

We have a 17 year old son with a diagnosis of Asperger's Syndrome and ADHD. He also has a swathe of learning difficulties including auditory processing disorder, a very poor short term memory [which means he has to re learn everything several times before it starts to stick], high levels of anxiety [resulting in him being incapable of attending mainstream classes at school since Grade 5 and unable to negotiate the world outside his home.] He has numerous sensory issues that impact on every facet of his life. He used to be very aggressive but that has moderated in recent years when we found appropriate interventions for him.

To do this, we had to leave our home, our jobs and our family support network in Tasmania [ I am a seventh generation Tasmanian and all my extensive family live there] and come to Brisbane. This was **essential** for him to go to school. In Tasmania he was not only consistently misdiagnosed but also completely unsupported in the school system and suffered great trauma over his primary years. The continuing trauma suffered by a friend's son, who was very similar to our son, but five years older, convinced us that we had to leave.

That boy has since, to our horror, committed suicide.

In Brisbane we have accessed 3 years part time at Autism Queensland's Sunnybank school and a part time placement in a Special Education Unit in a mainstream high school. We have also accessed the Autism clinic at the Mater Hospital and Minds and Hearts Clinic run by Tony Atwood. I don't have to explain to teachers and even the general population what Asperger's is. I have no doubt that without these interventions our son would still be violent and inaccessible.

We have two other children and my husband works on wages as a tradesman, I am a qualified Art Teacher but have not been able to return to my career due to Josh's needs and part time schooling. The cost of various therapies, psychological counselling and specialist private schooling and tuition has been astronomical. My parent's have helped us over the years out of their retirement funds. It's a fulltime job finding out the information we need to access the best pathways for our son. He is about to leave school and his stress level is through the roof and I cannot find anything suitable for him to transition on to. He is nowhere near work ready but he is not intellectually disabled just learning disabled and too frightened of the world to negotiate it at TAFE, for example.

The stresses over the years are unrelenting and huge, [at least he no longer so overwhelmingly stressed that he smashes the house up!]  
Our other two children are neuro typical, it's hard to understand where this came from. Anyone can become a carer at anytime.

I have heard of the National Disability Insurance Scheme they use in England where you can at least be assured that your child will receive appropriate education and therapy and the rest of the family will be able to continue a more normal life. It's sounds too ideal to be true. How different our lives could have been!

We struggle from pay to pay, we have very little superannuation and no savings. It cost us dearly to move to Queensland and the sale of our house was not anywhere near comparable to what it costs to buy up here!

We could have been a comfortable middle class family living amongst our own family in Tasmania if our country had had the foresight to implement a National Disability Insurance scheme years ago.

Our son will finish school this year with perhaps 9 points of the 20 he requires for his QCE because he can't cope in a large class situation. He has never had a Science lesson despite his interest in that area. He can ONLY learn one to one or in a very small group. So he hasn't learnt much because we couldn't afford private tutoring. School can't provide it either. Perhaps he would have been able to leave school properly educated if we had had a National Disability Insurance Scheme.

The stresses and worries of being a Carer are intense enough without families being crippled by the financial burdens and continual search for something better to help which half the time is still unaffordable and out of reach. Our personal struggle has been incredibly arduous and draining but it is nowhere near as hard as some of the families I have encountered. Some people have super human burdens to manage. It's impossible to adequately express the trapped feeling, the social isolation, the pain and dysfunction of living with a person who is exhibiting "challenging behaviours" year after year...what an understatement that is!

Anything that can be done to lighten families load and give them back some kind of semi normal life should be leapt upon as a basic human right! The only way to achieve appropriate education, therapy, support and shared care for the vulnerable members of our community is through a National Disability Insurance Scheme.

In my opinion, it is already overly late in arriving! So please, look beyond school age children too to the one's floating around out there with nothing to connect to.!

*Mia Clark*