

My name is . Last year, at 50, I received my autism diagnosis with both relief, celebration and also much frustration. I parent a stunningly amazing autistic 17 year old boy. He was diagnosed at two. My submission will be a representation of the past 15 years, highlighting both the gaps and gains, while recognising where we have received adequate or great support.

In 2004, when my son, was diagnosed, we were living in , Qld. There were no services in place to support him. At great emotional and financial expense we moved back to our home town of . Where there were some services and family support. At this time, I also had a new born daughter. One of my earliest recollections of the gaps at that time was the lack of fenced playgrounds. My two year old was an active and energetic boy who would run from me at a scary pace. I was breastfeeding my daughter and it meant we had to stick close to home. I approached my local councilor to ask for a fenced playground. The reasoning I used was, there were many fenced areas for dogs but not one fenced playground in my suburb. This is where the isolation began. My son was two! My councilor was unhelpful and his recommendation was to approach the Brisbane City Council myself. Of course, I had neither the stamina or resources at that point to do so.

We quickly contacted Autism Qld, who are the peak body in Qld. At that time, they had just started a playgroup, which we began to attend. We also enrolled at the SEDU (Special Education Development Unit) now known as an ECDP (Early Childhood Development Program). Both these programs offered not just an opportunity for some play therapy for my son, but an opportunity to meet other families and learn from the staff some very valuable tips to add to our toolbox we ourselves had been building through trial and error.

We learned Autism Qld was introducing an Early Intervention Program and put our son's name on the waitlist. He did not make their first program. I decided we had to make ourselves known to Autism Qld. We had to prove we were a family who would support the organisation that supported our son. With the help of my Mother, we had several fundraisers and not surprisingly our son was accepted the next year into their program. We were thrilled and we noticed lovely achievements and meeting of milestones in that time. We continued to volunteer and fundraise for Autism Qld and still do so now.

Along the way, I was reading and researching all things autism. There was no Facebook. There was not much information available. An alarming fact, was the prevalence of suicide statistics mentioned at the time. I can't remember the rates but I do remember that at that time it was reported that approximately 30% of autistic people would develop a mental illness. Again, something I knew nothing about at the time.

We felt our best option was to sell our home and live with my parents. We did this for three years. This freed up our finances to support our son with identified therapies like Speech and the EI program at Autism Qld. We also unfortunately fell victim to opportunists along the way. Reiki??? Yep they never even touched my son. We paid a person \$150 an hour for advice on managing difficult behaviour and saw him at least six times. Not once did he meet or observe

our son. We were certainly taken advantage of. I don't think there is still enough regulation around services provided and offered to families. I also personally believe that some in the industry create fear and desperation to prey on families wanting to offer their autistic child a great start in life.

I was still reading many books, both anecdotal and research based. I was stepping up as an advocate for my son and so we entered schooling life. During his young life, we had always demanded and ensured he had continued mainstream connections. Initially with playgroup, daycare and then a Kindergarten. When [redacted] started Prep at 5 in 2007, he was non verbal, he had minor challenging behaviour but was toilet trained and was beginning to grasp the concept of turn taking.

I must also mention the difficulty of accessing my community. We found it stressful. We found ourselves judged as bad parents and my dear sweet little boy judged as a naughty kid. We persisted. My intuition told me, our son, needed to experience life outside his home. With the little knowledge we had, we supported him in this endeavour.

Prep is a lot of little kids who are all still learning the social cues of life. By the end of that year the gap between [redacted] and the other kids widened. The social skills gap. They all progressed to Grade 1 with friends and playdates and birthday parties. The parents became friends and again our family was left behind. You can't force people to include you. BUT, inclusion shouldn't really be a learned or demanded necessity. I began advocating for inclusion. We still felt isolated.

At the age of 6, [redacted] was diagnosed with ADHD and was successfully medicated and shortly after was diagnosed with anxiety. His anxiety medication took the edge off but [redacted] has needed a lot of support on an ongoing basis to manage his anxiety. We do this by offering a calm, stable routine at home. We maintained a great relationship with his Primary school and ensured that consistency was carried on at school also. We focused on him and not his academic record. This worked for him. [redacted] was still friendless and doing parallel playing at school and believed he had lots of friends and was happy. He endured some low level bullying in Primary School, but due to his communication delay was unable to explain. We just sometimes would hear from older kids with siblings in his year. These siblings were children of friends of ours. The community isolation continued. As a family, we were very rarely invited to events organised by other families from school.

When [redacted] was 7, my mental health deteriorated rapidly. We had lost our home. We were financially vulnerable and I was very lonely. I believe social media was not helpful for me at this time because I was constantly seeing the get togethers of people who would be my Facebook connection but not my friend in real life. I had my first admission into a private psychiatric facility on January 9, 2011. That year I spent more time in hospital than I did out of hospital. My family suffered. I suffered. As I write this submission, I am an inpatient at that same hospital. Admitted on January 7, 2020. Nearly 9 years to the day of my first admission. During the past nine years I have had many admissions. I have had 21 cycles of ECT (electro convulsive therapy), I have

attended numerous day programs, spent vast amounts of money on therapy with my psychiatrist and psychologist and expensive non-PBA antidepressants. The few people I had built friendships with through the parents in my daughter's year shunned me. At this point, I want to again reiterate the benefit of an earlier diagnosis of autism for me would have been. Much of what I went through could possibly have been avoided as I believe I have been misdiagnosed. Yes I was depressed and suffering anxiety but this was from a lifetime of masking. I also was diagnosed with complex PTSD due to a trauma endured in my early childhood. I had long admissions, taking me away from my family. My recovery was hindered with my feelings of guilt and failure. I came close to suiciding about seven years ago. Fortunately I had shared my plan with my husband thinking he would feel relief and instead was admitted involuntarily into the same facility for the first time ever. This is something I am so grateful for. This would have been a devastating legacy for my children. I was still isolated.

My care was of a very good quality and I consider myself lucky to have a great team of clinicians treating me. Something many don't benefit from.

At the moment, there is a Disability Royal Commission happening. I will be putting in a submission on behalf of my son and one on behalf of myself.

The transition to high school for the first six months was successful. I was hopeful. Then the bullying started. I have documented every incident. All communication with the school, the Regional office, the Minister for Education and also The Premier. Education Qld has a poor resolution process. There is no accountability when you are complaining about the system to the very same system. Some of the things I faced was a staff member disclosing my mental illness in a meeting. This was a tactic to disarm me and discredit me and it took the wind out of my sails. Many similar things happened and I can provide proof due to the meticulous documentation I maintained. I would be happy to present it in person. This will all be a part of the submission to the Disability Royal Commission on behalf of my son.

The relationship with the school was pretty poor. We worked very hard to maintain a friendly rapport but certain staff were rude, insulting and impossible to deal with. It got to the point where we had to ask for a different contact person at the school. At this point my son had been at an Education Qld facility for 11 years. During that time, I had successfully had nothing but friendly and lovely relationships with all staff. In 2017 Education Qld published its Inclusive Education Policy. I read it with optimism. I emailed it to the then Principal requesting a meeting. One of the key points was collaboration with parents. Something we have always tried very hard to establish. We know consistency with the school and homelife was very important. The Principal refused my request.

Instead, I had to then contact the Autism Hub (part of Education Qld) and negotiate a meeting with the Principal, an Autism Coach and an Inclusion Coach. Imagine if the Principal had said yes with my original email. This is a failure and unfortunately without an economics degree I can't begin to determine the additional costs to our tax payers. These meetings happened with

me at first and then I found out they were meeting before our due meetings also. I called them out on this and they claimed they were talking about other issues. This could be true but they need to be so very transparent. Education Qld is the complete opposite of transparent.

During this time the HOSE (Head of Special Education) who we had a difficult relationship with due to her hostile conduct, falsely accused me of being abusive. I went straight to the Principal and lodged a verbal complaint. He wanted to have a meeting with the HOSE and myself. This is when we refused to have any further contact with her. The Principal later confided in me that the HOSE had admitted she should never have said that but I have never received an apology. During all these years of difficulties with the school, we shielded our son from this. We knew it was important that the staff were respected by him as that was the only way he could continue to be successfully educated.

When [redacted] turned 14, with support from us, he started applying for after school work. During this time he also started offering the neighbours in our complex his services. He took their bins out on a Sunday evening and brought them back in the next day when he returned from school. I was well aware that the employment and underemployment rate for autistic people was higher than the average for disabled people. I felt sick about it but knew if [redacted] could secure after school work and was building his resume, it would be a great launchpad for life after school.

Two years! He applied for work for two years. Lodging online applications with fast food chains and large retail outlets. Not a single interview. He did resume drops at small local fast food outlets. He received one trial. With no offer of work. I believe many make an immediate assumption of incompetency when faced with a person who is different or disabled.

After chatting with [redacted], we decided to help him start his own microbusiness cleaning wheelie bins. This launched on January 1, 2018. He is still trading. He works very hard. I have devoted a lot of my time helping him set up and manage his business. I don't get paid. Nor do I expect to get paid. One thing I would like to mention at this point is [redacted] dreams. Apart from his dream to be a racecar driver his dreams are ordinary and typical. He wants to live in a unit on the Gold Coast. One day marry and have kids. He wants to work and drive a car and there is no way he can achieve these simple dreams living on a Disability Pension. In fact, [redacted] does not know that a Disability Pension exists. This Pension is a great source of income for people who have no capacity to work. We know [redacted] has the capacity and is competent. He simply needs on the job training that is incremental. That is achievable and with training that meets his learning style. I know because I have worked beside him cleaning bins. Slowly scaffolding his skills and confidence and watching him take on more and more.

[redacted] has an amazing brain. His ability to retain information is superb. It just has to be relatable. You can ask him a question about any Supercars or F1 race, driver, team, even the weather at a certain event and he can tell you. He is funny and charming. He is loved by his customers. He is one level from becoming a Pro online gamer in iRacing which is a simulated racing game.

is a talented Go Kart competitor but sadly was born in a family who could not financially support him with his dream. He wins every race Go Karting when he has the opportunity.

We are involved parents. We stay abreast of research and developments. I advocate and attend many events to make connections. I began the conversation 18 months ago with my Federal Member, . One of my proudest moments was to attend and speak at the launch. Thankyou Senator Hughes for persisting. I am tireless, I am unpaid and I self fund my advocacy.

Running business and watching his self confidence soar to heights we could not envisage has been the very best thing I have done for him. It does involve a lot of work. I get burnt out. I worry about the longevity of his business. His Facebook page is called . He has over 7000 followers and we shamelessly use his page for advocacy. We also always advertise other businesses owned by people with disabilities when we hear about them.

We want every autistic high school student to have the same opportunities has had. His life is so different. He has graduated high school. He is known and loved by his community. We do not feel isolated. He has a girlfriend. He traveled to Dubai for his schoolies week and attended his first F1 in Abu Dhabi. These are things three years ago we doubted would be possible. Even us, his parents have put limitations on him. We have learned to change our language around . For example instead of saying can't get his learner's we say hasn't got his learner's yet. Adding that yet is so important because we should never say never. Another worthy mention is the language medical professionals use with parents. Yes they need to be measured without promising the world but they also should not be limiting. pediatrician told me he would never talk or live independently. He made these predictions to the mother of a two year old. I left his office with a piece of paper with one word on it - autism.

No parent should have to work so hard on helping their child become employable. This is something I strongly believe. I am glad I do it. I wouldn't change a thing but I give up a lot for this to be possible. My daughter has less time with me. I still cannot pursue any form of employment (which I would dearly love). The ripple effect again can't be measured. Maybe that economics degree would help. But I know this: will be a taxpayer. He will not be a welfare recipient. spends money in his community. hires kids from his high school. As his Mum I have also learned my own value. I have learned I am creative and resourceful. I am determined and I can take myself way out of my comfort zone to advocate for my son.

I am now trying to write a business model of business. It will be generic. It will be useful for any youth who lives with a barrier. Barriers should not be something our youth deal face while still in high school.

Life would have been easier for us if we had not felt isolated. Life would be easier for us if we had not had to sell our home. HCWA was launched when was seven. We immediately

celebrated for those who follow while feeling genuine sorrow at what could have been. We have been proudly self sufficient with our financial obligations. We have worked hard to keep relations with schools both workable and friendly. Despite the difficulty we faced with a certain staff member.

We are parents. This is what we do.

One of the ongoing frustrations I have felt is the unwillingness of each State's peak bodies to collaborate and work together. Let's level the silos. Duplicated funding is given for the same or similar research. Far too much is spent on finding the cause or cure of autism. By all means understanding autism is important. But there needs to be more funds directly offered to support autistic people.

has now successfully been an NDIS participant for almost a year, with his review due shortly. I know this is something not everyone can say. The NDIS is still cutting its teeth and for such a large initiative, I guess it will still be sometime before we see better processes in place. As an autistic person, I struggled to understand my son's NDIS plan and it took me sometime to make it work for him. I do believe the NDIS needs to change its name and branding. Insurance. When you think about insurance you think about how you have house, car or health insurance. It is there in case something bad happens to you. Australian taxpayers think disability is something bad that happens to other people. Many of us disabled people are living happy and meaningful lives. The only challenges are imposed on us by other people, systems or bad design. If we changed the name of the NDIS to the National Disability Investment Scheme, it would immediately help change the mindset of mainstream people not impacted by disability. People who think the worst thing in the world is to have an autistic child. The best thing in the world for me has been having an autistic child. Of course it's been hard, but faced the hardest times not us. We just supported him through that.

I would not know a thing about Supercars if not for . I would not learn about Bathurst or F1 or drifting or Craig Lowndes if not for . I would not sit for hours on the couch watching motorsports with my son and feeling joy when his team wins. Watching my son do a shoeie with lemonade. When wakes up he explodes into our day with joy and exuberance. He is affectionate and loving. He is counting down the dates to turning 18. He can't wait to vote.

Difference is something many people fear. If we could from a young age encourage and embrace difference, many people would have easier lives. Acceptance and inclusion should not be a sometimes or a when it suits or if it is affordable. There are very many long term side effects from isolation. I believe our story could be different had the early days been different. Imagine if we had stayed in . Imagine if we had never sold our house. Imagine if Kmart or McDonalds hired my son. People should not become headlines for change to happen.

graduated from high school on 15/11/19. I naively expected him to slide into life away from school with ease. I did not prepare for his transition at all. He has barely left his room apart from

his trip and bin cleaning. I find myself now having to help him figure out what life outside school for him should be. I didn't think I would have to do this but I do. I have to establish a new routine for him. I have to encourage him to see his friends and participate in activities. He wants to. If he preferred to be a homebody I would of course respect that. is an outgoing and very extroverted young man. But I am still going to have to scaffold his executive function around planning and getting out and about. I am tired and very overwhelmed as I write this. I know a lot of that is because I am not functioning too well with my mental health. I know I will rally and pull myself together. Sometimes I just wish it wasn't so hard. But my son is not hard, circumstances are.