

Submission
No 108

**INQUIRY INTO THE PROVISION OF EDUCATION TO
STUDENTS WITH A DISABILITY OR SPECIAL NEEDS**

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Strive

Families Supporting Families Coping with Autism

Submission to the

NSW Parliament General Purpose
Standing Committee No. 2

Inquiry into the

“Provision of Education to Students with a Disability or Special
Needs”

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**Submission to the NSW Parliament General Purpose
Standing Committee No. 2 Inquiry into the
“provision of education to students with a disability or special needs”**

Overview

We welcome the opportunity to present a submission to the General Purpose Standing Committee No. 2 Inquiry into the “provision of education to students with a disability or special needs” on behalf of the *Strive Autism Support Group*.

Who is Strive?

The Strive Autism Support Group (based in the lower Hunter Valley, NSW) was formed in 2007, by a group of dedicated parents of individuals who have a diagnosis of autism or Asperger’s Syndrome – both forms of Autism Spectrum Disorder (ASD).

We are therefore key stakeholders able to bring a unique and personal insight into this discussion.

What is Autism Spectrum Disorder (ASD)?

This umbrella description includes autistic disorder, Asperger’s disorder, atypical autism and PDD NOS. Autism Spectrum Disorders are lifelong disabilities that affect the way a person communicates and relates to other people and the world around them. People affected by autism typically display major impediments in three areas: 1) social interaction, 2) communication, and 3) behaviour (e.g. restrictive interests and repetitive behaviours). There is no cure for ASD, however, a child on the Autism Spectrum can become higher functioning and enjoy an improved quality of life through advanced behavioural interventions and educational solutions. Therefore, education solutions for ASD children are of central importance to improvements in the life long battle with the condition.

The exact numbers impacted by ASD are unknown, due to problems with measurement (many on the Autism spectrum present with other issues) and detection (diagnosis can take up to 2 years once investigation begins for some, with only around 60% of those with ASD diagnosed by age 5). However, a study commissioned in 2006 on the prevalence of Autism Spectrum Disorders, concluded that around 1 in 100 Australian children has a form of ASD.¹ This study is now 4 years old, and reviews data, that is 7 to 9 years old so the current number is likely to be greater than this.

¹ Bob Buckley - Computational Genomics Laboratory, John Curtin School of Medical Research, The Australian National University 2006.

This works out to be more than 12,000 children (aged under 18) in New South Wales alone or around 1,100 in the Hunter Valley (when looked at in isolation).

Although one umbrella label, ASD is used to describe these individuals, they are all different. Common attributes may be present (including sensitivities to noise, light and textures, social developmental delays, speech delays and literal interpretations) but all individuals on the Autism Spectrum are unique. You only need to sit in on a class of ASD students to see this first hand. Whilst many will be able to achieve independence, approximately half of all those affected with ASD will need assistance for most of their lives. These children and their families have a lifetime need for care and support. The level of care required may be reduced by educational interventions and support that are effectively delivered to assist students to reach their highest potential.

ASD has greater prevalence for those aged under 18 than does cancer. ASD is a defining health epidemic of our time, calling out for visionary solutions.

How this Strive Submission can assist you

The General Purpose Standing Committee (The Committee) No. 2 has been formed, amongst other things to review the adequacy of funding for children with a disability or special needs (such as children with ASD) attending NSW schools. In particular:

The Committee is to (amongst other issues) look at:

1. Whether a student's funding allocation should be based on their functioning capacity rather than their disability;
2. The level and adequacy of current special education places;
3. The adequacy of support services for children with a disability in mainstream school classes;
4. The provision of a suitable curriculum for intellectually disabled and conduct disordered students;
5. The level of access to professional support services, such as speech therapy, occupational therapy, physiotherapy and school counsellors;
6. The adequacy of pre-service and post-service teacher training;

A society is truly judged by how it treats its disadvantaged (including those who are disabled). All children are deserving of and entitled to an education. ASD children are deserving of the same educational opportunities as all children, independent of where they live and how their disability presents.

As parents of children on the Autism Spectrum, we want for our children an independent life, free from welfare dependence and full time care. The key to this, is an education delivered comprehensively and in a timely fashion, whilst our children are still young.

We, as representatives of families (including parents, carers and teachers) seek a voice in the formulation of policies and allocation of funding for resources for the education of children with ASD.

The level of NSW State Government resources made available to provide Educational Support for Children with Significant Learning Difficulties, including children with ASD, is clearly inadequate to deal with the task. This position is supported by the Teachers Federation, the Federation of Parents and Citizens Associations and the Parents Council².

A number of parliamentarians are also on the (recent) record echoing that services are woefully inadequate, including The Hon Robyn Parker MLC³.

The Issues being reviewed

We now take the opportunity to present our perspective in relation to some of the key questions posed by the committee.

1. Whether a student's funding allocation should be based on their functioning capacity rather than their disability;

Those on the Autism Spectrum possess a wide range of abilities. Some are more high functioning than others. Programs and supports must be tailored to the capacities and needs of the child. No one strategy or solution fits all ASD kids. The needs and skills of children vary considerably, and no one program will fit every child. Therefore, a capacities based funding allocation is the way forward.

Accurate assessment of students' ability to function in classrooms can only be accurately determined by contextual observations over a period of time. A diagnosis alone (whatever the area of special need), does not provide the individual, case-specific information required to determine appropriate funding allocation. Accurate evaluation can only be made after a thorough, setting-based analysis with input from all parties- family, teacher, support workers, advising professionals, etc.

The difficulty both government & non government main streams schools face with this capacity based approach, is that it is very time consuming and hence perceived to be costly. However, specialist ASD professionals that can support teachers, teacher's aides (in class shadows), parents and students directly in a meaningful way will lead to greater inclusion and ultimately greater achievement by students⁴. These professionals can assess students, monitor and change programs (on a weekly basis if needed) to provide greater flexibility. If enough appropriately skilled professionals are provided in schools and resources are properly targeted to the needs and capacities of students then ASD students can be better supported.

2. The level and adequacy of current special education places;

It is recognised that one-on-one intensive intervention is the ideal teaching setting for children with severe autism⁵. However, specialist units with limited class sizes and additional supports are valuable for all children on the Spectrum, particularly in the early years of a child's life. Currently there are insufficient places available in specialist units and insufficient suitable placements, resources and supports within the mainstream environment for children on the spectrum.

² Hansard 25th September 2008, NSW Legislative Assembly.

³ Hansard 25th September 2008, NSW Legislative Assembly.

⁴ Tony Attwood, Asperger's Syndrome: A guide for parents and professionals, pg174.

⁵ per the Hon Helen Westwood - Hansard 25.9.2008.

In terms of the level & adequacy of places, we quote the Hon Robyn Parker from 2008.

"Families need this assistance not just in Sydney, but in outer metropolitan areas and right across New South Wales. The number of public school students diagnosed with autism has risen by 65 per cent in the past three years in New South Wales"⁶.

Have the resources allocated to ASD students increased in real terms by 65% over the past three years?

Most children diagnosed with ASD are currently schooled in mainstream classes. In the Hunter Valley, the peak provider of special educational places for ASD children is ASPECT. The Hunter ASPECT Base School & associated 7 satellite schools can only offer a total of around 80 places for children in infants and primary (K-6) and no high school places. This is woefully inadequate given the 625,000 + total population base of the Hunter Valley⁷.

This means that the vast majority (over 90%⁸) of the approximate 1,100 school aged ASD children (in the Hunter Valley) are schooled in mainstream places.

All children have the right to an education and all children can learn. Children are individuals with differing personalities, needs, wants, interests and levels of development. Children learn in different ways and at different rates and benefit from programs based on individual needs. Children should have access to appropriate assessment and intervention at all levels of schooling.

3. The adequacy of support services for children with a disability in mainstream school classes;

The particular behavioural and environmental issues faced by ASD students, requires that they be given task appropriate resources within a suitable classroom environment, to level the educational playing field. Just as physically disabled students in wheel chairs for example need ramps to access class rooms and desks appropriate for their chair needs, ASD students require appropriate physical spaces within classrooms, to factor in their special behavioural needs and sensitivities. If these needs are not addressed in mainstream classrooms then education is not fair for all. Just because our children at first glance appear like all other students, doesn't mean they are not in need of special attention.

Our ASD children occupy classrooms marked by bright lights, and screeching sounds. They find it difficult to sit for periods of time and can struggle to focus on goal directed activities. They seek out repetitive activities, to calm and sooth their behavioural needs. They feel the need to break learning patterns with firm physical inputs (pressure related physical activities).

⁶ per the Hon Robyn Parker - Hansard 25.9.2008.

⁷ The Hunter Economic Research Foundation states around 100,000 students in the 2008/09 study using 2006 census data - in Hunter Valley schools alone (year 12 or lower).

⁸ Based on a NSW state-wide, ASD school age population, prorate for the Hunter Valley for population, based on around 1,100 ASD students (year 12 or less) in the Hunter Valley.

Due to poor or simplistic communication tools, these ASD children can't always communicate their feelings, stress levels or needs. This can manifest itself as increased levels of anxiety and frustration and ultimately lead to poor educational outcomes.

There are experts in the ASD field of education that stand out in providing supports to ASD students in classroom environments. Those like Sue Larkey, offer practical supports to families, students, siblings, teachers & schools. Fidget toys, wobble seating, electronic timers, and the like can all assist, but are useful to differing degrees to different students. Others experts including Tony Attwood provide useful advice to assist families and professionals in meeting the needs of ASD students. These practical supports and ideas need funding to be implemented effectively in mainstream classrooms.

A neurotypical student is provided with every opportunity to learn, including a chair, a desk, legible text books, clothing appropriate for the assigned learning environment (including safety equipment), and a learning environment relatively free of directed stress. An ASD child, who struggles with basic tasks such as communicating unaided, when placed in an environment where the resources supplied are unsuited or inadequate for them, will exhibit higher stress levels and lag in achieving learning outcomes. If they can't sit and be engaged to concentrate, in a stress free manner – how are they expected to learn.

This requires flexible leadership in schools to adopt lighting, noise, timing, real time feedback, and instruction delivery changes.

4. The provision of a suitable curriculum for intellectually disabled and conduct disordered students:

Curriculum needs to be sufficiently flexible to empower teachers to meet the needs of students. A curriculum focussing on "core" life skills for those with ASD, with elective modules for other interesting areas (such as technology, photography, routine strategies), would be more appropriate for some ASD children.

Considerable effort is invested by families and professionals in developing family action plans. The family action plans need scope to be to be implemented in a classroom, with curriculum flexible enough to support this. Sufficient supports need to be provided including ongoing professional advice to support the learner and their families in implementing their action plans.

Some children on the spectrum have particular difficulties with communication. In particular they may have difficulties with the language of the complex and abstract concepts often found in mainstream curricula. They do not have the language to comprehend these global concepts.

In explaining 'big picture' concepts the words are very important. For example words such as "global warming" and "green house effect" may be misinterpreted by many ASD students. ASD children can indicate, when asked, that they understand what a green house is, but they may understand it as a house that is green in colour not as a building to facilitate plant growth. Their understanding may be extremely literal.

The even more abstract concept of a greenhouse effect as it relates to global warming is lost on these students completely. These children require substantial extra supports to even begin to understand these more complex concepts.

Targeted curriculum and programs (in some cases - one on one) that give students an understanding of concepts that are relevant to their lives are vitally important. Whilst relevant curriculum is available in a number of subject areas in the form of life skills courses, teachers must be more effectively supported in terms of additional time and expertise available on an ongoing basis to effectively implement these courses.

5. The level of access to professional support services, such as speech therapy, occupational therapy, physiotherapy and school counsellors;

The integration of occupational therapy, physiotherapy and other professional supports in the planning and implementation of class curriculum is essential to make sure the child is there - in the room mentally not just physically. Professional support services are gatekeepers who possess practical solutions to level the educational playing field for ASD students. They should be an important adjunct support for the teacher in the classroom.

The Denver Model (play-time) early intervention approach for younger ASD children, shows how by taking the lead from ASD children, looking for those things that they passionately play with and loading up educational objectives onto that play time platform, that significant improvement in ASD Children functioning can be achieved.

To allow primary school children to take the lead & follow up, requires intensive shadowing at the very least, or one-on-one teaching supports to enable this strategy to work. Mainstreaming with poor to no support makes this winning Denver model style unattainable as a useful teaching strategy. ASD children can not be taught as if they are 'slow' – delayed learning neurotypicals. They have unique learning needs.

There are some private schools operating (such as that in Baulkham Hills – Sydney) which work on a one-to-one teaching basis, but has private annual fees (effectively) of at least \$36,000 p.a. - well beyond the reach of all but the wealthy. Tailoring schooling strategies to ASD children will be expensive, for society. Just as ensuring schools are sensitive to the needs of Aboriginal children, or those operating using wheel chairs or with sight impairments, are justifiably expensive. Given the prevalence & scope of the ASD issue for schools, and the growth in numbers being experienced, we call for fair treatment for ASD children, for fair learning opportunities, despite the costs involved.

6. The adequacy of pre-service and post-service teacher training;

Specialised training and ongoing support for teachers is the only comprehensive answer. Providing already overworked teachers with more general information on ASD, is not resourcing the teacher to deliver the learning outcomes to the student. The goal of mainstreaming ASD students is a poor goal, when the specific one-to-one supports are not available within the mainstream classroom.

Teachers can and do develop a kind of fatigue in relating to ASD children in mainstream schools, as they themselves have inadequate time, lack resources specific to ASD children needs, and face massively increased paperwork associated with having an ASD child in their mainstream class.

Merely empowering a general teacher with an information day is paying lip service to the real & particular needs of ASD children. Specialist ASD teachers build up, through constant exposure to ASD children (in classrooms) over many years, an invaluable experience that is lost when spread too thinly. That resource should be concentrated for maximum effect. A mentoring support service that allows mainstream teachers access on a regular basis to a teacher experienced in this area can greatly increase the effectiveness of the classroom teacher.

Comprehensive pre-service and post-service teacher training that promotes inclusive, integrated approaches to student development and engagement in learning gives teachers the awareness, skills and confidence required to successfully support the integration of students with special needs.

In-school placements provide invaluable experience that cannot be drawn from textbooks and lectures. Learning to be preemptive and identify when children are beginning to feel stressed or confused so you can support them appropriately *can only be learnt in classrooms, working closely with children.*

The feedback loop between the child's family and teacher needs to be much shorter for ASD students (when compared with neurotypical students). Teachers need time allocated during working hours to enable them to make contact with all stakeholders, including parents, professionals and mentors regularly.

ASD children are different ability children, usually with a learning delay but where they receive appropriate teaching (targeting their capacity constraints) they can and do become high functioning, in learning environments. They are not to be written-off as too hard, and chronically under funded, for their specialist education resource needs.

Some of the struggles from our members

Almost all of our membership has personal examples of the struggles, in seeking out a fair and equal learning opportunity in the formal NSW education system, for their children on the ASD. Here are 2 representative examples (of the many we are confronted with) of the challenges they and their families face.

Example 1

".....Our son Lucas is 4 years old (diagnosed with classic Autism and anxiety syndrome), he is now attending Aspect at one of their Hunter Valley satellite classes. Last year when he turned 3 we went to enrol Lucas in our local pre-school , as we live in a rural area we only have one preschool and it is community run. At that time we were in the process of getting Lucas tested as we had an idea of what he was suffering from but no formal diagnosis, and because this was the case ,our local preschool informed us that our son was not able to enrol because they could not apply for funding for a teachers aide until our son was formally diagnosed.

The reason being that they did not have the capacity to look after a child with autism without a supporting aide. This is just one of the many hurdles our children face every single day of their lives. They not only get excluded from something so simple as being able to go to preschool but also the teaching staff and aides are not even trained to understand and work with children with Autism.

As a parent of a child with autism it is so terribly important that our children be treated and understood in the best and most positive way because every little bit of intervention that they receive makes such differences in our children's outcomes.

We are all told by our specialist doctors that our children need at least 15 to 20 hours of intervention a week but that is in reality impossible because all early intervention programs only offer you 2 hours a week, after which you have to send your child to a mainstream preschool, school, high school.

Where they are taught by teachers who really have no formal training in Autism and likewise with the aides and that is if the aide is not shared. Imagine just for one moment, a day in your lives where everything you did not come naturally to you, where voices ,the humming that electricity and lights produce caused you actual physical pain and what you take for granted as mundane everyday actions were no longer that easy to complete let alone understand why you had to do them. Our children face this everyday of their lives and that is why they need so much of us and of you and our education system....."

Example 2

".....Our journey has been a long road from our initial thoughts that our child may have a disability. Our GP guided us to a paediatrician and many consultations and opinions that have varied from professional to professional.

The timing was critical; waiting lists to see professionals became drawn out. Eventually in our first meeting, we were told that our child had a problem but he didn't really know what to say, we would have to see a specialist in the field of the Autism Spectrum. This next meeting was a disaster with our child not complying in the confined doctor's surgery and still a clouded version of a diagnosis. We were referred to a clinical psychologist. The Doctor said he would be able to confirm a diagnosis.

After months of stress of unknown of how we were going to deal with this new problem in our life, we were given the diagnosis that stands today and our son is now five.

Great we now have a diagnosis so the journey begins. Months on waiting lists to see speech pathologists and Occupational therapists who are not located in our immediate area highlighting the need for greater physical access to more specialists in the local area.

We started on a waiting list for Hunter Prelude (Kurri Kurri early Intervention program) eventually gaining a place making progress with only 2 hours a week. The staff were wonderful but our child turned three and was not able to stay, progress halted again.

As most people with a child on the spectrum are aware this is the critical time for these children. The local pre-school was selected because of the size and open space in the play area. The aid at the school had no training on dealing with children on the Spectrum. Visual cards were introduced but on many occasions were not used by the staff even after they were trained on how to use them. Intense individual speech therapy introduced the visual system.

Our son started Early Intervention placement at Aspect Hunter Base School in Shortland, some 50 minutes from Cessnock (where we live and work), with access to 2 hours a day two days a week. I had to give up my work for this travelling.

It was a wonderful program and our child started to make progress in the system. Our thoughts are if he had more hours this would have been a big benefit. Our child has continued his schooling with Aspect in a satellite class 20 minutes from our home and he has settled, making steady progress.

Two years ago I founded a support-networking group in our area, STRIVE. It now supports over 100 members. I am always talking to parents with children on the Spectrum about concerns with the public systems lack of supports for children with specialised learning needs. Feedback from parents indicates that they would like their children to attend Aspect schools but can not afford the fee's.

We are still on a waiting list for speech therapy at Cessnock public hospital which has been about 2 years. 18 months ago I sent paperwork into DADHC which after numerous follow up calls and one interview was told that our file had been misplaced. We have since moved on to private speech therapy.

The common theme from the start our journey, which has not changed, is the lack of services available for parents like myself with a child on the Autism Spectrum. The next problem we are about to encounter is the transition from Aspect School which will end at 8 years to a public/private school that will accommodate our child and how we are going to source an aid as we continue the journey. We would like to continue the Schooling with Aspect but this School will be 50 minutes from our house. I would have to again give up work to make this happen and I would not be able to pick up our daughter from a Cessnock School....."

In conclusion

We want a fair go for ASD children, in the educational environment. Now representing over 1% of the school population, these uniquely challenged members of our society, demand equal access to educational opportunities. This can lead to the development of pride in work, excellence, and independence.

To properly address the needs of ASD students requires specialist teaching supports, delivered at all levels of education (pre-school, primary & high school) using flexible curriculum (applied on a capacity basis and targeting specific student needs).

To become high functioning, contributing members of society ASD students need help and constant support early on, else they and their families face a lifelong dependency on care.

Help our children to become high functioning and valued members of society.

Submitted by

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most welcome to attend.