Waiting for Wellness: Phase 2

Case Study report

healthwatch
Lancashire

Introduction

In October 2023, Healthwatch Lancashire published their report ‘Waiting for Wellness: An investigation into people’s experiences and the accessibility of mental health services in Lancashire’. This was in response to hearing an increased amount of feedback regarding accessing mental health services and long waiting lists. One of the main findings of this project was that young people were struggling to access the mental health support they needed.

As a result, Healthwatch Lancashire felt it was important to conduct a second phase to ‘Waiting for Wellness’ to explore in more detail, the experiences of young people when accessing mental health support.

Abbreviations

CAMHS	Child and Adolescent Mental Health Services
PDA	Pathological Demand Avoidance
ASC	Autism Spectrum Condition
ADHD	Attention Deficit Hyperactivity Disorder
ELCAS	East Lancashire Child and Adolescent Services
IRS	Initial Response Service
EHCP	Education, Health and Care Plan
CAF	Common Assessment Framework
SALT	Speech and Language Therapy

Methodology

Healthwatch Lancashire spoke to 142 people (110 young people, 31 parent/carers and 1 college wellbeing officer). Respondents completed an online survey with the option to complete a follow-up case study with a Healthwatch Lancashire engagement officer to discuss their experiences in more detail.

Twenty people shared their experiences through a case study; ten have been included as quotes in the main report and a further ten are outlined below. All case studies have contributed to the themes and recommendations made within the main report.

Lack of support for those who are neurodivergent

Out of education

The following case studies are from parent/carers whose child has either autism or ADHD and due to a lack of appropriate mental health support, they are not longer attending school.

Case study 1:

“Around 9 years ago my son was diagnosed with autism profile pathological demand avoidance. He began deteriorating in primary school and at the time had psychological support through the team at Fylde and Wyre. He was referred to CAMHS in 2016 and they put him on medication for anxiety.

In 2017 when he was 8 years old, he was given medication by the paediatrician for ADHD but this was not documented in his files.

He was seen by a psychologist in 2017 for six months and said there was nothing else they could do; they can’t do any more for him. During this point there was a suspected ADHD diagnosis.

CAMHS said they would do an assessment, but the school wouldn’t support him, he was abused at school, and this made things a lot worse for him and the family. We were told that CAMHS were the only place that could help him with trauma but when we arrived, they told us that they aren’t trained in trauma support.

CAMHS wanted to do their own ADHD assessment with school in May 2018 but school was not supportive, CAMHS said they’d relook in August 2018 but they never did.

Four years we waited for an ADHD assessment and psychological assessment. We eventually went private as he had now been out of school for years as the barriers were too great and he was deteriorating.

We went through five CAHMS team leaders and all of them told us that the autism profile didn’t exist, and they can’t support him as he has autism.

He went for his private clinical assessment in Rugby with the psychologist that was trained in autism and PDA and had a learning disability nurse with her. She produced a report and the report stated that he needed moving to learning disability team and he had complex traumatic stress disorder and autism.

CAHMS did recognise the report and gave him ADHD medication, but they didn't acknowledge the transfer to the learning disabilities team. I didn't feel that being under CAMHS was appropriate at that moment as they weren't doing anything for him or supporting him other than medication.

He was having very big barriers to education and medical practitioners as all those who have come into contact with him have had no training of autism. Isn't this mandatory training?

The team leader said to us, "I'm a mental health support worker, we can help him with his anxiety." None of the team had specific autism training even though this is mandatory, and they didn't have specific training in abuse. I asked for individual funding, but nothing came from this.

In 2021 he was given six appointments with the psychologist where she sat in front of him and asked him loads of questions. I asked if this could be done in a different way including play therapy and I was told they couldn't facilitate this. This was not the right approach for my son, and they were not going to be able to fully assess him if they just sit and talk to him

My son has now been told he needs to see an ADHD nurse to continue his medication I don't understand why it can't all go through one person; it is hard enough he needs to explain himself every time someone new comes in. Seeing all these different people is traumatic and we can't always get appointments on the same day in the same place. I don't think they understand the ramifications of someone who has autism coming out to appointments, the week before is awful and the week after. This is a massive ordeal for him and the family and this really does take a toll especially when they are new doctors and nurses.

It took us 31 months to get to tribunal and what they have put in place hasn't happened. The local authority tried to take his diagnosis off him in his EHCP. They denied him the support he needs. CAMHS refused to provide evidence to support him not attending school and said they don't support young people not attending education. I had to pay for a GP letter to explain why my son isn't in education.

I have done my own research on how to help and support my son through webinars and support online, but I haven't been helped by anyone else. My son has been let down by school and CAMHS and no support has been given to him except medication for three years. He is 15 now and I'm concerned with how little support he has been given in three years, there is a massive failure. Why don't the team at CAMHS have mandatory autism training? How are they supposed to support young people if they don't know how to do it effectively."

Case study 2

“My daughter struggled with school from the beginning, with difficulties from very early on and nothing was really put in place by the school. We didn’t see the concerns that were arising as autism, and the school never reported that she needed any referrals or support.

When we finally realised, or maybe accepted, she wasn’t just ‘quirky’ and asked about a referral for an autism assessment in Year 2, the SENCO told us she was sure our daughter would get a diagnosis which was a shock when the school had never mentioned autism before to us.

When we spoke to the school about our concerns over her anxiety and mental health, the school repeated she needed no further support. As her anxiety around school continued to rise, everything continued to get worse at home.

She hit a tipping point…she was off school for 6 days. We saw a GP face to face who was supportive and wrote a letter to state she was unable to attend school due to her Anxiety and future issues would be related to this. The GP referred her to CAMHS but then rang to tell us the CAMHS referral had been declined due to not going through a local service more suited to her needs first. We were also told her difficulties weren’t great enough to be going through CAMHS. The GP advised us to self-refer to ACE, a local Mental health charity working with children aged 11- 19, which we did but knew there was a long waiting list of 6 months plus.

We then got referrals to support after asking for years, which started with an Early Help referral. We had five months of support from the early help Family Support Worker which started 4 or 5 weeks after she’d hit crisis point. She identified significant attention and concentration difficulties both at home and school and strongly supported an ADHD referral, which the school agreed was necessary and fully supported.

We had a second CAMHS referral by the GP declined as CAMHS said we had all the relevant information about local services and she was on the ADHD waitlist, so she didn’t need CAMHS input.

A CAMHS worker referred her to Child Action North West (CANW) for play therapy after we’d rung to check where she was on the ADHD waiting list and had asked us how she was getting on. Via this referral my daughter initially saw a mental health practitioner at the YMCA, who didn’t know what to do with her when she couldn’t answer the questions or engage with her, and was too anxious and flitting around to even do a craft activity- they weren’t fully trained to work with autistic or neurodivergent children. She sent the referral back to CANW to ask for someone with more autism experience.

We were then referred to Key Charity, and their CBT practitioner completed one home visit to assess my daughter, but also said they had to discharge her as they couldn’t get her to engage. Key Charity were time limited to 6- 8 sessions and sent a discharge letter back to CAMHS to state she felt my daughter had school trauma with huge mistrust of professionals and needed 6-12 months of therapy to support her with this.

I don't feel that any of these assessments helped my daughter as they didn't have relevant expertise and training to help support my autistic daughter with her anxiety, or they couldn't provide the longer term input needed to support a highly anxious autistic child who is unable to engage within 8 sessions.

We were desperate for support and help and we were being pushed back every time we tried. She was getting worse. Our daughter was hitting her head into the walls in meltdowns, bending back toenails to make them bleed underneath.

At the end of March 2022, we had a difficult triage appointment with ACE on a Friday at 4:30 when she'd had a bad day at school, and ACE initially said they couldn't work with her as she was far too volatile and reluctant to engage. The ACE psychotherapist advised me that she thought we should consider medication for our daughter's anxiety through CAMHS.

ACE were a huge support to me, writing a letter to confirm my daughter was unable to attend school, attending meetings with the Local Authority, Educational Psychologist and school, signposting me to any services or websites she thought could be helpful. However, as a charity, their funding was stretched, and the second 6 month block of therapy my daughter was offered did not have the funding continued

Eventually, our daughter's EHCP was finalised after 38 weeks, a long time over the legal timeframe of 20 weeks. In September 2023 my daughter was given a diagnosis of combined type ADHD by CAMHS.

I use Facebook groups and forums for help and support from other parents. I would use anything to help support my daughter and it is a long and lonely road with a child who struggles to leave the house and has significant anxiety.

My daughter is now 13 and would be in Year 8. She has been out of school for over 18 months, and out of formal education for 2 years.

The difference between her and her twin brothers who have just started Year 7 at a local grammar school and are spreading their wings, is heartbreaking. Living with a sister with significant mental health difficulties has been hard for her brothers- it has affected them having friends round, and family holidays and days out have been impossible. Financially, we have been heavily impacted as my husband now works 3 days where I work 2 to support a daughter out of school.

While my daughter is now recovering, is more interested in things like the tropical fish, and is more relaxed, laughing and smiling at home where she feels safe, we feel stuck. The difficulty with knowing what is autism, what is ADHD and what is mental health difficulties is tricky and now we have no further input. All I feel I can do is hope she continues to get better without further mental health support, and that the ADHD medication helps her.

There is a massive gap for children who can't access CBT or talking therapies and there are huge waits for any support. There is a such a gap in the services with no adequate or suitable support available for autistic children and young people.

It is also hard to find the right services, to get referrals to CAMHS accepted and to get any sort of alternative provision if your child can't attend school. It has been the hardest and most stressful experience of my life.

My main hope is for her to be happier again and that by sharing our story, we can help to improve services, to try and prevent more families from going through the same experience we did. I feel if there were more appropriate mental health services and support which could have been accessed much earlier, maybe my daughter wouldn't have ended up as she did, and maybe she would have been able to recover and return to school."

Case study 3

I have a 14-year-old son who is currently out of school, he can't cope with the mainstream school level. He is diagnosed autistic, he masks it at school and is very able.

I asked the GP for help at the age of 8 for mental health support, the GP said no and sent me home with leaflets but none of them were age appropriate and wouldn't help him. The GP wouldn't even attempt to refer and said CAMHS has a massive waiting list, and he wouldn't get on anyway.

He was then 10 and he had deteriorated, and he struggled at school, so we moved him to another school. He was going through an autism diagnosis at the time. He went to high school whilst going through the EHCP [Education, Health and Care Plan] process, his school wasn't supportive enough throughout the diagnosis.

He really did not get the support he needed and he had a break down after the first term. We then got referred to CAMHS from the GP and through the early help assessment. We attempted mental health support but they could only offer online but this wouldn't work for him and didn't support his needs and he found it very stressful.

We eventually got through to CAMHS; he was on the wait list for 6 months after his initial assessment. He was only just out of school and he had a massive metal crash. They did an assessment and a report very quickly which didn't really say much and this didn't help him as all and wouldn't acknowledge he had any mental health needs. They then tried to discharge him and I as a parent said no you haven't done anything to support him yet. He needs assessing properly by someone who understands autism.

They offered him play therapy and suggested sand play but this was not acceptable for my child as he was struggling with communication and even leaving the house was terrible. I suggested Lego play and they said they couldn't do that as they had no Lego and weren't prepared to buy any.

The staff within CAMHS didn't have the relevant and up to date training they needed to support people with autism. We eventually got to see the Mental health doctor but I felt that I was counselling him and teaching him about autism. This was unacceptable and unhelpful.

He did leave and told me that “I am leaving as the team in Lancashire don’t have the training that they need to support children with autism and I cant do my job effectively if I cant help young people.”

The Lancaster AND Morecambe CAMHS weren’t commissioned by the (was CCG) ICB appropriately and no one was trained in autism in the area and this was not acceptable. I had a chat with one of the managers after this doctor left and she admitted that they weren’t commissioned to help support mental health support with young people who have autism.

Everyone was lovely in CAMHS but they all failed him and they all admitted that they don’t have the training in place to support young people with autism. Nothing was in place and no one in the team had any training available to help support these young people coming through.

We have been through tribunal and have had to push for his updated EHCP as they wouldn’t release it.

He was 8 when I started asking for help and he is now 14 and no support or help available. He has now been out of school for three years. His EHCP has now come through but the targets are not being followed and there is no budget to help support him.

He now accesses mind jam and this has been a saving grace. The local authority started paying after his first term and has now got face to face support who comes to the house for three hours a week. He is incredible and has been with him for a year and a half.

1. Don’tlie to parents, tell them the truth, these referrals to CAMHS shouldn’t be happening to people with autism as they can’t cater for their needs anyway so why have they been referred.
2. CAMHS practitioners don’t have the correct autism training and won’t put anything in place to help support these young people.
3. More support and guidance for parents would have been helpful, you need support links, support groups, just anything would have been helpful.
4. More guidance for parents around the process their young person will be going through so they will be aware of what is coming.
5. We have lost trust in the process and it makes you wary to use them in the future. There is no money in services so the support you get it inadequate and can cause damage.

Case study 4

“My son was 4, he started primary school in 2016 and within a month of starting he started displaying different behaviour. He became very aggressive in school and I was being called into school a lot. This then escalated very quickly and it got to a stage where we were working with school to see what's going on. School weren't being very helpful at all.

The school nurse recommended a CAF [Common Assessment Framework]and I hadn't heard of that before but the school wouldn't do one. I pushed for help externally as school weren't helping at all.

We found another school for him when he moved into year 2. Early help started in the new school, the headteacher thought he had Aspergers or anxiety. Early help had concerns about how he was presenting, they did some work with him to understand what was happening.

The ADHD referral got rejected straight away as they said he didn't meet the criteria. We then went down the ASD pathway. The school were doing generic work with him and accessing school counselling. The school weren't listening to me at all throughout the process.

I was sent on so many parenting courses which I didn't feel were appropriate for me. We had the ASD appointment in early 2019 and that came back that he didn't meet the threshold for a diagnosis. Then it was full circle as they referred him for an ADHD assessment.

He was starting to hurt his sister at home and then started attacking me and his dad. We took him to the doctors to see what was happening. I was desperate for help and support. They made an urgent referral to CAMHS.

ADHD team appointment came through and his scores were above the threshold beforehand and decided they wouldn't continue as he was on the ASD pathway. I made a complaint at that point as they told us he didn't meet the needs for a diagnosis of ADHD, but he had the whole time.

He had all the assessments, and we were referred to CAMHS pathway psychotherapist. They felt he had ADHD as well and discharged him from CAMHS.

The school didn't feel he needed an EHCP and that was a constant battle. Late 2020 we saw the ADHD consultant; he was diagnosed there and then, and she believed he was also autistic. The ADHD consultant wanted him reassessed for PDA as she believed he had that also.

He was referred back into the ASC pathway and a psychologist within CAMHS. He was put on medication to help with his behaviour through CAMHS. We had the second autism assessment in 2021 and the consultant said they didn't think he was autistic, and it was developmental trauma. They thought he needed a specialist school, the clinic letter came, and it did not reflect the conversation we had and said nothing in relation to what had been discussed. There was a multi-disciplinary meeting attended and they wanted to revoke the ADHD diagnosis, I felt very overwhelmed, and I felt they were going against everything.

They completely changed the report and said he didn't have anything they said he'd been given. CAMHS offered me a few months later a second opinion on his ADHD diagnosis. The first consultant revisited the case, and he didn't really give much information and then left not long after. The next consultant was very helpful, and he did believe he had autism and ADHD, but he was then told to leave by CAMHS. We then got put through to a third consultant who was very unprofessional and caused a lot of problems for me and my family. He spoke over my son the whole time; he said autistic children can't mask and can't speak in certain ways.

My son was then locked in the room and told we couldn't leave the meeting. A member of staff opened the main door and allowed my son out onto a busy main road when I wasn't there. It took me about 45 minutes to get him back to the car. The clinic letter that followed didn't reflect what happened in the meeting and they wouldn't correct the letter. I made another complaint about this consultant via CAMHS, and I asked for a parental EHCP. This was rejected and I appealed it and they then agreed to do a needs assessment and they said he didn't need the EHCP. I appealed this again and they agreed to it in the end.

I went private in March 2022 for a PDA assessment; the results were autism with a PDA profile. This was a sense of relief that someone had finally believed us.

Summer of 2022 and he told his friends he didn't want to be here anymore, and he wasn't happy. A day later he attempted to end his own life, so I rang the CAMHS duty team, and they told me he hadn't attempted to end his life and he would have to make a successful attempt for the crisis team to be involved. I made another complaint and they agreed to send out the crisis team to help support my son. This will be a two-week intense programme and on the first visit they attempted to get him to engage with a game. This was all they did, they tried to engage him with ways he couldn't engage and had no training of autism.

He was then discharged from CAMHS as they said they couldn't help him or support him.

Late 2022 after all the complaints CAMHS they agreed to do a full holistic assessment on my son with a new consultant. We saw this new consultant in January 2023 and has been amazing with us. We had around 5 meetings over two weeks, and they were very thorough and went through everything from start to finish. He really listened to me and my son, he was satisfied that he met the threshold for ADHD and diagnosed him

We had the SEND tribunal in June 2023 and the local authority said he should be in a mainstream school even though he can't manage a mainstream. They changed their mind a few days before tribunal and said he did need specialist school provision. The judge granted us the specialist secondary school.

Since then, the school we wanted our son to go to said they could meet his needs, unfortunately can't meet his needs. He went for transition in September, and they couldn't manage him and his needs. He's now been out of school for 11 weeks and the school has now said they can't meet his needs and he needs a bespoke out of school package.

He is going to be supported by an Education Otherwise Than at School (EOTAS) package. But this is something we need to source ourselves."

Case study 5

"My 14-year-old son had started with anxiety related symptoms at the age of 7 years. He had anxiety around attending school and avoided going to school. He didn't meet any of the necessary criteria for CAMHS and didn't meet the criteria for an autistic assessment. He got rejected from a SALT [Speech and Language Therapy] referral.

He once told me he may appear happy on the outside but inside he was not happy, can you imagine how this made me feel?

I went to his GP to discuss his anxiety as I was struggling to get him into school. I was told hat he needs to be referred to Child Action Northwest. I also made a self-referral to N-Compass and there was a 3-4 month wait for this. We were also referred to the Butterfly Project and this helped him briefly.

He was better during lockdown, but I noticed he was becoming anxious around his friends when they came over. He then started high school, he was ok and attended The Bridge Project which was to assist with the transition to high school.

I arranged for private counselling and my son was eventually diagnosed with autism, we had to pay privately for an assessment. Even if he had met the criteria there is a 3 to 4 year wait for this type of assessment.

He then suffered autistic burnout and as a result I decided to set up a Parent Support Group for parents of children with undiagnosed autism and a high anxiety profile.

I have set up this support group, as I don't want to see anyone else to go through this experience, I want to use my lived experience. This whole experience with my son has affected my mental health and as a result has had to reduce my hours at work. My son has now been out of school for 18months and" it is a constant battle of health and education".

I have now gone through the complaints process, and they have accepted that they have not followed section 19 of the childcare act. We now have the EHCP but this has been a massive battle. We have paid out so much in solicitors fees for them to release his EHCP as they wouldn't give it to him.

There was no support offered to me at all throughout the process only what I had to go and find myself. Parents are suffering as well and no one takes in to account how it impacts the family when the child is in crisis and no support is being given to the young person. The autism pathway is awful in Lancashire anyway and they don't recognise PDA as a form as autism.

Most referrals to CAMHS are around 3-4 years and no support is given whilst you are waiting for help. What are parents and young people supposed to do until that time?

There is a lack of understanding in schools around SEND, not enough training in place for people who are looking after these children. I feel like the support is a postcode lottery and it really is down to pot luck. Children are being punished for their behaviour when it is actually ADHD and autism but the staff don't understand."

Discharged without treatment

The following case studies involve young people being discharged from CAMHS due to staff having a lack of neurodiversity training and so cannot provide appropriate mental health support.

Case study 6

"My son who was 12 at the time had a mental health breakdown and was on the autism pathway which he had been put on by primary school. He was going through the transition from primary to secondary school and had extreme anxiety. The high school didn't agree that he needed to be on the autism pathway and the school would focus on his anxiety and not his autism.

My son has PDA profile of autism, and I didn't feel the school were meeting his needs of autism and only focusing on his anxiety and using methods that don't work for him

He had a mental health breakdown in school, but the school didn't notice until it was too late and there was nothing they could do. Education and health do not talk at all and I felt like health was pushing on education and education was pushing on health.

We spoke to the school about CAMHS and they didn't know we could self-refer. The school councillor was full at the time so they said that this was not an option for my son.

We finally got through to CAMHS but there was a 9-12 month wait for an intake assessment after the initial triage phone call appointment. During this time we were not given any support and just had to wait. We eventually ended up paying for a private mental health nurse to go in to school to see our son. She knew he had anxiety disorder and autism after spending very little time with him.

Unfortunately, my son had another mental health episode and we ended up in A&E with him. The nurse gave him diazepam and said I am going to call CAMHS now and get him moved up the list as an urgent referral

CAMHS called a week later and told me that he doesn't meet criteria and they weren't sure why he had been escalated to urgent. He deteriorated dramatically as he said no one believes me and no one will help me. This made him become suicidal and threatened to harm himself. I rang CAMHS back to explain what was happening and they said he needs a referral to a psychiatrist.

Another two weeks passed, and we were seen by CAMHS and they talked through everything with us, they said he needed to be seen by a psychiatrist and it shouldn't be a long wait. While we waited, we were offered VID which means that they record me and my son engaging in conversation, and someone analyses it. I'm not sure what this had to do with myself or my son, they said it's the only thing available to us while we wait.

We received the appointment within two to three weeks, and we went to see the psychiatrist. At this point my son was in a state but attended the appointment with both me and his dad. The care we received was horrific, his bedside manner was dreadful, and he didn't cater for my sons needs at any point during the appointment. He didn't listen to my son and went on to say, "if you weren't diagnosed with autism at a young age then you're not bad enough to be diagnosed now."

He then went on to say, "autistic people can't mask, and I don't understand why school haven't picked up on it if you do have it." The doctor began arguing with my son saying he didn't believe him, and it felt like an interrogation. He said, "you know you have to go to school to get qualifications, otherwise you'll struggle to get as job."

The psychiatrist was rude, abrupt and did not know how to speak to someone with autism. This then caused my son to have a massive anxiety attack in the room. The psychiatrist would not let my son leave the room and blocked the door to stop him from leaving. My son needed to leave that environment and have time to calm down and use his techniques that he's been learning. The doctor followed us out into the hallway, not allowing us any privacy, where my son was now bent double struggling to breathe and exhibiting clear signs of severe distress. His father was soothing him and rubbing his back to try to calm down, I was in tears. The doctor began barking orders at him in an aggressive tone that went as follows; "listen! listen to me now! The only way to exit a panic attack is to follow my instructions now!" at which point he began issuing breathing instructions with a raised tone.

The doctor asked us to go back in the room, we were unsure as my son had just had this awful experience and I didn't want to take him back in. The doctor said "you need to come back in if you want to get the help you need." So we went back in the room with him and we started talking about his EHCP and that the report he could write would help towards his EHCP paperwork. The psychiatrist refused to help and said that's not the reason you are here.

Four days later we received a four-page document from the psychiatrist and the letter was awful. All he talked about was his behaviour and didn't mention anything we spoke about in the session. The report had nothing in that helped my son and this was awful for my son as he felt he had not been listened to again.

After this letter was received my son became very suicidal and began deteriorating very quickly. I phoned CAMHS for advice and they told me to hide all medication and ensure someone is with him. How does this support help, my son needed emergency help and I was being told to hide all medication.

My son was discharged from CAMHS following this report and we were told it needed to go back to panel, the panel decided that he needed to see a clinical psychologist and told it was an 18 month wait.

They admitted that they only had one clinical psychologist, but they are off sick at the moment. They recommend that I go private and to make a complaint about the care we had received. They said there was nothing else they could do for him, and the wait times were very long, and they were very overwhelmed with the wait times and young people waiting.

We looked for private psychologists and struggled to find one who specialises in autism or help with PDA profile autism.

We managed to find a private clinic called enhancing futures in Rugby and they did a full assessment and profile on my son. They found he had PDA Profile autism, ADHD, Panic disorder and Educational trauma.

Unfortunately, my son will struggle to get back into education after the traumatic two years we have been through with him. Training is needed for staff as the ones we saw did not know how to talk to my son who had autism

I recommend the following

- Training is needed for staff working within CAMHS including psychiatrists in order to help support young people with autism.
- There is a massive gap between health and education, no support or knowledge around non-attendance for young people with autism who experience burnout.
- No communication between services when you are on the wait list.
- More support for parents and young people when they are on the wait list so they are not just left.
- More education for schools around mental health and autism and training the school are provided with."

Case study 7

"A member of my family was really struggling and had been going to the doctors for some time being told there was nothing they could do or putting him on medication. As a family we knew that he had autism and it was so difficult to be diagnosed. We went to the doctor and asked to be put on the pathway which they refused as they said, "he doesn't have autism he is depressed they are the same thing." This really did not help matters and the family became even more frustrated.

We tried to access CAMHS support for him as he was 12 years old at the time but as we had queried autism the mental health teams wouldn't help him. They said it wasn't depression and he did have autism. There was a massive imbalance between the two services. CAMHS said they couldn't help him due to him not having a diagnosis and they wouldn't be able to cater for his needs.

We ended up paying privately to get a diagnosis of autism and we finally got that diagnosis, but it felt very late in the day. The support since has been limited and the doctor still wants to treat him for depression. CAMHS have said that they can help but as he is now under autism services this may be quite difficult."

Negative experiences of CAMHS

Case study 8

“In Year 10 I developed anorexia. I lost weight a lot, and I became very very ill. I was put on bed rest, and I was sent to an eating disorder clinic within the NHS. I had to go to the hospital to for physicals because of my weight. The mental help I received was minimal, they mainly focused on increasing my weight until they could discharge me, instead of helping me deal with the weight gain. Eventually, it led to the police coming to my home because I was suicidal, as the mental help I received from the clinic was so bad it actually left me feeling worse. I'm still at the clinic, like 2 years later but I only go there for physical health checkups and medicine reviews.

I was referred by the clinic when I first got there to CAMHS to be treated for the eating disorder, but CAMHS would only treat me when I got to a healthy weight, which didn't make sense to me because gaining weight was the whole reason I needed help. I became very suicidal and was on the CAMHS waiting list for about a year and a half before my parents decided that the situation was getting critical, so we went to my GP who referred me to Minds Matter, who have a bit of a shorter waiting list. That took about 6 months for me to get a call. I'm currently receiving calls from Minds matter every 2 weeks, though its mainly just assessment calls to see how they can help me, and I'm pretty sure they are thinking of sending me back to the clinic because they don't specialise in eating disorders. I also receive counselling at college and was put on anti-depressants by my eating disorder clinic to help me deal with the depression.

I still haven't had any help for the eating disorder, and every time my parents and I ask for it, a GP or counsellor suggests just increasing the dosage of my anti-depressants instead of getting help, so I think my parents are looking into getting private counselling for me. My health isn't very good now, as throughout this process I've had anorexia for 3 years, and things like my period and my body weight are messed up because of how long I've had it.

it would have been good to have the help tailored to what I said I needed rather than what the people at the clinic were saying. I always said I needed help with the eating disorder, but they insisted I should be treated for anxiety first. I also think that a lot of appointments I had were with students who were practicing talking to patients, so a lot of the time, my parents and I weren’t talking to actual doctors, it was the students instead.”

Case study 9

“When I was 13 I got referred to children’s mental health support through ELCAS. I was told if I had received a diagnosis then support would have been helpful but now, I have turned 18 I have no support and I’ve been dropped. I was referred to IRS, but they haven’t been helpful at all and don’t believe I need help.

I went to my doctor, and they put me on medication and rereferred me to IRS, but they have said they've already seen me, and they can't help me. All they say to me is they can't help, and I have to go back through my GP.

I then had to get the police and ambulance out to my house as I was a danger to myself, and they did a referral to IRS. I had an emergency phone call from the IRS, and they have said I have to go through my GP and they can't take a referral from the police.

I felt I was shut down all the time, and because I wasn't 'bad enough' they discharged me. Even though I was in crisis no one would support me. I feel getting mental health support under 18 is so much easier than when you're an adult."

Conversation with college wellbeing officer

Healthwatch Lancashire asked a wellbeing officer from a college, from their experience, what the issues students were facing regarding their mental health as well as any barriers they faced when trying to access support.

This staff member holds 1:1 sessions with students and from their experience, the most common form of mental health issue in the college is anxiety, low mood and panic attacks. They shared that many students have had a negative experience of CAMHS, with many being discharged prematurely. He shared that there is a gap in mental health support for those transferring from CAMHS to adult services and there is a desperate need for support for those in the meantime. There are large waiting lists for CBT from Talking Therapies.

Mental health and access to services for transgender and non-binary services is a growing issue for individuals. There are a number of students who are struggling with long waiting lists for gender hormone therapy. There is currently a 12-18 month waiting list for GIDS (NHS Gender Identity Development Service) when you are referred by a GP. This is triggering young people's mental health.

There are long waiting lists for Autism and ADHD diagnosis, with most young people waiting around 12 months for their first appointment. This is impacting students exams as the college cannot arrange exam arrangements without an official diagnosis.

The wellbeing officer shared that there is a ripple effect; the long waiting lists and barriers to accessing other services including Autism, ADHD and transgender services is triggering poor mental health.

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