

Submission to Family and Community Development Committee

Inquiry into services for people with Autism Spectrum Disorder

Throughout the past 50 years I have been very aware of the lack of adequate services available for people suffering with an Autism Spectrum disorder.

My son was diagnosed with the disorder of Autism when it was described as Kanner's Syndrome. He was a subject of a paper presented by Dr Margot Prior who has been a keen advocate for people diagnosed on the Spectrum. Dr Prior's paper outlined symptoms presented at the time but led to no suggested treatments.

As a family with a son requiring some direction we connected with the Mansfield Autistic Playschool giving us access to their visiting teacher program. This program was a privately organised idea introduced by Dr Joan Curtis. Fortunately this program still exist but the waiting list is extremely long and positions available are limited. I found this program at least a support to me as a parent as they offered an acceptance of the problems my son presented as well as suggestions for ongoing treatment. Up to this point we felt ostracised by the community who viewed our son as a very naughty, out of control and extremely spoilt child.

It is interesting to note that at the time there was only one other boy in this local area who presented with symptoms of Autism.

Throughout his primary school years we hired a private teacher to assist with the little education he could process. If it had been left to the school system he would have been placed in a facility for intellectually impaired children thereby depriving him of the opportunity for further development.

My son, now aged 52years, is continuing an IT course at Box Hill TAFE but still has great difficulty with social skills. He has had numerous jobs but they all come to an abrupt end due either to his social inabilities or to his being subjected to bullying and scapegoating. It has been interesting that he refuses to go on a disability pension as he see this as not appropriate for his condition and it would only give other people another reason to bully him. So he struggles on.

Now I find myself pedalling the same treadmill with my Granddaughter who was diagnosed at the ASD Clinic in Kew by Dr Sally Rigley. This occurred after a wait of over 2 years and at great expense to her family as it involved several trips to Melbourne as well as cost occurred for the consultations.

My Granddaughter has been seen by our local paediatrician. She has had some speech therapy over the past few years but no regular intervention.

Her mother and the headmistress of her primary school applied for a teacher's aide while she was attending primary school but this was declined as my granddaughter's verbal skills were considered too advance.

She has been subjected to bullying throughout her time at primary school and was offered little support from her teachers. Their understanding of this disorder was very limited and they did not have the time to attend to her needs on a one-to-one basis.

My daughter reports: The assistance they received was totally inadequate. During Primary school her daughter needed social pragmatics assistance on a daily basis, the specialist was available monthly. With the current system for the children for the assistance they need parents/carers have to upskill to become the speech pathologist, OT therapist, psychologist and general behavioural therapist. This serves to increase the stress burden on parents. It has been said that the stress of a parent of the children on the spectrum is equivalent to the stress of a soldier in a warzone "The current system increases the parents stress levels and often leaves them feeling extremely inadequate"

This child is now attending High School but is still in a fragile state. Her mother pays extra costs in an endeavour to widen her social skills having enlisted her in Guides, Ballet and Swimming. My Daughter has recently hired a teacher to assist with the learning of basic spelling and vocabulary. All of the above helps with this child's need for socialisation, physical development and general learning and are directly paid for by her mother who is currently on unemployment benefits.

Given my experiences over the years I can come to no other conclusion other than that the resources on offer for these children have improved very little over the past 50 years although many a parent has been crying out for assistance and understanding.

The assistance on offer in the country is on hotch-potch basis. It seems to be available to the children who are on the more severe end of the Autistic Spectrum Disorder.

Maybe this is because they are easier to treat as they are categorised as Intellectual Impaired and can be immediately placed on a disability pension.

Children like my son and granddaughter seem to fit into no category and are there for overlooked in the system being seen as nuisances or just too difficult to manage. The only real assistance they can have access to must be paid directly from the parent's pocket. Even this is inadequate as there are a limited range of resources and practitioners in most country areas.

We need to examine the services available particular in country areas.

At this point in time unless a child is actually swinging from the rafters and causing a huge disturbance they do not qualify for funding in the primary school system. If the child does not qualify for funding they are not able to access any support unit.

The early years of a child's development have been identified a crucial time for the child's future when aid should be applied as soon as possible, As in the cases mentioned above each child had some verbal skills and was there for not able to access any assistance. It would appear that those who can afford services get services or those who live in the Capital city get services. People in the country have to travel to the Capital and can only afford the time and money for intermittent therapy.

As our children leave school and try to enter the workforce they are faced with ongoing difficulties as there is no assistance provided for this transition. A transition that is that is both bewildering and

frightening for these young adults. If by chance they approach the employment agencies they are offered unsuitable employment or are just kept on the books by people who have no understanding of their needs.

Is it any wonder that these unsupported young adults become depressed or so anxious that they withdraw from the community and then, more often than not, enter the Mental Health System where they are given psychotropic medication to control their disorder? At what cost to the system?

In my humble opinion the occurrence of Autism has accelerated alarmingly throughout the past 50 years. When my son was young there was only two boys identified in this area. Now there are numerous cases being diagnosed. This is becoming an epidemic and is costing our communities enormous amounts of money. The demand for services can only increase alarmingly as time goes on and more children present with the condition.

In conclusion I would like to see a huge cultural shift with the acceptance of these children and a substantial increase in the resources available especially to our children in our country areas.

I believe that given the correct support these children can grow up to be valued, respected and productive members of our society.

Carole R Trotter

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