

Report into

Parents and young people's experiences of accessing:

CAMHS, EHCP'S and Transition to Adult Mental Health Services in Walsall

Supporting Evidence Report

October 2018

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Introduction

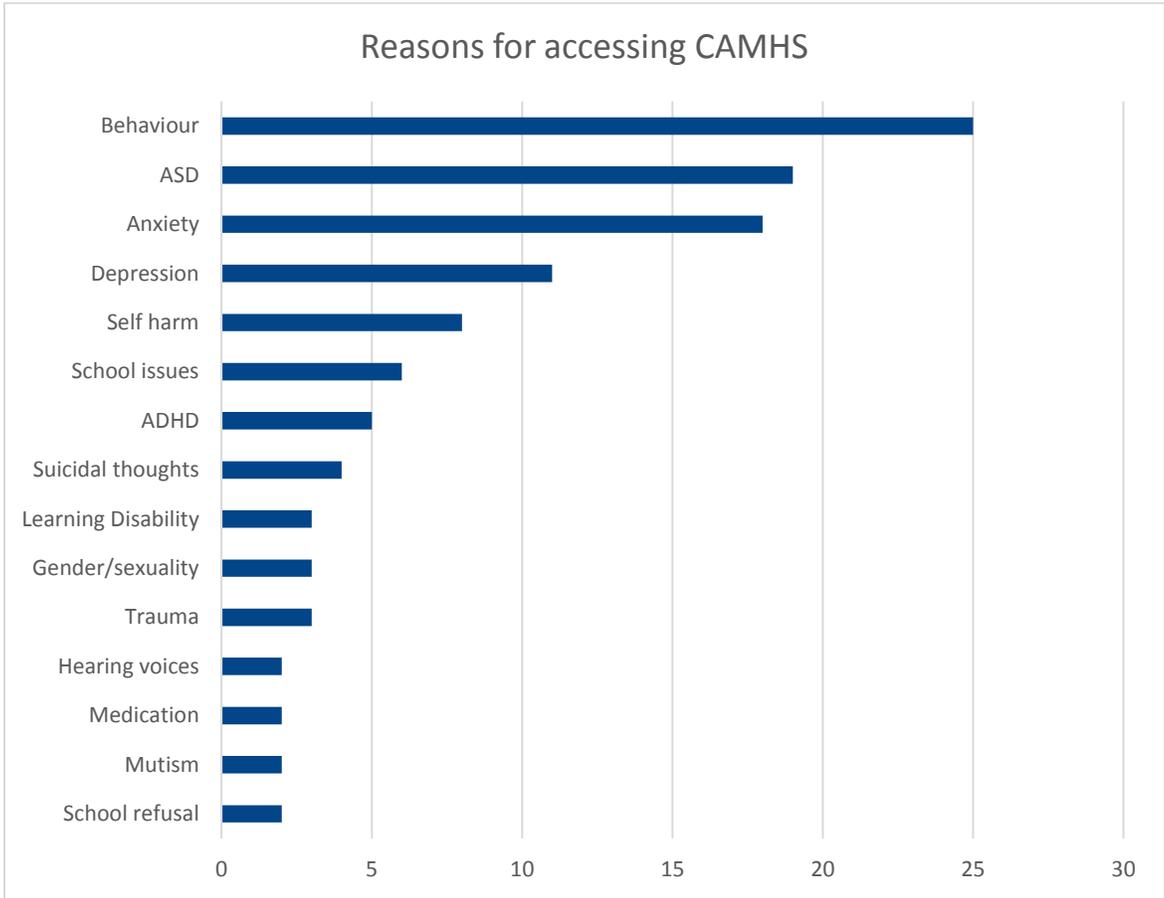
In 2017 Healthwatch Walsall completed a project looking at access to Child and Adolescent Mental Health Services (CAMHS), and the subsequent transition to adult mental health services for young people aged 16 and over. The background to this project can be found in the accompanying Summary Report, while this report gives a detailed breakdown of the responses we heard from parents and young people through interviews and surveys.

This report contains mention of self-harm, suicide and serious mental conditions. Some people may find the comments included distressing, so reader discretion is advised.

Findings

Who we talked to

We collected 86 surveys, conducted one focus group and carried out 16 detailed case studies. 57% of survey respondents were aged 5-16, 24% were aged 16-18 and 18% were aged 18+. 93% of these had first accessed CAMHS before they turned 16. 4 respondents had used learning disability CAMHS, and the rest had used mainstream.



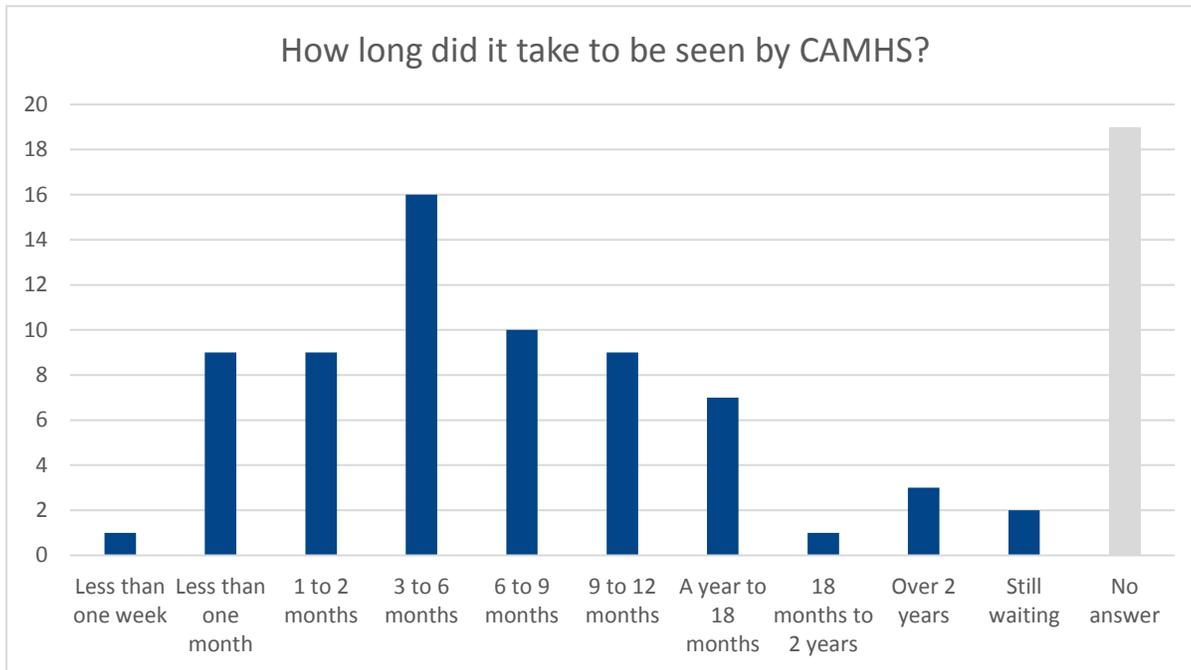
Waiting times

Patients and families now no longer needed to wait extended periods of time for vital support and Walsall CAMHS was able to offer the early intervention that was needed.

By working together, supporting staff within the service, developing new services and bringing in additional resources, patients will now commence treatment within four to six weeks of their initial assessment.”

<http://www.healthcareleadernews.com/how-our-ccg-reduced-young-peoples-mh-waiting-times/>

For the initial appointment with CAMHS, only one patient waited less than one week to be seen. 9 were seen in under a month, and another 9 in less than 2 months. 16 said it took 3-6 months to get an appointment, and 10 people waited 6-9 months. For 9 young people it took 9-12 months to be seen, and 1 more waited up to 18 months. 3 people had waited over 2 years, and 2 were still waiting to be seen at the time they were surveyed. The one eating disorder patient had received an appointment with CAMHS within 2 weeks, which is within the national KPI's.



Three children in our survey had been diagnosed in 2018, two were given an appointment within 1 month and the other was seen within 2 months.

There were not enough responses to say with certainty whether waiting times had improved over time, as on the whole people's experiences were very varied, but it is encouraging to see that in 2018 no patients waited longer than 2 months to be seen. It is also promising to see that since 2016, no one surveyed had waited over 9 months from diagnosis to the next appointment. For those diagnosed in 2017, the results were more varied. Three people were seen within 6 months of diagnosis, two did not answer, and one child who had received a diagnosis in August 2017 was still waiting to be seen in May 2018. Similarly, in 2016, waiting times varied from 1 week to 9 months.

Early intervention

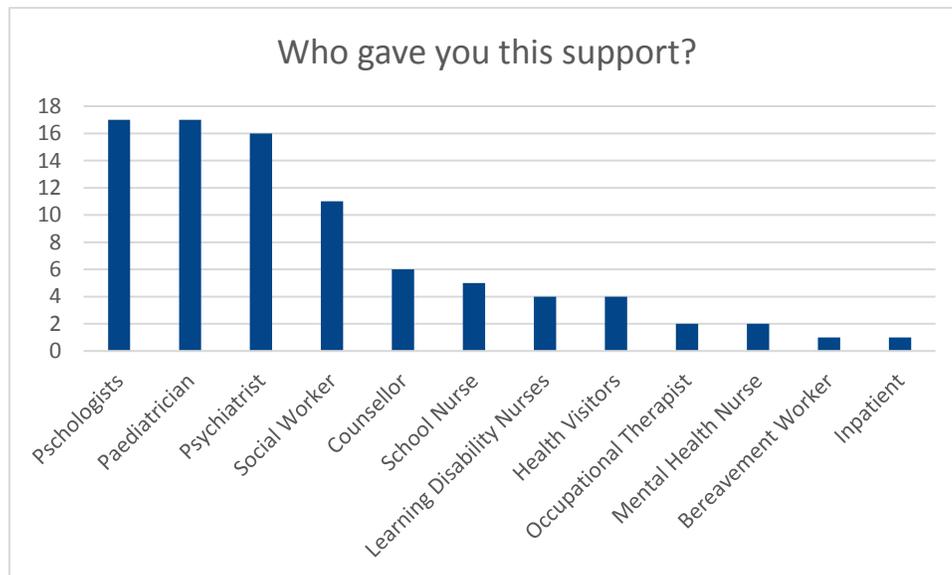
Only 10% of parents and young people we spoke to had received any early intervention in their mental health to prevent future difficulties. The interventions included: anger management, parenting courses, group therapy, counselling, early intervention team, appointment with a nurse, play therapy. The effects for those who had not received any early intervention included anxiety, stress for the family, breakdown, suicidal thoughts or suicide attempts, problems at school, and feeling let down.

Parent sought CAMHS help for child, 7-year-old. But due to an address error did not receive appointments in post. Took 18 months to identify and then another issue so on 3rd attempt after

two years got an appointment to see CAMHS. Parent feels that her child could have been helped earlier rather than condition worsening.

Who gave support?

For those who did receive support through CAMHS, the main sources were psychologists and paediatricians, closely followed by psychiatrists and social workers. Smaller numbers of young people had also seen counsellors, school nurses, learning disability nurses and health visitors. A minority had received support from occupational therapists and mental health nurses, one had seen a bereavement worker and one ended up using inpatient care.

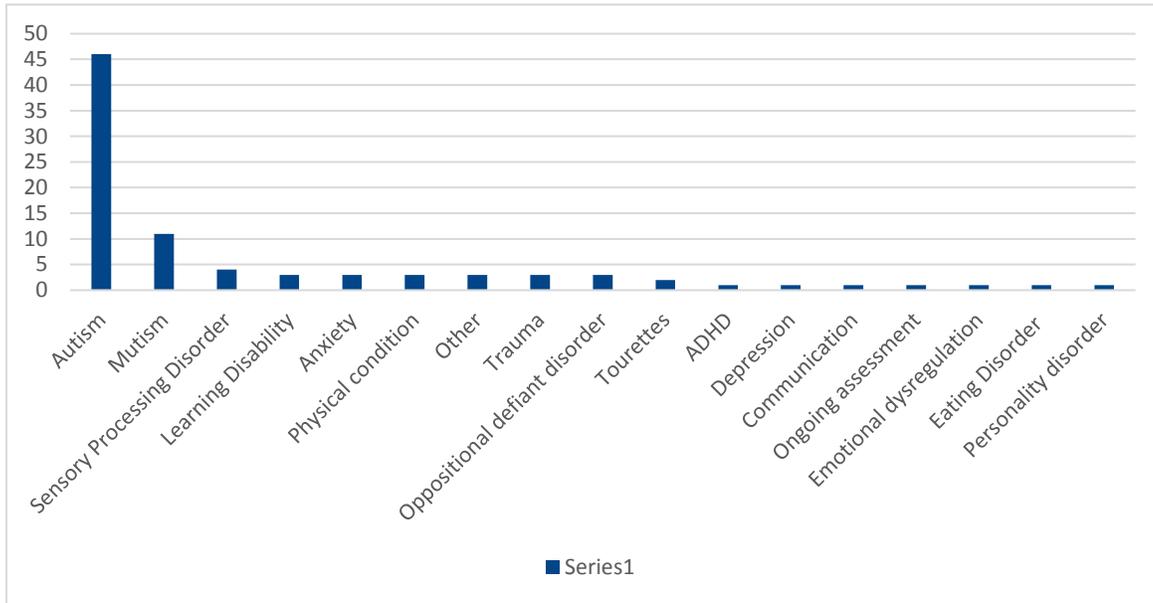


Type of support

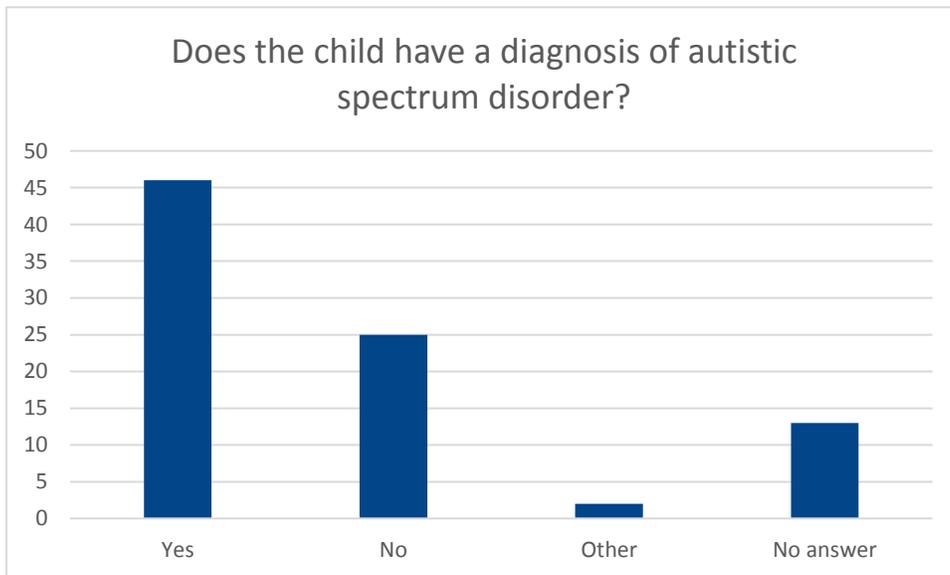
Not many people gave details about the support they received, but when they did give a response, the most common answer was “none”. 4 people said they had counselling, and 2 said they got 6 sessions with a counsellor, and 2 each said they received advice, help with coping strategies and general support.

Diagnoses

As several young people had multiple diagnoses, these results are given in numbers rather than as a percentage.



Almost half of the young people we spoke to had an autism diagnosis (46 out of 86). 11 young people had been diagnosed with elective or selective mutism. 4 had sensory processing disorder.



Crisis team

Only 30% of people who had used the crisis team said they felt supported by the service while facing difficult circumstances.

“There were delays in seeing someone, then the LD Services & the Mainstream Services argued amongst themselves, eventually he attempted suicide & ended up in a CAMHS unit. This experience broke him!”

“During a melt down son was violent and uncontrollable I needed to restrain him with 2 young children present and no other adult, they told me to call police! This was an autistic/disability and mental health issue.”

“Took hours to call back.”

“They didn't come out to me”

Transition to adult services

9 people said the support they received changed when they reached age 16. Four said there was no longer any support available to them. All four of these people had a diagnosis of ASD.

“Left with nothing, just carry on struggling alone”

“Discharged because of the age and told GP will have to monitor, so zero help, it's disgusting”

“In real terms he now has NO psychological support and a psychiatrist with very limited understanding of autism.”

“If they have not had access to help in child, then they get to adult and are denied help on that basis, rather than following national guidelines, which would suggest that they need help.”

“Moving to adult – if you've fought for child services and didn't get them they say “if you didn't need child services, why are you here now?”

“Referred to but yet to meet allocated adult social worker. My son turns 18 in 6 months.”

Four young people had been referred to adult mental health services, and one said their GP could refer them if it became necessary. Others were receiving support from other services.

“I was switched to the Early Intervention Team for formal diagnosis.”

“Now he is 17 he is being discharged back to GP, who can refer to adult services if needed.”

“Transferred to adult services at 18. Seen for eating disorders.”

“She left home and social worker got her help”

Two respondents who had tried to access adult services said they were refused, as they were told that there was not funding available for adults with ASD. One pointed out that they were not seeking mental health support due to their autism, but for other conditions. In addition to Asperger's Syndrome, one of the people who said they were turned away from adult services also had diagnoses of emotional dysregulation, ADHD, ODD and Tourette's.

“He's 18 now, we were told he can't access adult mental health services as there is no autism service, even though he was referred for other things – he has Tourette's and other needs.”

Patient suggestions and overall experience

“The whole family mentally, emotionally, financially ruined.”

“Soul destroying!”

“Services are poor. They fail our children and penalise them for something they have no control over”

“Throughout the treatment, it felt less like they were talking to me and listening than talking at me.”

Several parents felt that because their child had complex needs and were a challenge for CAMHS staff, they were discharged inappropriately from the service rather than being helped.

“Staff discharging him without help because he's got complex needs and is hard work”

“Worker's signing son off because he's hard work even though they've witnessed him hit me and try to throw a chair at me”

“My son was discharged too early and I felt he needed more sessions”

“In and out of CAMHS, he has complex needs and he's challenging, so when they couldn't tick the boxes they would discharge him.”

Walsall CAMHS referral criteria specifies that referrals “Post ASD diagnosis” did not meet the requirements for specialist CAMHS.

“Once they have been diagnosed there is no continuing support.”

People felt down by a lack of access to support.

“She was let down throughout the service”

“Lack of support following diagnosis”

“No help offered after diagnosis”

Others said that more early intervention would be beneficial to their child and family.

“Lack of early intervention and preventative approaches.”

“Early intervention would be much more productive – often with our kids you can tell that in a few months they will need an intervention (like during GCSE's). But CAMHS wait until they are in crisis and self-harming, and then it can be too late.”

“Early intervention is crucial and that is part of the Dudley model.”

Some felt that their views as parents were not taken in to account.

“Not listening to parents”

“Feeling that my views as a parent aren't listened to.”

“It would actually be a good idea to have an appointment with just myself without my son, so I could probably talk more openly about his mental health and behaviour as I do feel limited on what is suitable to say in front of him and how others feel about him”

“Sometimes the child has not been informed and explained about the condition, only told that they have autism or ADHD. Don’t think CAMHS understand as the child gets older they develop more of their sense of self and need to understand things about themselves.”

Some felt that the members of staff who dealt with them were not specialised or experienced enough to deal with their support needs.

“In real terms he now has NO psychological support & a psychiatrist with very limited understanding of autism.”

“One member of staff was not experienced enough or helpful, but they have now left”

“New CAMHS staff not trained well enough.”

“Not specialist enough, not aware of communication issues.”

“Not what we expected, we thought the worker would build a trusting relationship before they started therapy.”

“Staff are not autism trained and do not start with building relationships.”

The need for an adult or transitional autism service was highlighted.

“Adult [need to] recognise existing Autism diagnosis.”

“Yes, was referred [to adult] and they turned down the referral because they don't have funding for autism”

“Was referred don't know who to as they reused said they don't do autism yet it's not autism my son's medicated for, he has numerous diagnoses”

https://www.wcld.co.uk/kb5/walsall/asch/advice.page?id=RPWXD7-N_cs

Autism is not a mental health problem. But a recent study showed that as many as 71% of children with autism have mental health problems, such as anxiety disorders, depression, and obsessive compulsive disorder (OCD), and 40% have two or more. Simonoff E. et al (2008), Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample, Journal of American Academy of Child and Adolescent Psychiatry 47: 4: 921-929

<https://go.walsall.gov.uk/Portals/0/Uploads/SocialCare/Walsall%20Adult%20Social%20Care%20Commissioning%20Plan%202017-18Complex%20Needs.pdf>

Some said the support they received was too generic and didn’t feel tailored to them. Others felt that the approach was not flexible enough for their child’s needs.

“Maybe more tailored support since it felt more general.”

“You get 6 sessions with CAMHS, and after that you are discharged.”

“They will only see you for one specific issue - if the child has anxiety and autism they will not look at both in one set of sessions – no holistic overview or recognition that the anxiety and autism interact.”

“Cannot dip in and out when stress is high – like exam time – there is no flexibility”

“They came and did an assessment with him individually and then one with the family, [child] got really excited and thought that they would be finally listened to, and then they offered the one thing we had asked not to have. We had provision that had been working perfectly well for 4 years and then they pulled that out from under us. And they had the cheek to write to us and say the changes are for his “own good”. I’m never going to forgive them for asking what [child] wanted and then ignoring it. There was never an intention of listening to [child].”

Some highlighted the lack of a smooth transition to adult services and that some teenagers started to slip between the gaps.

“Not receiving any help or support when my son was younger. Now being told he is too old to be diagnosed or get help.”

One parent highlighted the need for a flexible service that her son could dip in and out of depending on his stress levels at the time. She elaborated that during the lead up to his GCSE exams his mental health had declined, but they had been discharged from CAMHS earlier on in the year.

“Longer term support because we know that certain times produce extra anxiety and can predict when we need support”.

Lack of support and early intervention had serious effects on young people and their families.

“I feel that my child’s mental health has worsened due to lack of suitable help, lack of early diagnosis and suitable understanding by schools for appropriate educational environments. Too many years wasted due to the system and not enough help and suitable advice and primary school not wanting to fully support getting son statemented and in the wrong environment which was clearly damaging to his mental health and also his siblings and myself the parent... lack of correct help”

“The whole system has ruined my son’s mental health and also mine and his sisters.”

“Left to get worse isolating him and rest of the family”

“Affected home life, relationships.”

“It’s affected my mental health continually fighting for support but keep being refused”

“I got really suicidal and experienced a lot of breakdowns”

“We never managed to get any support for siblings.”

“It’s had a really big impact on my younger son.”

“The impact on the other sibling(s) is huge.”

Case Studies

Case Study 1

Healthwatch Walsall spoke to a parent at a FACE event in March 2018. The parent is a single parent with mild learning disabilities. The parent has two children are 15 and 20 years old, that have difficulties currently and in the past: around schooling, communication and anxiety issues. The younger child was bullied at school and was showing signs of mental health concern. The bullying continued so badly to the point that the parent had to take him out of school.

The parent had tried to get support through Walsall SEND, to resolve the bullying and get the child support in school generally. But there was communication issues and SEND did not support the child as the parent hoped.

The child was sent to college under a special scheme, the parent hoped for some support from the college being a place of education. But the college said they only get paid for basic education and not an EHCP.

The parent felt that their child needed to be assessed again due to his quietness, anxiety and difficulties. The parent spoke directly to CAMHS and asked for a new assessment to be done.

The parent also informed Healthwatch that her son had been kicked off his apprenticeship, that x had attended, because x has autism and doesn't speak (no bad behaviour problems) and parent feels that this is Disability Discrimination. The 15 year old child has now been diagnosed with selective Mutism. Since recent assessments x is waiting to find out about additional diagnosis.

Healthwatch facilitated opportunities for the parent to raise the profile of parents children's problems at a strategic level and most recently the parent has had a meeting with Walsall Brough Council. Walsall Borough Council were very concerned about how long these issues have been going on and have categorically made it clear that plans will be put in place to support her child in September 2018 at college even without an EHCP in place.

Case Study 2

A parent sought CAMHS help for child, 7-year-old. But due to an address error did not receive appointments in post. Took 18 months to identify and then another issue so on 3rd attempt after two years got an appointment to see CAMHS. Child is now 13, has EHCP in place. Child receives medication, but doctor has changed dosages. Up and down which has not helped. The parent feels that her child could have been helped earlier rather than condition worsening. Diagnosis was the issue, timescales it has taken.

Positives

- They explain things well

Negatives

- 18 months to wait for an appointment
- Told would get help but discharged
- The child had showed 50/50 borderline diagnosis, parent and school had to push CAMHS to have diagnosis recognised
- Parent feels that any test should include observation of the child rather than a questionnaire/ tick box method of diagnosis
- Got a discharge letter with another families' name on

Case Study 3

Family with 2 children. When moved into Walsall only took 3 to weeks to get appointment. Age 13 been involved with CAMHS for 7 years and Age 15 been involved with CAMHS for 6 years. Children have Autism and Asperger. Diagnosed 2011 and 2012. Both got EHCPs. They currently receive regular 3 monthly review meetings, meds checked, weight checks and other, almost like Health check and had help sessions in past. But worker on help sessions has left and not seen new worker, due to ill planned appointment and one session forgotten by parent. School is excellent and very supportive. In parent's experience CAMHS has been excellent but aware not the same for other parents. But thinks that CAMHS may only still be involved because kids have ADHD, feels if it was only autism then CAMHS would not deal with. Also, they are reluctant to diagnose PDA (Pathological Demand Avoidance). CAMHS seem to say if child has AUTISM or Asperger's then has PDA where children have different Autism traits and not necessarily have PDA.

Feels CAMHS could improve:

- Diagnosis – recognise traits such as PDA, ODD.
- Don't rely just on a GPs report, see child and assess for themselves.

Case Study 4

x is now 18, refused to receive a statement for autism and it took until x was 13. "I wanted [x] to be able to get the most appropriate education. I was told [x] had to go to mainstream school and [x] refused to go to school on many occasions. At the mainstream school we were told by SEND that [x] would have one to one tuition – this never happened. [x] was eventually placed into Jane Lane school. However, they failed [x] as they couldn't cope and was excluded. No support was put in place. I eventually found [x] a good support school. [x] is now 18 and out of education. [x] has recently had several Adult Social Workers that keep changing and I feel [x] has been let down."

Case Study 5

[x] is now 13 he received a statement when [x] was 7 and diagnosed with ADHD, Autism, anxiety and having learning disabilities. "We feel that the system has let us down. [x] has this year been discharged from CAMHS who have not been able to help [x] with [x] ADHD. We were told that they would be coming out to support his behavioral issues. No one has come out and we are unsure why [x] has been discharged from service. [x] is on a considerable amount of medication; the GP though is really good".

Case Study 6

"[x] is 8 years old and we originally received an appointment at CAMHS two and half years ago. We were told that [x] had attachment disorder. We were not happy with this diagnosis and we asked for another assessment. [x] had an assessment for autism in Jan 2018 and it has taken until July 2018 for us to receive an assessment. Now hope that school support can be put in place"

Case Study 7

The child is 9 years old and has aggressive behaviour and self-harm issues. In September 2016 the child was assessed for ADHD. In a letter from CAMHS, April 2017, it was indicated the child did not have ADHD. The parent wished further clarification and arranged a meeting with CAMHS but the CAMHS worker who was due to undertake interview and overseeing child's case was not available so another CAMHS worker attended the meeting with parent. But it seemed the CAMHS worker had not read case notes and knew little about the child and their behaviour and had not seen the child. After a chat with parent who gave a brief overview of child's family history. The CAMHS worker implied it may be down to an absent parent's condition who was a schizophrenic and the child

may have picked up their behavioral traits. Parent feels cannot be as child would have been 3 months old and not seen the absent parent for the past 9 years. The child was discharged from CAMHS and the parent made a complaint to CAMHS in September 2017. The parent has heard nothing, no response to date. The child is still having problems at school who won't refer to CAMHS because the parent feels that the school think they will end up dealing with it. The child has attended friendship courses and a sensory course, but it does not seem to have helped. The parents neighbour whose child also has issues has got an appointment much earlier with CAMHS. January 2018 as opposed to September 2018, though the parent's child was known to CAMHS earlier than the neighbour's child. Neighbour's child had an appointment in January 2018 and received a diagnosis of ADHD in April 2018. A more positive experience for that parent. It is felt that the school has staffing issues, and so reluctant to deal with child and Walsall CAMHS have not even read child's file. CAMHS gave the parent information that was 3 months out of date. Parent has had dealings with Staffordshire CAMHS who they feel are much better than Walsall CAMHS.

Case Study 8

"[x] initially accessed CAMHS 3 years ago, [x] is now 12. We have 6 months checks with CAMHS and [x] had been supported very positively. The support that [x] received is really good. [x] was diagnosed with ADHD, Autism - Aspergers Syndrome, and emotional deregulation. [x] currently goes to [x] school who really support him".

Case Study 9

Parent was very happy with service from Walsall CAMHS. Only took a couple of months to get child appointment. Child was diagnosed and received medication which seems to have worked. There was some issue around medication if working but after a couple of weeks was put back on and was working. Is still on now. School has also been good. Child sees family support worker on a two weekly basis which helps. Parent feels that the service has been good and worked for the child.

Case Study 10

Child is 14. Parent explained that at 8 their child was diagnosed with Sensory Processing Disorder, but there were signs of autism. When child was 9, parent asked for another assessment after taking their child to the GP and explaining the child's behaviour. GP then referred the child to CAMHS. Once a secondary assessment that had been undertaken the child was diagnosed with autism however due to it being identified as 'high functioning autism' the child has been discharged from CAMHS. The child's school had not been informed of their diagnosis

Case Study 11

"I am now 17 and for 2 years I suffered from depression and anxiety due to family circumstances. My Social Worker referred me to CAMHS 2 years ago. CAMHS have really helped me with my depression and they have been very supportive. My talking therapies have really helped".

Case Study 12

Child was originally referred to CAMHS by consultant in February 2017 was suffering high anxiety. [x] appointment came through for September 2017 and [x] was seen by LD nurse who explained they are a small team of 3. The parent was advised that there was not long to wait as waiting list was not long. The nurse took [x] history. [Parent] was told could refer straight away for medical assessment and was put on waiting list. 8 months on they are still awaiting appointment. [x] has not been assessed and not received any medication. So, is where [x] was at start of process, or worse off. The parent has rung CAMHS twice and left voicemails which has not been returned so no contact. The last time was Nov/ Dec 2017. In January 2018 [parent] received a letter from CAHMS to say [x]

was on waiting list and they would be in touch shortly. Now May 2018 and no one has been in touch and parent has not had a return call.

Case Study 13

"In and out of CAMHS, [x] has complex needs and [x is] challenging, so when they couldn't tick the boxes they would discharge [x].

I kept asking for a home visit or to meet at Pinfold Medical Centre as it's closer to home, but they said no. Later I overheard staff on the phone organising home visits for other people.

[x is] 18 now, [x] was discharged from CAMHS aged 16 and a half. We were told [x] can't access adult MH services as there is no autism service, even though [x] was referred for other things – [x] has Tourette's and other needs. [x] is highly dependent on me, and [x] has extreme anger.

[x] also has physical health problem – [x]'s hypermobile and needs orthotics in [x] shoes. [x]'s got back pain and been tested for juvenile arthritis.

People think [x] looks "normal" until [x] has a meltdown and then they say "we can't deal with this".

We struggled for years and then at 16 [x] was dropped.

It has a big impact on family and siblings. [x] siblings go to young carers and My Place but they get bored there. I had a carers assessment years ago, they gave me money for decorating. Recently tried to get another carers assessment, still waiting.

[x] was diagnosed at age 8 and a half. CAMHS did anger management with [x], and on the last day [x] got in a fight with a girl, but they still discharged [x] from the course. The Dr was good, but only monitoring medication. She wrote supporting letters when we needed them.

There was no flexibility with appointments, they don't account for parents working. When you did go, the worker asks, "how's things" and you have to recount all the negatives in front of the child.

CAMHS can't deal with [x] issues, so they discharge [x] because it looks better on their records, and that's when you can actually get an appointment, because the waiting lists are ridiculous.

Who is there to enforce that they change? Things never change, I've heard the same things for years.

We originally got the diagnosis through school, the teacher picked up on it and spoke to a doctor friend. In Secondary school, CAMHS went in for appointments, but we weren't always told about them. [x] had a few workers, they would ask questions and just stare at [x], which made [x] feel uncomfortable. They should know enough about autism not to stare at [x], some people struggle with eye contact.

Case Study 14

A parent's [x] 12, has be ASD and ADHD been waiting for a CAHMS appointment which has taken too long. They had attempted to get a CAMHS appointment for [x] who had said in Jan 2018 that due to the bullying at school [x] wanted to commit suicide. Although SENCO Team had set up an emergency appointment, which was in mid March, taking three months although it was identified by their GP as a priority. [x] doesn't have an enhanced health and educational plan (EHCP) and they have been discharged from the

Social Worker Team. However, [x] is becoming more depressed and coming home from school with bruises.

HWW met with the parent at a FACE event during outreach. HWW were contacted by the distraught parent who has been told the appointment was in March and that it had been missed and as a result [x] was from the process of CAMHS. HWW have raised concerns to CAMHS in relation to the bullying, concerns about [x]'s safety and concerns that [x] had never missed an appointment so why had [x] been discharged. We have been liaising with CAMHS to support the parent to come to a reasonable agreement. In discussion with CAMHS it was made clear that the appointment had been arranged for March and that a letter stating if the appointment is missed then the patient will be discharged back to GP. HWW attempted to arrange another meeting with [x] and CAMHS but due process means that because of demand on services an appointment can now only be made GP emergency and that no specific child carried priority unless it is vital important. We will be informing the CCG and asking for their views on due process. We have though been able to support the parent with specialist advice on looking at supporting [x] through tier 2 school nurse through positive steps, to question the school over why [x] doesn't have a health and educational plan. We have also advised the parent to formally request that [x] is seen by an educational psychologist on advice by CAMHS. The parent called again in April and was very concerned about [x] being bullied at school [x] has spoken to a teacher but the teacher didn't raise it as a safeguarding issue after [x] said [x] wanted to die. The parent has raised the issues with the school but no prevail and mom feels that the school doesn't seem to be concerned about [x]'s welfare.

Case Study 15

"[x] has been having issues, bullying others, making weapons, storing disinfectant etc. [x] had a referral to CAMHS who said that there was nothing wrong with [x]. But [x] continued [x]'s poor behaviour. Including setting off alarms so fire bridge would come out. Family members had chat and it seems that its part due to the loss of [x]'s grandad. May be the case but I have sought another CAMHS referral from my GP but CAMHS rejected it. Parent informed us that they had attempted to call CAMHS on numerous occasions but could not get through".

Case Study 16

"[x] was initially referred to CAMHS at Canalside Bloxwich, at 3.5 years old whilst undergoing assessment for autism via the community pediatrician at the child development centre. [x] experiences severe anxiety and symptoms similar to PTSD. My [x] is now 5, and we still meet regularly with CAMHS. We see two psychotherapists once every 6 weeks for a 50-minute session. We have found CAMHS to be an invaluable service, I couldn't have coped with my [x]'s issues and concerns without them. From offering advice and support, to writing letters that we can use when visiting places that trigger extreme stress reactions - such as the local hospital. They have listened to us worry about my [x]'s situation, and as the years have passed and it has become apparent that my youngest may have autism, they went above and beyond, by talking to the people at the child development centre to allow for a smoother process of [x] being referred and assessed. Life would be much harder without them".

Secondary Information

Through discussions with staff from Rethink, Walsall Enablement Service we found that they had similar information that we had obtained around the lack of services for young people with autism transition to adulthood.

Rethink

A number of clients have struggled with transition from CAHMS to adult services – the reoccurring theme is that many are discharged without any other support in place.

Many will try to access adult services like ours at Rethink but due to the current commissioning of the service for adults 18+ we are unable to work with them – we don't currently have anywhere to signpost them on to.

If they do engage once they are 18 we find that they have become more complex and have often self-medicated with drugs/alcohol – most are left feeling abandoned and that transition from CAHMS to adult service does not work.

Acknowledgements

Healthwatch Walsall would like to thank all participants who took part on this work for their valid contribution and time. Special thanks to the organizations who have assisted us during this consultation.

- Families and Carers Empowered (FACE) Parent and Carer Forum.
- Walsall College - Mental Health Awareness Week
- Sai Medical Centre Health Fayre
- Walsall Manor Hospital
- Walsall Urgent Care Centre
- Prince's Trust Walsall
- Walsall Carers Centre
- CAMHS Canalside
- Rethink Mental Illness
- Autism West Midlands

Appendix 1

Survey

In 2017, Healthwatch Walsall undertook a public consultation to identify what the public wanted Healthwatch to focus on during the year. There were 5 priority areas identified including young people's access and experience of using CAMHS services and transitional services through to adulthood. We would very much like to gather your / your child's views. We are looking for the views of children / young people between 5 and 20 years old using CAMHS in the last **4 years**. Any personal information **shall not** be passed onto any third party and you / your child's information will remain anonymous. This survey can be completed by a parent or you as the young person. We will use this information to discuss any possible service changes with the Commissioners of the services.

Q1 What is your age or age of your child?

- 5 to 16
- 16 to 18
- 18 Plus (Adult)

Q2 How old were you/ your child, when you first tried to access support though CAMHS?

- 5 to 16
- 16 to 18
- 18 Plus (Adult)

Q3 Why did you/ your child need this support?

Q4 How long did it take to get an appointment at CAMHS?

▼ less than one month ... Over 2 years?

Q5 Have you accessed Learning Disability CAMHS or mainstream CAMHS services?

▼ Yes ... Neither one

Q6 Has you / your child been diagnosed with Autism?

▼ NHS information sheet ... No, but they have a diagnosis of a different condition

Display This Question:
If Has you / your child been diagnosed with Autism? = No, but they have a diagnosis of a different condition

Q6a If other please state other disability / diagnosis.

Display This Question:

If Has you / your child been diagnosed with Autism? = NHS information sheet

Or Has you / your child been diagnosed with Autism? = Yes I have

Q7 When did you receive diagnosis? Please select the month and year

Jan

Feb

Mar

Apl

May

Jun

Jul

Aug

Sep

Oct

Nov

Dec

2018

2017

2016

2015

2014

2013

2012

2011

2010

2009

2008

2007

2006

2005

2004

2003

2002

2001

Display This Question:

If Has you / your child been diagnosed with Autism? = NHS information sheet

Or Has you / your child been diagnosed with Autism? = Yes I have

Q8 How long after this did you receive support from CAMHS?

▼ less than one month ... Over 2 years?

Display This Question:

If Has you / your child been diagnosed with Autism? = NHS information sheet

Or Has you / your child been diagnosed with Autism? = Yes I have

Q9 Who was this support from? (please select all that apply from the list)

- Psychiatrists _____
- Pediatrician
- School Nurse
- Learning Disability Nurses
- Psychologists
- Health Visitors
- Social Worker
- Counsellor
- Bereavement Worker
- In patient
- Outpatient
- Other, please answer

Display This Question:

If Who was this support from? (please select all that apply from the list) = Other, please answer

Q9a Please tell us what kind of support you accessed if it was not listed in Q9?

- Please specify _____

Display This Question:

If Has you / your child been diagnosed with Autism? = NHS information sheet

Or Has you / your child been diagnosed with Autism? = Yes I have

Q10 Please give some details of the support you received?

- Please specify _____

Q11 Have you ever used the crisis team services?

Yes

No

Display This Question:

If Have you ever used the crisis team services? = Yes

Q12 If you did use the crisis team do you feel you were supported at this difficult period?

Yes

No

Display This Question:

If If you did use the crisis team do you feel you were supported at this difficult period? = Yes

Q12a If you feel the crisis team did support you please tell us why?

Please specify _____

Display This Question:

If If you did use the crisis team do you feel you were supported at this difficult period? = No

Q12b If you feel the crisis team did not support you please tell us why?

Please specify _____

Q13 Did you or your child experience any early intervention to prevent mental health difficulties?

Yes

No

Display This Question:

If Did you or your child experience any early intervention to prevent mental health difficulties? = Yes

Q13a If yes, please state what the experience was?

Please specify _____

Display This Question:

If Did you or your child experience any early intervention to prevent mental health difficulties? = No

Q13b If no how did this effect your/ your child's mental health?

Please specify _____

Transition to adult services

Display This Question:

If What is your age or age of your child? = 16 to 18

Or What is your age or age of your child? = 18 Plus (Adult)

Q14 Did the support you received change when you became 16?

Yes

No

Display This Question:

If Did the support you received change when you became 16? = Yes

Q14a If Yes, please could you give us details of how it changed?

Please specify _____

Q15 Have you accessed / or been referred to adult services, and if so please give details who you were referred to?

Please specify _____

Please could you give us your views of your journey through CAMHS/Adult mental health services in the next few questions?

Q16 What has been most helpful?

Please specify _____

Q17 If you were not happy what went wrong?

Please specify _____

Q18 What do you feel has been missing in terms of support?

Please specify _____

Q19 Would you be happy to share your experiences in more depth and be the subject of an anonymous case study?

Yes

No

Q20 If Yes, please give us your name and contact details

Q23 What is your age?

- Under 18
- 18 – 29
- 30 – 39
- 40 – 49
- 50 – 59
- 60 – 69
- 70 – 79
- 80+
- Prefer not to say

Q24 What is your gender identity?

- Female
- Male
- Female to Male Transgender
- Other
- Male to Female Transgender
- Other, please specify _____
- Prefer not to say

Q25 Do you consider yourself to have a disability?

- No
- Yes
- Prefer not to say

Q26 What is your ethnic group?

- White English/Welsh/Scottish/Northern Irish/British
- White Irish
- White Gypsy/Irish Traveller
- Any other White background, please describe _____
- Mixed White and Black Caribbean
- Mixed White and Black African
- Mixed White and Asian
- Any other mixed/multiple ethnic background, please describe _____
- Asian/Asian British- Indian
- Asian/Asian British- Pakistani
- Asian/Asian British- Bangladeshi
- Asian/Asian British- Chinese
- Any other Asian background, please describe _____
- Black African
- Any other Black/African/Caribbean background, please describe _____
- Black Caribbean
- Arab
- Any other ethnic group, please describe
- Prefer not to say