**Submission No 113**

# INQUIRY INTO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS IN NEW SOUTH WALES SCHOOLS

**Name**: Name suppressed
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# INQUIRY INTO THE PROVISION OF EDUCATION TO STUDENTS WITH A DISABILITY OR SPECIAL NEEDS

## INDIVIDUAL SUBMISSION

### CONTEXT

My son, who turned eight in January 2017, has attended two schools: a local Public school for Kindergarten (2014), and a systemic Catholic school for Years One and Two (2015, 2016). We are now (2017) registered to home-school him, and will be doing so for the foreseeable future.

### DISABILITY DIAGNOSIS

My son went into Kindergarten without a diagnosis. He was diagnosed with Autism Spectrum Disorder, Level 1 on 17th September, 2014.

By the end of 2014, he had developed Major (or Clinical) Depression.

By October 2015, he was again experiencing Major Depression and had been additionally diagnosed with Generalised Anxiety Disorder. He was medicated on the anti-psychotic Schizophrenia drug, Risperidal, later changing to a low dosage of the antidepressant, Fluvoxamine. He continues to take Fluvoxamine.

In January 2016, a Stanford-Binet 5 psychometric test revealed him to be twice-exceptional (gifted and autistic).

In his Individual Adjustment Plan, prepared in Term 3 2016, he was considered to have Level 3 support needs across most domains (Curriculum, Social Skills, Safety, Transition, Personal Care, Collaborative Planning).

### EXPERIENCE

When my son began Kindergarten, he was undiagnosed. Nevertheless, I was proactive and informed the school and his teacher about various anxieties (social and general), phobias (particularly around eating and toileting), and sensory challenges that had been identified during his time at preschool.

As Kindergarten progressed, my son found the increasing academic challenges and social demands of the classroom and playground more and more difficult to navigate. In Terms 2 and 3, 2014 he would come home catatonic, unable to complete basic self-care needs (eating, toileting, undressing) and unable to participate in any social interaction with his two brothers or either parent. At bedtime, he would engage in prolonged violent, self-injurious meltdowns before falling asleep weeping, exhausted. In the mornings, he would violently protest any attempt we made to prepare him for school: his school refusal occurred every morning, and was aggressive, self-injurious, and prolonged. It was underpinned by a growing deep self-loathing at how profoundly he felt he was failing at school.

I brought this behaviour to the attention of his classroom teacher and his Principal repeatedly. I met with them individually, and spoke with the School Counsellor, to make them aware of what we had, with the help of a Clinical Psychologist, identified as the major triggers for his distress (lack of friends, academic rigour, perfectionism and risk aversion, a chaotic playground, and his literal interpretation of rules).

We privately employed an Occupational Therapist (OT) to help our son at home with his fine and gross motor skills, and at school with his social skills. We continued to see a Clinical Psychologist (privately funded) to address his anxieties and behaviours.

The primary reaction of the school was inaction. I was treated as the stereotypical overprotective mother, my concerns were left unaddressed, and my son was left unsupported. My meetings with the Principal seemed ostensibly productive (she committed to mentoring him, and to taking a personal interest in his case since she deemed him a 'gifted under-achiever', an area of interest to her). Yet, these platitudes were never actioned, and my son's anxieties deepened until he slipped into a depressive state.

There existed a publicly dysfunctional relationship between the Principal and my son's classroom teacher (an Assistant Principal). My son's classroom teacher told me that since I had involved the Principal in my son's care, she, his classroom teacher, was unlikely to be able to support my son or me any further. I realised from my interactions with the classroom teacher and the Principal that my son was used as a political football between the two women.

We sought a diagnosis for my son primarily because we hoped that it would force the school to address his needs. It was clear to us that our son was probably on the autism spectrum, but our major impetus for having him formally diagnosed, was the apathy and ignorance of his school.

When we presented the school with our son's formal diagnosis, it was also ignored. His classroom teacher repeatedly and literally threw up her hands and complained she didn't know what else to do for our son: since his behaviours primarily exhibited at home not at school, we should turn our attention to ourselves and stop blaming the school. The Principal refused to support my son when he got his diagnosis: she made it clear that since he was autistic, he was probably not gifted, and therefore of little interest to her. She did not see me or visit my son across the whole of Term 4 after his diagnosis.

We asked for specific triggers to be addressed within the classroom. For example, our son had a phobia of Disney and Pixar movies, which were shown regularly (along with other television shows) to the Kindergarten class. The teacher's response was to remove my son from the main classroom to an alcove leading to the toilet so that he could no longer see the television, although he could still hear it.

We requested that an IEP be prepared to support our son's learning. It took nearly five weeks for it to be prepared, and then it was not actioned. We were never invited to contribute or comment on the IEP, or to see or speak with the Special Education / Special Needs teacher, despite my requests to have her involved in our son's care.

We withdrew our son from school several weeks before the end of Term 4 to protect him from further exposure to the toxic school environment. We re-enrolled him in a Catholic Primary School for 2015, the Principal of which assured us it had a wealth of experience with autism and was committed to meeting his needs. There was involvement from the start at a System level, and we started 2015 with the hope that it would be a new and positive start to schooling for our son.

In Years One and Two, then, my son attended a systemic Catholic Primary School. Whilst we had support from the Sydney Catholic Schools office at a systemic level, and whilst the staff were considerably more knowledgeable and sympathetic to my son's needs, he still suffered another episode of Major Depression at the end of Year One, this time accompanied by suicidal ideations and actions. When I reported his suicidal action (running across light rail tracks) to his classroom teacher, she told me that my best course of action was to ignore him and 'let him try' since he was simply attention-seeking. It was not until we involved a Paediatric Psychiatrist that the school took his suicidal ideations seriously, and not as a conscious effort on his part to elicit sympathy.

It is not my purpose to recount here every detail or criticism of my son's three years of mainstream schooling in NSW. His first school was guilty of gross negligence and failed in their duty of care to my son; they certainly did not adhere to the Education Standards of the DDA. The same charge cannot be laid against my son's second school. Yet it was in that Catholic Primary School that I witnessed firsthand several concerning trends that seem to characterise mainstream ‘inclusion’ of children with special needs and disabilities. These are listed below.

## CONCERNS

1. **Lack of staff education.** The one constant in my son’s experience of schooling is the lack of education and knowledge of the staff in whose care he was. Even staff that were ostensibly special needs trained, or had had previous experience teaching children on the autism spectrum, had very limited, stereotypical, and ill-informed understandings of autism and its impact in the classroom. There seemed little understanding of the strong connection between sensory needs, anxiety, and autism. Recommendations made by an Aspect Educational Outreach consultant were ignored because the reason for their implementation was not understood. The importance of preparation and consistency was either not understood or ignored. Many staff felt that if they had taught one child on the autism spectrum, they were then qualified to teach any child on the autism spectrum, without acknowledgement that the autism spectrum is so broad that each child needs individualised attention. It is of paramount importance that, if schools are to be genuinely inclusive, a much deeper and more nuanced understanding of autism needs to be acquired across staff.
2. **Reactive, ad hoc, and incomplete interventions.** Most interventions suggested by the school were put in place ‘after the fact’ in a reactive fashion, and were only implemented in an ad hoc way (that is, only occasionally, or only in particular circumstances and contexts). Not all staff were informed of interventions, so that continuity was not assured across teachers and school contexts. Often when classroom teachers were ‘too busy’ or there were changes to routines (school Masses, for example, or the Athletics Carnival), expectations were changed and interventions were suddenly withdrawn. Interventions were often put in place only to be ‘withdrawn’ or ‘discontinued’ without reason or closure. For example, a rewards system suggested by the Aspect Educational Outreach consultant was terminated without warning because my son, apparently, had ‘lost interest’; no system was suggested to replace it. Or, the goals attached to a reward system were changed, but my son did not understand the changed goals and so suddenly stopped ‘earning’ his rewards. Proactive interventions suggested by professionals (such as mandated, regular ‘legal’ breaks) were often implemented for a short period, and then withdrawn when progress was made. Rather than seeing such proactive interventions as ongoing needs, they were often removed as ‘having worked’. Of course, my son’s behaviour would deteriorate after the removal of one or other of these proactive measures, and the school would again implement a reactive intervention.

3. **Speed and inconsistency of delivery**. Although many of my son's needs were time-sensitive, and needed immediate attention, often interventions and changes took weeks and even terms to implement. Indeed, on three occasions, my son's Individual Adjustment Plan (IAP), ostensibly written in Terms 1 and 3, were not completed until Term 2 or 4, meaning that their proper implementation was almost impossible. When professionals recommended certain interventions, the school would take weeks to respond to those recommendations, and further weeks to implement them.
4. **No accountability for follow-through.** My complaint that interventions and supports for my son were reactive, ad hoc, incomplete, inconsistent, or slowly delivered in part stems from the fact that there is no accountability at a school level for the implementation, or lack there-of, of specific supports. Although I would ask the staff to commit to (a) a person responsible for implementation, and (b) a timeline for implementation, the school often would not comply. Even when a particular staff member committed to taking responsibility for implementation, there was no consequence for failure to follow through, except my complaint (at both school and system level).
5. **Individual teacher based.** The success (or lack thereof) of my son at school was intimately tied to the individual in whose care he resided. When procedures, processes and approaches are left to individual teachers, rather than effected at a school or systemic level, success is left to chance. Without strong leadership from the Principal and the System, individual staff are given too much power to make those ad hoc decisions which often adversely impact children with additional needs.
6. **Least qualified teaching most difficult**. Although my son is twice-exceptional and gifted, he also has significant learning difficulties, particularly in reading and writing. Although the System allocated complex needs funding to my son, the school used that funding to allocate him a Learning Support Officer (LSO). My son is unarguably a very challenging child to teach, and yet his learning was most often entrusted to untrained and unqualified LSOs. The net result is that they could not teach him, and ended up as babysitters, removing him from the classroom, and doing his work for him. This year during home-schooling, I have identified many significant gaps in his learning that suggest that my son is still working at an Early Stage One level, despite his giftedness. This is at least in part because my son was permanently attached to carers who were not trained to teach him at school, and his teachers abdicated responsibility for his learning while he was in the care of the LSOs.
7. **Universal Design for Learning (UDL) and Differentiated Curriculum not utilised.** In no classroom have we experienced or witnessed UDL or a genuinely differentiated curriculum to support my son. He was often withdrawn from his classroom but was not engaged in learning in a meaningful way. His giftedness was not addressed,

nor was he given any provision for his learning disabilities in terms of differentiated assessment or adapted ways to demonstrate his learning. Given the prevalence of neurodiversity in mainstream schools, education in UDL and differentiation is paramount to successful inclusion.

8. **Staff resistant to accepting parent reports and expertise**. My reports of my son's behaviours at home were invariably met with disbelief. Since he did not behave at school in the ways I recounted he behaved at home, both schools implied that I was exaggerating his behaviours at home. Anecdotally, it is a prevalent trend in autistic children to 'keep it together' at school, only to 'fall apart' in the safety of the home environment. Parents should be trusted and believed, even when their reports are inconvenient and require school action. Equally, parents' expertise in their own children should be trusted, respected, and deferred to. My expertise in my child (for instance, understanding that his suicidal ideations had moved from 'attention-seeking' to something far more serious) was often undermined, albeit couched in the patronising platitudes of being an 'overly good' or 'rightfully anxious' mother.
9. **Diagnosis-centred.** The schooling system is inherently 'diagnosis' and *not* needs-centred. My son's needs remained the same throughout his time in mainstream schooling, but it was only when more and more formal diagnoses were amended to his file, that he received the support he needed. His needs have always been complex; we have also always made sure each school was aware of our professional team's recommendations to support those needs. It was only when a formal diagnosis was given, however (for example, Generalised Anxiety Disorder), that his needs were taken seriously enough to be addressed in the classroom. This diagnosis-based criterion for funding is both limited and outdated, especially given the NDIS's new focus on needs-based rather than diagnosis-based funding.