crimes as a result of this trend. <https://www.nationalcrimeagency.gov.uk/what-we-do/crime-threats/drug-trafficking/county-lines>

- 'There is a lack of appropriate support and our local BeeU team are stretched within their service.' (SaTH)
- 'The Crisis Team are under immense pressure and work tirelessly to support young people in the community with the resources that they have. Step down from Crisis can be difficult, again due to lack of service provision in mental health.' (Mental Health Professional)

What works well

- 'I find structure and consistency works well with these young people. Where possible, care plans are individualised to help support the patient and their family. We try to care for our patients in the least restrictive way possible, whilst maintaining their safety.' (SaTH)
- 'It works well to have children in a "normalising" environment - a regular hospital ward rather than a dedicated mental health unit (except where absolutely necessary).' (SaTH)

How things can be improved?

- '[SaTH] are employing a Youth worker and a Mental Health Specialist Nurse to help support these patients. The hope is that they can provide a holistic care model for these patients to ensure they get the care and support they need whilst in hospital but also upon discharge.' (SaTH)
- 'There needs to be more provision for inpatient beds for patients with eating disorders especially.' (SaTH)
- 'More training and education is important and we try to facilitate that as much as possible, but short staffing and funding can sometimes cause barriers to implementing this.' (SaTH)
- 'Encourage a culture of staff proactively seeking education on mental health issues [within SaTH]; improve funding, staffing and service provision for CAMHS services so that there is adequate help for children in the community with the goal of avoiding hospitalisation altogether.' (SaTH)

Education

We heard from two people working in Primary Schools, two in Secondary Schools and a member of staff from the local specialist school.



The challenges

- 'The support is not available quickly enough. Early help support is not available to prevent children reaching crisis point. School are often not informed when health, social care agencies are involved. School staff are being offered a lot of training, e.g. mental health training, ELSA⁶, etc. which is good but these staff are not trained mental health professionals, they cannot provide counselling and crisis support and they often have other roles in school also, e.g. TA [Teaching Assistant] , Teachers, and can't provide the support regularly enough without it impacting negatively on other areas of their roles. The huge rise in mental health needs is greatly outweighing the capacity in schools to support this.' (Primary Head Teacher)
- 'The MHST [Mental Health in Schools Team] do not have a clear criteria for schools to refer by.' (Primary School Inclusion Manager)
- 'Issues around BeeU's definition of 'crisis'. They will often say a child has not yet reached crisis point and so cannot receive the help we think they need. The issue is for BeeU to prove the child is not yet in need.' (Assistant Principal in a Specialist School)

What works well

- 'Having a counsellor in school (school funded) that children can access.' (Primary School Inclusion Manager)

How things can be improved

- 'Could still do with more organisations to make referrals to as NHS Trailblazers⁷ have a high number of cases.' (Mental Health Lead in a Secondary School)
- 'More immediate support to be available for issues such as self-harm. More pathways for youngsters with differing needs' (Mental Health Lead in a Secondary School)

⁶ Emotional Literacy Support Assistant

⁷ Trailblazer Programme What will they do? The Mental Health Support Teams' (MHSTs') main role will be to provide earlier care for children and young people who may be experiencing mild to moderate or early symptoms of mental health problems, which tend to be outside the scope of traditional NHS services.

<https://www.england.nhs.uk/mental-health/cyp/trailblazers/>

- 'Schools not having to take on the full responsibility of referrals to panels and pathways or to follow-up when parents have had no feedback/appointments.' (Primary School Inclusion Manager)
- 'Stricter definitions and guidance for when children have hit the 'crisis point'' (Assistant Principal in a Specialist School)
- 'Roles within BeeU need addressing, children need access to specialists not staff who have no official training.' (Head of School in a Secondary School)

Message from a Head of School in a Secondary School

'There has been a significant increase in poor mental health of children, with self-harm, taking tablets and watching social media harm sites. Low mood and lacking in self-esteem and self confidence. Drug taking has increased which in itself brings increased concerns.'

'There are such a lack of services available for referral with most referrals either a waiting list of over 12 months, which could even be one day too late let alone 12 months. Most referrals come back to schools stating it does not meet criteria therefore school can take it to Early Help! I would like the question answered "When did school teachers train to become Mental Health Nurses?"

'Schools are struggling to meet capacity and have most referrals sent back to them unless the child is blue lighted following a serious suicide attempt, then the child is required to see a specialist, but again on discharge, the statement is school can take the lead. Is this truly the right way we should be supporting our most vulnerable children?'

'We are lucky to be part of Trailblazers and if we didn't have this it would be a huge concern. We also have an area to support vulnerable students that is staffed full time from 8am until 5pm. This however is now at capacity for ratios but also room size.'

'Referrals need auditing to see how many are rejected and returned to school for them to take responsibility.'

The charity and voluntary sector

We heard from two people who work for a local mental health charity and five people working with a charity supporting young people up to the age of 18 around substance misuse (drugs and alcohol)



The challenges

- 'Substance misuse – often co-existing mental health issues and self-medicating with substances – especially cannabis & alcohol – in the absence of mental health support such as talking therapies. Really common in young males with unsupported neurological conditions such as ASD & ADHD too. With girls we see a lot of emerging EUPD [Emotionally Unstable Personality Disorder] combined with substance use. Anxiety, trauma, depression, social anxiety, suicidal ideation, issues with emotional regulation are common themes among those we support' (Substance Misuse Worker)
- 'Young people & their families struggle to get the support they need from BeeU – we have had some brilliant joint working with certain practitioners but there seems to be a barrier with accessing MH support in the first place & other services are left to try and fill the gap. Understandable cuts to services nationally mean the BeeU service has lengthy wait lists – the turnover of staff can be difficult for young people too once they have built up a therapeutic relationship. [We] now have a joint working protocol with BeeU to try to best support young people with coexisting substance misuse and mental health issues – Nice Guidelines recommend young people should not be denied MH treatment due to substance misuse.' (Substance Misuse Worker)
- For young people: 'Waiting lists, not answering the phone or leaving it ringing for ages, not returning calls, cases being closed too soon. Being made to feel that you are not important.' (Substance Misuse Worker)
- 'Due to the lack of resources and funding in young people's mental health, it feels like young person's mental health services are always trying to restrict access to their services, looking at ways not to accept a referral. This is understandable when they just don't have the capacity to deal with the need.' (Substance Misuse Worker)

What works well

- 'Given time to talk and express themselves and being listened to, I feel this helps [children and young people] to communicate their emotions and feelings in a relaxed calm environment.' (Mental Health Charity Worker)

- 'The model of motivational interviewing⁸ is very effective.' (Mental Health Charity Worker)
 - 'A quick response works well to help young people to feel supported. A trusted adult who wants to help works well. Support during out of hours.' (Substance Misuse Worker)
 - 'Being open and honest and letting them know that you're there to support them and not to judge them or tell them what to do.' (Substance Misuse Worker)
 - 'Having an established positive relationship with the young person. Having positive working relationships with our partner agencies, which facilitates good communication and effective partnership working.' (Substance Misuse Worker)
-

How things can be improved

- 'More funding nationally for young people's mental health services' (Substance Misuse Worker)
- Message to BeeU: 'Answer the phone, reduce waiting lists, return calls to family, clients and professionals. Listen to other people's opinions and work as a team with other professionals. Don't close cases too soon.' (Substance Misuse Worker)
- 'Support being given to young people quicker and being able to give support to help prevent young people getting to crisis.' (Substance Misuse Worker)
- 'Certainly in our own Organisation, targets are often a barrier to good practice such as; the arbitrary target working with young people no more than 6 Months – This is not based on research evidence and does not take into account most of the young people we work with are in regular crisis with very complex needs; it takes time to develop a positive therapeutic relationship with such complex, hard to reach young people, who are often mistrusting of professionals, who have had many dip in and out of their lives. The same is true for Young People mental health support – flexibility based on need is required not unrealistic targets. So much more investment is needed in mental health provision for young people in all

⁸ 'Motivational interviewing is a counselling method that helps people resolve ambivalent feelings and insecurities to find the internal motivation they need to change their behaviour. It is a practical, empathetic, and short-term process that takes into consideration how difficult it is to make life changes.'
<https://www.psychologytoday.com/gb/therapy-types/motivational-interviewing#>

areas from early intervention up to in-patient provision.’ (Substance Misuse Worker)

The views of a private Counsellor

A major challenge is ‘Having to wait for support; services seem to wait until the YP is suicidal before they will help. GPs are often excellent but responses to requests for help are often slow.’

‘Young people are dying waiting to be seen by mental health services, parents are unsupported and confused by the way teams do not communicate and the inconsistencies i.e., a young person might not see the same social worker/counsellor or be passed between teams with no opportunity to build trust.’

There needs to be ‘an easier way for professionals and services to communicate and more support for parents.’

Service provider response

Shrewsbury and Telford Hospital NHS Trust, Director of Nursing:

 ‘This is a very important and useful piece of work and one for which we are grateful to Healthwatch Shropshire and Healthwatch Telford & Wrekin for, as well as to those whose views have helped shape the report and its conclusions. We always strive to put the voices of those we care for and their families at the heart of what we do and so this report will play a crucial role in helping shape the services we offer in the future and the way in which we deliver them. I would also want to add my thanks and gratitude to my colleagues in the Trust who continue to work so hard and so compassionately to provide care in this very sensitive area.

As the recent inspection of the Trust by the Care Quality Commission set out, mental health provision within SaTH has improved but there is more still to do. In reading the report, it is clear that we have not got everything right for everyone we care for and that there is more we need to do in this area. We are committed to taking the actions needed, alongside our partners, to continue on our improvement journey in the care and treatment offered to Children and Young People that come into our hospitals.

As the report also highlights there are challenges across the whole health and social care system. As an organisation we will continue to work collaboratively with our partners, bringing effective cross sector working, with shared responsibility and accountability and mutual respect, to ensure mental health and wellbeing is everyone's business.

Our improvement work focuses on developing the continuity of care across services and supporting the transition process. We have systems in place to ensure that Children and Young People are cared for in the most appropriate environment for them. This often includes Paediatric services, however, should a young person aged 16–17 choose to be cared for in another area of the hospital, we now have designated adult wards where they can receive their care. We are continuing to upskill and train our clinical teams with knowledge and skills with regards to mental health so that when a Child or Young Person is in our hospitals, they receive care by trained staff with the specialist support from Midlands Partnership Foundation Trust.

Workforce planning continues to be developed to ensure mental health staff are embedded at all levels within our organisation. This includes registered mental health nurses across some of our wards, and in the Emergency Department. We have a mental health matron for Children and Young People and one for our adult services. At the executive level, as the Director of Nursing I am the Safeguarding and Mental Health lead and would finish by offering my assurance that that mental health is a key priority for the Trust Board

Thank you again for the valuable insights offered through this report.'

Midlands Partnership Foundation Trust



'Thank you to Healthwatch for providing this useful feedback about our services, It is always important to hear the voices of Children and Young People (CYP) and their families and we take all feedback as an opportunity to deliver service improvements. We are sorry that not all the feedback was as positive as we would like to hear but we will use it to inform our service improvement work.

Nationally there has been an increase in CYP mental health referrals as well as an increase in the urgency of some of these referrals. This has been exacerbated by Covid, both for the CYPs themselves as well as the staff availability. MPFT are reluctantly having to operate waiting lists for services. Our objective is to address

these waiting times and to improve the partnership working with the other providers so that families and CYPs receive the best possible service for them in the most timely way.

Some families may receive letters explaining that the recommendation for treatment will not be provided by MPFT; this is not a rejected referral, this is a redirection to the most relevant service. Whilst MPFT BeeU services and the other partner providers work closely together to ensure that CYP and families are given the best and quickest treatment possible; there is always room for improvement. We always try to engage CYP and their families in reviewing our work as can be seen in our participation work (see attached word document).

Although the MPFT BeeU service is described as a service for CYP from 0 to 25 years, the service is primarily for 0-18 year olds; the only cases that are retained by MPFT BeeU services until they are 25 years old are those young people with significant and complex needs who have been receiving treatment within the service prior to turning 18. This can lead to confusion for families who might assume that the service is available to all CYP from 0 – 25 years old. We will endeavour to help parents understand this in our literature and on our website. Where it is deemed necessary, a smooth transition from the CYP service to adult services is supported.


Our hard working clinicians in MPFT BeeU services have been working tirelessly to provide the best services possible and we receive compliments through our PALS service about our clinicians and the excellent work that they do.

In addition we will be working with schools and supporting the North Midlands Autism In Schools Pilot Project which will enable us to develop and build on our existing Diagnostic Only Service.

We have designed a short video of some of the recent service improvements that our clinicians have made to show the sort of work that is going on behind the scenes for our children and young people. <https://youtu.be/XIJscubZo90>

We want to improve our services so once again thank you to Healthwatch for this useful feedback.'

Shropshire, Telford & Wrekin Clinical Commissioning Group, Director of Quality:

 'Thank you for the opportunity to respond to Healthwatch Shropshire's report on the experiences of children, young people and their families when accessing crisis mental health services.

The report makes sombre reading and reinforces that we are not getting things right. As a system we are working together to improve our offer both in the short term and in the future to deliver a more sustainable and supportive service that focusses on prevention and support.

We have already:

- Undertaken an analysis of what we have and the gaps in services to support children and young people.
- We are bringing in a team from 'I Thrive' (Anna Freud centre) to work with the whole system to look at what we offer and how we work together to ensure everyone understands the issues that children and their families face with mental health and wellbeing

Acute Mental Health

- We have invested in a children's crisis team to treat children at home and prevent hospital admissions- or if an admission is needed to support them on discharge to ensure they do not decline in their mental health
- We are working with the regional provider collaborative to ensure more effective use of Tier 4 beds
- We are looking at options to develop a crisis bed/place of safety within the area
- The team also provide in reach support to the acute hospitals in Telford and Shrewsbury
- We have another 'mental health in schools' team starting training in March

Autism

- We have invested in a new team to undertake autism diagnosis
- We are working with education and local authorities to ensure there is support while waiting for an assessment and after diagnosis
- Autism support in schools_ 6 schools in STW area 4 Shop, 2 T&W
- Working with CAMHs providers to focus on Autism in the schools (in addition to current BAU offer)
- Education sessions for schools
- CYP voices and self awareness sessions
- We have invested in an Intensive support team based on positive behavioural support to support those children with behaviours of concern

ADHD

- We are reviewing the ADHD pathway and have put in additional financial resource to address the waiting list for eating disorders
- We are recruiting to increase the size of the team as we are well aware of the lack of capacity
- We are commissioning support from the online charity BEAT
- WE have an in-reach nurse into the PRH

The system partners are also working through the right model of delivery based on clinical evidence to ensure all the CYP pathways are unserpinned by the best clinical evidence and that CYP and their families are supported at whatever level and throughout their journey. We can and must do better.'

Acknowledgements

Healthwatch Shropshire and Healthwatch Telford & Wrekin would like to thank the organisations who helped to promote this survey. We particularly thank the children and young people, the parents and carers and professionals who have shared their views and experiences with us.

Get in Touch

Please contact Healthwatch Shropshire or Healthwatch Telford & Wrekin to share your views and experiences of this service or any other health and social care service in Shropshire. We gather comments anonymously and share them with service commissioners and providers to highlight areas of good practice and identify areas for improvement.

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Appendix 1: The on-line survey

Mental Health crisis services for children and young people

Tell us your experiences

We want to know about the experiences of children and young people who have received care and/or treatment either in hospital or in the community because they were in 'crisis'.

When you fill out the questions we don't need to know who you are and you will not be identifiable. We only want to know what help you received, what you thought of it and any suggestions you might have about how things could be improved. We know that services really want to hear what you think.

As well as asking for feedback from young people, we also want to hear from the people who are supporting them, family, carers, health care professionals, social workers, school/college staff or volunteers, who might have ideas about improvements that could be made where things haven't gone so well.

Please note: To comply with required age limits we cannot accept experiences from those under 13. If you are under 13 and wish to share your experiences please ask your parent or carer to do so on your behalf.

Children & Young People Mental Health Questions

* Mandatory question

1. Please tell us who you are:*
- I'm a young person who has received mental health support
 - I'm a parent or carer of a young person who has received mental health support

- I'm a health care professional supporting young people's mental health
- I'm a social worker supporting young people's mental health
- I work / volunteer for a voluntary organisation supporting young people's mental health
- I work in the education sector supporting young people's mental health

If Q1 is health service professional, social worker, voluntary group, educational support worker

2. Please tell us the organisation you work or volunteer for:
 - Free Text
3. Your job title:
 - Free Text
4. What age range are you involved with supporting?
 - Free Text
5. Please tell us a bit about the needs of those young people you support
 - Free text
6. What works well and what doesn't work so well when young people need crisis support?
 - Free text
7. Can you make any suggestions of how improvements can be made?
 - Free Text
8. Is there anything else you would like to tell us?
 - Free Text

If Q1 is parent or carer

9. How old is the young person you are supporting?
 - Free text
10. A bit about them and what led up to them receiving the latest help
 - Free text
11. What things do you most remember about the help they received?
 - Free text
12. When did they receive this help?
 - Currently receiving help
 - In the last 6 months

- Between 6 and 12 months ago
 - Between 12 and 18 months ago
 - More than 18 months ago
13. How could the help be improved? For example, the support available while they were waiting for specialist services.
- Free Text
14. Where were they treated? Please select any services involved
- The Redwoods centre, Shrewsbury
 - A&E at the Royal Shrewsbury Hospital (RSH)
 - Ward 19 or another ward at PRH
 - A ward at RSH
 - Through the BeeU service
 - Inpatient care outside of Shropshire
 - Other [Please specify]
15. Is there anything else you would like to tell us?
- Free Text

If Q1 is young person

16. How old are you?
- Free text
17. A bit about me and what led up to receiving the latest help
- Free text
18. What things do you most remember about the help you received?
- Free text
19. When did you receive this help?
- Currently receiving help
 - In the last 6 months
 - Between 6 and 12 months ago
 - Between 12 and 18 months ago
 - More than 18 months ago
20. How could the help be improved? For example, the support available while you were waiting for specialist services.
- Free Text
21. Where were you treated? Please select any services involved
- The Redwoods centre, Shrewsbury
 - A&E at the Royal Shrewsbury Hospital (RSH)
 - A&E at the Princess Royal Hospital (PRH)

- Ward 19 or another ward at PRH
- A ward at RSH
- Through the BeeU service
- Inpatient care outside of Shropshire
- Other [Please specify]

22. Is there anything else you would like to tell us?

- Free Text

For all

23. Submission confirmation*

The information contained in your response, along with the others we receive, will be used to produce a public report, no individuals will be identifiable in this report.

I give permission for my response to be used in this way and to be stored by Healthwatch Shropshire in accordance with their privacy statement so that they can use it help improve the delivery of health and care services in Shropshire and across the country.

Thank you for taking the time to share your experiences. If you know of other people who have experiences to share please do send them a link to this survey. The more we hear the more influence we can bring to bear.