

## SELECT COMMITTEE ON AUTISM

### SUBMISSION

#### Background

I am the mother of two children, both with a diagnosis on the autism spectrum. We live on the Gold Coast in Queensland. I am an active member and volunteer with Autism Gold Coast (a support group), take part in research associated with autism and have long term ongoing friendships with other parents and carers in the autism community in our area.

My son, (born 2006), has diagnoses of Autism Spectrum Disorder (ASD), Attention Deficit Disorder (ADD) and anxiety. He received his ASD diagnosis in 2011. Because he does not meet the special school eligibility criteria, he attends our local state high school, he is currently in year 8 and moves between special classes and mainstream classes. He has an NDIS plan, which we self-manage.

My daughter, (born 2001), has diagnoses of ASD, ADD, anxiety and clinical depression – she is currently 19 and has only recently received her ASD diagnosis. She is currently studying at Griffith University on the Gold Coast.

#### Education

I strongly believe that we need to provide a more equitable education to students with ASD. Unfortunately, there are shortcomings at all levels of the education system, from the curriculum to the schools themselves and legislation and policy relating to disability.

The current legislative framework in QLD governing disability in education ([Disability Discrimination Act 1992](#) and the [Disability Standards for Education 2005](#)) fails to legitimise the needs of students with ASD, exacerbates stigma and marginalisation of these students and allows education providers to implement a minimum effort or avail themselves of the broad and loose exceptions that are available. It also fails to provide any clear pathways or guidelines for recourse or redress.

#### Issues we experienced – mainstream schools

- Difficulty finding a school that has the ability to accommodate our son's learning profile.
- Our son was rejected enrolment by a private school due to his ASD diagnosis, despite his sister attending that school.
- Little or no understanding of ASD by regular teaching staff, even less by teacher's aides. Many teachers are well intentioned and caring but still ignorant, and too busy, to look at applicable teaching strategies or accommodations. Some teachers were openly discriminatory or abusive (emotionally and physically).
- Many teachers were unaware or untrained in providing strategies or evidence-based practices to assist neurodiverse students learn and navigate the system and if, on occasion, I met with a teacher to try a new method, for example: forewarn him before a transition is made, this would rarely be followed through.
- When my son was in the early grades – in particular Prep through to grade 2, he did not (so much) have meltdowns but withdrawals (eg hiding under the desk or chair or

he would take himself off for a walk) and often, that is where I would find him in the afternoons. Despite my discussions with staff and my concerns, I was made to feel that it was far easier for teaching staff to ignore him, because they didn't know *how* to deal with him and, in any event, they had enough to do with teaching the other children, especially those who wanted to learn. I have often felt that it's a waste of time even sending him to school and, also, that I was letting him down sending him to a place where he did not seem wanted and certainly was not receiving the same education and opportunities as his peers were/are.

- Time and again, I was/am told how difficult he was/is, how disruptive he was/is, how he doesn't want to learn, how he is not engaging with the class - without the school providing assistance or options or understanding. It is hurtful, judgmental and unhelpful. Often, I walk out of meetings with teachers and staff not really knowing what they wanted or expected (given that he had a diagnosis and the school was receiving additional funding for him.)
- Over the years, classrooms have become more inclusive, but the curriculum has not, and differentiation just seems like a paper shuffling process.
- There continues to be a dearth of staff training and implementation of programs and learning systems which address the unique learning profiles of students with developmental disabilities as such, they continue to be marginalised and stigmatised.
- IEP's are a bureaucratic process without intention or meaning.
- Quite often, my son was provided with a teacher's aide for an hour-or-so a week, which (according to the school) constituted compliance with the current policy. This is not adequate and ignores the great ability and potential of my son and many other children with ASD and *totally* fails in allowing them to properly access the curriculum.
- My son was often punished for poor behaviour instead of being taught alternative behaviours and creating, and using, positive learning environments.

Currently, no-one seems to be winning here, especially the students with ASD.

- **Classroom teachers** are overwhelmed, distressed and untrained to deal with the learning profiles of many of these children.
- **Regular students** are being disrupted and bear witness to the trauma these children experience when their needs are not met - as often the treatment of children with ASD is poorly managed.
- **The students with ASD** are being let down by the system. They are not learning to their potential. They are misunderstood and often the victims of emotional abuse and verbal and physical assault.
- **School administration** rely on obfuscation, lack of funding and resourcing to justify their actions.
- **Parents and carers** of children with ASD are left frustrated, unsupported, disappointed and overwhelmed by the thought of any system of redress (and this is on top of the everyday exhaustion and stress of dealing with a child, or children, with ASD).

Further, we can assume that the education system is not working for children with autism when we hear information such as this provided by the Australian Bureau of Statistics (2015), "the unemployment rate for people with autism spectrum disorders was 31.6%, more than three times the rate for people with disability (10.0%) and almost six times the rate of people without disability (5.3%)".

### How these problems might be addressed

- Train or employ teachers and staff with specific pedagogical expertise so that a realistic level of accessing the curriculum can be reached.
- Require schools to implement learning systems that better accommodate the individual, heterogeneous aspects of developmental disabilities.
- Allow for differentiation, interventions that are idiographic in application and support that is associated with outcomes.
- Implement universal design resources to assist teachers with differentiation.
- If the government requires high functioning children with ASD to attend a mainstream school, they need to accommodate them in a functional, realistic and supportive way and legislation (not just policy) needs to reflect that and include options for redress.
- There needs to be some accountability and some realistic data to show that practices are being implemented and are (or are not) working.
- Establishment of a national framework which is instructive in providing equitable education and the use of evidence-based practices.

## **Diagnosis**

### Issues we experienced

- A developmental paediatrician failed to diagnose our son when he was first referred by a GP at 2 ½ years old, due to delayed speech and behavioural concerns. Two years later we were referred back to this paediatrician, following attendances at a university psychology clinic, at which time, my son was given his ASD diagnosis.
- On each occasion, we had to wait up to 6 months for a paediatric appointment.
- There were few relevantly qualified people to diagnose ASD in the area at that time.
- Seeing a paediatrician is costly. Our son has a friend whose parent has chosen not to engage at all with the diagnostic process due to her understanding of the time and initial outlay and ongoing costs associated with ASD and its management.
- The requirements stipulated and the costs associated with proving an ASD diagnosis to NDIA was diabolical. In Queensland, we have always been informed that only a paediatrician can provide an ASD diagnosis but the costs of having this done to receive any funding, for many people, is prohibitive. What's more, how funding is allocated by the NDIA is difficult to understand. I am aware of one family who receives approximately \$74,000 for their son, who also attends a mainstream school (which is fine) as opposed to ours, who receives about \$7,000. Within my own circles it is impossible to make sense of the variability in funding made available.

### How these problems might be addressed

- Develop a national framework as to:
  - available/accepted diagnostic criteria.
  - who can provide a diagnosis.
- Improvements to the ASD diagnosis process. We should strive to implement more reliable diagnostic/assessment methodology.
- Availability and costs of specialists should be reviewed and perhaps some form of standard implemented (recommended)?
- Diagnostic integration with the NDIS.

- Clearer guidelines for parents regarding the diagnostic severity scale (DSM 5) and NDIS funding availability.
- Timely attendance to diagnosis is critical, especially in the early years. Time delays of 6 months are unacceptable, especially at this crucial time of development.

## **Females on the spectrum**

### Issues we experienced

- My daughter began seeing a psychiatrist in September 2014 - age 13 (due to extreme social anxiety and withdrawal) and despite him being informed, on many occasions, that we had autism in the family, she was diagnosed with, and treated for, clinical depression only. Over the next few years, she was prescribed many different drugs and attempted to take her life. After 4 years, we took her to another psychiatrist – she was then given an ASD diagnosis.
- In my view, the original psychiatrist's failure to properly address and diagnose autism, could have cost my daughter her life.
- When my daughter first started experiencing more complex difficulties, she was given anti-depressants and mood stabilisers. It was a struggle for her to articulate how she felt. She was continuously told that once the right drugs were found and her mood improved all would be good so, there was a long period where she was not taught how to respond, behave, socialise and manage ASD symptomology, let alone accessing any evidence-based support/services. She also did not want to draw attention to herself and did not want her school to know she was taking medication for depression. It was a horrible and unbelievably stressful 3 or 4 years.

### How these problems might be addressed

- A complete review of the diagnostic criteria as it applies to females. From my own experience, much more weight should be given to a parents' or carers' observations, especially in their youth when self-management and effective communication and other executive functioning challenges can inhibit their expression of how they are feeling.

## **Government services and the NDIS**

### Issues we experienced

- Support services have improved, marginally, with the advent of the NDIS. Prior, and to a certain extent it's still the case, government services were woefully inadequate. I attended a meeting with Disability Services in Robina, Gold Coast, when my son was about 6 years old to try and find out about, and access, support services and/or funding to attend services. They asked me to bring my son to the meeting. The interviewer went to great lengths to let me know how undisciplined and badly behaved my son was. She did not appear to have any understanding of ASD whatsoever. No funding was provided.
- Even now with some funding through the NDIS, it is difficult, confusing, and we are often not overly confident about the services being provided. In the last 2 years, we have had 6 different LAC's and support co-ordinators and they all tell me something

different about services which I am interested in accessing. There are some very good services, but it feels like it is the luck of the draw.

- It continues to be difficult to understand and apply for services, through the NDIS, which specifically assist people with ASD. For example, speech therapy is easy, but finding support to help build confidence or executive functioning or motivation, seem a bit too far out of the box and services are limited. Every day my son is challenged by social norms and skills that us regular folk take for granted. Furthermore, he lacks the communication, or dialogue, to make people understand these challenges, as a result, he is constantly reprimanded, misunderstood or ignored by adults and ridiculed and bullied by his peers – what supports do they have for that? ..beyond rudimentary social skills groups.
- As mentioned above, there are significant discrepancies as to how much funding individuals might receive through the NDIS.

#### How these problems might be addressed

- Public servants or their contractors, who are deciding on the amount of funding and which services would be appropriate, should have a decent understanding of:
  1. ASD; and
  2. what evidence-based practices would best suit the individual's needs.
- A national framework – which provides clear guidelines as to what supports are appropriate and valid for the different levels of ASD. Including what constitutes Australia's measures of evidence-based practices in-so-far as supporting people with ASD at the various levels and life stages. We need co-ordination and cooperation.

#### **The social and economic cost**

##### Issues we experienced

Social isolation. My children have rarely been invited to birthday parties or social gatherings. Engagement in team sports and sleepovers have been almost non-existent. We have no family close by, so it has led to a very quiet, isolated and insular life. Also, some of the demands of having ASD children, such as being asked by their schools to pick them up early, appointments, and days of sickness and anxiety, made it impossible for me to continue my career. A diagnosis affects whole families.

I just wanted to end this though on a more positive note – people with ASD can be extraordinary. They are society's inventors, scientists, mathematicians, collectors, coders, programmers and artists and, as Temple Grandin says, 'we need all kinds of minds'.

Individuals I know with ASD are successful because of their neurodiversity not despite it. We need to accept them for who they are and see, understand, support and nurture their special skills and abilities.