

INSIGHTS

Family reflections: autism

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Hugo has just turned 7 years old, and with every birthday I look back on how far he has come. From a premature baby in the NICU and the special care unit to a healthy and happy dinosaur obsessed 7-year-old boy. At the time of his birth all we could focus on was the beeping of his oxygen machines, were the tubes feeding him enough? How to change a nappy through an incubator around all the wires of my tiny baby. So many specialists, new terms, new conditions on how to care for our premature baby. Being first time parents, we followed the strict advice from the doctors and specialists.



Every 6 weeks we saw the paediatrician to check Hugo was meeting his developmental goals. At first it was all about bulking and feeding, then he had a compromised immunity which saw him have many long stays in hospital with respiratory issues until finally diagnosed with severe asthma. Hugo was in the medical system since the day he was born and the number of doctors and paediatricians he had seen was a lot! Too many for none of them to ever mention autism.



When it was time for my maternity leave to end and go back to work, given every time someone sneezed near Hugo he would end up in hospital with respiratory issues it was recommended he didn't go to a big day-care centre to avoid big germs and viruses until his immunity got stronger. He attended a family day-care with three other children. It was this educator that first started saying things like, he can't seem to play with the other children, he doesn't listen like the other children, you might want to check out if he has echolalia which we quickly googled was the repetition of another person's words. We bought this up with the paediatrician who sent us for some hearing tests with no other worry despite me asking if this meant autism as my google search of the term echolalia led me to this commonality.



The same educator was the first person to say to us, "I think Hugo might have autism". We took that statement like a bullet to the stomach and at the time felt like the worst thing anyone had ever said to us as we didn't know what autism meant. Of course, the drive home and that night we were both on our phones googling, in denial but not in denial. Yet at the same time our precious Hugo had stopped sleeping and starting his day prior to 4am, our wonderful eater had stopped eating and would only eat

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the same one or two things, tantrums were no longer tantrums they were multiple massive meltdowns triggered by anything and everything. Everyone just kept saying he was a wild child.

It became obvious compared to his peers his language, speech and social development was not the same as the others at the playground or at day-care. What I thought was cute repetitive sayings on the drive to day-care became indicators of his repetitive behaviour. The fact he would only eat his dinner if the lemon juice bottle was next to him and other behaviours indicated his anxiety and rigidity for routine. Hugo was impulsive, hypersensitive, hyperactive, had challenging violent behaviours and was unable to cope with the smallest of day to day tasks.

The first psychologist we saw when Hugo was 18 months old diagnosed him with sensory processing disorder and recommended an OT assessment and start sensory therapy. We were already seeing a physio OT since he was 6 months old due to low muscle tone and help with sitting, crawling and walking. We were confused at the different OT disciplines. The report from the psychologist said early indicators of autism but was too young to diagnosis and to watch and see and wait until he was 5 years old. This was the same narrative from ALL of the specialists and paediatricians we saw over the next 3 years.

I am not shy of sharing my opinion or advocating for my son, but I could not get a clear answer or diagnosis for him. Which meant for the next 3 years we tried everything the professionals said to do, from ear tests, sleep studies, vitamins, allergy tests, absent seizures monitoring, blood tests, OT for sensory, OT physio, chiro for his body, brushing him for his sensory, diets, calming sensory clothing and toys. The list goes on and on.

I was turned away from the local public child and developmental unit for an assessment as he was deemed "not delayed enough" when they asked me if he could walk to the fridge, point and say milk, which he could. That was the qualifying question? Trust me I had some words when we were back at that same unit years later for cognitive and IQ tests prior to school when they recognised the name and then read all the reports on our son, they apologised, but really, I wondered how many other families struggled for years desperately trying to help and support their child to be turned away.

Fortunately, we were able to afford another private developmental paediatrician, the wait was long but worth it. Within 5 min of meeting Hugo, she said there was no doubt he was on the spectrum. And with extensive testing at 4 years old, Hugo was diagnosed with autism spectrum disorder, level 2. As much as this was what we sought an answer to, we still felt shattered and heart broken. Immediately our thoughts went to worst-case scenario, what would life be like for him? We were told he would never go to a mainstream school and to start looking at special needs schools, look into behavioural, speech and OT therapy. I would need to quit my job and throw everything into early intervention every week. More tests were required to understand cognition and intelligence which told us he didn't have an intellectual disability; however, the quotients indicated he "could not" go to a mainstream school.

We went straight into action mode, and I did quit my job, and found an early intervention centre who specialised in autistic children and other developmental disorders. The team gave us all a sense of belonging and the team got us and our son. It was like the first time we were heard. The multi-disciplinary team, together with a goal orientated programme meant we had one plan. No longer clutching at straws, Hugo was getting the support he needed. We saw Hugo thrive, not just survive, targeting and tailored early intervention across behaviour, speech, OT we saw Hugo go from strength to strength.

Fast forward to today, Hugo is beyond amazing. Seven years old, bright, creative, funny, loving and loved. He is a walking encyclopaedia for dinosaurs and he's our little warrior. He attends the local school

in a mainstream setting. Hugo sees, feels and responds differently to the world. He has many passions, talents and strengths but also daily challenges which can be complex and requiring therapies, strategies and accommodations which will be lifelong.

We often wonder what might have been if at 18 months on our first appointment Hugo was diagnosed and received early intervention from that point. Would his struggles today be minimised? What if all the other professionals didn't say let's wait and see. Don't get me wrong I follow what the experts say, but why with autism is the narrative wait and see by so many? The early indicators were there, every form I have filled in one of the first questions is what was the pregnancy like? What gestation was the child born? The majority of the wait and see was because Hugo was premature, so developmental delays were expected. So, if they were expected, why not look into other conditions where developmental delays are a sign?

I would like to see more research into prematurity and autism as our time in the NICU and with his paediatrician could have prepared us for the potential of autism. How many of those other children in the NICU have an autism diagnosis? Is there a significance of premature babies with autism? What's the correlation if any when oxygen assistance is needed from birth, what does the lights and sounds in the NICU do to the sensory system at a premature age?

Early intervention helped Hugo overcome a lot of challenges; however, he is in this tricky cohort of autism. From a distance he looks like a 7-year-old that has "a lot of energy" and it isn't until you spend a whole day with him can you see the autism, the ADHD, the sensory challenges he faces. My biggest question that keeps me up at night is what services and support does he move to and at what stage and age? When does psychology treatment take over from early intervention? And at what age and what are the signs or flags to look out for as he enters pre-teen, teenage years and beyond?

From an education point of view, he isn't suited for special needs schools, or support classes in a mainstream setting right now, however doesn't qualify for teachers aid and was granted only a small number of hours of learning support (according to the education department). However, his struggles and challenges are real from literacy and some cognition areas and there is a lack of research about best practice intervention outside of 0–6 years or for teenagers on the spectrum and adults. Looking ahead we don't know what Year 2 onwards looks like for him, we keep getting told the gap between him and his peers will widen considerably at this stage of development and with a lack of research or studies regarding autism in education settings, pre-teenage we are nervous about how best to support him.

Looking even further on from the teenage years, high school and beyond there is a lack of insights, understanding and studies of the transition to different lifecycle stages and what does that mean for autistics? I would love to see studies in this space, so I can get the best knowledge, recommended strategies, resources and tools to support him throughout these stages of life. There is a lot in the neurotypical space about raising boys, raising children but not so much about raising an autistic child.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

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