

Submission S108

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Family and Community Development Committee

Autism Enquiry Report

Submitted by [REDACTED] to the

Family and Community Development Committee

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Family Background

I am the mother and carer of [REDACTED]. I am 59 years old and my husband, [REDACTED] is 65. Our only daughter, [REDACTED], was born in 1996. She is 19 years old, has mild to moderate Autism, an intellectual disability and suffered from an acute psychotic episode 6 months ago. She is currently taking anti-psychotic medication.

[REDACTED] psychiatrist ask me to make this submission to the Family and Community Development Committee.

[REDACTED]

[REDACTED]

We live in the Southern Region, City of Glen Eira.

Preschool years - Accessing services and quality of services 0 to 4 years

[REDACTED] milestones were always delayed as a baby. We were told that she had developmental delay but we did not understand that this was a lifelong diagnosis at the time. When she was 12 months old she was diagnosed with failure to thrive so we needed to see a pediatrician at the **Royal Children's Hospital**. The pediatrician noticed when she was 18 months old that her speech was delayed so referred us to a speech pathologist.

The speech pathologist referred us to the **Alfred CAMHS** where she was diagnosed with Autism and an intellectual disability at the age of 2 ½. I believe Alfred CAMHS provided us with a thorough assessment but there was very little follow up on that.

We were then referred to the **Department of Human Services** who met with us once and gave us a list of services to access. After 3 months we received a letter telling us that [REDACTED] would no longer be on their register for services.

Autism Victoria, now called **Amaze**, was my first point of contact after receiving [REDACTED] diagnosis but at the time they were only offering ABA therapy. We decided that this wasn't for us. I saw the social worker there at the time but didn't find that helpful.

As [REDACTED] primary carer it was up to me to research the services list and find an appropriate early intervention program for her as well as any other services she would need. [REDACTED] needed speech therapy but we had to fund this ourselves.

Moira is one of the services that we were referred to by DHS. I contacted them and [REDACTED] was provided with an **Interchange** family. We were ineligible for a case worker and camps because

of this. ■■■ stayed for a weekend a month with her Interchange family who were very supportive of her. They have 3 children, all around ■■■ age. They continued to have ■■■ stay with them until she turned 18. As the children reached their teenage years they had lots of weekend interests so ■■■ lost interest and didn't want to go any more.

The Association for Children with a Disability was a life saver for me. (I researched this myself) It is a service completely run by parents of children with disabilities. They provide a booklet of services called **Through the Maze** and phone counselling. It is run and staffed by volunteers.

Glen Eira City Council provided us with a carer for ■■■ once a month for 6 hours. We still have this service. It is partially funded by the City of Glen Eira. The carer is great and the service is excellent.

■■■ spent a short time at the **Port Philip SDS** early intervention program but the teacher didn't seem to understand Autism so we moved her to **Bayside SDS** which was excellent. After this she attended a mainstream four year old Kindergarten which I had put her name down for before we realized the gravity of her diagnosis. The Kindergarten was wonderful. The teacher there strived to make sure that ■■■ blended in and enjoyed her experience there. ■■■ also had an Integration Aide, who was withdrawn in Term 4 because she was doing so well. I had to appeal that decision to get the Aide reinstated for the final term of Kindergarten.

■■■ also attended a study that was being done at **Monash University**, Clayton. It was excellent and gave us the skills to address ■■■ behavioral issues. It involved a 20 week program where we would attend a group session with a psychologist and have individual sessions as well. Childcare was provided to us. The purpose of the study was for the government to provide support to new parents of an Autistic child. It was only available to parents of children under 5 years. I don't know if this program was implemented. Nobody gave me the information for this. I discovered it myself while researching options for ■■■ and us.

Primary School and Secondary School - Disability service providers and Education 5 to 18 years

As we live in the Southern Region the nearest schools to us were **Port Philip SDS, Katandra Special School and Southern Autistic School**. We visited each one and decided that Katandra was the most suitable option. She could catch the bus when she was older and it was a small school. We also wanted her to attend a local primary school so it was decided that she would go 1 day a week to **Gardenvale Primary School**. ■■■ attended on this basis for a year and one term. The Primary School was great. Her teacher made sure she was included but my experience at pick up and drop off was not so happy. I saw other children teasing her and excluding her. The teacher told me that ■■■ was seeking out adult company at lunch time. Because of her Autism, ■■■ didn't understand that this behavior is not something a person should have to accept.

Katandra Special School was not a happy experience at all. The staff seemed to consider their jobs to be babysitting. ■■■ didn't learn anything at this school. Some other parents and I decided to start a fundraising committee, which didn't exist at the time. The Principal took no interest in what we were doing and only contributed after I notified the Education Department of her lack of interest. We were having various problems with the school so saw the psychologist at the school. The conclusion she made was that we were troublemakers and we should "go elsewhere"

As a result we researched other schools but had to venture out of the Southern Region and out of the bus zone. We chose **Ashwood Special School** where ■■■ began at the age of 5 ½ and continued right through until the year she turned 18. We had an exceptional experience at this school and cannot speak highly enough of the Principal and staff who put so much energy, positivity and their own time into creating an enjoyable learning experience for the children. This attitude also extends to parents and families. The support we have had from the school has been invaluable.

Social Life and holidays

This is, by far, the most difficult area to cope with. We have found it difficult to form and maintain friendships with people from ■■■ school because of the distance. Most of the children at her school used the bus service but ■■■ could not use the bus because we live outside the region. As a result I have driven her to and from school throughout her school years. I taught her to use public transport, when she was ready so she caught the bus for her final school year.

Connecting Teens was a social group that ■■■ attended for teens with Asperger's Syndrome. It was in Ashwood so again we had to travel a fair distance to get her to and from. She cannot attend any more since she turned 18. It is very popular and was started by a parent of a child with Asperger's. Most of ■■■ friends live in the Eastern Region which means it is difficult to arrange outings and requires driving her long distances to and from a friend's house.

Holidays are difficult as we need to take ■■■ with us. Travelling with ■■■ is difficult. ■■■ and I have only had one week's holiday on our own over the last 19 years.

Current experience

■■■ is currently attending a Transition to Work Program at ■■■ in Dandenong on the Futures for Young Adults funding. She is enjoying her time there and has recently completed work experience at Big W. She travels to ■■■ independently. We are very happy with this organisation. It is a very supportive and positive environment. Dandenong is a long way from where we live but the quality of services closer to us was lacking. ■■■ also attended **Yooralla** in the city but she didn't like it.

A closer to home option was **Connecting Skills, Oakleigh** but my husband and I did not think that they would be able to provide the support that ■■■ needed. We have since discovered that some of ■■■ classmates who went there have withdrawn because they were not happy with the service.

I have recently applied for **Disability Support Services** for [REDACTED]. It was an extremely difficult process to go through. **The Department of Health and Human Services** insisted that I have a case worker. My efforts to find one have over the years have not been successful. I insisted on having the application forms sent to me as I am acting as [REDACTED] case worker. There was a 4 week time limit to lodging the application. I had to gather evidence from [REDACTED] doctor, psychiatrist and other organisations within this period of time. We now have a case worker but not without a battle

Conclusion

During the past 19 years our experience with accessing services, information, advice and support has been a lot of hard work, in fact, a full time job for me in the beginning. I am now in that position again as I look towards [REDACTED] future as an adult. [REDACTED] school years were good but I still had to find recreational activities that were suitable.

I found out about these by researching the internet and recommendations from friends.

Dealing with Government departments has always been a battle and there is never enough funding to address everyone's needs. I have been made to feel on many occasions that I do not deserve help from the Government.

The NDIS was hopeful when first introduced but, as usual, there are cuts being made.

I sincerely hope that the Family and Community Development Committee can make a difference to what things have been like in the past.