

Submission
No 379

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

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**Submission to
General Purpose Standing Committee No. 2**

**Inquiry into the provision of education to students with a
disability or special needs**

Autism Aspergers Advocacy Australia (known as A4) thanks the Committee for this opportunity to raise the concerns of our members over education for students with autism spectrum disorders (ASD).

A4 advocates for people with Autism Spectrum Disorders (ASD). ASD **all** involve, according to the diagnostic criteria, “severe and pervasive impairment”. The ASD group of diagnoses includes Autistic Disorder, Asperger’s Disorder¹, Atypical Autism (from the ICD-10) and Pervasive Developmental Disorder – not otherwise specified (known as PDD-NOS). It can also include Childhood Disintegrative Disorder.

Data from Centrelink Carer’s Allowance registrations shows that over 1% of school students have been diagnosed with ASD. Each the diagnosis of Autistic Disorder or Asperger’s Disorder was signed off by a health professional. The number of Australian students diagnosed with ASD has more than doubled every 5 years.

Australian students with ASD, including students from NSW, experience especially poor outcomes following their education. National data shows that most (nearly all) people with ASD are granted a Disability Support Pension within 5 years of leaving school. The AIHW has reported that people with autism have some of the highest rates of severe or profound disability. Many people with ASD need constant supervision and support yet CSTDA data shows few people with ASD get any government funded disability service.

Since the early 1980s, Governments have been hell-bent on shutting down residential institutions and casting vulnerable clients into a harsh world or into the care of their families. The rationale for dismantling institutions that were cornerstones of civilisation came from examples of people whose experience in such institutions was less than ideal, and especially from people who enjoyed life as part of the community much more than the cloistered and segregated experience they had in an institution.

Some people with disabilities function well in their community. They are successful at school, and as adults they succeed in employment and live quite independently. There are many other people with a disability who would be substantially better off if our community were more accepting and supportive of their difference.

Many students and their families believe they could have much better outcomes if schools and the community were more inclusive and provided appropriate resources to support for their inclusion in their mainstream school and more generally in the community.

¹ The media and some education administrators are inclined to say Asperger’s Disorder is “a mild form of autism”, which is wrong and misleading.

No doubt the NSW Education Department will present itself as especially inclusive of students with a disability. But the Department is hypocritical. The NSW Education sought and obtained the support of the Federal High Court in its decision *Purvis v New South Wales (Department of Education and Training)* ([2003] HCA 62) that allows any and every school to exclude completely any student that the school says/believes **might** behave in some manner that the school just doesn't like. There is no protection for a student; no safety net giving students in NSW any right to an effective education.

The biggest barriers to inclusion of students with ASD in mainstream education settings are:

- Bullying
- Resource limits on support for students with ASD
- Ignorance about ASD and the lack of understanding, training, skill and experience needed to ensure students with ASD succeed in mainstream settings.

Unless these challenges are overcome, students with ASD who are placed in mainstream schools experience poor and inequitable education outcomes that have severe long-term effects ... as described in the UK Adult Psychiatric Morbidity Survey, 2007 (see www.ic.nhs.uk/pubs/asdpsychiatricmorbidity07).

Without sufficient resources, Inclusion is ideology and dogma that insists everyone with a disability should be fully included in the community and that segregation is entirely bad. Inclusion targets institutions that cater for the most vulnerable members of the community, such as special schools and mental health facilities. Inclusion dogma is entrenched in Government policy development for education and disability services.

Inclusion does not have practical approaches for the most vulnerable members of the community. Abolition of segregated special-purpose settings leaves many of the most vulnerable members of the community isolated and without appropriate services. The effect is the opposite of the intent ... which is never good.

While some institutions became quite "toxic", not all institutions were/are entirely dysfunctional. It is clear that some services were/are highly regarded by their clients and their clients' families. Some people with ASD do very poorly in inclusive settings and are better off in an appropriate segregated setting. It was never a pure "black and white" issue.

It is essential to offer a variety of education options for students with ASD. Far too many bureaucrats and politicians see Inclusion as the silver bullet, the one simple solution that fixes all the problems. The bad news is that there is no silver bullet for the problems associated with educating students with ASD.

We tend to blame institutions for the human failures of the people who run and work in them. We should not abolish schools simply because some of them support/supported bullies, masochists, child abusers and paedophiles. Education is too valuable. We need to improve our schools so they prevent and avoid negative experiences and outcomes.

Inclusion dogma has yet to show that it is universally valid: it needs to show that everyone benefits from dismantling other key institutions ... institution such as the NSW Parliament, gaols, hospitals, banks, universities, schools, nursing homes, etc. Once Inclusionists dismantle or abolish those institutions, they might then return their attention legitimately to institutions that were established to help people who

have little ability to articulate and defend their preferred environments to government and the media².

In the meantime, the community needs to work hard to ensure our most vulnerable citizens have appropriate services and support. The ABC TV's 4 Corners program, Breaking Point, that first went to air on 15/2/2010 (see <http://www.abc.net.au/4corners/content/2010/s2817123.htm>) shows enormous unmet need for disability services in NSW. It showed families in desperate situations (though it hardly touched on many of the less palatable aspects of their situations).

The recent 4 Corners episode entitled Breaking Point showed that some people with disabilities prefer to spend time in segregated situations, together with others that they regard as their peers and friends. It showed that inclusion dogma fails these people in their most basic needs. In respect of autism, the word itself shows a focus on "self" over community. Policy that promotes or insists on Inclusion disrespects the preferences and aspirations of many people with ASD. In this way, Inclusion policy fails its own ideology.

The 4 Corners Breaking Point episode shows the Inclusion model is failing Annie, the poster girl of Deinstitutionalisation. It also shows that respite services in NSW are utterly inadequate, and families are asking the education system to meet their needs.

The existence of some areas of failure does not mean that it is wrong to try to include people with a disability in mainstream settings. Many people with ASD want controlled and appropriate inclusion in their community but they do not want to be dumped unsupported and vulnerable in community situations that are not of their choosing. We need choice of a variety of settings for people with disabilities. Our community needs to support these people in a variety of settings. And all the settings need to be safe for these people.

A big problem with the process of modern government is the way it manages the services it provides. Government makes services that are successful, targets for funding cuts. Funds are cut from services until they cannot function. Then the Government regards the service as a failure. Further, the administration and regulation of services is in the control of bureaucrats who have no practical knowledge of the services they regulate ... people whose track record is of indecision and inaction (standard techniques of mediocre management).

Another issue is the seemingly endless succession of government inquiries with little or no outcomes. For example, the ACT Government is currently inquiring into the "Needs of ACT students with a disability" (see <http://www.parliament.act.gov.au/committees/index1.asp?committee=117&inquiry=821>), an inquiry that follows a series of similar inquiries ... all of which made no discernible difference. There is a concurrent inquiry into respite services (see <http://www.legassembly.act.gov.au/committees/index1.asp?committee=115&inquiry=964>) that volunteer advocates are also expected to respond to. These inquiries are conducted in all states and at the Commonwealth level.

Members of the ASD community suggest your inquiry should be aware of the commentary and advice from Baroness Warnock, once a leading proponent of Inclusion (see http://news.bbc.co.uk/2/hi/uk_news/education/4071122.stm and <http://www.publications.parliament.uk/pa/cm200506/cmselect/cmmeduski/478/478i.pdf>).

² Often their challenging behaviour is their clear expression of their preferences, but for a range of reasons government, policy makers and administrators do not listen to their clients, their advocates and people who do understand these communications.

At this time, the NSW Government needs to undertake substantial rebuilding of service that it dismantled over the last 20-30 years. Many of the services were quite "organic" in nature ... so the parable of the bicycle and the frog comes to mind: when you dismantle and rebuild a bicycle it might even work better than before, but when you dismantle and reassemble a frog it doesn't work at all. The Government should be aware that the absence of appropriate disability services is prohibitively expensive.

Following are specific response to the terms of reference.

1. The nature, level and adequacy of funding for the education of children with a disability

Currently funding for students with disabilities is aimed towards additional staffing support for a student's participation. For students in NSW with Autism Spectrum Disorders, funding varies dependents on misinformation and prejudice about diagnostic categories. For example, Asperger's Disorder is not regarded as involving "severe or profound impairment" (see Pervasive Developmental Disorders in the DSM-IV) so a five-year-old entering Kindergarten with a diagnosis of Aspergers Disorder can access at most 3 hours per week of aide funding. Compared to 9-14 hours per week of aide funding for students with other severe or profound impairments such as Autistic Disorder, this is inequitable. Moreover, the process of school personnel and disability program consultants determining the each student's support needs (perhaps, in conjunction with families and carers) is not always effective. And many families don't know what they signing up since it is not explained adequately to them.

Many families or carers do not know about or are unwilling (or unable) to appeal if a student is disadvantaged or they are dissatisfied with a funding review (<http://www.schools.nsw.edu.au/media/downloads/schoolsweb/studentssupport/programs/disability/guidelines.pdf>)

Clearly, funding for students with ASD in NSW has not kept pace with the growth in the number of students. Twenty to twenty-five years ago, funding for children with ASD was grossly inadequate. Since then the number of children has increased more than 25 times but there has been little or no discernible increase in state funding of services for children with ASD.

The Commonwealth Government created the *Helping Children with Autism* package. The main element of the package contributes \$6,000 per year for two years towards early intervention for a child with ASD. Advice from the Commonwealth Department of Health and Ageing says best practice for children involves 1,000 hours per year of early intervention for 2 or 3 years. The providers on their provider panel cost at least \$120 per hour so the annual cost is of a program for a child is at least \$120,000 per year. The Commonwealth's contribution is 5% of the cost of best practice early intervention for children with ASD.

2. Best practice approaches in determining the allocation of funding to children with a disability, particularly whether allocation should be focused on a student's functioning capacity rather than their disability

Effective allocation of funding to children with a disability is surprisingly simple.

- a) Determine what is required to provide an effective education in an appropriate and agreeable manner.
- b) Decide how such a service will actually be delivered.

- c) See how much the service and the agreed delivery costs. Add 10-15% to ensure that the money is properly administered and the required outcomes are achieved.
- d) Families need to be active and respected partners in this process: they do not need to be there as a tokenistic gesture.
- e) Schools must be accountable in terms of outcomes for students. Schools tell families that, according to law, the school does not have to formulate an Individual Education Plan (IEP) for a student with autism who is placed in a regular class unless the student has learning difficulties that have been specifically identified. Students with ASD have severe impairments that typically affect their learning (though they may not have been formally assessed for specific learning difficulties): it would be quite unusual for a student diagnosed with one of the ASD to not need an IEP.

This is not “rocket surgery”.

The fundamental problem is that bureaucrats and politicians want to divide the miniscule funding they grudgingly allow students with a disability while trying to convince the community of their generosity and compassion. This will always fail.

3. The level and adequacy of current special education places within the education system

For students who cannot learn effectively in regular (mainstream) classes, the NSW Department of Education has limited Autism Support Classes in Sydney (Leichhardt, East Hills and Revesby). Families experience delay and limitations to accessing this option. Students can only stay in this program for two years: then they must return to their local school or, if t eligible through an IQ test, families can re- apply for entry to other supported classes (IO, IM, Special School Placement).

The 4 Corners Breaking Point episode (see above) showed that there is substantial unmet demand for places in combined education and respite facilities.

Some families have been so disappointed by state run services for students with ASD that they have created specialist setting for students with ASD. The ASD-specific schools in NSW include:

- Aspect’s schools (see <http://www.autismspectrum.org.au/a2i2i6i1195l186/aspect-schools.htm>)
- The Giant Steps School (see <http://www.giantsteps.net.au/our-services/our-school>); and
- The more recently created Woodbury School (see <http://www.woodbury.org.au/>).

But many families cannot afford to put their child in these ASC-specific schools. Places in these schools are not keeping pace with the growth in ASD diagnoses. And families need to be able to access the school and transport their child to these schools on a daily basis.

Many families prefer their child to be closer to mainstream education so the opportunity exists (even if it is rarely realised) for inclusive activities, integration and reverse integration. Most teachers in mainstream/regular classes that include students with ASD prefer to be near a specialist ASD-specific setting as they get better access to training, resources, support and understanding of their peers.

Families report that many more ASD-specific places are needed; they cannot get students with ASD into ASD-specific satellite classes or ASD-specific schools. Some families complain they struggle to get a placement for their child in any special school.

Instead, they are pressured into placing children with ASD in mainstream schools that do not want them there, that do not have the resources they need to support the students. Researchers at Macquarie University found that families are pressured to accept exclusion of their child from school when the school does not have sufficient support for the student.

4. The adequacy of integrated support services for children with a disability in mainstream settings, such as school classrooms

While there are numerous success stories, there are still far too many disasters. There is a tendency to persist with inappropriate placements, inadequate resources and absent expertise. In other cases, the school blames the student and/or the family for anything and everything that goes wrong.

In some cases schools exclude students and restrict attendance when a school does not have the resources they need to support the student (see <http://www.theaustralian.news.com.au/story/0,25982712-13881,00.html>)

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

This question itself illustrates a significant part of the problem, which is the fundamental failure of authorities to appreciate the nature of the special needs of some of our students. In many instances, the "curriculum" issues are relatively clear to anyone with relevant training, experience and real empathy for these students. Too often, the missing element is appropriate pedagogy and essential clinical support.

6. Student and family access to professional support and services, such as speech therapy, occupational therapy, physiotherapy and school counsellors

The challenge for the NSW Government is to start providing best practice early intervention that prepares students with ASD for education.

Families in NSW report that their children do not get the professional services they need at school. Currently, families must follow up services that they need and most of the time the schools have no link with external providers. Also, school personnel and disability consultants are not always welcoming to outside assistance.

Bureaucratic illogic is problematic. Families, advocates and education advisors are keen to place students in inclusive mainstream classes. They argue that the child can succeed in a mainstream setting with appropriate support, especially things like support for sensory and behavioural challenges ... so the decisions is made to place the student in a mainstream class. Then the education bureaucrats and administrators doing resource allocation for the school decide (on the basis of their specialist knowledge — actually, bizarre pseudo-logic) that any child who is placed in a mainstream setting could not possibly need sensory or behavioural support ... so they refuse or ignore requests for professional support, or make no effort to obtain professional support that is essential to success of the child's placement.

Part of the problem is that the NSW Government simply does not provide enough professional services for people with ASD. The other challenge is that allied health

professionals simply do not get the training they need to be able to adequately support students with ASD.

Notice that the list of professionals given in the question omits behaviour specialists ... professionals whose expertise is crucial for supporting many students with special needs with their education.

7. The provision of adequate teaching training, both in terms of pre-service and ongoing professional training

Teachers whose focus and/or responsibilities are students with ASD need significantly more specialist training than they currently get. Of particular concern is their lack of awareness of how little many of them know and their reluctance or inability to obtain professional assistance when they require it.

Students with ASD in mainstream classes may have support staff. Classroom teachers with little or no training, knowledge or experience relevant to the supervision role are expected to supervise the support staff. Support staff need specialist training and supervision that is unavailable in mainstream schools.

8. Any other related matters.

Get back to A4 when the issues raised above have been resolved or eliminated.

We wish you luck with the inquiry and hope there will be discernible outcomes from your efforts.

Sincerely
Bob Buckley
Convenor

19/2/2010