

National Assembly for Wales

Children, Young People and Education Committee

CAM 07

Inquiry into Child and Adolescent Mental Health Services (CAMHS)

Evidence from : Service User

I am a carer of someone who is currently using child and adolescent mental health services in Wales (Pembrokeshire). My daughter (aged 17) has been with CAMHS for more than 2 years. She has a diagnosis of Asperger's Syndrome and suffers from depression and general anxiety disorder. She was self harming and suicidal. She spent 3.5 months, during 2013, as an in patient at an adolescent mental health unit in London as there were no beds any nearer to home. She was also at Bridgend for two weeks after leaving London and before coming home.

Availability of early intervention services for children and adolescents with mental health problems.

My daughter first started experiencing problems at school and after some initial support from a teacher we were contacted by the school to request our permission to refer to CAMHS, we agreed. At this stage we did not know about the Asperger's Syndrome. This happened during year 9 when my daughter was 14/15. The referral took a little time but I don't recall being overly worried about any delays at this stage. Once referred, CAMHS fairly quickly picked up on the possibility of Autism and went on to make a fully assessment. This took some time, but my understanding is that it happened much quicker than it otherwise would of outside of CAMHS. The diagnosis did provide us, and my daughter, with some relief as we now had some understanding of the underlying reasons behind the mental health issues. So our first interaction was reasonable to good. There were delays in the process but nothing too bad.

Access to community specialist CAMHS at tier 2 and above for children and adolescents with mental health problems, including access to psychological therapies.

Following her diagnosis of Asperger's Syndrome she was referred for a course of CBT. This is where our problems started. Our actual experience was typified by delays and long gaps between sessions: delays in getting the CBT in place and then the people who were supposed to be providing the therapy not being available for three weeks at a time on several occasions. Hence my daughter went without seeing anyone for unacceptable periods of time while she was in a vulnerable position. As parents we were sidelined and not included in any care approach. We were made to feel like part of the problem rather than part of the solution. We didn't know how to cope at home and no support was offered to us as parents as our daughter's mental health problems continued and escalated.

The effectiveness of the arrangements for children and young people with mental health problems who need emergency services

The situation deteriorated and resulted in several visits to A&E and a couple of admissions to the children's ward at Whithybush hospital (Haverfordwest) following A&E consultations. Still regular CAMHS appointments and regular, consistent CBT were not forthcoming. We were still largely excluded as parents; although I was involved in sessions that took place on the ward on the occasions that my daughter spent as an inpatient at Whithybush hospital. As the situation continued to deteriorate I ended up having eight weeks off work sick, stress related at first and then a flare up of Rheumatoid arthritis.

In March 2013 my daughter reached crisis point and had to be admitted to an inpatient unit. We live in Pembrokeshire and the nearest bed that could be found for my daughter was in The Royal Maudsley Hospital in South East London, miles from home and family. She spent 3.5 months there with us as parents travelling to London most weekends to see her. Despite the distance my daughter received excellent care and support in London. As parents we were kept fully informed and involved for the first time. This time in London has equipped our daughter with skills to help her cope and has probably been life changing. We are truly

grateful for the care our daughter received in London. Importantly this experience gave us an insight into what good care is and the difference it can make. We always felt involved in care plans at the Royal Maudsley, both us as parents and my daughter as patient. It contrasted with our previous experience at the local community level where we (parents) felt excluded from care plans giving rise to significant worries and stresses.

The extent to which the current provision of CAMHS is promoting safeguarding, children's rights and the engagement of children and young people.

All was going well at the Royal Maudsley until we came to discharge. As we were preparing for discharge a bed became available in Bridgend and we were asked if we thought it would be a good idea for our daughter to move there as part of her transition home. My daughter was also asked. The way it was presented made it seem like a sensible option. We had a Care Plan meeting coming up the following week and thought that discharge plan would be drawn up at that meeting to cover the discharge from London to Bridgend and Bridgend to home.

What actually happened was diabolical. A bed came up in Bridgend and we were told if we didn't take it immediately the bed would be lost to us. This was on the Tuesday before the Care Plan Meeting that had been set for Friday. I asked for the transfer to be delayed until after the Care Plan meeting so it could all be planned appropriately. We were told again we had to take it now or lose it. My daughter was moved by train, accompanied by a mental health nurse from London, on the Thursday morning before the Care Plan meeting just 24 hours later. She was given less than 24 hours notice of this move and was not able to complete therapy sessions or say goodbye to key people who had been supporting her over the last 3.5 months. In the end we as parents were just told she is going to be on a train on Thursday, despite our appeals

to delay until the weekend to allow the care plan meeting to go ahead.

The doctors in London said they would meet with us as parents to go over diagnosis and future plans at the time the Care Plan Meeting had been planned for. We accepted this invitation. It meant that we 'called into Bridgend' on our way to London to see our daughter who'd arrived there just a few hours earlier. She was clearly upset, but we had to leave to go to London. The meeting in London was very helpful and we are grateful to the doctors who gave generously of their time to explain things to us. On our way back from London the following day we went straight to Bridgend, our daughter was still very upset and wanted to just leave. We also discovered at that time that there were in fact 3 beds available in Bridgend so the argument that the move had to be made quickly otherwise we'd lose the bed was clearly nonsense. We met with the consultant at Bridgend who spent 2 hours going back over old ground with us and our daughter because he did not have our daughter's notes. This went on for at least 10 days: going over old ground, revisiting things that had already been ruled out and making no progress, in fact making things worse. By the time he actually got the notes we had decided that our daughter should come home. A discharge meeting was set up and a representative from the Community team was there. Plans were put in place for community based care and our daughter came home. Those community plans did not translate into actual support and we were left for several weeks without any support.

When I followed this all up the explanation I was given revolved around funding and a shortage of beds. Our local health authority wanted to stop out of area care and brought our daughter back to save money. There was also pressure on beds in London, which meant they needed our daughter's bed for another admission. So politics and economics were central rather than the care needs of our daughter.

So back to **Access to community specialist CAMHS at tier 2 and above for children and adolescents with mental health problems, including access to psychological therapies.**

Following the discharge meeting at Bridgend the community plans did not translate into actual support and we were left for several weeks without any support for my daughter who had just been discharged from in patient care.

Six months on things have improved. We (parents) seem now to be treated as part of the solution or general support network for my daughter and have had 4 or 5 family therapy sessions which have been very helpful. CAMHS are still struggling to get regular CBT sessions in place for my daughter but she is seeing someone on a weekly basis now (although not for CBT). However this latter development is only due to the fact that she has shown signs of deterioration in her mental health status. Prior to this we were experiencing the typical delays and gaps in CBT provision and appointments.

The extent to which CAMHS are embedded within broader health and social care services

The staff at CAMHS seem genuinely committed and want to help but chronic staff shortages; out of area placements (although we are actually grateful for our out of area placement as the quality of care was so high in London); and crumbling buildings are making their task very difficult. I'm sure these staff shortages, with very full referral list, were behind the lack of support for us as parents in the start. I believe that more involvement of, and support for, families early on might prevent escalations. In our case for instance, if we'd felt more able to cope would my daughter of needed in patient care at all? We had no support from CAMHS but also no support from wider social care services. I applied to Pembrokeshire County Council for a Carer's Assessment. I had a letter

back refusing, saying they are not doing any Carers Assessments for the foreseeable future. No one has advised us on DLA for my daughter or any other support that may be available to her. We do not have a social worker and no one has approached the subject of transition to adult services yet. My daughter education has suffered as she did not sit her GCSE's last summer and she has recently had to drop 2 of her 3 AS levels as she wasn't coping. The School have been very supportive but I know they also feel that a lack of support and communication from CAMHS makes their job harder (not just in my daughter's case).

If you want to ask me anything about the above narrative I'd be happy to do so.

Kind regards

Parent of a young person under CAMHS care.