

**INQUIRY INTO TRANSITION SUPPORT FOR STUDENTS
WITH ADDITIONAL OR COMPLEX NEEDS AND THEIR
FAMILIES**

Organisation: Autism Aspergers Advocacy Australia (A4)

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The Hon. Niall Blair, MLC
Chair of the Standing Committee on Social Issues
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Dear The Hon. Niall Blair, MLC

Subject: Inquiry into transition support for students with additional or complex needs and their families

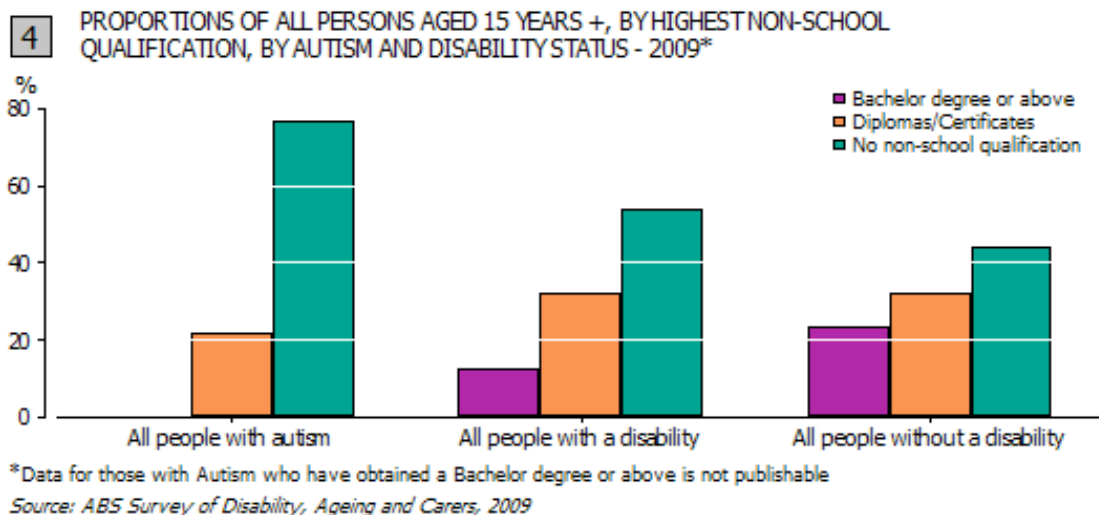
Students with autism spectrum disorders (ASD) need particular attention in education. National data from the Australian Bureau of Statistics (ABS) (see <http://www.abs.gov.au/ausstats/abs@.nsf/ProductDocumentCollection?OpenAgent&productno=4428.0&issue=2009>) shows students with autism have difficulty in education.

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.

Children with autism need a high level of support to attend school, with 41% needing a counsellor or disability support person and 51% requiring special tuition. Of those children with autism attending school, 24% did not receive any additional support (excluding attending a special school or attending special classes in mainstream schools).

Education outcomes for students with autism are “disappointing” (abysmal).

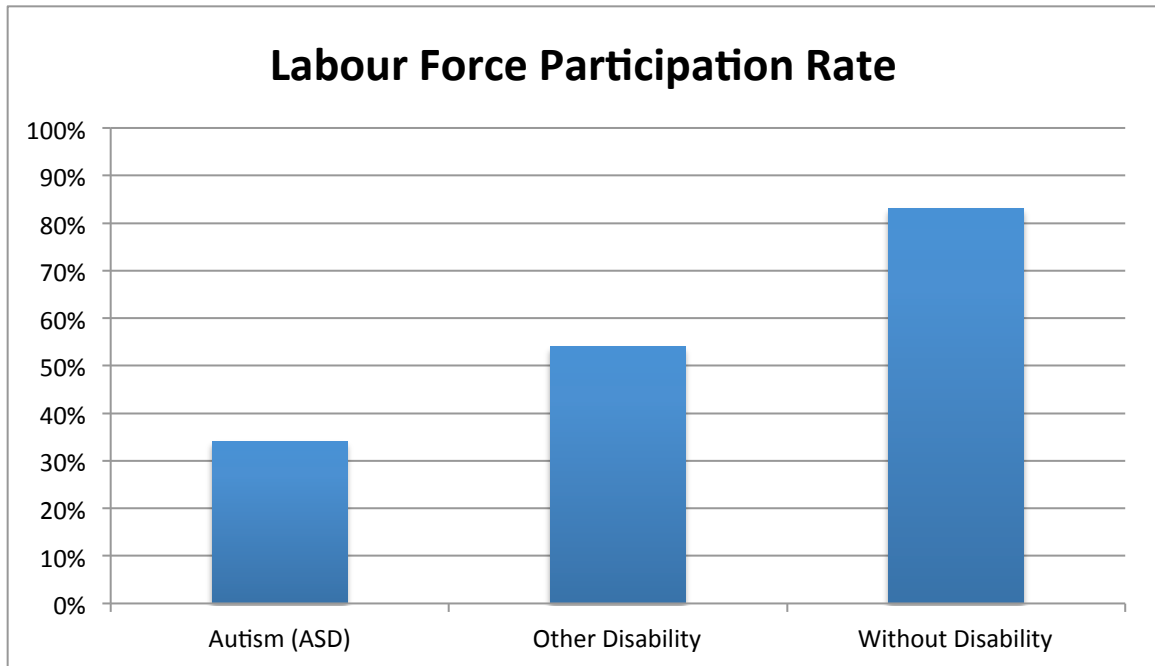
Of people with autism who had finished school, 77% had not completed a post-school qualification. This is well above the rate for both the rest of the population with disability and people with no disability.



Labour force participation is the ultimate measure of how effective education turns out to be. Nationally, employment outcomes for people with autism are particularly poor.

As with restrictions in education, autism also correlates with restrictions in participating in the labour force. In 2009, the labour force participation rate for people with autism was 34%. This compares with 54% labour force participation rate for people with disabilities and 83% for people without disabilities.

NSW, being the most populous state, contributes significantly to these statistics.



Following is our attempt to address the terms of reference for the inquiry.

1. The adequacy and accessibility of appropriate support for students and their families

Transitions occur from pre-school to primary school, high school, further education, vocational training and employment. For students with Autism Spectrum Disorders and their families in New South Wales, transitioning from preschools to Kindergarten, moving between schools, moving from mainstream to supported education settings and special schools and transitioning from supported education settings to mainstream schools are usually difficult transition periods placing students with Autism Spectrums Disorders at significant risk of emotional upheaval and participation failure.

Students with Autism Spectrum Disorders have difficulty transitioning into post school educational, employment and supported services such as:

- TAFE
- University
- Private Educational Colleges
- Apprenticeships
- Employment participation
- Supported employment participation
- Adult day-care services

People with ASD experience significant barriers to entry, participation and completion of studies. Reasonable adjustments are rarely made leading to long-term disengagement, reduced social participation and long-term isolation. Individuals with an ASD remain on the disability support pension over the course of their adult life, leaving them to live in poverty.

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Poverty is a known social determinant that places individuals at higher risk for chronic illness including mental health illness, the reduction of life expectancy and a high cost burden to health and welfare services.

The New South Wales Department of Education and Training produced a guide for transitions to school for young students with special learning needs. It alleges transition support is available for students. Ideally, the early learning support team oversees transitions: there are actions for the team to carry out the year before a child starts school. More often, DET staff and families have minimal communication and families only hear from DET staff if they require parent permission to do a child care visit in determining the child's level of functioning.

Typically, minimal effort goes into deciding and/or preparing the destination of each transition; then the details are left to be "worked out" when the student

arrives in the new setting. Transitions for students with autism are ill prepared. While “normal” students quickly settle into established education programs, there is often an extended period for students with autism of “getting to know the student” once he/she arrives. Students with autism experience the set back of an extended initial period of inadequate education with each transition.

For families of students with autism, they are often made to believe that they have choices with regards to schooling options during transition preparations. Families get their hopes up when applying for school placements. Supported

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placements are limited in NSW and families often need to wait a long time to access adequate educational placements as nothing is guaranteed. The delay in receiving adequate and appropriate support adds significantly to the social, emotional and developmental impairment for the student with autism.

An educational panel determines where a child should be placed based on the child’s IQ results and availability of limited supported places. For students who move on to a mainstream class, support can range from 2 hours per week (highly inadequate) to 10 hours per week, (for most students with an ASD inadequate.) Students with Asperger’s Syndrome only attract 2 hours per week as they are only deemed as needing social and emotional support. Students with autism need support in all areas, and specifically with communication, social skills, behaviour support and sensory issues, in addition to their general academic needs.

Decisions about education services and support are made without adequate information about the child’s education support needs. The decisions are based more on the resource limitations than on the student’s individualised need for educational support and disability-related services.

The NSW DET has specific and restrictive regional boundaries where families are able to enrol their students. Principals have the power to accept or reject applicants if they are out of the area. Schooling options are already limited for students with autism. This restrictive practice impedes opportunities for families to seek appropriate school support. More often than not, young students with autism end up being placed in mainstream classrooms without adequate teacher training, resources and support.

It is common practice in NSW DET schools to indefinitely limit a child's Kindergarten attendance to a few hours per day and some principals are able to use this as an excuse for extended transition time to settle students in. This denial of access to education is very discriminatory and families are unable to do anything about it. Many mainstream schools "do their best" but they lack the capacity to cater for students with autism. Students with autism need quality education with appropriate generic disability and autism-specific services and support for their autism.

During transition to school meetings, families are not informed about what supports their students can get. Most often, parents are asked to sign for funding applications and that is the extent of their involvement during the transition process. Families of students with disabilities or developmental delay face increased anxiety and stress daily. Taking away the family's autonomy to be a part of their child's transitioning process without the provision of adequate knowledge to make informed judgement adds to increased stress level and have legal implications.

Transitioning from primary school to high school is a stressful process due to the lack of educational facilities for students with autism and their families. In Inner Sydney, options to send students to high schools with adequate support are limited. Increasingly, families are opting to home school due to various issues including bullying from other students. This is a major indictment in the failure of the school system to adequately support students with autism, with

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Post-school options/placements are limited; some young adults enter vocational schooling but end up having difficulties finding suitable employment. The lack of support in this age group is unsatisfactory and a major concern for families.

Far too many students with autism experience sudden and unplanned transition away from school to school exclusion (see <http://a4.org.au/a4/node/392>) or school refusal. We observe that the Education Department may not collect and is not reporting publicly how many students with autism are excluded from school, or just “disappear” from the system with the reason unknown.

National data shows educational outcomes for students with autism are abysmal. We have no reason to believe students with autism in NSW do any better than the disgraceful national average for students with autism.

2. Best practice approaches to ensure seamless and streamlined assistance during transitions

Recommendations from the research literature include:

- Long-term planning is needed and should be conducted well in advance of the point of transition.
- Preparation of physical school environment as well as positive attitude of education staff.
- Transition planning and preparation should be real and properly resourced, not tokenistic.
- Families and children need to be included in the transition process and provided with adequate information to help them make decisions.

- Families should be informed and included when exploring options about special education provision.
- Collaboration between staff and families needs to take place to make sure resources are available for smooth and successful transitions.
- Children who require support need individualised plans that are communicated effectively; the documentation must be prepared in collaboration with families the student and agencies involved showing clearly the team roles, responsibilities and actions.
- Smoother transitioning can be facilitated by moving away from a one size fits all model to an individualised service provision which takes into considerations the individual student and the important role of their families.
- Collaboration is required at all levels.
- Teaching children skills required for their next learning environment.

3. Any other related matters.

The United Nations Convention on the Rights of the Child says all children, including children with autism/ASD, have a right to education. But the NSW Education Department pursued the matter of *Purvis vs NSW* to the High Court ... that decided any school can exclude a student because the student **might** behave inappropriately. The High Courts decision means schools (and other organisations) can exclude anyone whose behaviour makes them uncomfortable. As a result of the actions of the NSW Education Department, schools do not need to make reasonable adjustments for students with ASD, as was shown in the recent *Walker vs Vic* case in the Federal Court (see <http://a4.org.au/a4/node/375>).

The Productivity Commission's report on disability services and support is scathing. The Productivity Commission recommended substantial improvements to early intervention and to care and support. It did not make recommendations relating to education. Since education is mostly the responsibility of the state government, it is up to the NSW Government to

Government officials and other claim increasing prevalence of autism spectrum disorders “can be properly explained by a greater awareness of milder presentations”. But the evidence indicates this is not correct: the ABS reports that in 2009, “an estimated 64,600 Australians had autism ... more than double the prevalence identified in 2003”. Also, “of people with autism, 74% reported having a profound or severe core activity limitation”. Had the number doubled due to “milder presentations”, the rate of severe or profound disability would be below 50%. The *alleged* proper explanation (which is really just a hypothesis) contradicts the observations, which indicates the hypothesis is most probably wrong.

Acknowledgements

The A4 Management Group prepared this submission. The primary input came from A4 members living in New South Wales.

Yours sincerely

Bob Buckley

Convenor

22/8/2011

improve its education of students with a disability to keep up with the rest of the disability sector.

The Commonwealth Department of Health advises that best practice early intervention for a child with an autism spectrum disorder is intensive ASD-specific early intervention for at least 20 hours per week for a minimum of two years. Children with ASD need effective early intervention to prepare them for school. Children with autism who have not received treatment and rehabilitation to maximise their learning skills before they enter school do not get optimal benefit from their education. And they need significantly more support in school ... if their behaviour does not lead to exclusion.

The same report says ...

There should be systematic connection and integration between the early intervention program and the next stage for the child, whether it is transition to school or to another therapeutic or special educational setting. Parents, teachers and therapists need to collaborate in preparing the child for transition.

from <http://www.health.gov.au/internet/publications/publishing.nsf/Content/mental-child-autbro-toc~mental-child-autbro-best>

The Commonwealth's Helping Children with Autism package provides at most 5% of the early intervention that a child with autism needs. The NSW Government provides even less intensive ASD-specific early intervention for children with ASD.

Without adequate preparation, children with autism/ASD do not succeed in school. So 77% do not get any further qualification and labour force participation is just 34%.

There is a lot of misinformation about autism spectrum disorders in the media. For example, claims of fake diagnoses (see <http://a4.org.au/a4/node/385>) and diagnosis "blowouts" (see <http://a4.org.au/a4/node/367>). Be aware that the substantial increase in ASD diagnoses is happening in every state in Australia and most other countries with adequate records.

(see <http://www.nationalautismassociation.org/autismincreases.php>).