

Submission for Inquiry into Services for People with Autism Spectrum Disorder

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Issues relating to

- The availability and adequacy of services provided across health, education, disability, housing, respite, sport and day services
- The adequacy of services to be provided under the NDIS
- The social and economic cost of failing to provide adequate services
- Public awareness and education on autism

I am making this submission on behalf of my two severely autistic sons. I am also making it in the interest of other severely intellectually disabled people with no way of communicating. Neither of my sons have speech or any effective way of communicating.

I can only speak on behalf of the most severely, challenging, autistic and intellectually disabled children and adults. It is important to remember that the autism spectrum includes an enormous variety of characteristics and intellectual abilities. However, around 50% are believed to be low functioning having either no communication or no meaningful speech (only so called echolalia – repeating back what is heard).

My oldest son has intellectual delay and autism, obsessive compulsive disorder and undiagnosed mental illness, thought to be schizophrenia. He is 35 yrs old and lives in care in a flat which is attached to a main residential house. He requires and has a carer at all times when at the residence. 5 days a week he attends a day programme for male clients with severe intellectual disabilities, mainly autism. My oldest son has lived in care for a number of years, since he was barely 17.

My youngest son also has intellectual delay and severe autism. He suffers the effect of severe chronic constipation daily as well. He is 25 years old and lives in care at the same facility and also attends the same day programme as his brother. My youngest has only lived in care since he was 19, which is barely 5 years.

Both have epilepsy.

I will also mention that the boys' father, my husband, passed away eight years ago, so what we deal with we have to deal with on our own. One thing I have realised since then is how mentally challenging it is to deal with major issues without anyone to share them with. I have discovered that even when children move in to accommodation you need to be there for them just as much, if not more, to make sure they are cared for properly.

I have lived with autism for 35 years and have experienced and been through so much over the years I might write a book! These are some of the opinions and conclusions I have come to and comments I would like to make:

- **(b) AVAILABILITY AND ADEQUACY OF SERVICES PROVIDED.**

Education:

The number of autism specific schools must increase.

There needs to be many more autism specific schools for children with low IQ and challenging behaviours.

My oldest son spent 8 years at a residential autistic school, where he was taught virtually 24hrs a day – the staff at the residence followed through the teacher programmes after school till bed time, which meant continuity, which is what autistic children need badly and is not always possible to provide in the home. The children came home about every second weekend and holidays. There is still only one such school in Victoria, with an ever increasing waiting list.

The school is also big on physical activities and offers plenty of opportunity for such, mainly outdoors. It was ideal for our son who was not only challenging, but hyperactive.

This particular residential school saved our family; it would have been impossible for our marriage to survive without the breaks the school gave my husband and I. There should be more residential autistic schools, but there particularly needs to be more non-residential schools for severely autistic children.

To live with a child with severe behaviours is so draining, physically, mentally and emotionally it just cannot be described adequately. To see him or her hurting themselves; biting, hitting their face, head banging against walls, breaking toys, furniture, windows, etc, blood everywhere every other day, is something no one should have to experience.

There must be enough early intervention programmes, for the sake of both the autistic child and their family, to help break some of these absolutely devastating behaviours. Children and families in this situation should not have to be on a waiting list!

Our younger son, whose behaviour was not as violent, lived at home and went to local Special Schools. The autistic school was too far away for him to travel every day and we also felt he might benefit being with children who were not all autistic, but often more social. He spent several years at an excellent Special School. However, as he got older and bigger and he began realising this, the other students, and some teachers, were intimidated by him and he used this to be put outside in the court yard by himself. He spent most of the time in a court yard by himself in the end. Special schools do not have the staff ratio to be able to deal with older students with challenging behaviours, whereas autistic schools have a higher staff ratio. I insisted my son would leave school at 16 instead of 18, which is the norm for special schools, and go to an autistic day programme for young adults a year "early". Initially the Education Department would not agree to move him, but when I mentioned "discrimination", since you would not force an able bodied child to stay at school that long, the Education Department had a change of heart...

A person with disabilities should not be forced to stay at school till the age of 18 if it is not beneficial for him or her. They should have the right to decide if they want to finish school earlier just like any other child. This has to be reviewed if we don't want to discriminate!

However, having said how important it is to have autism specific schools with adequate teacher ratio as well as teachers with adequate autism training, the importance of integration a few hours a week into regular schools for low functioning children cannot be ignored. There are subjects that many severely autistic children would enjoy, such as arts and music and with a capable aid there is no reason they should not have that opportunity. Both my sons were integrated into kindergarten and primary school settings and they loved it! It was, however, a battle to make this happen, but it should not be.

Understandably, children with poor learning abilities have to be in a special school to learn what is appropriate and beneficial to them. However, a special school also enables a special child to pick up inappropriate behaviours from other students.

Besides, ordinary children also benefit from the experience!

Therefore, every autistic child in a special setting should have the opportunity to have an aid to experience being with nondisabled children in their earlier years and have the opportunity to learn social skills.

Words cannot describe how absolutely exhausting it is to live with a child with severe autism like my oldest son. Everything had to be exactly the same all the time to how he perceived it should be: you could not give him a different cup to drink out of, you could not enter the greengrocer's through a back door, you could not take a short cut in the car, etc, etc. All day we were faced with terrible meltdowns and blood pouring from his nose when he would hit it, or from his hand when he would bite it, in frustration. He always had a scab on his hand and his nose still looks like a boxer's nose. The other problem both our boys have is over acute hearing. It would send our oldest son into a rage if the phone rang or if we used any electrical appliance. Imagine the challenge when we had to use the washing machine, electric mixer, hairdryer, etc, etc. Even the sound of scissors when having to have a haircut would send our oldest son into a rage and it used to take four of us to hold him down. In most photos from those days he has long hair. Luckily it was still in fashion with long hair in those days, the eighties!! And did I tell you autistic children are not good sleepers....We suffered constant

sleep deprivation with both our boys when they were younger. We lived on Berocca (high potency, fast acting vitamin B) to counteract the lack of sleep and drinking too much wine, which leads me to the next issue:

Equal opportunity to learn to the best of their ability

One of the major causes for frustration and meltdown is lack of communication. I am not sure whether autistic schools all are lucky enough to be equipped with computers and ipads, etc, like mainstream schools, or not, but I know that there is very little or no interest in trying to teach autistic adults to use computers. Trying to organise this for my sons has been like banging your head against a brick wall. Yet, my youngest son picked up other communication programmes like the Picture Exchange System really easily and I am confident he would be able to use a simple device and app.

Communication is the number one issue that needs to be addressed and would make life much less frustrating for not only the clients, but everyone around them! Something must be done about this.

Finally I want to highlight one common characteristic of autistic people that is very rarely appreciated by the community, including some educators: the distortion of some of an autistic person's senses. He or she may have over acute hearing, which can mean that they can hear something a normal hearing person cannot pick up or that a sound is unbearably magnified to them, for instance a gentle wave on the beach might sound like a tidal wave to them. They can have an over acute sense of smell, and they can also have an under functioning sensory so that they have an extremely high threshold for pain, etc. When recently there was an up roar over a boxlike structure at a place for autistic people, nobody obviously stopped to ask if or why any of the clients there enjoyed it. However, one client responded that he liked and needed being in it at times and explained why. Why do we assume that we who are not autistic are the ones that know how things should be? Autistic people are very different in some ways, but that doesn't mean that is not the right way for them.

My oldest son went through a period when he could only sleep if he had his specially made, super heavy doona – he probably could not feel a normal one and probably felt uncovered and insecure under the light weight of an ordinary one.

Finally, under education I would like to bring up a point that has been upsetting me for a while: there seems to be no requirement for mainstream schools to teach children about various disabilities and the way they affect the person suffering from it, particularly intellectual disabilities which you cannot see like a physical one. It seems that the interest these days is mainly focusing on awareness, rights and respect for the LGBT community!! They don't stand out in the community quite as much as some autistic people do! One of the hardest things over the last 35 years has been trying to cope with rude, ignorant comments from equally rude people and hidden giggles and comments from children. Whilst it is true to say that the general public are much more aware of autism today than 35 years ago, they largely think of autistic people as high functioning with special skills.

More respite services

Respite services are absolutely vital if you are to survive looking after a severely autistic child. What is the option if you have a child with such challenging behaviours that you cannot cope anymore, there is no residential school, as the one our oldest son was lucky enough to attend, and not enough respite services? You have to relinquish your child and the DHHS has to find accommodation "somewhere", rarely suitable, as I understand from other parents. DHS, as they were called, never

had proper emergency accommodation, let alone enough permanent care accommodation. Children who have been given up by their parents tend to “float around”

for a long time sometimes before being found a permanent place to live.

There was not enough respite services when our oldest son was young, a bit better when our younger son grew up, but totally inadequate when he turned 18 and had to access respite for adults.

The last 18 months he lived at home he went to respite twice – one night each time – and I had to drive for about 1 hour to drop him off and pick him up. How can you expect families to cope with such little relief!?

More residential accommodation

Both my sons now live in supported accommodation.

My oldest son, who is the most severely disabled of the two, has not had a problem being granted sufficient funding to remain in his own space with 24 hour staffing.

However, I have had to fight very hard for my younger son to remain in his own separate space.

He lived in a residential unit for 8 clients when he first moved to this place in Red Hill. My son was so unhappy the first couple of years I considered having to take him back home – not sure how I would have found the energy to look after him at home again – because it broke my heart to have to take him back after the weekends; he used to try to get back in the car again with me or even run after the car when I left.

The other clients in the house were also low functioning, non verbal and some aggressive as well. My son has, like his brother, **over acute hearing** and becomes totally stressed out at certain noises and particularly angry voices, even on TV, as well as certain echoing sounds, loud engines sounds, banging, etc.

My son likes his **solitude**, but in a house with clients who do not understand the concept of respecting others’ privacy, it was impossible for him to have the privacy he needs.

It is imperative that people understand that these types of problems are not uncommon for autistic people and if not dealt with properly can have really severe consequences for everyone.

My son was eventually moved to a separate unit and become a happy person again. However, he was only moved to his own flat on the condition that overnight staff would not be provided due to inadequately funded hours at the unit. Instead an alarm, which was connected to the staff sleep over room in the adjoining house, was installed so that if he got up during the night the staff would be alerted. Funding has since been further cut back and I am constantly told that when NDIS comes into effect he might not be able to have his own space at all. In fact the department and the service provider conspired to try to get him into another house with three other clients with particularly challenging behaviours. I made so much noise about it, it has been agreed at the moment to give him enough to stay in his own space! The funding is not ongoing, but reassessed every 6 months

DHHS and the service provider both refuse to understand that his problems are not temporary, but permanent and if he was moved back into a situation where he would have to live with other clients his behaviour would deteriorate and send him back to square one!

My son became incontinent again after he moved into care. I have requested funding (\$8,000) for active night staff to try to retrain him, but the department knocked it back. Therefore, my son who is an obsessive drinker during the day, wakes up every morning absolutely **saturated**. His doona, pillow and often the mat under the bed too, as well as sheets, have to be washed every morning. It is disgusting to let my anyone live like that. If he cannot be retrained someone should get him up to the toilet during the night, and also make sure he has not had a seizure (he has developed epilepsy

over the last 8 months). His doctor requested that he had someone monitoring him all night initially, but this never happened. Luckily, the next time he had a seizure was before dinner and a staff member was still with him and rang an ambulance.

Another issue which affects autistic people negatively is the frequent change of staff in these settings, particularly if a casual staff member turns up who has never worked with a client previously. There is never a proper handover, as in hospitals and age care, because neither the agency the casual worker is employed by, nor the care facility is prepared to pay for an extra 10/15 minutes that it would take to hand over information!

There are thousands of people on the register for supported accommodation, not all autistic of course, but many. It is only that I have jumped up and down so much and begged, lobbied politicians, and threatened that both my boys now live in care. It is also thanks to the fact that I am reasonably capable of writing letters and have a fairly good command of English. It is definitely not luck, as some people have told me! Hard work and stress has got us here. Unfortunately, many families are for whatever reason not able to make so much noise and, therefore, have to cope as best they can with their child at home, sometimes till they are quite elderly. It is appalling that not everyone who needs accommodation have been able to get it.

- (c) **THE ADEQUACY OF SERVICES TO BE PROVIDED UNDER THE NDIS**

From what I have been made to understand from the DHHS and my boys service provider, the ones most likely to **not** have their needs met and adequately funded under NDIS, are people with the most severe disabilities and needs, like individuals with low functioning autism. Totally unfair of course, but in the end what counts it seems, is what someone can bring back to society. Children and adults on the other end of the scale, like Aspergers, can most likely be very useful to society and the economy!

- (d) **EVIDENCE OF THE SOCIAL AND ECONOMIC COST OF FAILING TO PROVIDE ADEQUATE SERVICES**

I have no figures to support my claims, but it should be obvious that when you have a severely autistic child you cannot work full time unless you have other family member to help out. The carer hours we were given were never sufficient to work more than part time. My husband and I never had family to help out. And even if there are plenty of family close by they would not always be able to cope with your child on a regular basis.

Other consequences of inadequate services and support is a high divorce rate within families with autistic children, depression and other stress related illnesses, few opportunities to socialise as it is very difficult to take a severely autistic child to many public and social occasions. Our rather big circle of friends my husband and I had when we were first married dwindled very rapidly after our first son was born...