

Inquiry into services for people with autism spectrum disorder

I am a mother of 3 boys with 1 being diagnosed with Autism Spectrum Disorder (ASD). We live in the north west of Victoria near a small rural town which is 20 kilometres from Mildura. My son was diagnosed when he was 4 years old and to me and my husband it was quite a shock and a steep learning curve. We didn't know that many children diagnosed with this condition (this was in 2004).

Our first contact with a government agency was with the local council's maternal health nurse service who performed a test on my son and established that there were some warning signs. Then a lady from the council came and carried out more testing in our house and then we were referred to a paediatrician. We were also referred to Early Intervention and it was here that a cognitive and autism assessment was carried out. We were very grateful for all the support that we received from these health and disability services and we were also lucky enough that it didn't cost us any money.

In the early days there was no private occupational therapist (Now there are 3 in Mildura) and so after our stint at Early Intervention (that finished when my son went to school) we did travel to Adelaide. Going to school meant for us that now we had to fund our child's therapy. It is still ongoing and we are still paying.

How wonderful that now the federal government is providing the Helping Children with Autism funding. The range of therapies and choices of therapists is fantastic to see. Hopefully with the NDIS this will make funding available to all age groups as children with autism don't miraculously recover when they reach 7. A little bit of support can make a big difference to a family's life.

We have been a very proactive family and with support we have been able to walk alongside our son as he develops into a young adolescent. We have had challenges along the way but being able to refer to specialist, other parents and family has made our journey not so bad after all. It definitely is like the poem written by an autism mum "You might plan to go to Rome but being diverted to Holland is not so bad after all".

I have been a part of the local support group (Sunraysia Autism Spectrum Support Group) who has been funded partially by Carer's Support Services and partially by local donations and fundraising. The support group is a place for parents to share stories and form relationships with others who are travelling along similar paths.

From this experience of being in the support group I have met other families that are doing it hard. In consultation with the support group and Lower Murray Medicare Local an Autism case coordinator was employed in our region. This was like our region winning Tattslotto. She was a face for parents to meet and have a chat with. She then could provide advice on navigating the maze for a diagnosis and treatment. When this role was active the diagnosis time frame got down to a few short months or less.

Now there are no Medicare Locals and we do not have an Autism case coordinator in our region that fulfils this role. We are back to in some cases a year for a diagnosis through the local Child and Adolescent Mental Health Service(CAMHS) at the Mildura Base Hospital.

What my dream would be: for the NDIS to allow therapy to be funded for all people diagnosed with Autism Spectrum Disorder; Children with a IQ higher than 70, diagnosed with ASD, to have support at Kindergarten, Primary school and Secondary School; for regions to have a local Autism specific case care coordinator to support families; and more funding to speed up the diagnosis process.

When my son went to primary school he was the first that the school had seen. He qualified for a teacher's aid (we were lucky and grateful). During his time at the primary school there has been up to 5 diagnosed children. This is a school of 120. That means that in this cohort there was a ratio of 1 to 5.4. That's a large statistic. That's amounts to every teacher needing to be special ed trained. I hope that this is happening in our universities.

Over the years the support group has tried to find out statistics on ASD in our area but to no avail. We thought that as every parent with a child with ASD gets carers payment then there would be a way to establish this data. But apparently no! Schools also would have records of how many children are diagnosed. But I have never seen this published either. For planning reasons all these figures would be beneficial to any location so that services could be maintained or expanded. For instance, the CAMHS could employ more staff so that diagnosis times were shortened to a more realistic time frame. Imagine waiting a year to find out that your child has perhaps ASD or dyslexia or ADHD, all with different treatments.

I embrace this process of giving people a voice. I just hope that it is heard. There were days on my journey when it was very difficult but I have the personality type to withstand the negativity that is sometimes forced upon parents of supposedly naughty children. Sometimes all parents need is to be heard and empathised with. I love all my sons and I love being able to guide them in their journeys to adulthood where ever that may be.

Thank you for this opportunity,

Donna Milne

Mother of a 15 year old boy with Autism

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