SUBMISSION TO THE SELECT COMMITTEE ON AUTISM

Sunday, 1st March, 2020

Submission details

Introduction

I write this submission on behalf of my son, , a 19 year old man with autism, and on behalf our family unit.

It is my hope that our experience as a family can be looked upon not as criticisms of processes and procedures, but as ways of determining better practice in the field.

Sometimes it is said that we should never look back, we should always look forward. We cannot look forward without looking back and learning from the past.

It is also my hope that the joining of our story with the stories of other families and stakeholders might put together the pieces of a puzzle that can be improved upon not only for people today, but also those to come after us; people with autism and their families, carers, educators and friends.

Specifically, I will be covering my experiences and opinions on:

- Diagnosis
- Education
- Housing
- Employment
- Mental Health
- The NDIS/funding/research (mentions only)

Diagnosis

My son, now 19 years of age, was diagnosed as autistic at the age of 4 years and 10 months (15 years ago). As such, I do not feel qualified to speak on **current** diagnostic processes per se. He was diagnosed under DSM IV, which I know no longer applies to diagnostic criteria.

At the time, the waiting list in the public health sector for diagnosis was extreme, and as such my then husband and I decided to pay for a private assessment. It was not cheap. At the time we were a single income family, and the cost was quite a strain on our household finances.

This was our first instance of experiencing the nature of autism diagnosis/support process and practices as being **crisis driven**, which is a term you will see often in this submission.

I speak today, however, about a new diagnosis that I believe needs to be investigated – Pathological Demand Avoidance (PDA)

I have recently become aware of this relatively new profile on the autism spectrum, and believe my son to have it.

First described in the early 1980s in England by Professor Elizabeth Newson, this profile on the spectrum needs to be supported with non-traditional autism strategies. If it is not, the chances are high that the child/adult will develop trauma.

PDA is currently not recognised in DSM V as part of the spectrum, and as such cannot be officially diagnosed. There are currently a handful of specialists in Australia who are what is called 'PDA aware', who will offer a suggestion during assessment that a child might have a 'PDA profile', but cannot give a diagnosis of 'Pathological Demand Avoidance' per se due to it not being officially recognised as a condition.

Through nobody's 'fault' (as PDA is quite new, nobody realised my son had the profile), my son has been incorrectly supported throughout his childhood, by professionals and somewhat by me as his mother. Well-meaning specialists and educators gave us the wrong strategies to assist my son to develop to his full potential.

My son is now a 19 year old young man who is highly traumatised and suffers from mental health issues such as depression, anxiety and anger management. He rarely leaves the house, and will not interact with most people be it family or professionals. He has been so traumatised by not being supported correctly in his formative years, that he trusts nobody, not even me (his own mother). He has withdrawn from society almost completely, will not shower regularly and has very few skills in self-care. Significant mental health issues have formed, as collateral damage from incorrect support strategies for the PDA profile that I now believe he has.

He is very intelligent, but as a result of not being diagnosed as having the PDA profile, he cannot contribute to society in what 'society' deems a meaningful way. He is unlikely to be able to ever get a job and pay taxes. He is lonely. These are the social and economic costs of failing to provide adequate and appropriate services through not recognising PDA as a profile on the spectrum, and my son and our family is just one instance of this. There are so many more out there, you will no doubt read more stories like this.

Under the guidance of professionals who were not PDA aware, I was starting to think that we were not only facing a life of ASD, but potentially one of the more 'scarier' mental health issues as well. In desperation I consulted Google, looking for possible symptoms that might tell me he had Bipolar Disorder, Borderline Personality Disorder, that perhaps he was a Psychopath, or Schizophrenic – because the behaviours displayed in PDA can be very similar.

I no longer consider that he has any of these diagnoses anymore. He is simply part of a cohort of people on the spectrum who have not yet been identified as having the PDA profile, and who need to be identified to be able to receive appropriate supports.

The acknowledgement of the existence of PDA will be most important when it comes to finding and funding supports for the PDA profile under the NDIS, and in the education system.

I include at the end of this submission some links to websites that explain PDA, its presentation, its support strategies and its complexity. (Appendix A) I encourage the committee to visit these sites to learn more about the condition if members are not already aware of its existence.

An injection of funding for research into autism so that PDA can be researched further would also be very welcome.

Education

My son spent his education years in Specialist Setting. This was because mainstream school was not appropriate. However, Specialist Setting was not completely appropriate for him either.

Being diagnosed as ‘high functioning’ (a term which in relation to my son I do find highly inaccurate), he was a student for which there was literally no appropriate setting in the traditional school system, either mainstream or specialist setting. A square peg in a round hole, and there are plenty more like him.

We tried ‘part time’ home schooling.

We tried reduced hours at school.

These and other strategies did not work.

As he moved into his teens, I used to say that on any school night you could look through our lounge room window and think to yourself that ours was a situation of domestic abuse perpetrated by my son towards me, because due to his autism, my son is not able to process his anxieties and he quickly escalates. He becomes verbally abusive, threatens suicide regularly, has been known to throw items around and threaten my safety at times. School was a huge trigger of anxiety, anger and trauma for my son, despite the best intentions of all concerned (including me)

As he became more traumatised through not being supported according to his (undiagnosed) PDA needs, he became more anxious, and the cycle perpetuated itself. We were constantly in **crisis** in relation to his attending school; should I push him to go, should I give him a break, how do we meet the requirement to attend school to a ‘certain age’, without consequences or legal sanctions when he was literally <u>unable</u> to attend on more days than he was able to attend?

Just before he turned 17 (the age at which a student needs to legally stay in school in Victoria), I pulled him out – he’d had enough, and I’d had enough, and the school and professionals we dealt with did not seem able to help.

One of his teachers even said to me ‘The strategies are working for all of the other boys, but not for ’. They simply were not aware of my son’s special requirements for his undiagnosed PDA profile.

I instinctively knew that there **was** a place for my son, which was home schooling. Alas, due to financial considerations (I was by then a single mother), and a fear of being unsupported during the process, it was never to be. I persevered with specialist setting, which ended up causing more problems than benefits because of my son's undiagnosed PDA profile.

There are many autistic children who have the undiagnosed PDA profile who would benefit from home schooling. In fact, they would thrive.

Families do have the choice to home school if they wish, it is the **access** that can be problematic, and usually the problems are financial in origin.

While there are many families who choose to home school their children for reasons other than disability, families of children on the autism spectrum, sometimes have no choice but to opt for Home schooling, either because they see the trauma that the traditional school system causes their children, or their child has encountered so many suspensions that it is no longer feasible for them to be in a 'traditional' school setting, whether it be mainstream or specialist.

As one person I spoke to put it, 'Home schooling is the most expensive private schooling option', because in order to proceed with home schooling a child, you need to stop working and you therefore lose income, but incur the costs that come with home schooling!

It is about the ability to **access to this mode of educating your child**, not necessarily the existence of the **choice.**

As per the Myschools website, I refer to the school that my son used to attend, and note that the funding per child at that school in 2017 (Northern School for Autism) is $48,008 per child. (Appendix B) This is made up of $10,087 from the Federal Government and $37,921 from the State Government.

Perhaps it would be possible for the government to allocate just half of that total amount of funding directly to a family who, through need, must educate their child at home? These children could easily be identified by practitioners who are highly skilled in the diagnosis and support of ASD and particularly PDA, if it were made a recoginised condition here in Australia. With accompanying documentation from these practitioners, these families could qualify for financial assistance in the form of the actual cost of educating a child with special needs, and could do it themselves at home.

This is not asking for more money, it is simply re-allocating it, in fact **reducing** the cost to the government, so that *some* of the family income lost through home schooling a child can be covered and used to purchase home schooling resources, memberships to home schooling networks (which is where a child gets their 'socialisation' through group excursions/music classes/physical ed classes) and other associated costs with home schooling.

I note that the Victorian Government do offer the 'Home Based Educational Support Program' for students who cannot attend regular school, sometimes for reasons of disability. I note further, however, that this program is based on the premise that the student will at some stage be ready to return to school, and as such it would not generally be appropriate for the Autistic student with a PDA profile. Further, the student already needs to be a recipient of funding under the Program for Students with Disability, which may not be the case (see below re the funding criteria limitations)

My son, now a very depressed, anxious and socially isolated young adult is testament to what can happen if a school setting is not appropriate for a student's particular need. He is testament to the need for PDA to be researched and recognised here in Australia, so that PDA can be included as a special Autism profile that requires unique supports within the education system.

I believe that home schooling should be easily accessible to children who are predicted to not be able to thrive in a traditional school setting, right from the start, **not crisis driven** when all other options have proved to be too traumatic to all stake holders. If the parents are keen to engage with their child's education in this way, especially if a specialist has identified the child as one who would not be successful in one of the more traditional settings, then financial barriers to this method of education must be removed.

My own son, once I pulled him out of school just prior to turning 17 years of age (when we were at our worst **crisis stage**), has now taught himself some amazing and quite advanced animation techniques, which in the long term could lead to work as an animator or a games developer. He does not have any 'formal' qualification in these things, he has taught himself the technical side of production. I am certain that he would have been significantly more successful in his formal education had I been in a position to home school him in a relaxed, familiar and individual led environment. He is 19 years old and doesn’t have any kind of formal secondary school qualification, not even a certificate of attainment.

An additional point here about the funding criteria in Victoria for educational supports for Children who are autistic. The Victoria Program for Students with disabilities lists three criteria that must be met to attract funding, one of which is a severe language deficit. This means that those students deemed to be ‘high functioning’ (ie they are verbal), do not succeed in attracting the support funding they need during their schooling years.

We encountered this in 2012, and I attach the transcript of an interview I did on regarding this situation. (Appendix C)

In the end, we needed to apply for funding under the ‘Severe Behaviour Disorder’ category, just so that my son could remain in Specialist Setting for his secondary schooling years. Despite being a parent who constantly tells her son to be proud of who he is, it was **me** that was forced to state that my son was just a ‘naughty boy’, and that his behaviours had nothing to do with his autism, as it is a requirement that the Severe Behaviour issues **are not** related to autism, if you are to be successful in attracting support funding under this category. I still cry when I think that I was forced to do this.

The situation regarding this third criteria still remains – the language criteria is ridiculous and needs to be removed, because it precludes so many students from receiving much needed support (Appendix D). It would also preclude students from accessing the Home Based Educational Support Program mentioned above.

I encourage the committee to research the statistics of funding levels in Victoria across the two categories of Autism and Severe Behaviour disorder over the past few years. It would not surprise me if the Behaviour disorder funding statistics have increased remarkably during that time, because parents and teachers of autistic children have learned that there is simply **no other way**. It’s disgraceful.

Housing

My son's autism precludes him from living in shared accommodation, due to his inability to understand the nature and requirements of sharing accommodation with other people.

Autism is a disability of 'social', and there is nothing more 'social' than sharing living arrangements with someone else. There may also be sensory issues for the autistic person (loud music, loud voices, TV on too much) and challenges in areas that would normally be considered 'cooperation', particularly for someone with the PDA profile of Autism.

Even for 'high functioning' autistic individuals such as my son, sharing a living space with someone else can be too much, and leads to meltdowns, panic attacks and trauma. Their behaviour can in some instances become verbally abusive and sometimes physically threatening towards others as a result of the trauma and confusion that shared accommodation expectations create. Living with other people is simply not an option, unless managed with medication that <u>may not be necessary were they allowed to live on their own.</u>

I am currently in the process of applying for Public Housing for my son as part of forward planning for the future. While not an arduous process, I have significant concerns about the length of time he will need to wait and the quality of the public housing that he will eventually live in. This is because individual housing seems to be in short supply. And options such as group housing are simply not viable for my son.

My son deserves to be able to live on his own, just like neuro typical people can live on their own if they wish. The difference, is that my son will **need** to live on his own, with intensive support through services provided by the NDIS. This should be something that is achievable for him, he has the right to live as he chooses.

Recently a block of land near my place of employment was sold, and the old factory that was on that block of land was demolished. What went up in its place? More factories. The land is huge, literally a three minute walk from a tram terminus, has a bus stop around the corner and is about a ten minute walk to the closest train station. This would be prime land for public housing, but instead it has gone to industry and profit.

The lack of public housing, and the long waiting list is discriminatory towards adults who **must** live on their own. In turn, this means that many families need to keep their autistic loved one at home with them for the long term, to care for them, as the parents/carers themselves move into their twilight years. Further, we also find that those parents/carers are drawing on the welfare system for carers payment/allowance, instead of contributing to the economy through some kind of formal employment. (I am lucky to have an amazing employer who is very understanding of our situation, and extremely supporting of me when I need time off to care for my son)

Surely it is economically beneficial to enable parents who CAN work to be in gainful employment, rather than be at home caring for their adult children with ASD who are unable to work and have nowhere else to live except the family home?

Now lets talk about respite. Again, it works for some, I might actually go so far as to say that from anecdotal evidence I have heard over the past 15 years, it works for most. But not for us. Again, I refer to the PDA profile, where it is more likely that a PDA child will not engage with, let alone thrive, within respite services. I have never utilised respite services while my son was a child, because he would never go, and I (thankfully) never pushed him to go. I was prepared to not have the respite because I instinctively knew it would create more problems for my son than create benefits. Sending him to an unfamiliar place with people he didn’t know, no matter how gently and slowly done, would simply result in the same outcomes as sending him to school. Distress and trauma.

Now that he is a young adult, however, it is not just me that needs ‘respite’ – it goes the other way as well, he needs to have some independence and time away from me too. He is unable, however, to go somewhere else, so **he** needs to stay in the home and it is **me** that needs to leave.

Respite needs to be flexible, particularly when we are dealing with autistic adults who may be ‘high functioning’ enough to look after themselves for a night or two with appropriate supports. It cannot just be about sending the autistic person out of their familiar setting, into an unfamiliar one. Respite can also look like this: the **parent/s** or **carer/s** having some time away.

I am lucky in that I have a supportive partner who does not live with us, and to whose house I go on most weekends for a break for me and a break for my son. Others are not so lucky, and I would suggest a ‘Carer component’ to NDIS plans that would pay for respite **for the parent/carer** in the same way that it is offered for the participant, with the flexibility to include the support workers required to support the participant in their home, while their informal supports are having a break. You can do this now, but not if you can’t afford the cost to go somewhere for the much needed break. This would surely be the case for those families who are caring for their adult autistic children on a full time basis, without the ability to earn money through employment.

Employment

It is highly unlikely that my son will ever work in a traditional job.

He has managed to teach himself several skills (as mentioned in Education section) and if given the chance in the next few years, would likely be well positioned to work from home in some capacity as an animator or games developer, despite having no ‘formal’ qualifications on this.

He is unable to complete formal education, in a TAFE or similar, and is unable to complete online courses because of his Autism with a PDA profile.

Traditional work spaces (offices) and training spaces (TAFE, University) can be challenging for adults on the spectrum, with all of the associated noises, social requirements, timetables, different buildings, team work etc. There of course are some people on the spectrum who can overcome these challenges, but there are many who cannot.

I would love to see a ‘mentor’ scheme developed, whereby business mentors (voluntary or paid), visit young adults with autism in their homes and talk them through how to set up an online business, or teach them skills for online business. It’s the 21st century for goodness sakes, and plenty of people work from home these days, but for autistic people it’s not just as easy as ‘starting up’. They need specialist assistance to do this as they try to navigate the paperwork, tax systems, marketing options etc.

There are plenty of resources in the University sector – assisting someone with autism to set up a business model could attract additional credits for final year business students as an example.

I think of my own son, and I consider how wonderful it would be if he had someone who was able to guide him through things like monetising his YouTube channel, creating more viewers, approaching game development companies, developing a business building strategy. Someone who could show him how these things can be developed so that he can earn money, pay taxes, provide for himself and improve his self-esteem in the process.

Mental Health and Autism

This is our most recent challenge, and I feel very qualified to speak to it.

My son has developed depression, anxiety, some paranoia and OCD. He regularly talks of suicide and tells me that he can’t live this life any more.

I strongly believe that these are not primary diagnoses, but they have come about as ‘collateral damage’ from insufficient supports during his formative years (I note that given his age, he also missed out on the ‘Helping Children with Autism’ package that was rolled out by the Rudd/Gillard government during their first term of government).

However, much like his education, any treatment we have received for his mental health has once again been **crisis driven**. There seems to be little to no preventative measures in place for young people on the spectrum in relation to their mental health.

We have tried: psychiatrists (x2), psychologists (x2), social worker (x1), behavioural specialists (x2), Headpsace and Orygen Youth Mental Health.

It actually distressed me when I heard the head of Orygen on the radio saying that we need to ensure that we catch mental health issues in youth early, so as to prevent suicides.

Why?

Because earlier that week, Orygen staff had been to our house, met my son, made an assessment, and advised that they couldn’t help us; they deemed this a ‘disability’ issue, not a ‘mental health’ issue.

I’m not sure how receiving text messages from your 18 year old son threatening to kill himself, drink poison, or throw himself under a truck can be classed as ‘disability’ more than ‘mental health’.

I’m not sure how the need a few years ago for the CAT team to take my then 15 year old son to the hospital after threats of suicide and harm to others can be classed as ‘disability’ more than ‘mental health’?

But I can tell you that this is our experience, and that this is also the experience of others – just like in education and in housing and in employment, there doesn’t seem to be a ‘place’ for autistic people who are also experiencing mental health issues.

And I note that this has been ongoing since approximately the age of 12. It wasn't an overnight development, we have been in **crisis** with his mental health for nearly eight years, with very few positive gains.

It does not escape me that this is a very complex area, and that the existence of Autism in my son creates a difficult environment for engagement and discussion of mental health issues. I am also aware that his PDA profile is one of the things that are causing him to reject the need for regular medication. Currently, we use an anti-psychotic to reduce escalation when it gets to **crisis** levels, and I am still not completely comfortable knowing that I am in a position where I am actually carrying out chemical restraint on my own son.

However, there seem to be very few crossover areas and specialists that can work with both conditions at the same time. This may be due to the fact that there hasn't been enough research done in this area. It may be because there are not enough specialists available. Certainly it is because there is a disconnect between the sectors of Mental Health and Disability, and this must be rectified.

Further, there is I believe, much scope for the NDIS to move into funding mental health services, to enable continuity of care between specialists. It is highly frustrating to have to repeat histories between providers. A Behaviour Management specialist can be engaged under the NDIS, but when it comes to Mental Health, it's a psychiatrist or a psychologist that is required, which as I understand it, the NDIS do not cover. Additionally, it requires a psychiatrist or psychologist who is proficient in ASD as well as mental health. The pressure that is placed on parents and carers through not being able to access ALL required professionals through the NDIS is extraordinary.

Conclusion

It is often said that if you have met one person with autism, you have met ONE person with autism.

I summarize my points below:

1) It is important to investigate and recognise the PDA profile of autism to allow appropriate diagnostic and support services
2) While home schooling is available as a choice for families, it is the access that is often problematic. Financial barriers to home schooling need to be removed so that families who are prepared to put careers and income on hold to educate their child can easily do so
3) Acknowledge that autistic adults have the right to choose to live on their own if they wish to, just like their neurotypical counterparts. Create more public housing and wider NDIS funding of supports to enable this to occur
4) Find ways to encourage and support meaningful work-from-home opportunities for adults with autism who may never be able to work in a traditional workplace but have amazing intelligence and skill sets to offer.
5) Greater communication between (or combination of) the NDIS and mental health services, which are currently too fragmented and piece-meal.

It is only with appropriate legislation and processes that we can truly accept and support our autistic citizens to live their fullest and most productive lives.

I thank the committee for their time and commitment, and would most definitely welcome the opportunity to discuss our family's experiences in person when the committee hearings come to Melbourne.

APPENDICES

APPENDIX A – Links to information Pathological Demand Avoidance

Pathological Demand Avoidance Australia and New Zealand

http://pdaanz.com/

PDA Society UK

https://www.pdasociety.org.uk/

National Autistic Society UK

https://www.autism.org.uk/about/what-is/pda.aspx

And, if you really want to find out about PDA from an Australian Perspective, there's a conference on in May that you could attend (speaking tour at various venues across Australia)

https://www.hoopdeedo.com.au/?gclid=Cj0KCQiAtOjyBRC0ARIsAIpJyGMAnPkNNEcZzoJL0HeoOOed71InTLZPQpSJzyeMbfLwatr9095__aEaAsBfEALw_wcB

APPENDIX B – The cost of educating a student at the Northern School of Autism (in 2017)

Website Link:

https://www.myschool.edu.au/school/45091/finances

APPENDIX C –

Website Link:

APPENDIX D – The current Criteria for Autism funding under the Victorian Program for Students with Disabilities (please refer to the Autism category)

https://www.education.vic.gov.au/school/teachers/learningneeds/Pages/psdhandbook.aspx#link4

-Submission ends -