

Life with Jacqueline

Our guest speaker at the recent Foundation Dinner was Organising Committee member and Mater Dei parent, John Adam, who shared the story of his daughter Jacqueline. At the request of many, John has given us permission to reprint some of his speech.

Jacqueline is my no.4 daughter and is 13 years of age. She has been a student at Mater Dei for 2 1/2 years and is autistic.

Jacqueline was born quite normal. She was a lovely baby. However a few months down the track we realised something was wrong. All her milestones including crawling, walking, talking, acknowledging people, etc. were delayed. To find out what was wrong and how we could fix it, we did the rounds of the doctors, occupational therapists, speech therapists, psychologists. You name them, we went to them.

"...we could not just accept our children's disability and manage their behaviour... we had to do anything that we could to allow them to reach their potential..."

In fact it wasn't until Jacqueline was 4 that anyone put a label on her problem. We received a report from her preschool saying that she was exhibiting autistic tendencies. The report was prepared by a counsellor who had seen Jacqueline for one day. I can tell you that the first time parents get told that their child is disabled is one of the most traumatic moments of their lives. It was like a knife to the heart. Anne and I simultaneously said, "No that's not right!" and "How could someone be so insensitive with so little contact?" Immediately, Anne and myself hit the internet to find out what autism was and very quickly we convinced ourselves that there was no way that our daughter was autistic. We called a meeting with the preschool and at that meeting we also convinced them that they were wrong. It was not until Jacqueline was 7 1/2 years of age that she was officially diagnosed as autistic. Although we did a lot of things in those ensuing 3 1/2 years, we still wonder what could have been if we had known her difficulties at the age of 4.

So what was it like bringing up an autistic child? Basically the early years could be categorised by one word, namely tantrums. Jacqueline would put on tantrums, consisting of the usual crying, screaming, throwing herself on the ground, kicking and punching, every time she did not get what she wanted. But Jacqueline's went further than most tantrums. On a number of occasions she put her fists through window panes. She kicked and broke windows and her favourite was ripping off her clothes anytime, particularly in public. We of course had no idea what to do. We also did not appreciate that all she was doing by throwing tantrums was telling us that the world we were demanding her to live in was terrifying her.

So every time Anne took her shopping, that would result in one, two or more tantrums. Every time she got in the car, had to put a seatbelt on,

had to get dressed, had a bath, she would throw a tantrum and the worst of all was saved for washing hair.

And then the fun started when Jacqueline had to go to school. This was all too much for her. We chose the public school system because they could offer a teacher's aid one hour a day. The first day it took us two hours to get her dressed, have breakfast and get her in the car. I could not count the number of tantrums that took place that morning. But then Jacqueline's terror really started when she got to school. Jacqueline has two significant phobias. The first one is a fear of change. To take her into an unfamiliar environment is just so scary for her. Her other pet hate is a fear of crowds with people looking at her. She is OK one on one but as soon as you expect her to mix with a large crowd she just simply can't do it.

So on the first day when we took her to school in a uniform which she hated, to a place she didn't understand, with 150 kids plus parents and teachers staring at her, it was just too much to take. That resulted in her putting on her "A" grade tantrum, an absolute "doozie" and it took Anne and the teacher's aid over an hour just to get her into the classroom. That was the end of it for us but Jacqueline's nightmare continued.

She was at a place and she didn't understand why she was there. She had no idea what was happening, she couldn't talk to anyone, she didn't know how to make friends and therefore had none. Anything to do with academic teaching went straight over her head. She simply hated every minute of her time there. This went on day after day and month after month. The school, with good intentions, was simply babysitting Jacqueline and managing her problems. After a few years we transferred Jacqueline to St Thomas More Catholic Primary School at Ruse. I cannot speak too highly about the teachers at that school.

My life changing lunch happened when Jacqueline was 9 years of age. I was at a conference in Melbourne and also at that conference was Scott Phillips who is here tonight. Scott asked me whether I could have lunch with him at some time during the conference. His 2 year old daughter Bronte had recently been diagnosed as autistic and he wanted to talk to me about that. I naturally said yes. I assumed that Scott wanted to pick my brains about how to bring up an autistic child. Well we went to lunch and everything that I had thought would happen went out the window.

Within a few minutes Scott showed me that he had already done more in 2 months since Bronte had been diagnosed as autistic than I had done in the previous 3 years. He lectured me, and rightly so, that we could not just accept our children's disability and manage their behaviour but we had to change their lives, we had to do anything that we could to allow them to reach



Jacqueline teaching her father, John, some dancing steps.

their potential. That lunch resulted in many, many changes to my life. I will always credit Scott for changing my life for the better.

As I said, many things changed and one of the changes was to send Jacqueline to Mater Dei. Mater Dei is naturally different to a mainstream school. There are no history classes, there are no geography classes because there is no need for them. Jacqueline's curriculum is tailored to her and she learns to cook, learns to swim, learns the value of money, learns to read, form relationships, look after her personal hygiene, learns to play in playgrounds and learns how to be independent. These are her HSC subjects. And is she progressing? You betcha.

When she goes shopping now there are no tantrums. She in fact goes up to the shopkeeper and buys items, hands over money and gets the change. She is able to swim, cook, bath herself, dress herself, look after her personal hygiene, unlock doors, turn on TV's, operate DVD's and use computers. Earlier I referred to her fear of crowds. Two years ago the children of Mater Dei put on a performance. In that performance, in front of 550 people, on this very stage, Jacqueline was a squirrel. This is the kid that found it difficult walking into a room with people in it yet, she was able to perform on a stage, and I might say, didn't miss a beat in front of all you people.

Over the last 2 1/2 years since being at Mater Dei her behaviour is 1000% better and she is so much happier. Children with disabilities need lots of help. I don't think there is enough money in this room to give these kids all the help they need. However the money that has been raised by this dinner over the last 5 years has brought unbelievable results. To be at the recent opening of the outdoor sensory playground and see kids who probably could never have played in a normal playground, play so well and happily together was just fantastic. So thank you for your support over the many years.

Finally I have told you about a number of Jacqueline's faults and Anne insisted that I had to tell you about some of Jacqueline's good sides. Well that will be easy. Jacqueline is one of the cutest and loveliest kids you will ever meet. We are so lucky that we have her in our lives and because of her I am so much a better person. She is just one of the best mates you could ever have.