

Report Into

Parents and young people's experiences of accessing:

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

Summary Report

October 2018

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Healthwatch Walsall

Healthwatch Walsall (HWW) is the independent consumer champion for health and social care in your local area, delivered by Engaging Communities Staffordshire. Our job is to identify the consumer views of those using health and social care services across the borough and give local people an opportunity to speak out about their concerns and health care priorities. We also deliver signposting to local services and give information on what is available.

Everyone who uses health and social care services has the right to expect a high standard. Healthwatch can help local services achieve these standards, by carrying out projects such as this one and producing a set of recommendations. Our role is to:

- Seek out people to discuss their local health and social care services
- Use what they say to help decision makers improve the quality of local services
- Reflect the diversity of Walsall’s population, including children and young people
- Build on any example of good work that is being achieved
- Work in partnership with services – not in opposition
- Sit on the Health and Wellbeing Board and ensure progress is achieved

Background

In 2017 Healthwatch Walsall undertook a public consultation to gather the views from the public on what should be the priority areas of work for Healthwatch Walsall to focus on in its forthcoming year. One of the focus points was access and support through children and adolescent mental health services (CAMHS) and experiences of support from childhood through to transition to adulthood with an emphasis on children who have been diagnosed with autism.

Aims & Objectives

Our aims for this work were to gather views from family members and young adults **on their** experiences of using and accessing CAMHS, access to and experiences of support through transition to adulthood. We undertook this work through a survey with family members and young adults and by also gathering case study material. Our target age range for this work was 5 to 20. Our aim was to survey at least 50 family members / young adults.

Some of the key information that we wanted to ascertain was:

- Have improvements been made to waiting times and access to CAMHS?
- What is the mental health support provision available for young people with suspected or diagnosed autistic spectrum disorder in Walsall?
- What are young people's experiences of the transition from CAMHS to adult mental health services?
- How are children and young people who have been diagnosed with autism being supported?

Consultation and Engagement

We distributed our survey via web link and paper copies and collected case studies by meeting with people face to face. We met parents and young people at events across Walsall, including: FACE events, CAMHS Canalside open day, Walsall Manor Hospital, Walsall Urgent Care Centre (Community Site), Elmwood School, Walsall College Mental Health Awareness Week stand.

Findings

We collected 86 surveys, conducted one focus group and have gathered information from 16 case studies. Although we have received detailed information and personal stories, **the case studies have been anonymized due to data protection and to protect all parties involved in our work.**

Reasons for accessing CAMHS

Of the 86 young people who answered our survey, 25 said they accessed CAMHS due to behavioural issues. 19 of the 86 young people said autistic spectrum disorder was the reason for them to seek help from CAMHS. 18 young people went to CAMHS with anxiety issues, 11 due to depression and 8 due to self-harming behaviour. Other reasons for accessing CAMHS included problems at school (including bullying), ADHD, suicidal thoughts, learning disability, gender and sexuality, trauma, hearing voices, medication and mutism.



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

*Parent's experience, CAMHS has been excellent but aware its 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 Pathological Demand Avoidance (PDA).**

***CAMHS responded to this comment and informed us that “we are not reluctant to diagnose PDA, we are not commissioned to do so”.**

Waiting times

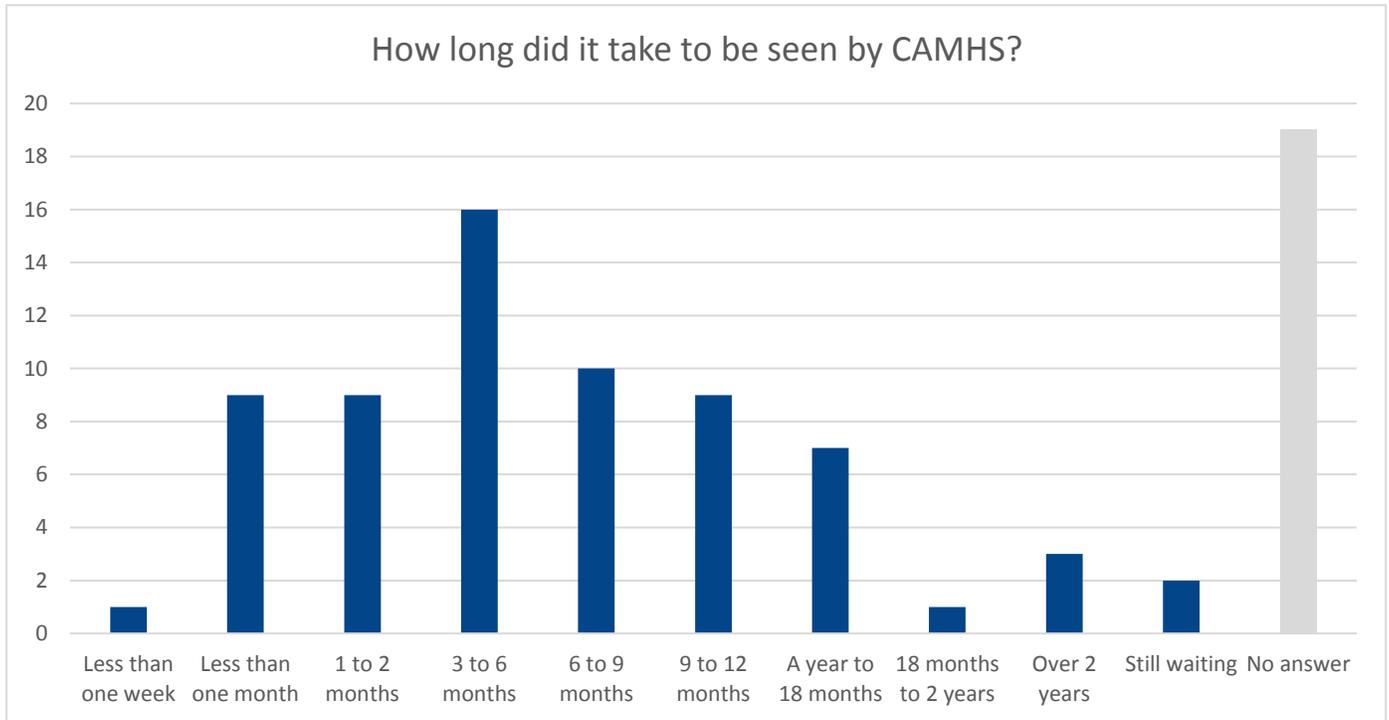
In January 2018, the CCG spoke about improvements that had been made to CAMHS waiting times. Training was provided to expand services to include Dialectical Behaviour Therapy (DBT) and support for Looked After Children. Through a GP Liaison service, they were able to stop rejecting referrals and instead signpost them to the appropriate services. The crisis team was also launched, and CAMHS staff in schools created a stronger link between health and educational support for children and young people.¹

¹ <http://www.healthcareleadernews.com/how-our-ccg-reduced-young-peoples-mh-waiting-times/>

“All of the above interventions saw a reduction and a complete halt on CAMHS waiting lists for treatments. 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.”

Our survey results appeared to reflect the improvement in waiting times described by the CCG. 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. However, as the graph below indicates, waiting times were highly varied across the survey respondents.

One patient with an eating disorder had received an appointment with CAMHS within 2 weeks, which is within the national KPI’s.



Through our survey results it highlighted that CAMHS waiting times had improved over times and 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.

However, when we collected case studies from parents, there have been some issues around waiting times. One parent described their son's journey. He was referred in February 2017 for anxiety and saw a learning disability nurse in September 2017. He was put on the waiting list for a medical assessment, and 8 months later they have not received an appointment. Another parent described waiting 12 months between referral and the initial appointment, with the process starting in 2016. They also said that their son’s last four appointments had been missed, so they had not been seen since January. Another parent told us their daughter had been waiting for a year and a half to receive support, which had resulted in her losing her place at college.

Healthwatch Walsall recognise that some of the parent’s comments fall outside the newly commissioned CAMHS services. 15% of responses were from respondents that had accessed CAMHS services over 3 years ago.

Access to CAMHS Support

We spoke to parents who had concerns about their child's wellbeing and behaviour who could not get the support they needed from CAMHS. One parent described that their child had been experiencing behavioural issues but had referrals rejected*.

*CAMHS response to this parents' comment *"CAMHS are not commissioned for behavioural difficulties and usually support should be provided by school nursing, only where there are mental health difficulties would they be accepted by CAMHS"*.

Types of support

For those who did receive support, the main support was through psychologists, closely followed by psychiatrists and support workers. Smaller numbers of young people had also seen counsellors, 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.

Early Intervention

Only 10% of patients / family members we spoke to felt that they 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, and 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 12 months to identify this admin error, after two years they got an appointment to see CAMHS. Mom feels that her child could have been helped earlier rather than allowing his condition to worsen in the intervening years. **

- CAMHS commented before the report was published that *"we acknowledge that there was an error made with the young person waiting for 12months but this has now been rectified and that a pathway has been reviewed so that the error should never occur again"*.

Crisis Team

Only 30% of those who had used the crisis team felt supported by the service. Those who did feel supported said that the staff were helpful. However, for one family a delayed response from the crisis team had led their child to end up in inpatient care after a suicide attempt, and two other people said the crisis team would not come out to them at all. Two parents were told to ring the police to deal with their child, rather than the crisis team. We were also informed that there have been several occasions where a trained member of the crisis team has not been available but would call back to parents on the same day however this has not taken place.

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. 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.

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

One person 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, Oppositional defiant disorder (ODD) and Tourette's.

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

Four young people had been referred to adult mental health services, and one said their GP could refer them if it became necessary. One person was getting support through a Social Worker. One of the people who had accessed adult services said that being referred to the Early Intervention Team helped them start their recovery.

He is now 18 and out of education. He has recently had several Adult Social Workers that keep changing and I feel he has been let down.

It is important to highlight that here are no adult ASD service commissioned in Walsall CAMHS, and that there is currently at time of writing this report no post diagnosis support in Walsall. There is also a review of transition being undertaken and it is hoped that the process would improve in the future.

Education and Mental Health

For young people with mental health issues, it is essential that health and educational services work together to provide holistic support. The CCG have said that placing CAMHS staff in schools has strengthened this link. However, we heard from several parents that there was a breakdown in communication between CAMHS, SEND and school. Effective and timely communication is essential between stakeholders in order to support the health and wellbeing of children and young people with difficulties.

Son is now 18. It took until he was 16 to get a statement for autism. I wanted my son to be able to get the most appropriate education. I was told he had to go to mainstream school and he refused to go to school on many occasions. At the mainstream school we were told by SEND that he would have one to one tuition – this never happened. My son was eventually placed into Jane Lane school. However, they failed him as they couldn't cope and he was excluded.

OTHER SUPPORT SERVICES

During our research parents were also able to share their experiences of other support services that are intended to support children and young people (none CAMHS).

EHCP (EDUCATION HEALTH AND CARE PLAN)

An EHCP is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHCP's identify educational, health and social needs and set out the additional support to meet those needs. We have spoken to several parents who have told us about the difficulties getting a plan in place and also the support that should be provided through the plan.

Our case study evidence has identified that, even with a diagnosis or identified support needs, in some circumstance EHCP's have not been put in place. We have also been told by two parents that they were informed that they would have to pay or find funding for an EHCP, although one of the children had been assessed with autism and another was known to a number of services supporting children and young people.

“My son has a diagnosis of Autism and severe anxiety. We have never received an EHCP from the local authority or school. CAMHS have been very helpful and told me to ask for my son to see an Educational Psychologist but the school haven't helped. We have only just had an appointment”

Overall experience

Lack of support and early intervention has serious effects on young people and their families. There is a negative impact on siblings and parents as well as the young people themselves. Some felt that the members of staff who dealt with them were not specialised or experienced enough to deal with their support needs. Parents felt that staff did not build a rapport with their child. Others said that the care their child received was not tailored to them or centred around them.

'They came and did an assessment with him individually and then one with the family, [child] got 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.'

However, for those families that got the support they needed, They noted that the SEND support was invaluable.

"Life would be much harder without them."

Parent was very happy with service from Walsall SEND team. Only took a couple of months to get child appointment. Child was diagnosed earlier and received support which seems to have worked. Mom feels that the service has been good and worked for the child.

Dealing with Complaints

Through our case studies, several parents have told us that they have made complaints to several service providers. The most common areas of complaints were around:

- Schools and the SEND team not providing EHCP's (Education and Health Care Plans).
- Failure of mainstream schools to understand autism and providing protection (from bullying) and support.
- Being informed by a psychologist that son or daughter doesn't have autism or being able to have a reassessment as their behavior was not out of sought at time of diagnosis. Difficulty and failure to statement children.

Autism

Although this work was focused on information around CAMHS we have gathered several case studies from parents highlighting in their opinion failings within the SEND team around communication, getting back to parents, promising additional support which is not followed up. Issues were also raised around appropriate schooling at mainstreams schools where problems around bullying and anxiety were not being addressed by the school.

Conclusions

Our evidence has highlighted that timely and clear communication with parents with children who require support needs is essential for their health and wellbeing. There have been several occasions where communication between professionals have been poor or parents have not been informed about support that they could access. It has been made evident that some parents are unclear who provides which service.

Transitional to adulthood for many young people is difficult in particular for those who have autism or mental health conditions. Currently a number of young adults diagnosed with autism feel that they are finding it hard to access support once they become 18. From our work it has been identified that many parents feel that there are clear communication improvements needed between service providers, so that the support pathways are much clearer and more accessible.

Recommendations

The recommendations from our findings are for note by a number of providers of services for children and young people.

- Improved communication between schools, colleges and Walsall SEND team around the EHCP process and to ensure that if parents need support with the EHCP that it is received.
- Schools / colleges and SEND to be more transparent on what support and funding can be accessed for children who have difficulties / disabilities that access mainstream school.
- More support around early intervention with children that are struggling and to ensure that children do not have to wait to be statemented to access resources.
- Reduce waiting times for access to the SEND support services for those in particular need.
- Improve access to Crisis Team (CAMHS) including better communication.
- Clearer information for parents and young adults in relation to who provides specified and specialist services.



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