

A family's struggles and lived experience of ADHD

Hi, my name is 'Anna' and I am a qualified health professional. My husband and I have been together for 30 years and we have 2 sons. This is a family story of how ADHD has severely impacted and affected our family.

My son has never been the classic 'hyperactive' child often portrayed rather unhelpfully by the media. Instead, he had been silently struggling to cope and his schools missed all the subtle signs (messy handwriting, difficulty following instructions, forgetting homework and missing deadlines). They failed to recognise that he was having difficulties and simply told him time and again that he 'was not trying hard enough'. As parents, we noticed some changes which worried us and raised them with his teachers. We were concerned that his educational development was flatlining, he was missing his personal targets set by the school, he was slowly withdrawing himself from his peers and most importantly his self-esteem, self-confidence and self-belief were deteriorating. The school dismissed our anxieties as his performance was still considered 'average', despite the fact that according to their charts and reports, there had not been any improvement in his educational development over several years and that he was on a downward trajectory.

My son is a very private person who finds it difficult to share his thoughts and feelings. He was trying his best to cope by 'masking' his struggles and trying as hard as he could to deliver on the expectations and demands of school life but without appropriate support, his constant frustrations eventually led to extreme overwhelm and utter exhaustion that he could no longer handle attending school. He had become so drained, demoralised and tired of trying, of putting more effort in than his peers but to find himself falling farther and farther behind. We did not have much support from school and as it became clear to us that his mental health was deteriorating, we asked our GP for a CAMHS referral and after what I can only describe as a tortuous process, he eventually received a diagnosis of ADHD.

Experience with CAMHS

Our experience with CAMHS has been one that has been filled with extreme frustration. As I work in the health system, I do have an understanding of the funding issues that are faced but there are some aspects of care that are very poor and cannot be excused by 'lack of funding'. There is a considerable lack of regard to appropriate forms of communication. My son complained that his diagnosis was not well explained, and the clinicians constantly used medical jargon which made it very difficult for him to fully understand and participate in discussions. He also felt that he was not listened to, with clinicians often talking over him and 'telling him what he was feeling' before he had finished what he wanted to say. These issues were brought to their attention on a number of occasions, but nothing changed.

They also took a very 'ableist' attitude concentrating purely on the negative aspects of ADHD. This was particularly unhelpful as he was already incredibly demoralised and yet there was no balancing or supportive information provided to help him understand the many positive attributes that can be celebrated with this condition.

In terms of treatment, CAMHS' main focus has been exclusively the provision of medication, with no regard or understanding of 'Holistic Patient Centred Care'. It did not seem that they felt they had a duty of care to engage in partnership working with other services such as his school or GP as they did not feel that it was their place to:

- provide any advice about reasonable adjustments and environmental modifications which should be considered in school to support him, as recommended in NICE guidance

- consider wider potential causes for his low-mood (despite his history of severe Vitamin D and iron deficiencies). Instead they were focussed only on prescribing anti-depressants and even informed us that they 'are not responsible for his physical health' so we would need to contact the GP if we felt that was a concern!

Fighting for an Education

Attempting to gain coordinated support to help my son re-engage with education has all but broken us. We asked the school to apply for an Education and Health Care Plan, but they refused stating that his educational needs were not severe enough, so we applied for one ourselves. This was turned down by the local authority, on the basis that his needs were purely health related and not educational. We took this to tribunal and the decision was overturned, with the judges being quite scathing about the local authority's refusal to acknowledge that when health needs prevent a child attending school, they have become an educational issue! There was then yet another battle as there was no understanding of how to undertake a comprehensive educational needs assessment for someone with ADHD, nor the value of specialist Speech and Language and Occupational Therapy assessments as part of the process.

Throughout this whole process, services were disjointed and did not communicate with each other, my son remained without an education and nobody seemed to care. We tried a phased return to school but he found it too difficult and overwhelming, mainly because no reasonable adjustments had been made to enable him to participate. It astounds me that nobody from the school or LPT's Healthy Together team seemed to be concerned about my son, especially on a safeguarding perspective as no visits were made to see if he was safe while he remained off school. Instead of proactively finding ways to support my son, the school suggested that we off-rolled him instead.

Had it not been for some excellent support from SENDIASS, I fear that my son would have fallen into a deep depression. With their help, we were able to secure some home tutoring for him to see if he could engage again. This was a life saver for him, and thanks to some really good tutors, his attainment started to rise and he began to recover some confidence. Despite having missed the entire Year 10, he managed to get very good results (7s and 6s) for his GCSEs and has now moved onto A levels.

Constantly Misunderstood

However, as a result of his diagnosis, we faced discrimination from sixth forms which refused him entry (despite him meeting their academic requirements) on the basis that they thought he would be problematic and too disruptive (although there is no history of any major discipline issues in school). I simply cannot find the words to describe the added emotional distress that such actions have caused my son, after all that he'd been and fought through, and just when he felt things were starting to get better, his emotional health declined again.

There is so much prejudice against ADHD as people are misinformed and think of it simply as a behavioural condition. ADHD is a neurodevelopmental condition, it is not a mental health illness nor necessarily a disability (depending on the severity and intensity of the symptoms). However, those affected can be 30% behind their peers in the development of 'executive functioning' skills which are critical for learning. Such impairments can lead to difficulties in processing information, keeping attention, planning, prioritizing, organising, time management, completing tasks (homework) etc.

ADHD is not a choice and executive functioning impairments need to be identified and supported to level the playing field for these children. There is currently little appreciation in the system of how incredibly draining it is for someone with ADHD to stay focused in class,

how classroom noise can be so distracting and frustrating and how being required to write notes while listening is such a complex and cognitively demanding task that exhausts them. Without support, not only is their self-confidence and self-esteem eroded but it also impacts directly upon their ability to engage, learn and thrive. In the face of these challenges, some children externalise their frustrations by becoming disruptive while others internalise them, trying their best to silently compensate, as was the case with our son. If not addressed, this can lead to mental ill health which can increase the severity and intensity of ADHD symptoms to such an extent that it causes great impairment and ADHD then becomes a disability.

A Disjointed and Failing System

We have had to fight our way through the system that should be there to protect our son and help him achieve his potential, but which instead has served to traumatise him. For a child who has an above average IQ, it is so difficult to comprehend that we are in this position because it could and should have been prevented had warning signs been heeded. His school experience has left him lacking confidence and suffering with anxiety and self-esteem issues. Similarly, his experience with CAMHS has left him completely disillusioned with the health service to the extent that he has now started disengaging. My son is a victim of repeated psychological trauma directly caused by a flawed system that has neglected to provide him with appropriate support to grow and flourish and that has unnecessarily subjected him to an Adverse Childhood Experience.

The psychological impact on us as parents has also been significant. The stress, anxiety and emotional distress of fighting for support whilst watching our son struggle and deteriorate cannot be underestimated. We too have become victims of this inadequate system and it has taken a toll on our mental and emotional health over the past two years, leading to unplanned time off work (adding economic cost and burden to the system).

My son has benefited from a stable home and has been sheltered from the effects of socio-economic deprivation. Despite being professionally educated parents, we found the system very difficult and stressful to navigate. It is very easy to see how any parent would struggle with this and that many would simply give up. Who will then fight for these children and support them to reach their full potential? More importantly, why should any parent need to fight for an inclusive education for their child that is non-discriminatory and that proactively recognises, plans for and meets the learning and wellbeing needs of neuro-diverse learners? Why should any child be subjected to such trauma and mental health distress when trying to access an education?

The Value of Prevention

A system that neglects to identify and support the needs of every child with ADHD leaves a trail of extended victims in its wake. As a result, the personal, social and economic costs are incalculable; evidenced by research reporting the disproportionate representation of people with ADHD in respect of broken families, suicides, lost careers, school exclusions, educational under achievement, homelessness, teenage pregnancies, substance misuse, sexually transmitted infections, involvement with the criminal justice system, accidental injuries and eating disorders. Such significant inequalities are unjust, unfair and unacceptable which makes ADHD a public health concern that needs to be addressed.

Prevention is key as early diagnosis with appropriate support and interventions can greatly improve life chances and reduce inequalities. The current deficit approach being taken is causing great harm to our children and requires a fundamental re-think. Instead of purely focusing on weaknesses and seeing ADHD as a challenge, a strength-based model which identifies and harnesses many of the unique strengths that come with ADHD can serve to

empower them to achieve. The ADHD brain has a unique trademark in the ability to hyper focus when interest has been piqued, for the ability to 'think outside the box' and in having a hyperactive and high energy brain that never rests. By channelling their unique strengths in the right direction, these can be a huge asset in maximising their learning and enhancing their problem-solving skills, creativity, innovative thinking and productivity.

An Inclusive Education that values and embraces neuro-diversity by seeing ADHD in a positive light and teaches to their strengths can therefore have a powerful positive effect where children are enabled to learn and not traumatised trying to learn.