

From: Inquiry into Abuse in Disability Services POV eSubmission Form
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Sent: Saturday, 23 April 2016 12:06 AM
To: FCDC
Subject: New Submission to Inquiry into Services for People with Autism Spectrum Disorder

Inquiry Name: Inquiry into Services for People with Autism Spectrum Disorder

Ms Narelle McCaffrey
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SUBMISSION CONTENT:

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Introduction

Autism is a neurodevelopmental disorder that usually begins to become apparent in early childhood. In essence, the autistic's brain develops differently and can impact on social communication, social interactions, behaviours, and sensory processing.

Approximately 1:100 people have been diagnosed with autism. Males are considered to be four times more likely to be on the spectrum than females. The number of individuals diagnosed in recent years has risen dramatically.

I am an autistic woman, and mother, with three autistic children. Two of my children are school age. They both attend a public mainstream primary school. My 8-year-old daughter qualified for level 1 funding under the program for students with disability (PSD), whereas my 6-year-old son does not meet the requirements for any funding.

Lack of services

Many believe that autism is a childhood disorder, or condition. Others believe that it can be cured. Neither of these are true. From what I have observed, the number of parents of autistic children being diagnosed as a result of reflecting on their own neurology, in the way I have, has been growing. The number of parents and other adults on the spectrum who remain undiagnosed, formally at least, is even higher. This is because the cost of diagnosis is high, and the services available to adults are few. Unless this changes, any data obtained on the number of individuals on the spectrum, is not reliable.

I was diagnosed with an autism spectrum disorder after my two older children were. From the outside, I appear to be a highly functioning, successful person. I completed my secondary education in 1990 and went on to study at university (for many years). I worked for 2 years for a manufacturing company, and then went back to university to study teaching. I taught in a secondary school for 2 years prior to having children. I am now studying a Masters in Disability, in the hope that one day I will be able to re-enter the workforce. Yet, I struggle to organise myself and my family. I have always struggled with this. I am unable to "keep house" well. My children rarely do homework, and are those kids who fail to return notes to school. When I mentioned to an allied health professional that one of the best ways to help my children would be to help me they were confused. No such help exists. Yes, there is now a focus on autistic adults – transition from

secondary school, employment etc., but, what about more practical, in home type services for the (seemingly) growing number of autistic parents? I honestly believe

Education

I am very blessed that the school my children attend demonstrates inclusion for all children as best they can with the funds have (from what I have seen). As mentioned above, my autistic son does not qualify for funding under the PSD due to excellent language skills. The current criteria for funding in the state education system fails to recognise and support that have sensory issues around noise and visual distractions, and who need support to navigate school with extremely high levels of anxiety. While I applaud the current government on steps being taken to create more inclusive learning environments for our children, to say that I am disappointed in the response to the very recent review of the PSD is an understatement. My son, and many like him are at risk of disengaging from school, and unless parents have a large sums of money to pay for supports for their children, this is unlikely to change.

The recent PSD review mentioned the autistic children who do not qualify for funding because of their language skills and it made a number of recommendations. One recommendation that is being funded will supposedly help those autistic children are currently unfunded. The confusing thing is, the money in this package is to be used on language programs. This makes very little sense for a child who already has good language skills. A new PSD funding model was recommended as part of the review. This 3-tier model would provide schools with resources to better support these (currently) unfunded children, yet the government, failed to respond to this. One of the recommendations that had the greatest opportunities to help those who need was not responded to.

Conclusion

There are many autistic individuals who receive no support either in the community, or education. The understanding of autism by member of society needs to grow.

Should you wish for me to comment further, please do not hesitate to ask.

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File1:

File2:

File3: