

## Personal Story

My son, John (not his real name), is an only child as his father & I split up when he was very young (approx 10 weeks old). Until recently (17 years later), I had never remarried.

John was a late diagnosis – at approximately 12 years old. I knew very little about autism at that stage, although I knew it was not something you wanted. Years ago I had met a lady who had a son with classic ‘Kanners’ autism - he was non verbal, banged his head repeatedly against the wall and shrieked loudly. I remember it being only a very brief encounter but also being a little frightened at the time, not really knowing much about what her life must be like.

My own son’s diagnosis came about partly because I had exhausted all other options but also because the school my son was attending at the time suggested he may have ‘Aspergers Syndrome’. I wasn’t really sure what that was but initial snippets of information I gained access to provided some answers for his behaviour, but also didn’t seem to fit the bill as most people with Aspergers I had read about had an area of ‘genius’, or special interest that they were fixated on and John had none of that.

Niavely, I thought if you had Aspergers you had a particular area of interest & since John didn’t, then he couldn’t have Aspergers. Another factor was the belief that kids with Aspergers are academically bright, and since this was also contrary to our experience, I wasn’t sure if this did sum up our situation. Since then I have learnt so much more since then about the spectrum of Autism disorder, or ASD, and where and how Kanners autism, high functioning autism, Aspergers, & PPDD fit in. We went for further testing at the Child Development centre, and some months later, it was confirmed that my son had Aspergers, or was ‘on the spectrum’.

Initially, the diagnosis came as a relief but simultaneously was devastating also. This ‘thing’ finally had a name, and hence information was available about it, but in equal measure it was no longer something he would grow out of, or get over – this was permanent! I did not know what this would mean for us as a family – all I knew was that it was never going to get better, no amount of dedication or therapy was going to fix it. There was only me to bear the consequences of this, only me to blame.

You see I had been carrying this particular burden on my own for a really long time – I was exhausted by John’s behaviour, his reliance or dependence on me to interpret, manage and make sense of the world for him. Perhaps at this stage easier to share a little of previous events....

At 2, I had identified something as being ‘not quite right’, agreed upon with child development ‘experts’. We undertook speech language therapy when his speech patterning failed to develop normally, this continued well into his primary years. I got the blame for that – supposedly because I had anticipated his every need, he had no need to verbalise. Secondly, since John frequently was unwell with ear, nose,

throat issues, I repeatedly took him back to ENT, convinced he was 'not hearing right'. My insistence at this and the intolerance of the ENT specialist drove her to send us to the Child Development Unit for an assessment – even if only to shut the 'neurotic mother' up. We went through further tests, but John's non compliance in the testing situation stressed me out, and resulted in the auditory specialists to conclude that most probably John did have a central auditory processing disorder, but until he was old enough to comply with the tests they would never know. We then saw a psychologist, and speech and play specialists who in the end diagnosed 'global developmental delay'. The most beneficial thing out of all of it was the occupational therapy (OT) program that enabled John to overcome some of his 'sensitivities' and make life a little easier for him and I both.

At primary school, a particularly observant teacher noticed his failure to write in straight lines and suggested I get his vision tested. Enter the scene Paul Dixon and vision therapy programs, and a diagnosis of visual perception disorder. More identification of the things my son could not do well, more of me feeling like a failure, but also some hope, pro active activities and small measures of progress.

Then John got seriously ill around Christmas 2000. He vomited continuously for 14 days, rupturing his esophagus and necessitating a stay in Waikato Hospital for 2 weeks. Leaving hospital with a gastrostomy peg and attempting to get back to some semblance of 'normality' was hampered by the fact the primary school he had been attending could not deal with his 'peg'. He had been there a couple of hours when they rang and asked me to collect him and not to bring him back to school. This was the final straw for an unsupportive atmosphere from a doctor who wrote 'mother neurotic' on our medical records to a headmistress who upon my request for teacher aide assistance after the CDC diagnosis said "what are you so worried about – there are others far worse off than you". We moved, choosing instead to shift to Hamilton - in part to be closer to the base hospital as John was still being admitted on a semi regular basis, but also to find a better life.

With the move came changes in school, doctor & home life. The new school took it upon themselves to give John '1 to 1' speech training – after all he was 6 going on 7 and no one outside immediate family and those he interacted with on a regular basis could understand him! They also supported my efforts with the vision therapy, and for a while all went well. He made progress at school but struggled with the social and physical aspects. He also was extensively bullied, although by no means as badly as he had been in Morrinsville – there I knew he had been bullied but had underestimated the extent until I had a child who actually wanted to go to school.

Anyway, after an initial period of shock, my emotions then turned to extreme grief – all the negative things I had associated with 'autism' were now my life, and it 'sucked' big time. Initially, I felt to blame, that I had somehow caused the autism, and this was my penance. Then I felt incredibly angry at the medical & education systems that had let me down so badly when I had sought help at 2, 5 & throughout John's primary school years, especially upon learning that if we had known, there are

a lot of behavioural programs that we could have done which would have assisted us earlier. Thankfully, a kind CCS social worker assisted me in dealing with the grief, & anger. Additional respite care (time away from John), was arranged, I enlisted the help of a supportive couple within my church to have my son when things got too much for me, joined an autism support group; got counseling & enrolled for any training I could get.

The disruption, after diagnosis, to our family life was huge – as a single parent with some health issues of my own and a relationship that had just broken up (primarily due to my son), the first 6 – 8 months after diagnosis were VERY hard. I felt incredible swings in emotion, was quite severely depressed, withdrew from my friends and workmates, and additionally, felt guilty about how I felt about my son. He had not changed but my ‘world view’ had changed dramatically. I could not see how people with ‘neuro-typical’ children (the term used for ‘normal’ children by those within autism circles) could understand what I was going through. Neither was I ready to connect with others within autism circles, I felt a poor representative as others were doing a fine job of getting on with life whilst I still had too much grief associated with this.

In the end, it was probably the training & information that came through Autism New Zealand (& our local branch of the national association) that most helped me. I went to a S.P.E.L.L. training course – free, thankfully, for parents & caregivers, that helped answer some of my questions, and gave me some understanding of what life was like for my son. The acronym stands for Structure, Positive expectations and approaches, Empathy, Low arousal & Links, and outlines how to do this for your child. Several months later I attended a ‘social role valorization’ (SRV) session sponsored by CCS that gave me some hope & direction for the future. The premise regarding SRV is that it is the social roles that we have that define our worth in society, disability comes second, so if we can find, reinforce and nurture those roles our children will be valued and cared for members of the community they live in, and this has benefit beyond our lifetime. It also was a huge challenge to what are our expectations for our children, and how do we communicate these to our kids.

Then I attended a CCS Mothers Weekend – fabulous respite, care for the caregivers out of which I have made a firm friend, and held onto that friendship whilst others have been lost.

Next, I attended a conference in Rotorua – sponsored by CCS & Standards Plus - here I met some incredible & inspiring individuals working in the field -abled & ‘disabled’ alike. I also had a number of my own prejudices and stereotypes challenged and confronted, not so much by anyone in particular, but because I was seeking meaning and reason as to why this was my life, and what was I to do with it now.

In particular this conference gave me a glimpse that having a child with a ‘disability’ was NOT necessarily a death sentence, but could be considered a ‘gift’ that could inspire others and be quite fulfilling and exciting. Since we live in a society that regards kids with disabilities as somewhat ‘less than’, our challenge in having them

accepted, even accepting them ourselves, means we are 'catalysts for change'. Our children enable others to confront their beliefs about what it is to be human, where we find and give our worth, how we see ourselves; and as the caregivers of people who expand the rainbow of human acceptance, we have an important role in ensuring compassion and acceptance prevails – in practice, in legislation, speech about them, employment and so on. Most importantly, for me was the insight and identification that if we are in it, we might as well make the best of it.

Most recently I have attended the NAS (National Autism Society) Help! course. Here, I have connected with a number of parents of kids like mine, broken the sense of isolation I usually feel and explored a little more of the grief associated with a diagnosis that your child falls outside the realm of 'normal'. I realize now, that I buried the grief 2 years ago, to a certain extent simply in order to function & survive our day-to-day existence. However, we are at a far healthier place and now our challenge is "what does this mean for us as a family?". I understand autism more, but am not alone in facing the challenges that come with having a child with autism, it's just "how do we act as those 'agents for change'?" - one day at a time, within each of our own communities, as a necessity to make valuable contributing lives for ourselves, and those of our children.

That's about it for now, although I realize I haven't included a lot about advice for others, or how I expect to be treated.

To health professionals – be careful in how you present diagnosis to parents. We are especially sensitive to blame, and need you to understand that often there has been quite a journey even before we came to you! Understand that we may be grieving, or have grief issues, and we especially need to feel that you are supportive.

To parents of a child with autism - get support, find out all you can about what you are facing, and then sift through what means something to you, and leave the rest. No one else can journey your journey – just as your child is unique, special and beautiful with talents and a personality that no one else necessarily appreciates, so too there will be things you can assist them with that others can not.

Understand that sometimes it is a solitary journey but have faith – the human spirit is stronger than you think, and if you've made it thus far, you just got to keep on going – one hour, one day, one step, one challenge at a time! Others may walk alongside you for a while, this includes health professionals, well meaning friends etc, but the journey is yours to make, with your child, together and alone. It is a gift, hard to see sometimes, but a gift!

To parents of 'neuro-typical' children, teach acceptance, compassion and helpfulness to your children. Understand that when you talk about your child's academic achievements, be big enough to encompass whatever level of achievement your friends child can make. Don't exclude us from conversations, after all, we are parents too; instead realize we have a whole different measure of achievement.

Ask us how we are feeling about our child's progress, what is hard, what is frustrating. You'd be surprised how many similarities there actually are! Don't be afraid to explore and expand your own definitions of humanity – most importantly by doing all of this, don't buy into the view that my child is somehow broken, less than, and capable of less than yours. He / she may be measured by different terms or standards but their achievements, in the face of adversity, are just as great!!!