

## AUTISM AROUND THE WORLD 2000

### AUSTRALIA

We live in what the Australians call the sunshine state of Australia – tropical paradise, beautiful one day, perfect the next! We live with our son Damian (10 yrs) who has Asperger Syndrome, and his sister Chiara (8 yrs). Damian was diagnosed 5 years ago, where I forgot to go through the grieving process and embarked on the trail of acquiring as much knowledge as I could about this syndrome that would affect all of us in different ways.

*How many people with autism/asperger are there in Australia?*

Australia's current population is approx. 18 million. Using the latest census data (1996) the Autism Council of Australia has considered all available information and states that 1 in 500 of our population will have an Autism Spectrum Disorder severe enough to require ongoing specialist support = 36,000 Australians.

Other figures show an approx. total of 110,000 with Autism of which 74,000 have Asperger Syndrome (obviously mild to severe cases). Take into consideration that these are the diagnosed numbers, there are most probably the same amount undiagnosed in the country. Latest figures for Asperger Syndrome are 1 in 300.

*What sorts of supports are there from government or the medical system?*

Types of government and medical support vary from parents receiving disability pension and transport assistance to schools receiving funds for special teacher assistants. Our state has formed a Disability Service hoping to offer more support to the parent with a challenging child, or assisting the adult wanting to become independent. But these packages are in preliminary stages. Supports vary from state to state in our country. There isn't consistency; some states are very proactive and some very uninformed. I think it depends on the individuals in power, some are aware, most aren't. There is still a long road for educating the people at the top.

*What sorts of supports are there from schools?*

Once again this varies from state to state. If a child has a medical (paediatrician) diagnosis they will receive more support than a child whom is diagnosed by a psychologist. This support is offered by the government in the way of aide time to either assist the teacher in preparation time, or having an aide in the classroom assisting the child, or releasing the teacher for inservicing or meetings. Children are ascertained a level from 1 to 6 (6 being the highest need). Children who on levels 5 or 6, require an IEP (Individual Evaluation Plan) written by the class teacher together with a support team. An example is a child on level 6 who in 1997 & 1998 received 25 hours aide-time per week, and then in 1999 there was a change in Government and this child automatically lost 17 hours.

*What happens to people with Asperger Syndrome if they are poor? If they come from well-off families?*

If you are on the lowest end of the socio-economic scale then yes you are disadvantaged. You can't access the professionals as easily and swiftly as somebody with the dollars. Ironically a family on the lower scale won't be able to afford the entry fees to the government funded unit for children with Autism, unless under special circumstances. Waiting lists at our public hospitals are lengthy, so of course these families miss out on early intervention, a bit scary if a child is severely depressed. A child who is born into a wealthy family can access a multitude of services, speech therapy, occupational therapy, counselling, music lessons, social skill classes, etc, on a weekly basis.

*How did you learn Damian had Asperger's? -- How easy is it to get a diagnosis?*

Damian's preschool teacher picked up on Damian's speech and social behaviour challenges – he was 5 years of age. This led us on the 'diagnosis' trail. First stop was a speech therapist that said he had more than just 'speech problems'. Second stop at the paediatrician's, who thought he had mild ADD. She then investigated further and a team of specialists who came up with Asperger Syndrome diagnosed him. After accepting this diagnosis, we then went to a psychologist for further treatment where we were then told, 'No, he hasn't got Asperger Syndrome'. Frustration set in. I wanted to stay with the first diagnosis, but Damian's father wanted to accept the 2nd diagnosis, so we agreed to try for the third opinion. Bingo! A diagnosis of 'mild' Asperger Syndrome was obtained.

Back in 1995 it wasn't as easy to obtain a diagnosis of AS, as it wasn't very well known. Even the doctors didn't have access to information that they could hand out to us that was 'parent-friendly'. But in the year 2000, there is a multitude of professionals who are more aware and keep an eye out for children who display characteristics of AS. One of our local hospitals has a team set up purely for diagnosis of children with a possible Autism Spectrum Disorder.

*What sort of help do you get from friends/family?*

Basically none. I have friends who offer their 'shoulders' for me to cry on, but when it comes to family it is a hard situation. Some family are still in denial and won't accept that there is anything wrong with Damian and so jeopardise any strategies. The only answer here is what is the best thing for Damian = consistency, so we have decided to distance ourselves from those family members. It is very confusing for the child to have parents who put strategies into place, and then when you turn your back to have family telling the child 'Oh, Mummy's silly, don't worry about it, you do what you want!'

*What is it like raising a child with Asperger's?*

It's not easy raising a child with Asperger Syndrome. Two steps forward, one step back is how I can best describe life with our child. But then I can't imagine life any other way now. It makes you appreciate people's differences.

*What was the most difficult thing to deal with?*

The most difficult thing to deal with is when I see his pain and suffering, when he hasn't understood something and is feeling humiliated, or his frustration about life leads to his anxiety and depression.

*What are people's (society's) attitudes towards the mentally disabled?*

*-- Do you think they're changing?*

Basically people are scared of something they don't understand. Ignorance breeds fear. The majority of people in this country still cock their head to the side when you mention 'Asperger Syndrome'! I do think society is changing, with more information and training, people are becoming more understanding of people with Asperger Syndrome. Knowledge is power.

*How would you describe your child's life?*

I can't say he has an easy life. He is an anxious child, and so each day seems to have its individual hurdles. He tries so hard to appear 'normal' at school that by late afternoon he is usually overly exhausted, mentally and physically. The weekends and holidays are his respite. He absolutely relishes these times and wants to stay at home most of the time, safe within his environment.

*What will happen to your child after you're gone?*

I'm not too worried about when he is an adult, because of the early intervention and independence 'training' that he has been surrounded with. He is clever enough to work out what in life is easiest for him to endure, and I predict he will live alone, have a few friends, go to the same shops, and virtually live an independent life with his little quirks but he will be happy. But if he ever falls down, there are many adult support systems set up for him to access.

I am mostly concerned if I pass away within the next 10 years, I know his father will look after him, but nobody knows a child like his or her mother! My role on this earth will not be complete until Damian has reached well into his teen years.

*Are parents organized or organizing in Australia? If so, how long has your Asperger Syndrome society been set up?*

Yes, parents are the best advocates for these children. There are many support groups popping up all over Australia. Within our state, we have an impressive support group that commenced back in 1995 with 7 parents. Now, 5 years later, the support group has become a network of 7 branches with a total of 415 members.

*How do you get together? What do you do?*

These wonderful committees organise monthly meetings with a guest speaker, parent morning teas, seminars, family outings, family camps, father's days, mother camp, and sibling group get-togethers.

*What was it like meeting your first parent who also has a child with Asperger Syndrome?*

Meeting other parents with children who have Asperger Syndrome is like meeting people who have a similar cultural background to you. They understood our language, our needs, our emotional roller coaster rides, and our difficulties within society and most importantly they understood our children.

*What would you change, if you could, for people living with Asperger Syndrome in Australia?*

The key word here is 'change'. There are so many things that need to be changed, but primarily people's attitudes. Without knowledge and awareness of Asperger Syndrome, society cannot and will not change to suit the needs of these children. We need a spokesperson, a celebrity who will stand up and say 'Hey, if I can understand Autism/Asperger, then it's OK'. Unfortunately people are like sheep, we follow, and hopefully society would follow the inspirational words of our celebrity spokesperson. Any volunteers???

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