

Family and Community Development Committee
Parliament House
Spring Street
EAST MELBOURNE VIC 3002

10 April 2016

INQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER

Thank you for allowing me to make a submission on this Inquiry. By way of background, I have one son, Andrew, aged 10 years, who was diagnosed with ASD at 3 years of age. He has attended mainstream kindergarten, with the assistance of an integration aid, for two years before he entered mainstream Primary School. Due to the inability of the State School he was attending to cater to his needs, we have been able to enrol him in a private school, where he is currently in his second year (Grade 4) of enrolment.

I wish to make submission on the following terms of reference points followed by further submission on the highlighted areas:

1. Terms of Reference Issues:

- a. The prevalence of autism spectrum disorder in Victoria;** In observing ASD related issues and media information, it appears that the reporting and diagnosis of ASD is increasing in great frequency each year. As a matter of course with dealing with health professionals, teaching staff and other parents it is very apparent to me that more and more children with diagnosed ASD are attending special and mainstream education facilities. This gut feeling by me appears to be supported by the following data:

“All recent studies support a rise in the prevalence of Autistic Disorder and the combined ASDs over time, especially since the 1990s and this is most likely due to a combination of changing diagnostic criteria and increased public and professional awareness of autism. There are no reliable Australian data on the prevalence of ASDs within Australia is estimated to be 1:160 children. Overseas data indicate that within the ASDs Autistic Disorder is likely to be the most common diagnosis given, while Asperger’s Disorder may be the least common. However given the current controversy over whether Asperger’s Disorder is indeed different from Autistic Disorder and that all children on the autism spectrum are significantly affected in their development.”¹

- b. The availability and adequacy of services provided by the Commonwealth, State and local governments across health, education, disability, housing, sport and employment services. It**

¹ Autism Victoria Professional Advisory Panel Position statement on: Prevalence of Autism Spectrum Disorders in Australia

has been our experience that the Commonwealth services are adequate to Andrew's needs. The State funding for Children With Autism, is excellent and addresses the issues found when an ASD diagnosis is made. This area of funding needs to be kept at or increased in my view, as we have learned by our experience that the earlier the support and intervention commences, the better the outcome may be. To be blunt, \$100K spent at this time and providing support and intervention at an appropriate level will save thousands later on by allowing the child to attend mainstream education facilities instead of special schools etc. Local Government services have not been accessed in Andrew's case and I have to admit, I am unaware of any specific ASD support offered by the City of Greater Geelong.

c. The adequacy of services to be provided under the National Disability Insurance Scheme (NDIS). Andrew was accepted under the NDIS for ASD in 2013. At this time, the support provided by the NDIS is exceptional. What lets this system down is the lack of providers in the supposed network, external to NDIS. While the funding from NDIA is adequate, in our case, the service providers are few and far between in the Barwon area and when found are not easy to connect with or plan extended support allowed for by the Commonwealth funding.

d. The projected demand for services in Victoria. As has been alluded to already, the increases in diagnosis and detection of ASD in children is on the increase and will place more demand on all levels of funding, support and facilities regardless whether they be Commonwealth, State or Local Government areas of responsibility. What needs to be done now is identify an estimated need for the future and plans to fund it with appropriate levels of money, health professionals and facilities.

2. Other Highlighted Issues:

Accessing services and quality of service. Early intervention was handled very well in Andrew's case with all support and advice coming from Gateways here in Geelong. The total package of Early Intervention was a black art to me, and when I went to the suggested authority on advice etc., being Amaze Victoria, I found the total experience with them a failure. Not only could I never get a straight answer from them, the Amaze dedicated contact person was either not at work, sick or had specific workdays and hours. I even tried to join Amaze as a financial member, twice, only to be informed some months later that the membership information had been misplaced or not actioned. If they cannot even control membership, I fail to see how they can offer advice and support to the ASD community in the whole of Victoria. Amaze is also Melbourne centric, although they do deliver training etc. in regional areas, the scope, subject matter and frequency of delivery is no where near the same level delivered in Melbourne.

Services in rural and regional Victoria. As soon as Andrew was accepted under the NDIS, the prices for therapies increased over night. In the Barwon area outside of Geelong, it costs \$180.00 in travel for a speech Pathologist to

travel to Andrew's school to deliver the session. Providers can be choosy in who they take onto the books and it is not uncommon to be told that they are not taking clients at any given time.

Before Andrew was accepted under the NDIS, Bellarine Health was seeing him for Speech, OT and Physio. As soon as he was NDIA approved, Bellarine Health dropped him off their books, and then later attempted to bill his NDIA account for in excess of \$7K for services that had already been paid for. I would bet London to a brick that this type of behaviour would not happen in the Melbourne metro area

Disability service providers. To best explain this issue, in real time, Andrew has access to two speech pathologists in the vicinity of St Leonards Victoria. One in Ocean Grove, 27 km away, and one from Scope 40 km. The one in Ocean Grove is not NDIS approved and is not even taking new clients. Scope is an 80 km round trip for us after school, if the therapist works after 3.30 pm, and cost \$190.00 of Andrew's NDIA funding to get them to travel to his school to deliver the session. Bellarine Health will not even take Andrew on for speech as he is at school and is outside their guidelines.

There are no Occupational Therapists in the ST Leonards/ Drysdale/ Ocean Grove area, so compound the above situation by three and you can see that just to get therapies delivered amounts to an not insignificant amount of the NDIA funding to support the child, just because you live in regional Victoria.

Education. The current practice of support funding ASD students in State schools is flawed. To allow the Principal of the school to have all the say in how the funding is spent is unfortunate. I have found in most cases that the funding has been used to employ a teacher's aid, not specifically for your child and class, and that is the end of any requests from the child's parents. In Andrew's case, Prep and Grade 1, a teacher's aid, on top of the full time teacher, two times a week. Grade 2 and he was level three funded, \$24K per year, placed in a 20 child (plus) class with one full time teacher and one part time teacher two days per week. Any attempt to try and get/suggest options for his education was met with the term "I have the full and final say in how his funding is to be used" by the Principal.

Even during student support group meetings, we found that the funding was not being expended in a fashion that would fully support the child at school. My advice to the State Government is that you are not receiving appropriate outcomes for the taxpayer funding you are supplying to school principals to allocate when and where they see fit.

As a result of the lack of support to Andrew and after being humiliated by the State School teaching staff, we decided to move him to a private school. Please note that then State Government ASD funding for Andrew ceased on the day he moved schools, so he still has ASD, however, you (State Government) seem to think he no longer requires funding support for his diagnosis while in the education system. This, I think is joke. Not only is the funding miss managed at State Schools, it is then removed from the child when you move them to a school that will put the policies and practices in place to support your child through school.

Advocacy Agencies. As with most Government agencies you attempt to deal with, there comes a time when frustration can cloud the real issues. I found

the use of our regional advocacy Agency very helpful when dealing with the NDIA, as it took the emotional investment out of the argument, meant that you could rely on another person to deal with and work through issues and make the whole exchange just that little bit more bearable. If I were to put extra funding into anything it would be into the Rights Information and Advocacy Centre (RIAC) (formerly Regional Information and Advocacy Council) which is a not for profit organisation operating throughout Geelong, central, northern and north-western Victoria providing information and advocacy support to individuals, families, carers and communities.

Thank you for allowing me to make this submission. All the points and comments are mine and I would be willing to amplify any of the points that I have raised if required.

Your Sincerely;

OSB

S. G AGER, CSM

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