

Cathy Talia-Parker

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To Parliament Of Victoria  
Family & Community Development Committee.

I am writing to you in order to address the Inquiry Into Services For People With Autism Spectrum Disorder.

First of all, as a mother of a male child with Autism, it was quite difficult getting an early diagnosis especially when symptoms are not as apparent as one would like them to be!

It was only by accident through my then local doctor when I took my son to see him regarding a nasty cold that he had observed more to worry about than I ever had thought! And that's when our long frustrating journey began in the world of Autism!! My son was then 3 years old. After all of our visits to see our local Health and Maternal nurses...Why had not one of them noticed that something was not quite right!? Should they be equipped with further knowledge and skills in relation to identifying any autistic features/traits that babies and toddlers are displaying?? Many mothers that I have come to know have asked the same question! This was and is a problem in the system!

Once referred to a paediatrician, as parents we still feel as though we have entered an unknown world...so many unknowns! The situation isn't completely clear, it only becomes more certain that our children aren't developing in the way that they should be as they grow and as the years progress. There are no real comprehensive answers for us but only suggestions! The parents themselves go on to find and make a plan for their children with very little knowledge! And for us as parents this plan and knowledge mainly developed via the internet. We were hoping that we would gain more knowledge and assistance from Autism Victoria but in the end it was all but very little. At this point unless one is proactive as my husband was then, it was all looking very bleak!

We discovered more about a therapy known as ABA... Applied Behaviour Analysis and how this may help our son and after much research, we made a decision that this was really the only formidable track we could go down! This was the only therapy that showed evidence of having helped children with Autism. There are of course many consequences that come with deciding on this option... the therapy needs to be intensive in the early stages and therefore it entails many hours each week, and it is also a very expensive therapy to take on with very little funding! So the sacrifice of not being able to work for many years so that the therapy could take place, and then it also being very expensive... became a major challenge for us, particularly for my husband being the sole income earner! And of course we had another older child to think about and cater for.

And many of our parents whom have children with ASD struggle with the above now. Many of these parents want to take on ABA therapy and see this as perhaps the most effective way to go, but they can't do so because they couldn't possibly

fund it on their own without some sort of ongoing assistance! This is an area which needs much consideration.

It's a very difficult road for parents and carers once the diagnosis of Autism has been made... it's a very disjointed process to endure many of us have found and still find! We need the umbrella with pathways that lead to somewhere! And perhaps it will be the NDIS that may facilitate this process??

Parents and carers of children with ASD are also faced with the dilemma of appropriate schooling as these children grow. I use the word "dilemma" because it truly can be for many of us! Many questions arise:

\*Where will my child fit in and where will he be understood?

\*Where will he be truly accepted and cared for?

\*Will he be able to go to mainstream school and will he cope?

\*If he does go to mainstream school, will his needs be met?

\*If he goes to a Specialized School, will his needs be met?

\*Which school has the most appropriate resourcing to best facilitate his learning?

And the list of questions continues as our children grow into young adults and have to eventually leave school!

Many parents and carers of children with ASD have great difficulty selecting a school because their children may be higher functioning and so most specialized schools don't suit and can't possibly meet the needs of their children, but then most mainstream schools aren't an option either! These children may struggle socially and their differences being apparent to others may cause division and non acceptance. These children are most likely to be aware of their differences from the outset and therefore the desire to be accepted and to be liked is a major challenge! This being more likely at the secondary level.

I guess that the BIG QUESTIONS here being:

\*Are there enough appropriate schools to cater for ASD children??

\*And can mainstream schools really endeavour to cater for students with ASD??

Many working parents, especially mothers, who want to work and continue their professions while their children with ASD attend specialized schools have also experienced obstacles and continue to do so.

There are no before and after school programs at these schools that working parents can access! Therefore these parents/carers who especially don't have family nearby struggle everyday to work their normal hours in a normal context! This especially becomes even more challenging when our children at their special school don't have transport access/bus access from the school because we happen to have selected a school not within the allocated zone. Remembering that we already have great difficulty selecting an appropriate school for our children as it is!

Due to all of the above constraints, I have not been able to continue my primary teaching profession as I would have liked and hoped!! I have taken up other work that fits within the hours of being able to transport my son to school no earlier than 8:50 am and having to collect him by 2:50 pm every school day. There are people from local councils and agencies that one may access however the consistency of these cannot be relied upon. Our children do not have the

communication skills to be able to let us know if they are not comfortable with a certain person or situation. Therefore, we as parents and carers need to have the reassurance that our children feel safe with the others we are seeking assistance from. This is not an easy thing!

I hope that I have been able to adequately provide you with some insight into the experiences that we have had and continue to have as parents of a child with ASD wishing to provide as much care and support for him as we possibly can.

Yours Sincerely

Cathy Talia Parker