

In response to the Parliament of Victoria's call for submissions for the Autism Spectrum Disorder Services Inquiry, I would like to share my journey, concerns and hopes for the outcome of the Inquiry.

Concerns were first raised with me about the development of my son by a child care worker when he was about 12 months old. He was not meeting the typical milestones for that age group and he displayed strong signs of sensory defensiveness. As a parent, it is very confronting to hear these concerns, and as a first time parent, I didn't know what "typical" looked like, so I sought professional advice. Initially it was to disprove them.

At first, the Speech Therapist and Paediatrician indicated that it was likely my son suffered from developmental delay rather than any disorder. He was suffering regular ear infections and it was assumed that this alone was impeding his language development. I sought the care of an Ear Nose Throat Specialist and he underwent what would be the first of four operations for the insertion of tympanostomy tubes. His speech didn't improve at the expected rate and the sensory seeking behaviours grew stronger. I was advised to begin the process of applying for an early intervention service. We were on a waiting list of more than 12 months and as he neared the age of 2, our Paediatrician observed that it was likely my son had a form of PDD-NOS (Pervasive development disorder not otherwise specified). This was a kind of no-man's land in terms of assistance with the cost of therapies and any form of funding so we were removed from the intervention waiting list (the qualifying criteria for intervention is a delay in 3 or more areas and our son was displaying only 2). As the gap between the development of a typical toddler and my little boy grew wider, the Paediatrician conducted the Childhood Autism Rating Scale test. My son was formally diagnosed with moderate autism aged 2 years and 8 months, with the Paediatrician, Psychologist and Speech Therapist now all concurring.

A diagnosis changes everything, but it also changes nothing. It changed the way I parented him, how I helped him understand the world, and it opened many more doors with regards to funding, but it never change the way I loved him.

So began the weekly sessions with the Psychologist, Speech Therapist, Occupational Therapist and monthly visits to the Paediatrician. Essentially, I 'drove' this intervention on my own, as many parents do until they are offered formal early intervention services and it was extremely tiring. My second son was born during this time and the three of us almost lived our days in the car, driving from one session to another, often juggling 2 or 3 appointments in a day. Among all of this, I managed to also work 3 days a week.

Through a chance connection, we became part of a small playgroup headed by therapists and offering supported play times one afternoon a week for children waiting for their place with an intervention service. This was a wonderful, safe space where children could explore and play, and mums could air their concerns, worries and frustrations with qualified staff and I found a way to fit it into our busy week. Unfortunately, the funding for this group was not continued and after 6 months, we were again on our own.

After 11 months of this arduous journey, we were offered a place within an intervention service and all the therapies were now thankfully centred in one location. My son responded well to the services

and it made a huge difference to how he learnt, his development of language and his management of the world around him.

The one thing I did find confusing at this time was the intricate web that is early intervention funding. The State and Federal funding is of course, offered separately, but for an already overwhelmed parent, making sense of it and knowing what did and didn't apply to us was difficult to navigate.

He completed kindergarten in a mainstream setting with the assistance of an aide and from there began school in a dual enrolment between mainstream and a special needs setting. He didn't adjust as well as I had hoped. The mainstream school found his behaviours too challenging for the 2 hours a day they had a funded aide for, and after the first term break, he moved full time into the special development school. This was the best decision for him.

The teachers, staff and therapists at his special development school are amazing people – I cannot speak highly enough of them. They have taught me therapies and strategies that I can use at home and we are constantly supporting each other's goals, with regular communication and consistent expectations in both environments.

With regards to health, I recently had an experience in hospital with my son when he needed emergency dental surgery. This was quite traumatic for my sensory sensitive child. The nurses, although wonderful and very caring, all agreed that this environment doesn't completely cater for these patients. Following the surgery, I required the services of a paediatric special needs dentist. The only one I was able to find was attached to the Royal Dental Hospital, with a 12 month wait list.

My son is now almost 9 years old and because of some changes in our family dynamics, I find myself thinking about respite services. I am ideally looking for a small group that can offer activities once a month on a weekend so that my son can begin to form social connections independently while I spend one on one time with my younger son. Upon enquiring with some local (and some not so local) agencies and our Council, I was told that due to funding restrictions, most services are now geographically zoned and there is very little offered in my area. My local Council service has a waitlist of up to 3 years. The area in which I live is one of the fastest, if not the fastest growth corridor in Victoria, with 120 families moving into the area each week. Couple this with the increased rate of diagnosis and it sees families missing out on this important service, and the pressure this places on a family unit is clear to see in statistics such as this one I came across a few years ago: the breakdown rate of autism-specific families is 80%. Without vital services like respite, that figure can only increase.

There is also a gap in the availability of suitable school holiday programs, which are also geographically zoned, or have long wait lists, such as Council programs. Some programs run by disability services are very costly – one in my local area run by an excellent disability service is \$880 per week, and while families can access their child's FACSHIA funding for this program, many families with a child over 7 years of age would be paying for this program privately. Another issue is that most children with autism don't transition well to new environments and unfamiliar people and routines. In the case of my son, it would take almost the whole holiday period for him to adjust to

the program and there would be considerable emotional consequences along the way. He would just get to the point of managing the environment when it would end and the point would be mute.

A number of respite service that extended to a funded (or even partly funded) school holiday program would offer working parents an alternative to high cost holiday activities or long waitlists and provide children who find transitioning to new environments challenging, the continuity of familiar carers and established social networks.

As my son progresses toward the senior years of his schooling and beyond, my concerns are similarly turning toward the services that will be in place for him and those like him who are transitioning from a school environment; those who struggle with relationships, social connections, gaining meaningful employment and the daily expectations of them in a world they don't always fully understand.

In 2008, the Victorian Auditor General documented that the demand for services for the intellectually disabled was increasing by 4-5% annually, while in March 2011, *"1,439 people were waiting for an Individual Support Package. People waited an average of 1.45 years for an ISP. While this has improved from December 2008 when wait times were around two years, at March 2011, almost 200 people on the register had been waiting five or more years."* These figures are, of course, not autism specific, but encompassing of all intellectual disabilities.

The response to the shortage of these services cannot simply be crisis-driven. A well -considered approach reflecting on the findings of relevant reports and recommendations of disability support agencies needs to be paramount, while allowing fiscal flexibility and commitment towards providing high quality services allowing individual choice with minimal waiting periods.

I hope that this inquiry serves as a tool to reshape the services, both existing and new that are available to support all children and adults with autism, and allows them to have access to everything they need at a time they need it to assist them in living happy, fulfilling lives where they can all reach their potential

I thank you for the opportunity to provide this submission and I look forward to seeing the positive changes this Inquiry brings.