

Prevention of and Early Intervention for Mental Health Difficulties for those with an Autistic Spectrum Disorder – A Parent’s View

I have a diagnosed Autistic Spectrum Disorder.

I'm fine at the moment but lots of issues associated with ASD can cause me anxiety.

I need support to develop my emotional literacy, to learn about anxiety and to develop coping strategies for this to prevent future issues. My family and I need to understand what is ASD, some simple support strategies and may need help learning to accept my diagnosis.

I need people around me to be aware of my sensory needs. They need to know that I may look like I'm fine when I am not and that I may hide the first signs of a struggle or deterioration in mental health.

I have a diagnosis of ASD or I might be undergoing assessments for ASD

I'm very distressed. My parents and my GP feel helpless. Some of my teachers do too. They want CAMHS to fix the problem.

CAMHS say I'm not mentally ill. ASD is not a mental illness. Distress is not a mental illness. The sensory, social, emotional and academic demands of school are unbearable and I spend a lot of my life in a state of significant distress.

Everyone is frustrated with CAMHS because they want this problem fixed but eventually they will just start blaming my parents.

If nothing is done to help me to manage my ASD related distress I will develop mental health problems.

Approximately 70% of people with autism also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that is further impairing their psychosocial functioning (NICE 2011).

I need my GP and CAMHS to communicate clearly the nature of my difficulties to school. I need a letter to say that I have significant distress due to the social, emotional, sensory and educational demands of school. I want them to develop a list of things for school to use when children like me are at risk of serious emotional harm.

I have an Autistic Spectrum Disorder but I'm not diagnosed

At the moment I'm sort of OK. The world is confusing and people get cross with me about things and I really don't get why. I'm very clever so I quickly work out what to do to stop people getting cross. People at school think I'm weird but I get by.

Some adults can say it's obvious that I have ASD. If my parents realise and ask for an assessment, the chances are it would be turned down because I'm not having enough problems at school.

Everyone knows that an early diagnosis will give me the best outcomes, however, I can only be assessed when my problems become so overwhelming they are visible to school staff.

For some children like me their diagnosis only happens after they have been admitted to a Tier 4 CAMHS inpatient unit.

I need the policy on the referral and diagnosis to be clear. I need it to be evidence based and well communicated to everyone who works with children. I need it to be followed. I need the adults who work with children to have the training to know what to do.

I have an Autistic Spectrum Disorder and a mental health problem (1 of 2)

I am lucky in some respects. The support I receive from CAMHS is good. I can't manage to go to the centre so I am able to see a psychologist in a place I feel most able to talk. The person I see understands the subtleties of my social communication disorder so the help is appropriate to both my disabilities and my mental health problem.

I am bright and my anxiety response is to freeze. I want to look like my peers so I mask my difficulties at school. This makes my mental health problems worse. My Psychiatrist, OT and psychologist have all tried to explain this to school. I need to feel believed at school. I need to be able to trust the adults, some minor adaptations and support to be applied consistently and kindly.

School staff don't 'see' the difficulties because they are not trained to understand or to notice them. School staff remain convinced that there is nothing much wrong. They don't tell CAMHS this and don't make the minor adaptations I need. Until this situation is resolved I will never get better or have the same opportunities of a happy, healthy, fulfilled life as my neurotypical peers.

I need school to be open and honest about their views and lack of understanding. I need everyone to work together. I need a written document of the adaptations I need and everyone to follow it routinely. I need the things that don't work to be evaluated and adapted until we find things that do help.

I have an Autistic Spectrum Disorder and a mental health problem (2 of 2)

My stress response is sometimes fight and sometimes flight. I struggle to learn too. Loads of 'behaviour' things have been tried but school was overwhelming so often my fight and flight responses were on a hair trigger.

I am traumatised by my past school experiences even though I am now in a special school where everyone understands most of the time.

Everyone agrees that I need some help to recover my mental health and I can see a CAMHS professional.

Unfortunately my social communication disability makes it hard to work with the CAMHS professional who has neither the time nor the skills to help me to communicate in a way that will ease my Mental Health problems. They say "I'm not ready to engage" and they discharge me. I feel like I have failed and my school, GP and parents feel there is nowhere else to turn. (Ensure that all children and young people with autism have full access to health and social care services, including mental health services, regardless of their intellectual ability or any coexisting diagnosis NICE August 2013).

I probably need some help from a SaLT with skills in ASD, and a more junior CAMHS worker (also especially trained in ASD and supervised by an ASD specialist Tier 3 professional) so I can build some trust and practice my communication skills. That way I would be able to access the help I need and be more resilient in the future