Going nowhere

A submission about **autistic students**
to the Education and Employment References Committee
Inquiry into

Current levels of access and attainment for students with
disability in the school system, and the impact on students
and families associated with inadequate levels of support

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Introduction

Autism Aspergers Advocacy Australia thanks the Senate Standing Committees on Education and Employment for the opportunity to provide our submission.

The title of our report, *Going Nowhere*, reflects the experience of most autistic students in school level education in Australia. While autistic students are in school, they mostly are *going nowhere*. When autistic students leave school, when their education has completed, they are still *going nowhere*.

Educations systems in Australia do not collect data/information about outcomes for autistic students. Arguably, there is evidence that they do not want such information collected and reported. There is some information available from other sources.

This report aims to increase political awareness of these outcomes for autistic students. Our goal is a first step: to simply get politicians to recognise that:

- autistic students are going nowhere in the existing education systems,
- autistic students have distinct needs that relate to their ASD, and
- currently, there are no plans to improve outcomes for autistic students.

We offer only cursory solutions to issues raised in this report since that would be getting ahead of the process. Without recognition and acknowledgement that education outcomes for autistic students is a problem/issue, there will be no progress, nor is there any point to describing solutions.

The crucial first step is for Government to recognise and acknowledged education outcomes for autistic students are unacceptable and must improve.

The next step is for Government to decide to try to improve education outcomes for autistic students. Only then is it worth considering how improved outcomes for autistic students might be attempted.

A4's long-term goal is on-going monitoring of education outcomes for autistic students and continuous improvement of best practice education for autistic students through evidence from ethically conducted quality research.

A4 hopes this Inquiry will promote that crucial first step: to acknowledge education outcomes for autistic students are currently unacceptable and must improve.

about *Autism Aspergers Advocacy Australia*

Autism Aspergers Advocacy Australia, usually known as A4, is a national grassroots organisation whose purpose is *systemic advocacy* for autistic people and people living with Autism Spectrum Disorder (ASD). Information about A4 is available on our website: http://a4.org.au.

about Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is believed generally to be neurological in origin, though cause and mechanism are unknown.

The diagnostic criteria for ASD given in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition 2013 (called the DSM-5) require that a person needs support in their life in order to meet the formal diagnostic criteria for ASD.

From 1994 up to 2013, the previous DSM-IV described several disorders that were known collectively as Autism Spectrum Disorders (plural) or Pervasive Developmental Disorders (PDDs). The World Health Organisation still uses this categorisation in its ICD-10. The main disorders are Autistic Disorder (DSM-IV), Childhood autism (ICD-10), Asperger's Disorder (DSM-IV), Asperger's syndrome (ICD-10), Pervasive Developmental Disorder – not otherwise specified or PDD-NOS (DSM-IV & ICD-10), Atypical Autism (ICD-10) – see http://a4.org.au/ASDformal.

In 2012, reliable data showed at least 1 in 62.5 school-age children were formally diagnosed with Autistic or Asperger's Disorders, 2 of the three main “autism spectrum disorders”. This ASD prevalence, from Australian Government sources, compares to US Government reports of 1 in 68 school age children in USA having “autism”.

Among children with disability, ASD is now one of the biggest disability categories. The number of children diagnosed with ASD has doubled every 5 years for the last two or three decades.

Some people who have been diagnosed with ASD regard their ASD as part of their being. They prefer to be referred to as an “autistic person” rather than a “person with ASD”.

More detailed information about ASD is provided in Annex C (page 23) below.

overview

Most of what follows, A4's submission, relates to the Inquiry's Terms or Reference. There are ten issues/questions in the Terms of Reference.

Following that we discuss the evidence base for inclusive education of autistic students. We conclude that education of autistic students in Australia is not evidence-based practice; it is experimental at best.

The submission has several Annexes that provide detail on several subjects.

Addressing the Inquiry's *Terms of Reference*

1. *current levels of access and attainment for students with disability in the school system, and the impact on students and families associated with inadequate levels of support;*

The following addresses three aspects of this question for autistic students being a) the current level of access b) the attainment of autistics students, and c) the impact of available supports on autistic students.

Current level of access

Most autistic students (students diagnosed with ASD) currently attend mainstream schools. Increasingly, education systems and their mainstream schools aim to offer Inclusive Education for students with disability.

Most families of autistic students want their autistic child to attend (be included in) a mainstream school. Few families want their child to go to a “special school”.

Sadly, many families have difficulty from the outset with getting their autistic child into a mainstream school. In relation to initial placement of autistic students, Lilley observed …

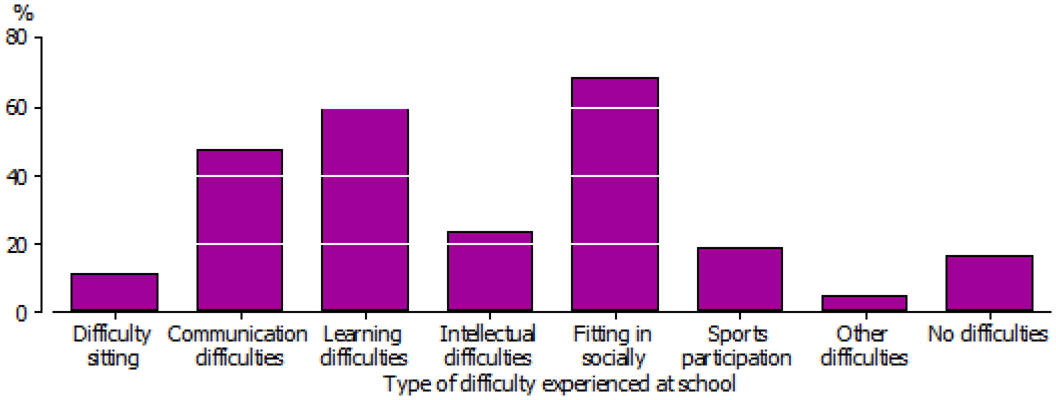
> ... continuing pervasive stigmatisation of children with autism and their mothers, as well as a systemic failure of all sectors of the education system in Australia to meet the promises of policies of school inclusion.
> Available from: http://www.researchgate.net/publication/262971075_Its_an_absolute_nightmare_maternal_experiences_of_enrolling_children_diagnosed_with_autism_in_primary_school_in_Sydney_Australia [accessed Aug 15, 2015].

While many families want to enrol their autistic child in a mainstream or “inclusive” setting, many schools simply won't accept, or at least discourage, enrolment of autistic students. Families have more success with public schools … and apparently they are having increasing enrolling autistic students in the Catholic Education System. There are few autistic students enrolled in non-Catholic non-government schools.

The Australian Bureau of Statistics reports that:

> In 2012, 5% of children with autism attended school and did not experience any educational restrictions. Of the 95% of children who did experience some restrictions, 6% of children were not able to attend school because of their disability and 44% needed to attend either a special class in a mainstream school, or a special school.
>
> For children with autism who were attending school, 86% reported ‘having difficulty’ at school, the majority of whom had difficulty with fitting in socially, learning and communication (Graph 3).

3 PROPORTION OF PEOPLE AGED 5 TO 20 YEARS WITH AUTISM, by Type of Difficulty experienced at school—2012



Source: ABS Survey of Disability, Ageing and Carers

> Children with autism may need a high level of support to attend school, with 36% needing a counsellor or disability support person and 39% requiring special tuition. Of those children with autism attending school, 13% did not receive any additional support (excluding attending a special school or attending special classes in mainstream schools).
>
> See http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4428.0Main%20Features52012

A similar situation existed in 2009:

> In 2009, 12% of children with autism attended school and did not experience any educational restrictions. Of the remaining 88% who did experience some restrictions, 3% of children were not able to attend school because of their disability and 47% needed to attend either a special class in a mainstream school, or a special school.
>
> For children with autism who were attending school, 82% reported ‘having difficulty’ at school, the majority of whom had difficulty with communication, learning and fitting in socially (Graph 3).
>
> see http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4428.0main+features62009

Many autistic students attend their school part-time … so they experience an incomplete program of education. Partial attendance is not appropriate and effective education: autistic students who are required to attend school part-time are denied their right to education.

A mother wrote recently on Facebook:

> The practices of "partial attendance", suspension and expulsion have a massive effect on both the child and the family. Suspension includes the periods of weeks when I have had to come and pick her up early from school multiple days a week. (Some days she didn't make it to 9am) It affects everything, but most particularly parents capability to work. Frankly I would prefer the government puts funding into schools and behavioural management rather than have to fund carers incomes when they are unable to hold a job because of their caring responsibilities. I am not able to work permanently or

> guarantee that I can be at a job at a specific time and this severely limits my employment prospects. The government expects us to be "working families" and this is impossible in our situation.

ASD advocacy groups regard the practice of "partial attendance" as denial of a child's right to effective and appropriate education. Suspension and expulsion are seen in the same light. These practices breech the child's right to education under international law, even though Australian law supports/promotes this type of blatant disability discrimination.

We understand that families get involved in "partial attendance" for a range of reasons. We understand that most families would prefer that the required resources and support were available for full time attendance.

A4 is not aware of any measures or reporting of partial school attendance for autistic students. Partial attendance arises through:

- the school "negotiating" with parents for on-going part-time attendance … usually due to insufficient support for the student's education [note: partial attendance may be illegal in some states];
- denial of access by the school through:
    - suspension … usually arising from the school having inadequate/inappropriate or no behaviour support in place;
    - expulsion … for the same reasons as immediately above;

International law says "the state" is ultimately responsible for ensuring every child can access education; it is not the family's responsibility. On this issue, Australian law is just broken (a total embarrassment).

Note that Australia's High Court decided in *Purvis vs NSW* that any (and every) school can refuse to enrol or can expel a student if the school suspects/believes that the student might someday have some unwanted behaviour. The High Court's decision promotes disability discrimination in schools … or potentially any service provider or community setting. The *Purvis vs NSW* was a major legal precedent in the denial of education for an autistic student in Walker vs Vic, where the federal courts failed to recognise the applicant's disability instead calling it "misconduct" or "misbehaviour". The federal court showed that it had no expectation of a school to make any "reasonable adjustment".

A significant number of autistic student refuse to attend school.

- More usually, the student refuses to attend school (even if the parent would prefer he/she did attend).
- Occasionally, the parents/family refuses to allow the student to attend their school.

Autism Asperger ACT did a survey in 2012 and reported on *school refusal*: see http://sofasd.org.au/d7/node/13. School refusal usually arises from experiences of the *disastrous legacy* of the inclusion experiment (see below) on autistic students.

Most, possibly all, autistic students are bullied in school. Processes for addressing bullying frequently blame the victim, especially when the victim is autistic. Many autistic students experience increasing anxiety or depression in school. Some are taught unwanted/challenging behaviour. For them, school become an inappropriate, unwanted or even damaging setting.

One of the most vocal initial proponents/champions or Inclusive Education and the Salamanca Statement, Baroness Warnock, observed the clear evidence and recognised a decade ago that Inclusive Education fails a significant number of autistic students. She had the maturity to change her mind and she penned a pamphlet titled *Special Educational Needs: A New Look* and said that Inclusion policy had "gone too far", had failed some students and left "a disastrous legacy" (see http://a4.org.au/node/743).

A subsequent House of Commons Education and Skills Committee inquiry into Special Education Needs reported:

> … with specific regard to special schools, the [British] Government has told this inquiry that it does not hold a policy of inclusion that is resulting in the closure of special schools. Lord Adonis, the Minister with responsibility for SEN, described the Government as being "content" if, as a result of local authority decisions, the current "roughly static position in respect of special schools" continues. Lord Adonis specifically said that the Government "do not have a view about a set proportion of pupils who should be in special schools".
>
> see http://www.publications.parliament.uk/pa/cm200506/cmselect/cmeduski/478/478i.pdf

Please note: A4 supports Inclusive Education when it is appropriate and effective; but Inclusive Education, as currently practised in Australia, does not suit all autistic students. **All** autistic students need effective education; education for autistic students must **not** be just for those who fit into mainstream settings.

There is a substantial body of evidence (see *Current level of attainment* below) showing some autistic students cannot access effective education in their existing setting.

Current level of attainment

Data show that the current attainment of autistic students in education is very poor. Many autistic students attend mainstream schools but do not access the education that they need. The ABS reports:

> Of people with autism who had finished school, 81% had not completed a post-school qualification. This was well above the rate for both the rest of the population with disability and people with no disability.
> See http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4428.0Main%20Features52012

Presumably, "finished school" means they are too old to go to school. From these data, we know how many autistic people *don't* achieve a high-school qualification (School Certificate, Higher School Certificate, etc.). We do know that just 19% of autistic people get a post-school qualification and 81% don't. This achievement rate is very low compared to the rest of the population; this is a seriously inequitable outcome.

Education is the foundation of employment for most people, so it is no surprise then that labour force participation and employment rates for autistic people are also *unacceptable*. The ABS says:

> In 2012, the labour force participation rate for people with autism was 42%. This compares with 53% labour force participation rate for people with disabilities and 83% for people without disabilities.
> See http://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4428.0Main%20Features62012

These data (from 2012) show that 64% of autistic people are unemployed (although the "Unemployment Rate" – the gap between employment and labour force participation – is about 4.8%). Attainments of autistic people following their school education are abysmal.

Impact of inadequate level of support

Currently, some autistic students start school on a part-time basis because the school does not have the resources it needs to support the student. Instead of asking their Department to provide the required resources, schools encourage/promote part-time attendance. Some parents accept that this is best for the student.

The only "impact" that Government cares about is "impact on the budget" and "impact on the ballot box". As yet, the disability and autistic sectors have not tried to exercise much "impact on the ballot box" … nor are we aware of any plan for the immediate future.

On the other hand, "impact on the budget" is inevitable. Government should quantify this cost … but does not seem to want to know.

A ballpark figure of $20 billion per year as the cost of ASD to the Australian Budget can be *guesstimated* based on data from the USA – see http://a4.org.au/node/1013. The cost of ASD in Australia could well be significantly higher since early intervention and education in Australia are likely to be less effective than in the USA.

The cost of ASD in Australia is substantial. More effective education of autistic students would undoubtedly be cost effective.

Australia has the worst poverty among people with disability in the OECD (see http://a4.org.au/node/426). Inadequate education support for people with disability affects poverty at the national level. Inadequate support for students with disability means poor education outcomes. Poor education outcomes means reduced employment and economic participation … which increases poverty among people with disability.

As autistic people have especially poor education outcomes, as evidenced by ABS data, it is expected that autistic people experience higher poverty than people with disability generally.

The personal cost for autistic people and for family members is also substantial.

Adults who are not “participating in the labour force” typically survive (mostly struggle) long-term on welfare. So inadequate resources in education often lead to welfare dependence … which was around 59% of autistic people in 2012. Such a life has a high risk of mental illness.

Suffice it to say, mental illness has a substantial impact on a person, their family and their community.

The impact of inadequate resources is not just on the autistic person who's affected. ASD affects the whole family. One study found that having ASD in the family sets families back $35,000 per year on average (see http://a4.org.au/node/881). Adequate support in education would reduce this impact.

As described above, mothers cannot work when schools call them frequently to collect their child.

Families with more income are more likely to be able to afford better long-term accommodation for an autistic family member.

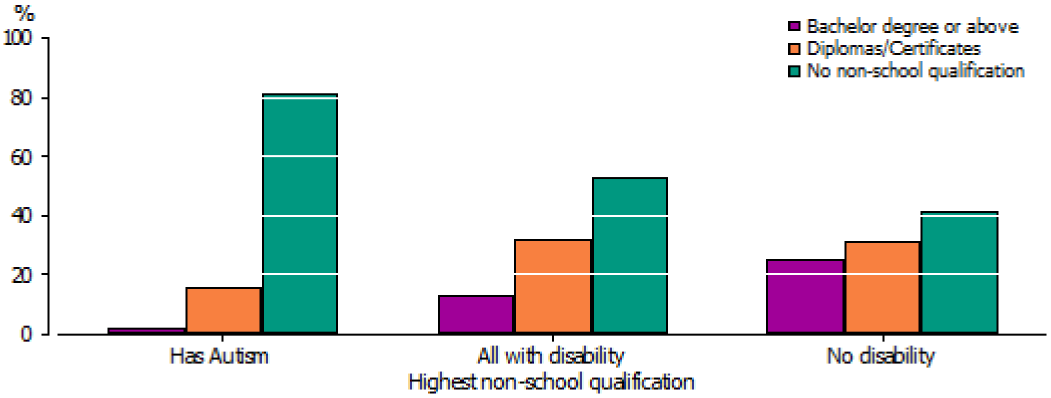
2. *the social, economic and personal benefits of improving outcomes for students with disability at school and in further education and employment;*

Government only cares about economic benefits; social and personal benefits are only useful in political spin.

Above, is reference to a conservative guesstimate of $20 billion being the current impact of ASD in the Australian economy. Improving school education outcomes for autistic students will improve outcomes in further education and employment. Improvement in any or all of these outcomes will undoubtedly have substantial economic benefits.

As shown above, 19% of autistic people have any post school qualification.

4 ALL PERSONS AGED 15 YEARS AND OVER, highest non-school qualification by whether has autism and disability status—2012



Source: ABS Survey of Disability, Ageing and Carers, 2012

Currently, entry to further education depends primarily on academic ability. There is little or no policy aimed at delivering equitable access to post-school vocational training/education for people with intellectual, cognitive or other learning impairments. Clearly, Governments in Australia do not take seriously equitable access to further education for people with disability.

Improvements have economic benefits for autistic people … but also economic benefits for other family members.

Here a radical thought: if the Government wants economic benefit, then it should include the value of informal care for people with disability in the nation's measurement of GDP.

3. *the impact on policies and the education practice of individual education sectors as a result of the More Support for Students with Disabilities program, and the impact of the cessation of this program in 2014 on schools and students;*

A4 was unaware of the *More Support for Students with Disabilities* program prior to seeing this question. The program was not discussed with ASD stakeholders (at a national level) in the planning stages; we doubt that the distinct needs of autistic students were adequately recognised and accommodated. Usually, a lack of consultation limits any program's efficacy.

This program seems to be completely different in each state/territory.

From accessing the program reports, we see the state education systems claim to have done as their part of the program. We also provide the number of children who are diagnosed with Autistic or Asperger's Disorders and their families receive Carer Allowance (child) on that basis.

State / territory	*Autism / ASD element*
ACT	Did not find autism/ASD mentioned
NSW	1,400 (online?) courses were accessed
NT	“up skilling” and raising awareness of ASD
Qld	21 students in the south; 59 schools in North Qld ... more ASD-related activity than in the other states/territory's reports
SA	Online training: Understanding Autism … 1042 participants
Tas	iPads and some pre-service & practice teacher training
Vic	<60 teacher scholarships, 9 teacher coaches … about 4,000 teachers in 500 schools.
WA	37 students in 5 schools + TEACCH in 10 schools; 11 teacher in “ABA principles”; workshops for 690 education assistants

Other than the ABS data, there are no measures of educational outcomes for autistic students.

While people may feel positive about the effect of this program, there is no evidence that it made a discernible difference for any students with ASD. Any effect will be minimal at best.

To have an effect, the Government has to seriously tackle the needs of autistic students. It needs to get advice from people who have delivered actual outcomes for autistic students through systemic reforms. None of these people are here in Australia.

4. *the future impact on students with disability as a result of the Government's decision to index funding for schools at the consumer price index after 2017;*

Since the number of autistic students with severe or profound disability is growing far faster than CPI, this decision is expected to halve education funding for each student with ASD every 5 years. The impact of this decision will be negative and large.

5. *the progress of the implementation of the needs-based funding system as stated in the Australian Education Act;*

Needs-based funding cannot be achieved with funding for schools indexed at CPI. Need-based funding is about funding for what students need. Funding that is fitted to budget constraints is not and cannot be needs-based funding.

6. *the progress of the Nationally Consistent Collection of Data on School Students with Disability and the findings, recommendations and outcomes from this process, and how this data will, or should, be used to develop a needs-based funding system for students with disability;*

Prior to this Inquiry, A4 had no engagement with the *Nationally Consistent Collection of Data on School Students with Disability* project.

We wrote to the project. We appreciate that we got a timely response which is available in Annex D (page 27 below).

Unfortunately, the *Nationally Consistent Collection of Data on School Students with Disability* project has been set up to **not** collect data or report on autistic students. It will be of limited use in developing a needs-based funding system for autistic students. The response from the project shows the collected data is not available to parents, carers, advocacy, etc. so it is not useful to us in developing anything.

As indicated above (see Question 4), the premise of Question 3 above prevents the possibility of “a needs-based funding system for students with disability” … so there is no point in asking that part of the question.

Ideally, the information about education outcomes for autistic students should be available via NAPLAN … but the education system excludes so many students with disability from NAPLAN that disability- or ASD-related data from that source are essentially useless.

The ASD community has prior experience of data collection projects. In 2009, the Parliamentary Secretary for Disability promised an Autism Register … but his Department was unable (or unwilling) to deliver it. We'll watch with interest to see if this project does any better at collecting data about autistic children/students and the outcomes they achieve.

We'd be interested to see data is available for parents … or for systemic advocates. We contacted the project to see what information it expects to release publicly but we didn't get a response.

7. *how possible changes as a result of the Nationally Consistent Collection of Data on School Students with Disability will be informed by evidence-based best practice of inclusion of students with disability;*

Education of students with disability is rarely informed by evidence; change in the education sector is typically driven by policy and budget constraints … and sometimes by fashion and prejudice.

As yet, we do not know what data will be collected or how it will be used.

Minor aspects of the collected data might have minor influences. We doubt that the data will drive the large scale change that autistic students need.

For example, the NDIS is a major change that is doubling national spending on part of the disability services and supports sector. Since the initial planning decided a budget, the whole NDIS effort is now about delivering within budget … even though the original estimates of the number of autistic people and the cost of early intervention were massively wrong. It does not matter that the initial NDIS planning ignored substantial growth in the number of people being diagnosed with ASD. The needs of autistic people are already irrelevant; the NDIS is not yet through its “trial” and already all that matters is sticking to the original budget estimate.

We are also concerned that possible changes in education for students with disability apparently will only relate to “inclusion”, and not to meeting individual needs and best-practice generally.

In relation to autistic students, we expect data collection like this can only reveal that better practice in their education is needed; it is unlikely the data collection and analysis will tell us what is “best practice”.

8. *what should be done to better support students with disability in our schools;*

A4's interests relate to ASD; we cannot comment on disability generally.

The purpose of an education system is to educate students including autistic students; it is not to *support* autistic students to just be “in our schools”.

In order to educate autistic students effectively and appropriately:

1. autistic students first need timely diagnosis … that leads immediately to
2. best practice early intervention for ASD that prepares autistic students for school (currently, very few Australian children access the intensive individualised ASD-specific early intervention that is recognised best practice as few families can afford it, Australian governments are confused over and rarely fund best practice early intervention for ASD; without demand and knowledgeable professionals there is very little supply of best practice services).

3. Once students reach school, they need to attend full-time in settings appropriate for the individual student … for most autistic students need some individualised programming in their education,
4. proper monitoring and reporting of each individual's progress.
5. Many autistic students need but cannot access behavioural elements for their program supervised by a qualified behavioural professional (currently, no Australian university trains people for the internationally recognised qualification, Board Certified Behaviour Analyst (BCBA) – New Zealand has two universities in the list).

The lack of behavioural services and properly trained behaviour specialists is a major contributor to autistic students having abysmal education outcomes. The failure of teachers to recognise the needs and to call on professional behavioural services is an unacceptable failing in the country's education systems.

9. the early education of children with disability; and

As indicated above, Governments have to ensure autistic students get best practice early intervention for their ASD before they enter school.

Typically, autistic students do not learn naturally or in the same way and other students. Many need to be taught what to do when a teacher says "do this" and demonstrates a skill. Autistic students often have to be taught to listen to a teacher … or to watch other students when they are not sure what to do. There are so many skills that autistic students don't just catch onto like other students. These skills need to be taught explicitly so an autistic student can go on to learn in a mainstream school.

Some autistic students need their early intervention to continue into their schooling.

10. any other related matters.

Related matters that would or could contribute to better education outcomes for autistic students include:

1. Autistic students need legal protection of their right to effective and appropriate education and protection from all forms of discrimination (these are rights that should be provided for them according to the UN Convention on the Rights of the Child).
2. Respect, recognition and valuing of informal family/carers … currently, most school staff pay this matter lip-service at best.
3. unified education and NDIS services and supports for autistic students.
4. Australia need to recognise the importance of behavioural science in services and supports for autistic people.
5. A wide range of research into ASD including social, educational and economic research … not just medical research.

Is one-size-fits-all inclusive education best for *all* autistic students?

Most education “experts” and policy makers regard Inclusive Education as the one-and-only model for all students with disability.

We are not aware of evidence to support this policy, and we doubt that such evidence exists (see Annex A, page 18 below). To the best of our knowledge, existing policy that insists on or recommends fully Inclusive Education for all autistic students is not evidence-based policy.

We are aware of some statistical evidence giving some support to Inclusive Education. For example, a review of research in 2012 found evidence to support Inclusive Education for children with Down syndrome (see http://www.downsyndroom.nl/reviewinclusive):

> Children with Down syndrome learn more academic and language skills in regular [inclusive/mainstream] education, not only because of selective placement. They are well accepted by their peers.

Note that these results relate specifically to students with Down syndrome. This research does not apply to autistic students.

> In the Netherlands, according to de Graaf (2007a), approximately 56 percent of all children with Down syndrome from the years of birth 1993-2000 started their school career in regular education. Of children with Down syndrome who started their school career at a regular school slightly more than 40 percent continued in regular education for the entire elementary school period. This implies that transferring mainstreamed children with Down syndrome to special school during the elementary years is quite common.

On this basis, conclusions about students with Down syndrome whose entire elementary school education was in mainstream/regular schools is just 56%x40% or a tad over 22.4% of students … not even a majority of students with Down syndrome.

This research does **not** tell us whether *all* student do best in inclusive/mainstream setting … or whether there are some students with Down syndrome who *need* (benefit most if) all or part of their education to be provided in a segregated setting.

The paper also concludes:

> it can be concluded that not only child characteristics but also school characteristics determine whether a child with Down syndrome will succeed or not in regular education.

Clearly, these research findings do not support the widespread *Inclusion only* policy of governments, teacher training and some disability advocates.

Research from <25% of students with Down syndrome is positive about Inclusive Education – but it cannot conclude that Inclusive Education is universally better based on such small representation.

Autistic students are by definition different from students with Down syndrome (though some children with Down syndrome are also autistic). Conclusions about autistics students cannot come from studying students with Down syndrome.

Conclusions about autistics students can only come from studying autistic students. Comprehensive research on Inclusive Education for autistic students is not available.

Several reports (cited elsewhere in this submission) give evidence of students who either did not learn in mainstream school (Inclusive education) and did learn elsewhere, or suffered various detriments in mainstream schools. This is unequivocal evidence that Inclusive education is **not** best for all autistic students.

A4 is inclined to a belief that “largely Inclusive education” may be best for most autistic students. Most autistic students need some “reasonable accommodation” for the autism … since that need is a diagnostic criteria for ASD and is formally recognised by their diagnosis.

Denigrating autistic students and their families when they make an evidence-based choice to access to education using some other model is just wrong.

ASD Education: experimenting on vulnerable children

Above, we've shown that we cannot find the evidence (that education academics and policy makers claim exists) of universal positive outcomes for autistic students in Inclusive Education. We have clear evidence of harm to autistic students – evidence that Inclusionists deny or ignore.

Nor do we know of evidence that special education is effective for autistic students. The main difference between them is that few if any people claim such evidence exists for “special education”. We are aware of numerous examples of unacceptably low expectation for autistic students in “special education” settings. Low expectations deliver sub-optimal results.

Basically, none of the education strategies available for autistic students in evidence based. So *all* currently available education placements for autistic students are experimental.

Current practice in educating autistic students is a massive experiment. The people conducting this experiment and their subjects seem to be unaware that they are *experimenting* on very vulnerable children. Everyone appears to be oblivious to the need to get ethics approval and informed consent from subjects in these experiments, the need to monitor progress and to report results.

Existing education practice for autistic students in Australia is an intolerable disgrace.

Outside the experiment, the ABS has repeatedly reported poor outcomes for autistic students. The ASD community and governments in Australia expect better outcomes for autistic students. Generally, people believe better outcomes are possible.

The education of autistic students will continue to be experimental until the experiments yield results that support evidence-based practice. So let's get the experimental design sorted, proper ethics approval and informed consent in place. Hopefully, a properly conducted experiment will yield results quickly and autistic students will benefit from evidence-based education practice in the relatively near future.

A4 would like education authorities to quickly either

- adopt ethically conducted research that has been completed overseas, or
- complete their own initial experiments on an ethical basis

so we can train teachers in evidence-based practice for educating autistic students. If the latter, A4 would like Education authorities in Australia to design their experiment on autistic students ethically and using best practice in experimental design … which requires informed consent from human subjects.

Annex A: “special education” in Australia's academia

The headline for a recent article by several prominent education academics claims “Australia lags behind the evidence on special schools”. Such a claim should be *evidence-based* … so A4's first question is “where is the evidence?”

The article highlights that “Tracking results from inclusion and special education is difficult”. The article admits that evidence is not available, is not being collect. Instead of evidence, it provides instead a list of excuses. Previously, A4 challenged “inclusion” proponents to show us evidence that inclusive Education is always best for autistic students (see http://a4.org.au/node/458). So far, no one has offered anything that they claim is evidence.

So as yet, there is no “evidence” relevant to Inclusive Education being best for all autistic students.

The article claims that “the accepted international view for many years has been to move away from segregating children with special needs in special schools”. Being an “accepted view” is no guarantee that such a view is right or best.

It's is worth noting that normal practice in Australian high schools is to create highly segregated classes with segregation based developmental stage (closely related to student age and/or achievement), skill or ability, area of special interest (subject area). Inclusive Education then dumps autistic students into these highly segregated groups that often have little or no connection or common interest with the autistic student.

Schools are segregated settings for students: they segregate students into small age-dependent communities. Mainstream schools are segregated in to Primary, Secondary and Tertiary. Many autistic students follow developmental pathways that do not resemble those of other children. They may never socialise effectively with children … expecting them to do so is futile for some. Most autistic students will spend their whole life socialising with adults; mostly, they have very little to do with teenagers. What is the benefit in forcing autistic people early in their life to fail to connect to other teenagers?

The article quotes ABS data showing “a 17% increase in special schools”. This turns out to be 7 schools. The number of primary school dropped by 34 and secondary schools by 7 … but it is wrong to conclude that fewer schools mean fewer children going to school. These data must not be interpreted shallowly. Generally, smaller mainstream schools are merging into bigger schools. No explanation of the changing number of special schools is offered: it is possible that special schools have fewer students and are being created closer to their students homes. This could increase both inclusion in their communities for autistic students attending special schools and the number of special schools; we simply cannot tell from the data.

The *Australia lags* article suggests that “inclusive education as a human rights issue” and links to a UNICEF article. The author of the UNICEF article has a long and deep commitment to, certainly a biased interest in, “inclusive education”. The UNICEF article, as is often the case, describes people's efforts to provide “inclusive education” but it fails to provide evidence of success for children with ASD.

The Foreword to the UNICEF article says:

> Inclusive Education (IE), as defined in the Salamanca Statement* promotes the "recognition of the need to work towards 'schools for all' / institutions which include everybody, celebrate differences, support learning, and respond to individual needs" .

This extract from the Salamanca Statement is ambiguous. I could mean that either:

- every school (education institution) should be suitable for every student … should every class in each school then be able to accommodate every student? Is it thus inappropriate to segregate students within the school in classes based on age, ability or some other categorisation? Or
- states who are responsible for universal access to education under international law needs to ensure every student is included in an effective and appropriate education –- that is, each child's education program is effective for that child … which is what the UN Convention on the Rights of the Child (CRoC) requires. The requirement is not that any and every school needs to be able to accommodate every student; it means that there must be an accessible place in education for every student and that placement delivers effective and appropriate education for each individual student. This does not mean full inclusion in mainstream is required for every student. Possibly/probably some social inclusion is essential for every child's effective and appropriate education.

While there are many families living with ASD who expect full inclusion for their child, A4's collective stand is that each autistic student needs an effective education. For some autistic students, full inclusion does not work. A4 prefers the second interpretation of the CRoC and the Salamanca Statement.

The case for inclusive education in the UNICEF article is given in the opening phrase of a paragraph: "Clearly there is a human rights and principled case for inclusion ...". No evidence is offered, no logic, no legal argument … just the author expecting/requiring that people accept her view. Apparently, some of Australia's senior academics, the authors of the *Australia lags* article, just accept this … presumably expecting the rest of us to do the same.

Well, A4 suggests this argument/expectation is academically inadequate. We are disappointed in such a poor academic performance in the field of education.

The *Australia lags* article points out that there is no clear definition of Inclusive Education.

A case for the right to education for children with disability, or children with special needs, can be based on parts of the UN Convention on the Rights of the Child (CRoC). Children have the right to education … but the CRoC says nothing about a child's education having to be "Inclusive".

The issue of whether an autistic child has a right to an education is discussed in Annex B (page 22 below).

The *Australia lags* article says "segregating people based on religion, race or gender" is inappropriate but apparently accepts the widespread practice of segregating students within schools, especially secondary schools.

Teaching in mainstream secondary (high) schools is highly segregated. “Inclusive education”: it usually involves segregating students on age (developmental stage), academic ability, interests, gender sometimes, etc. … then “inclusive education” for a student with disability, especially an autistic student, is the dumping of an isolated autistic student into an otherwise highly homogeneous group. And just hoping it works out for the autistic student.

The authors claim “inconsistency makes the results of students with disabilities almost impossible to measure and compare”. In our view, the fundamental goal of education is to prepare people for adult life. These measures show that decades or predominately “inclusive education” result in abysmal outcomes for autistic people (see the ABS's Autism and education), just as under-resourced “special education” did before then.

The academics suggest post-school outcomes are often not considered. Well, that's just rubbish. As is clearly shown above, A4 certainly considers post-school outcomes … though data is not always easy to access. The real problem is that “Inclusionists” ignore/reject anything that doesn't agree with their ideology.

The evidence does not show “inclusive education” always delivers appropriate outcomes for people with autism. The “inclusion” experiment failed for some people with autism.

The *Australia lags* article complains that “special education seems to be experiencing somewhat of a renaissance in Australia and a recent piece in The Conversation argued that this might be positive”. While Inclusionist are apparently incredulous at a suggestion that meeting evidence-based needs of individual students instead of faithfully adhering to ideology “might be positive”, the main issue/concern raised in *Can inclusive education do more harm than good?* is about behavioural issues, issues that the “Inclusionist” fail/neglect (refuse?) to recognise in their response. The article they object to concludes:

> In the messy reality of implementing the noble ideal of inclusion, there is not a universally clear path to best practice. Rather, there appears to be a worrying tendency to consistently preference ideology over the best interests of the child(ren).

The ABS reports that 6% of school age autistic children don't attend school at all. Previously, we mentioned that s*chool refusal* is a significant issue. It often results from bullying which is a major issue and is often mismanaged. A4 has no idea what level of exclusion/denial is imposed on students with ASD: most education authorities neglect their responsibilities to record and manage their denial of access for autistic students.

Autistic students get several mentions in a report on Home Schooling (see Home Schooling in New South Wales Dec 2014).

Apparently,

> … Minutes of committee meetings (included in an appendix) show over 100 paragraphs were deleted from the draft report. Most of these deletions contained evidence of problems within schools and/or evidence of successful home education outcomes.
>
> These removals appear ideologically driven and fundamentally change the message communicated by the report. It seems that even in a parliamentary inquiry into home schooling it was felt necessary to protect the school system from criticism. One result of this has been media reports suggesting that home education presents a risk to children - despite the committee receiving evidence to the contrary.

> The processes and results of this inquiry show that education remains an ideological issue - this time with political parties against parents and choice. ...
>
> see *Evidence of home schooling success erased from inquiry report*

Basically, evidence about Home Schooling, which is contrary to mainstream/Inclusive education, does not suit the Inclusion ideology … so it is systematically ignored/suppressed.

The report from the Select Committee on Home Schooling also says:

> **Recommendation 5**
>
> That the Board of Studies, Teaching and Educational Standards pursue opportunities for home schooling students to participate in NAPLAN testing, except in cases where it has been demonstrated that a student has a learning difficulty, disability or other special need.

The NSW Government's response to the report accepted this recommendation.

The Committee's Recommendation 5 and the NSW Government's response show that political authorities, presumably with the support of education administration in NSW, do not want to Include students with “a learning difficulty, disability or other special need” in the national monitoring of education outcomes. This shows clearly that interest in Inclusive Education in one of the world's largest education systems is superficial at best.

One author documents difficulties with Inclusive Education for autistic students and proposes that some schools have *Autism Inclusion Disorder* (see *Trading places: Autism Inclusion Disorder and school change*). Immediately, the questions arise: Is *Autism Inclusion Disorder* treatable? Can it be cured? Most likely the answers are: “partially” and “not completely”

It seems that many Inclusion zealots feel that meeting the needs of most students is good enough; it does not matter if fully Inclusive Education does not meet the needs of some autistic students … or may even damage some. Apparently what matters is the greater good. One author goes on to suggest that being the most popular product, or a product preferred by a majority, then the barrier to becoming a monopoly may be in the marketing: see Inclusive schooling: if it's so good – why is it so hard to sell?

A4 continues to ask: where is the data and …

please show us the evidence.

Annex B. No right to education for autistic students in Australia

Previously, we saw that a UNICEF article claimed:

> "Clearly there is a human rights and principled case for inclusion ..."

The Australian High Court disagrees. Previously, we also showed that:

> [The] High Court decided in *Purvis vs NSW* that any (and every) school can refuse to enrol or can expel a student if the school suspects/believes that the student might someday have some unwanted behaviour.

While Australia signed various UN conventions/treaties, Australian Governments fail/refuse to enact the laws required by these treaties. So UN CRPD "and other United Nations Rights Treaties" simply do not protect citizens under Australian law or through the legal system in Australia. It is factually incorrect to claim/suggest that disability advocacy in Australia operates "to protect and promote the legal and human rights of people with disability" because those rights do not exist for people with autism/ASD in this country.

Specifically, children with ASD do not have the right to education since the High Court decided in *Purvis vs NSW* that a school (and apparently any organisation that offers a service) can choose to exclude a person and deny them service if the organisation feels there is a risk of unwanted behaviour. Under Australian law, service providers are allowed to discriminate against anyone with a disability if they are worried that behavioural issues may arise.

There is no sign that Australian law expects a service's feeling/worry about risk of unwanted behaviour to be "reasonable" or evidence-based. There is no requirement for the state, who the international treaties says is ultimately responsible, to ensure there is a "safety net" system to catch students when the "mainstreaming" education system decides that it will discriminate lawfully against children/students that they feel may be problematic.

The ACT Disability Discrimination Tribunal (ACT DDT) decided in *Woodbury and Australian Captial Territory 2007 ACTDT 4* that "there is no evidence of discrimination as defined in the Act [*ACT DA 1991*]"; that is, while the ACT Education Department (provided education that appears effective for students generally, the ACT DDT decided ACT Education did not discriminate against these two children with autism/ASD by **not** offering them an effective education.

The Tribunal also said that, "122. Even if there had been discrimination, a number of "defences", in particular section 27, would have applied in favour of the [Government]".

There was no consequence for ACT Government officials who made false statements and provided false evidence to the ACT DDT. Autistic students in Australia do not have a right to a fair legal process.

Note that the legal system took 10 years to process these matters: there was no prospect of a positive outcome for these children with ASD.

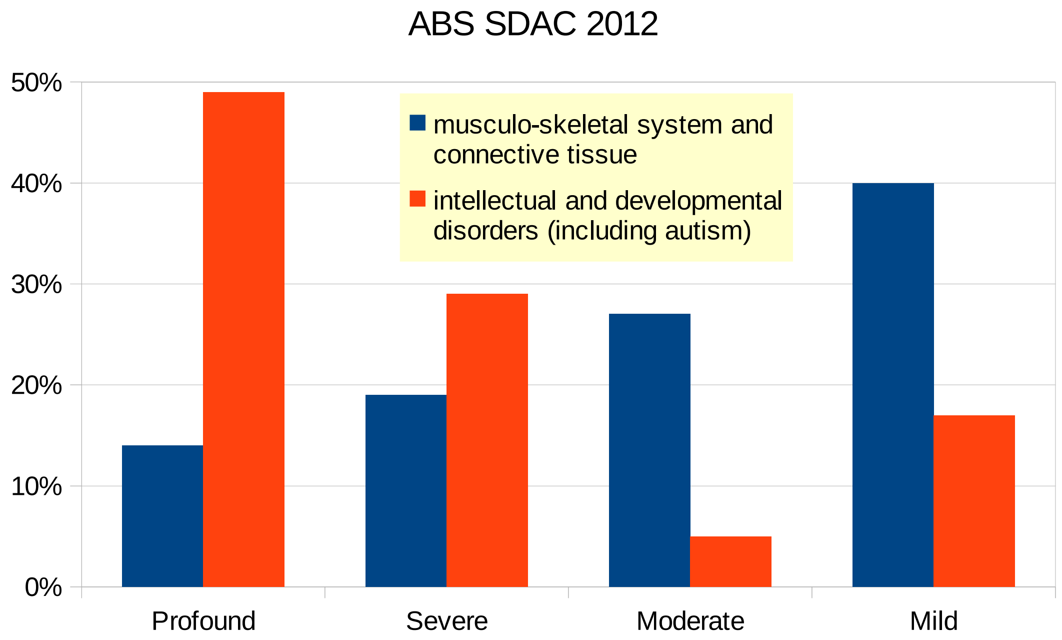
Annex C: Autism and disability

While Government likes to regard "disability" as an homogenous issue, it just isn't. For example, bureaucrats address disability issues such as "access" with simple approaches like wheel-chair ramps, adapted taxis and public transport (though there remains a lot to be done) … ignoring the fact that these approaches do not help severely autistic people who cannot use taxis or public transport unaccompanied. This means that severely autistic people cannot "access" many of the disability services they depend on unless a family member drives them there … which usually means the family member (informal carer) is always late for work, cannot work full-time or cannot get a job at all.

Recently, the Government's *National Disability Employment Framework – Issues Paper* (May 2015) said a major proportion of disabling "conditions reported were conditions of the musculo-skeletal system and connective tissue" … accounting for 1.3 (33%) of disability. The white paper omits that the same data show Intellectual Disability and ASD are a close second in raw numbers … and that ASD and Intellectual Disability are bigger categories among:

1. people with severe or profound disability (those who usually need more services and support),
2. young people (ABS SDAC), and
3. NDIS participants (56% in June 2015).

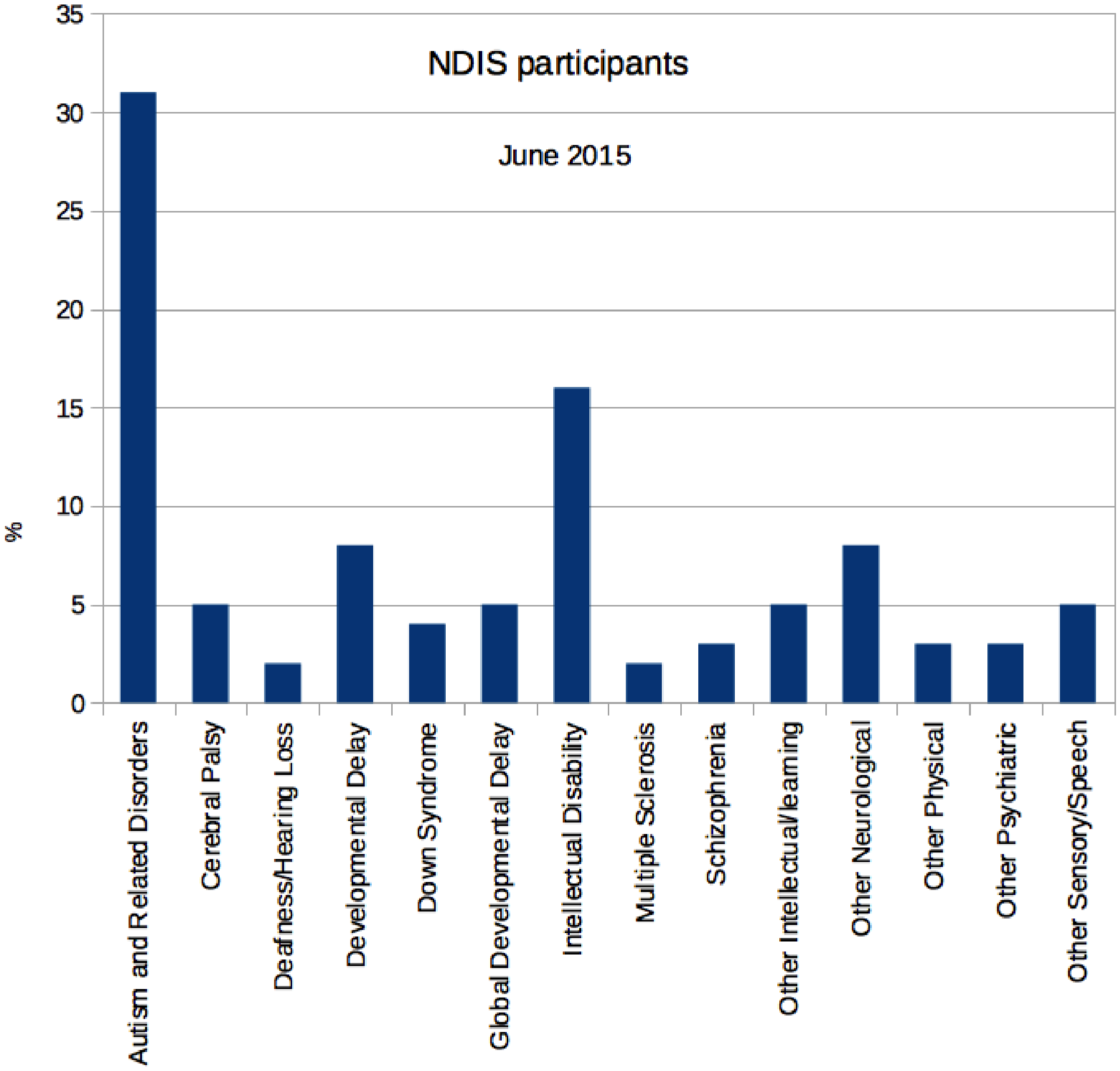
People with Intellectual Disability and/or ASD are mostly severely or profoundly impaired by their disorders, as the following graph shows:



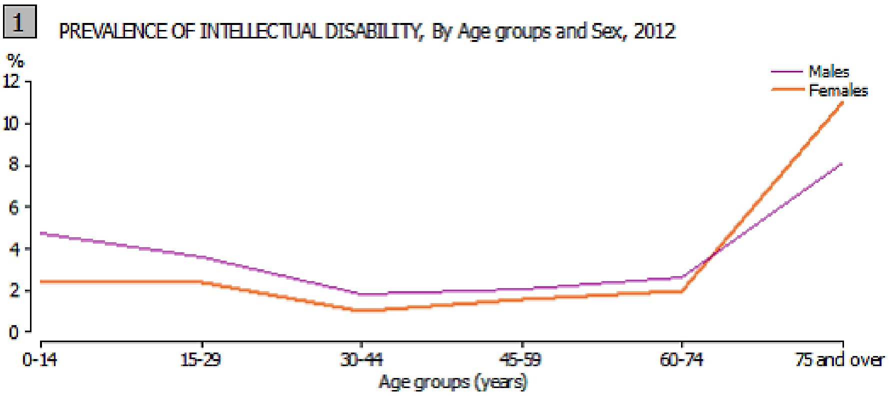
Basically, this means Intellectual and developmental disorders (including autism) need more services and support on average than disabilities that are more often moderate or mild.

Which means that improving education outcomes for people with Intellectual Disability and Autism will reduce the over all cost of their support. Better education for people with Intellectual Disability and/or ASD is better for the people living with these disorders and for the bottom line of the Australian Budget (so far, Government has ignored/dismissed/rejected A4's economic modelling, but A4 is willing to help Government with the detail for its own economic model if anyone is interested).

Numerically, “autism and related disorders” is the biggest distinct disability category in the NDIS. Following is a graph of Table 1.1.1(a) from the NDIS June 2015 Quarterly Report.

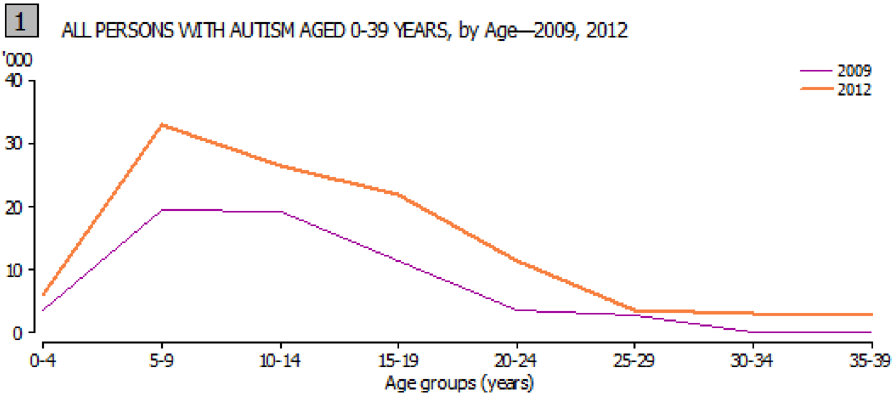


Autism and intellectual disability are the biggest component of school-age students with disability … both numerically and in terms of impact on outcomes. The ABS described the age profile of people it says have intellectual disability (see http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4433.0.55.003main+features102012):


1 PREVALENCE OF INTELLECTUAL DISABILITY, By Age groups and Sex, 2012

Source: ABS Survey of Disability, Ageing, and Carers 2012

And it describes the number of autistic people and their age profile (see http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4428.0Main%20Features32012):


1 ALL PERSONS WITH AUTISM AGED 0-39 YEARS, by Age—2009, 2012

Source: ABS Survey of Disability, Ageing and Carers, 2009 and 2012

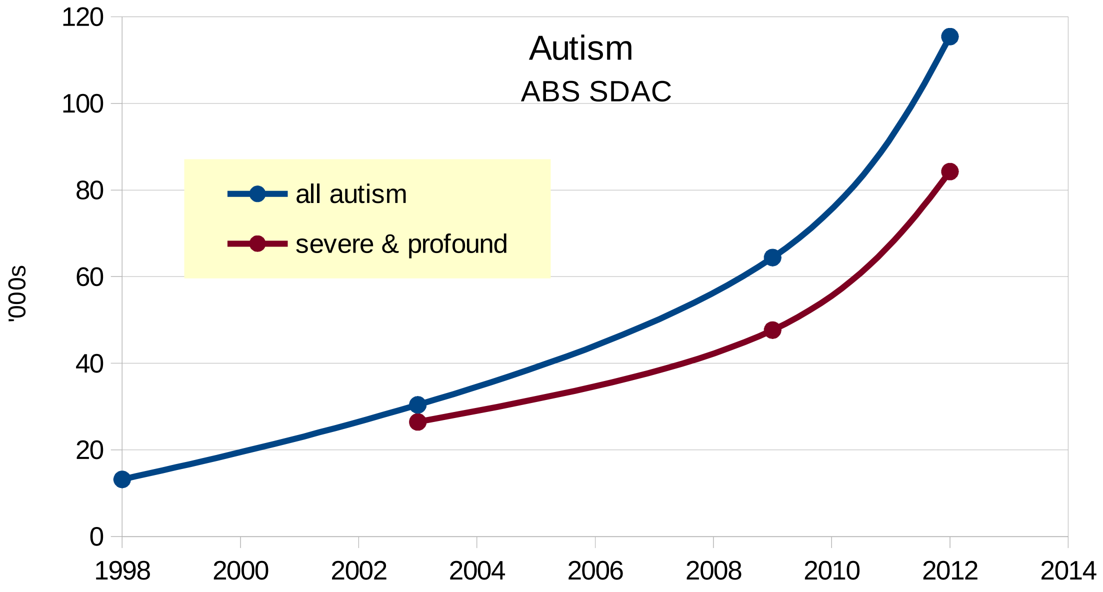
Note: the two graphs plot different things. The main feature is that there are more people with Intellectual Disability, and far more with autism, in the age range 0-30 years than above … except the ABS's idea of Intellectual Disability increases rapidly above 75 years of age.

In the case of ASD, substantial growth in the number of diagnoses has been reported for more than 20 years.

High autism prevalence in school students have been reported in NSW … see [Autism rates soaring in NSW public schools](). The media explains the growth as a massive conspiracy of teachers, parents and health professionals who allegedly “ticked the box for autism when they were unsure about the diagnosis”. Apparently, this conspiracy has been growing for 30 years, doubles in numbers every 5 years and spans many countries.

The USA CDC use autism prevalence in school students to estimate 1 in 68 students have autism.

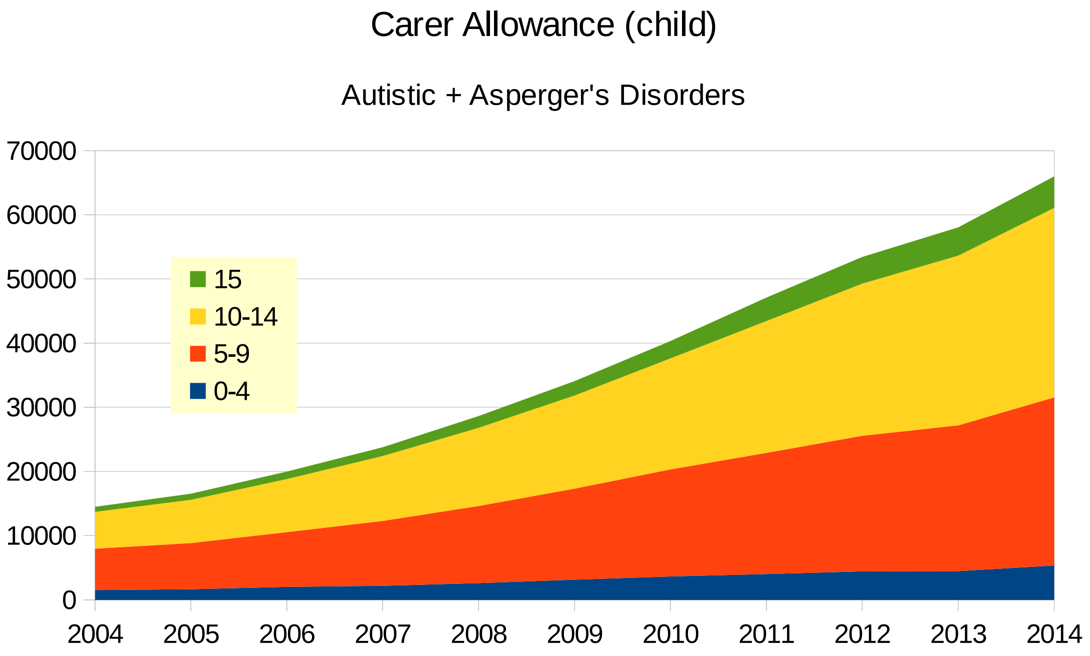
The following graph shows the increase in autism, all autism and those regarded as “severe” or “profound”, from 1998 to 2012.



Note that these data show most growth in reported ASD is among people with severe or profound disability; the increase is not due to diagnosis of people with mild (or moderate) disability as some academics and most bureaucrats claim/insist. Most people with ASD meet NDIS eligibility standards … among people with disability, ASD is usually associated with higher needs.

The following figure shows the number of Australian children who receive Carer Allowance (child) from the Government on the basis that they have been formally diagnosed and documented with Autistic or Asperger's Disorder. These data do not include children diagnosed with PDD-NOS. They are only for children up to age 16 years.

The detailed data show significant variations between states.



Annex D: Nationally Consistent Collection of Data on School Students with Disability

Following is the response to A4 questions on the Nationally Consistent Collection of Data on School Students with Disability. A4 commends the timely and honest response.

Dear Mr Buckley,

Thank you for your email of the 16 August 2015 regarding The Nationally Consistent Collection of Data, with particular reference to accessing information about students with an Autism Spectrum Disorder.

The Nationally Consistent Collection of Data on School Students with Disability has been implemented across Australia in a staged approach over the last three years. Detailed information and factsheets are available on the Australian Government Department of Education and Training website at the following link:

http://education.gov.au/what-nationally-consistent-collection-data-school-students-disability

The focus of the data collection is on the types and level of adjustment schools make to ensure that the students with disability are able to access their learning on the same basis as their peers. The collection does not count specific diagnosed disabilities; rather it identifies students who meet the broad definition of disability as defined by the *Disability Discrimination Act 1992.*

Students eligible for the collection are those where teachers have:

- consulted with the parents regarding the adjustments being made for a student
- evidence to support that a student meets the definition of disability.

This is outlined in the model:

http://www.schooldisabilitydatapl.edu.au/#modeldiagram_2

Please find below the specific answers to your questions:

1. When will (or did) the collection of this national data start?

The Nationally Consistent Collection of Data on School Students with Disability has been implemented in a staged approach over the last 3 years, with all jurisdictions and sectors (public and private) being part of the collection. 2015 is the first year that all schools across Australia will be taking part. This year’s collection is currently in the process of being completed.

There are no specific disabilities or diagnosis’s on the list. The data is broken down by the types of adjustments being made and the four categories are:

2. What are the categories of disability used in the data collection? Is there a list of disabilities and if so, what disabilities are on that list? And in particular, is Autism

Spectrum Disorder on the list ... or what category includes Autism Spectrum Disorder and its predecessors (Autistic Disorder, Asperger's Disorder, PDD-NOS, etc)?

Physical, cognitive, sensory and social/emotional
http://www.schooldisabilitydatapl.edu.au/#step3whatisthecategoryofdisability_2

Students with an Autism Spectrum Disorder are generally categorised in either the cognitive or social/emotional depending on the type of adjustment that is most predominately provided for the student.

3. How do parents access "information about the number of students with disability in schools"?

The Nationally Consistent Collection of Data on School Students with Disability is currently not publically available as the collection is still in the implementation phase.

4. Can parents access aggregate data about the number of students with disability in each state? And can they access the number of students with Autism Spectrum Disorder in each state? If so, how?
5. Is the number of students in each state with a disability and the number of students with Autism Spectrum Disorder available now? If so, would you provide those numbers? Can they be broken down into primary & high school, and government and non-government school (and if catholic schools can be separated as well that would help)?

Currently, aggregate data for the Nationally Consistent Collection of Data on School Students with Disability is not available. It is expected that data will be available during 2016 after the implementation phase has finalised.

As I mentioned earlier, the Nationally Consistent Collection of Data does not specifically collect data on student diagnosis and will not be able to provide the number of students with an Autism Spectrum Disorder.

I hope that the information provided will assist you with your submission.

Yours sincerely

<*name protected*>

Acknowledgements

The author thanks the members of A4's Management Group without whom this submission would have been less comprehensive. Also, thanks goes to the wider ASD community whose efforts to deliver best outcomes for autistic people are an inspiration.