



# Really?

A Review of

**Report on support provided for autism diagnosis and services and the potential for further reforms resulting from the National Disability Insurance Scheme and the National Plan for School Improvement**

*Bob Buckley*

*23 May 2014*

## Table of Contents

Executive Summary.....	3
Introduction.....	4
Review of ACT Government’s Autism Report 2013.....	5
Review of the Introduction.....	5
Review of Autism in Australia and the ACT.....	6
Review of Section 1.....	8
Review of Diagnosis of Autism Spectrum Disorders (ASD).....	8
Review of Intervention and Education.....	9
Review of the report section on Post school options.....	12
Review of the report section on supported accommodation and respite.....	13
Review of the report sections on Information services.....	13
Review of Section 2.....	14
Review of the section on the NDIS.....	14
Review of National Plan for School Improvement.....	15
Omission: Health Services and ASD is missing.....	16
Conclusion.....	17



## Executive Summary

The Legislative Assembly asked the ACT Government to report on “support provided for autism diagnosis and services and the potential for further reforms”. The Minister presented the report to the Assembly in May 2013. Following numerous requests, the Minister gave a copy of the report to representative of people affected by autism spectrum disorder (ASD) on 23/4/2014. The Minister took 11 months to hand over a copy of the report to the ASD community in the ACT.

This review of that report finds that the ACT Government's information about ASD and the service and support needs of people affected by ASD is often incorrect. For example, the report under-estimates the number of Australian children diagnosed with ASD by an enormous factor of three (3).

The information that the Government provided for the Assembly is not accurate. Effective planning depends on accurate information. For example, when planning and resource allocation is under-estimates the number of children needing services and support by a factor three, the 2 in 3 children miss out completely or each child gets just 1/3 of the services and supports that they need.

The ACT Government's report is deeply disappointing. It offers no **real** prospect for improving outcomes for people affected by ASD.

*Really?* It's just not good enough.



# Introduction

The Labor Party forced a motion through the ACT Assembly on the 10 April 2013

That this Assembly:

(1) notes:

(a) that April is Autism Awareness Month and 2 April was World Autism Awareness Day;

(b) the significant support already provided by the ACT Government to people with autism, together with the Government's recent commitments to disability support; and

(c) the potential impact that important national reforms in disability and education may have on support for people with autism; and

(2) calls on the Government to report to the Assembly by the last sitting day of May 2013 on support provided for autism diagnosis and services and the potential for further reforms resulting from the National Disability Insurance Scheme and the National Plan for School Improvement.

See <http://www.hansard.act.gov.au/hansard/2013/week05/1392.htm> or <http://sofasd.org.au/sofasd/node/46>

The Minister said “The government provides children with autism with a suite of services and programs, both in and out of school, which supports their development and education, ...” Sadly, independent assessments show that existing services fail to support the development and education of children with ASD. The Minister ignores, or seeks to contradict, the highly credible and deeply critical descriptions of existing disability services and supports ... such as the [Shut Out report](#), the Productivity Commission's inquiry into [Disability Care and Support](#) and the equally disappointing response to disability services in the ACT from the ASD community.

In addition, the [ABS 2009 SDAC](#) shows outcomes for people with ASD are substantially worse than average outcomes even for people with a disability. The Minister's motion ignores abysmal outcomes for people with ASD and tries to portray “a suite of services and programs, both in and out of school, which supports their [people with ASD in the ACT] development and education” as much more favourable/beneficial than they really are. Existing “services and programs” are far short of adequate for “their development and education”.

The ACT Government is trying to portray its service model as far better than it really is so it can continue to deny essential services to people affected by ASD.

The Minister's motion refers to “the potential for further reforms”; unlike the Commonwealth Government, her Government refuses to recognise/accept that the Shut Out Report and the Productivity Commission proved *the need*, not the potential, for substantial further reforms. There will be no real progress towards better outcomes for people with ASD in the ACT while the ACT Government denies that there are *clear needs for substantial further reforms* to services and supports for people with ASD.

Hansard (see <http://www.hansard.act.gov.au/hansard/2013/week07/2166.htm>) shows ...

**Ms Burch** presented the following paper:

Autism Support Services—Report on support provided for autism diagnosis and services and the potential for further reforms resulting from the National Disability Insurance Scheme and the National Plan for School Improvement, dated May 2013.

Bob Buckley, Chair of SOfASD, wrote to Minister Burch on 25/7/2013, 2/11/2013 and 13/3/2014 requesting a copy of the report. Eventually, the Minister's office provided a copy of the report on 23/4/2014: it took almost a year for the ACT Government to deliver a copy of this report about the ASD community to the ASD community. The report is now available online and can be downloaded from <http://sofasd.org.au/sofasd/node/55>.



## Review of ACT Government's Autism Report 2013

Following is a review/critique of specific sections of the ACT Government's report.

### Review of the Introduction

The report's Introduction declares ...

In this report autistic disorder, Asperger Syndrome and other pervasive developmental disorders are referred to as autism spectrum disorder (ASD).

Page 1

The report would be better had it said something like ...

*In this report, some of the pervasive developmental disorders described in the DSM-IV – particularly autistic disorder, Asperger's disorder and pervasive developmental disorder – not otherwise specified (PDD-NOS) – are referred to as autism spectrum disorders (ASDs). Recently, the 5<sup>th</sup> edition of the Diagnostic Manual of Mental Disorders (DSM-5) created a single diagnosis of Autism Spectrum Disorder (ASD) superseding the older (less formal) “ASDs”.*

## Review of Autism in Australia and the ACT

The report says ...

It is estimated that between 1 in 100 and 1 in 160 children has autism spectrum disorder (ASD), making it more common than many other childhood conditions. 2007 Centrelink data indicated an estimated prevalence of ASD across Australia of 62.5 per 10,000 for 6-12 year old children. This means there is approximately one child with ASD on average in every 160 children in this age group, which represents 10,625 children aged between 6 and 12 years with an ASD in Australia<sup>1</sup>.

<sup>1</sup> Overview to the Prevalence Report on Autism by the Australian Advisory Board on Autism Spectrum Disorders, 2007

Page 4

The 1 in 160 (or 62.5 per 10,000) figure quoted above probably comes from Centrelink registrations for Carer's Allowance (child) of Australian children with a formal diagnosis of Autistic Disorder or Asperger's Disorder around 2005. The Australian Advisory Board on Autism Spectrum Disorders (AABASD) released its report (see <http://www.autismadvisoryboard.org.au/uploads/pdfs/PrevalenceReport.pdf>) showing Centrelink data for Carer's Allowance had 1 in 160 Australian children aged 6-11 years old diagnosed formally with Autistic Disorder and Asperger's Disorder. These rates are not estimates, they are the number of children registered for Carer's Allowance (each registration requires a formal report from a relevant health professional) for the whole population of Australia. In 2010, after the number of children registered with these two disorders for Carer's Allowance rose to 1 in 90 (see <http://a4.org.au/a4/node/389>), the AABASD estimated conservatively that 1 in 100 Australian children have ASD.

By 2012, about 1 in 63 children with Autistic Disorder and Asperger's Disorder were registered with Centrelink (see <http://a4.org.au/a4/node/622> and <http://a4.org.au/a4/node/695>).

Similar rates were observed in the Australian Bureau of Statistics (ABS) 2009 Survey of Disability Ageing and Carers (SDAC). Note: the SDAC estimate of people with "autism" presenting as severe or profound disability is very similar to number from the Centrelink data, which adds confidence the result. Similar growth in autism prevalence is observed overseas, for example in the USA where the CDC had reported 1 in 88 then recently revised their estimate to 1 in 68.

### *The ACT Government's report under-estimates the number of children diagnosed with ASD by a massive factor of 3.3.*

The following table shows the number of children aged 6-12 years registered with Centrelink for their families to receive Carer's Allowance due to the child's Autistic Disorder or Asperger's Disorder from 2004 to 2013 (Centrelink refused to provide precise numbers for the age breakdown for the ACT from 2010 to 2012 so those numbers are estimates). This shows there are already 35,323 children, more three times the report's estimate of 10,625 children (in 2013, the time of the report) aged 6-12 years with ASD in Australia, and there will be even more when the NDIS is in place.

	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
Australia	7880	10305	12328	13847	16626	20891	24954	28732	32257	35323
ACT	158	190	219	258	307	331	~355	~371	~397	418

The number of children with autism aged 6-13 has grown 2.6 times in the nine years 2004 to 2013. Growth in ASD number is below the national average (the national number grew 4.5 times in the same period).

The report says ...

The number of people with a disability including ASD accessing Government services has increased steadily in line with increases in the ACT population.

Page 4

This data in the table shows “Total service users” grew from 3,477 in 2006-7 to 4,213 in 2010-11 ... which is an increase of 21% (which may be “in line with increases in the ACT population”).

The report is remiss in failing to highlight high growth in the number of children with autism. Clients with “Primary disability recorded as Autism” grew from 315 in 2006-7 to 522 in 2010-11. This is growth of 66% from 2006-7 to 2010-11 ... which far exceeds “increases in the ACT population” growth. Note: these figures (from the AIHW datasets) are higher than those given above for the 6-12 year old age range as clients a) are from a wider age range, b) may include some from the surrounding regions, and c) may include some people with PDD-NOS.

Notice that page 11 of the report says the February 2013 (public school?) Census found 645 students with ASD. This seriously underestimates people with ASD of school age since there are also students with ASD in private education, the Catholic education system and home-schooling. There may even be a few who are just excluded from education altogether.

When the ACT Government ignores substantial growth in the number of people diagnosed with ASD then its planning fails to address the needs of people affected by ASD.



# Review of Section 1

## Review of Diagnosis of Autism Spectrum Disorders (ASD)

The report says ...

The Health Directorate provides assessment and intervention services through Child Health Targeted Support Services which include:

- ...
- Ongoing care for medical conditions arising as a result of the diagnosis of autism including sleep disorders, behavioural disorders, nutritional deficiencies, attention problems, tics and epilepsy and mild to moderate mental health problems such as anxiety and depression;
- ...

page 6

The bit about “behavioural disorders” (behavioural disorder is among the diagnostic criteria for ASD) is of particular interest to people with ASD and their families. The Child Health Targeted Support Services unit has a web presence (click [here](#)) that provide no useful information. It’s page points to the [Community Health website](#) which fails to mention the services that the Minister describes. The Health Directorate’s Annual Report (click [here](#)) provides no information about this unit nor anything about services it provides for people with ASD.

The Child Health Targeted Support Services unit is not listed/mentioned in AAACCT's free (and comprehensive) “What do we do now?” booklets (available [here](#)). Apparently, people in the ASD community are not aware of, nor are they accessing, this service ... despite there being numerous cases of chronic behavioural disorder among the group and a desperate need for such a service.

It is not clear how the Health Directorate could offer intervention for behavioural disorders since the website (see [webpage](#)) shows a total absence of any qualified professionals in the ACT.

When we asked the ASD community whether they were aware of this service, one person describes it as a “Ministerial hallucination”. It is evident that this service is a figment of the Government’s imagination. Imaginary services do not help, they just frustrate.

The diagnosis process for ASD described in the report (see page 8) shows pathways that start with a GP, a maternal and child health nurse, an allied health professional, a teacher or a school counsellor; and progress via a paediatrician, a Child Health Medical Office (CHMO) or a psychologist.

The existing process is unnecessarily slow and complex. For years, the ACT Government has ignored calls from the ASD community in the ACT to create a single comprehensive childhood diagnosis centre, similar to the service found in children's hospitals around the country.

The report says

During 2012 Therapy ACT provided 85 comprehensive multidisciplinary autism assessments to families in the ACT

page 7

The ACT Government is closing Therapy ACT due to the NDIS. Where will families go to get their ASD diagnoses?

The report says

The DSM 5 will replace the current edition (DSM IV-TR) and will be published in May 2013. Under the new criteria Autism will be diagnosed as mild, moderate and severe.

Page 8

This is not correct. The DSM-5 has three (relatively experimental?) severity levels for two distinct parts of an ASD diagnosis. The DSM-5 severity levels are numbered and have descriptions. They are:

- Level 1 Requires support
- Level 2 Requires substantial support
- Level 3 Requires very substantial support

None of the DSM-5 levels is “mild” or “moderate”. The least severe says “requires support”. The DSM-5 warns repeatedly and explicitly against using severity levels in allocating resources. None of the DSM-5 severity levels says “can be dumped in mainstream education without support”.

The report claims:

Changes to diagnostic criteria in the DSM 5 are based on research findings to increase diagnostic accuracy. The DSM IV – TR is categorical where the DSM 5 is dimensional so that people with minor symptoms are captured.

Page 8

This is false. The DSM-IV (1994) and the DSM-IV-TR (2000) criteria for **all** Pervasive Developmental Disorders (which includes Autistic Disorder, Asperger's Disorder and PDD-NOS) involved “severe and pervasive impairment”. There was no option at all either the DSM-IV or the DSM-5 to capture/diagnose “people with minor symptoms” as having any Pervasive Developmental Disorder (or one of the ASDs – DSM-IV) or ASD (DSM-5). The Government’s claim (above) leaves little confidence in their diagnostic service (who probably wrote this part of the ACT Government’s report). Sadly, the ACT Government has regarded most people diagnosed with ASD as “people with minor symptoms” and failed to provide adequate services. Consequently, outcomes for people with ASD are abysmal (and profoundly inequitable) in education (see <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4428.0main+features62009>) and in labour force participation (see <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4428.0main+features72009>). The ACT Government refuses to recognise these extremely inequitable outcomes, let alone act to try and achieve more equitable outcomes for people with ASD.

The authors of the DSM-5 did not intend changes to “exclude a percentage, perhaps 20-30%, of high functioning individuals who met criteria under DSM-IV TR” (page 8). The intent was to capture the same cohort of people with “severe and pervasive impairment”. There is no evidence of a discernible group of “people with minor symptoms” who are formally diagnosed with ASDs ... despite what the ACT Government prefers to believe. (There are some signs of cohorts of informally diagnosed and people who are self-diagnosed).

## Review of Intervention and Education

The report says:

Autism Asperger ACT Inc offer family support services, with funding provided jointly by the Commonwealth and \$107,828 annually from the ACT Government.

Page 9

The Commonwealth does not fund “family support services”, it funds the *Helping Children with Autism* package. The ACT Government funds AAAct to employ a Family Support Officer. The level of funding in the ACT is well below the *pro rata* rate compared other states/territories.

The report says:

Two Autism Advisors are located at Autism Asperger ACT Inc offices

page 9

In fact, Autism Asperger ACT won a contract with the Commonwealth Government to provide 1.3 FTE Autism Advisors (not 2 advisers) as part of the *Helping Children With Autism* package. The contract runs out in June 2014; the Commonwealth Government did not renew the contract for the Autism Advisor service. The situation in the ACT is different to the NDIS launch in South Australia where the Commonwealth funded the Autism Advisor service for the first year of the NDIS launch. The NDIS does not offer an equivalent to Autism Advisor service ... so families who would benefit from the service will be worse off under the NDIS. This is a broken promise.

Despite the ACT Government's claims about Therapy ACT, the ASD community is highly polarised on the issue of benefits and effectiveness of Therapy ACT.

In relation to "intervention and education", The report says:

There are a number of research and literature reviews available to identify suitable interventions for people with autism that meet the criteria for Evidence Based Practice. At a broad level, there is consensus that the following factors are backed by rigorous research evidence: individualised supports and programs, highly structured and supportive environments, supported transitions between settings, a functional approach to behaviour management and family involvement.<sup>3</sup>

Interventions are numerous and no single intervention works for every child. It is important to recognise that no one child with autism will have the same pattern of strengths and needs as another. In addition, families differ in their goals, strengths, and needs. Research indicates that there are benefits from early, intensive, family-based treatment programs, so long as these are adapted to the child's pattern of strengths and weaknesses and take account of family circumstances.

<sup>3</sup> Roberts, J. M. A., & Prior, M. (2006) *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Australian Government Department of Health and Ageing, Australia.

Page 10

This misrepresents the Commonwealth Government's advice. The advice does not say "highly structured and supportive environments". Actually, the Commonwealth provides its own summary document<sup>i</sup> that advises every child with ASD needs 20 hours per week of intensive, individualised, ASD-specific early intervention for at least 2 years. Clearly, the ACT Government (and Therapy ACT) does not offer any such service. Their staff, like the vast majority of allied health graduates in Australia, simply are not trained to supervise or deliver intensive, individualised, ASD-specific early intervention programs.

The ACT Government does not even follow its own interpretation of ASD research. Instead of ensuring children with ASD are in "individualised ..., highly structured and supportive environments", as a false economy the ACT Government dumps as many students as it can without appropriate support in **inclusive group** (that is, not individualised) settings that often lack adequate structure.

The remark about "take account of family circumstances" is contrary to the *UN Convention on the Rights of the Child* (CRoC) which says clearly that it is the state's responsibility to ensure **every child** gets the treatment, rehabilitation and education services that they need. It is a state (Territory) responsibility, it is not dependent on "family circumstances". But Australian Governments have never taken their own state responsibilities, or the rights of vulnerable citizens in Australia, seriously.

The ACT Government (Therapy ACT) pays lip service only to *evidence based practice* (EBP) in relation to ASD. It shows little or no understanding of what EBP for ASD means ... for example, despite overwhelming supporting evidence<sup>ii</sup>, Therapy ACT strongly opposed any use of Applied Behaviour Analysis (ABA) or Early Intensive Behavioral Intervention (EIBI).

Ms Hayes, the head of Therapy ACT, told the Select Committee on Estimates 2010-11 (see <http://www.hansard.act.gov.au/hansard/2009/comms/estimates21.pdf>) that “We do not actually use the ABA intervention method ...”. Everyone with actual knowledge and experience of intervention for autistic disorder knows that ABA is an essential element of most, if not all, individual programs for children/students with autistic disorder ... and that many people with ASD needs ABA to support their education and adult support services. Clearly, a service that professes to *not actually use ABA* with children/people with ASD cannot meet the needs of people with ASD and has no credibility whatsoever.

Now the ACT Government is talking about “a functional approach to behaviour management”. The ASD community would be interested to know how to access any behaviour management service in the ACT from trained/qualified professionals.

Contrary to the *beliefs* of Therapy ACT and the ACT Government, key reviews<sup>iii</sup> find very little evidence supporting “parent-mediated” or “family-based treatment programs” for children with ASD. There is widespread consensus among researchers that “family involvement” is usually desirable, but is certainly not an essential element of best practice early intervention for ASD.

Therapy ACT has always said that “no single intervention works for every child [with ASD]” then used this as an excuse to not even try to offer appropriate or adequate early intervention for any child with ASD. Their argument does not make sense and is designed only to deny service to children with ASD.

The section headed “education” (starting on page 11) shows that a few children with ASD in the ACT get a maximum of 9 hours of early intervention in autism groups in Autism Intervention Units (AIUs), or 15 hours in bigger groups in Early Childhood Units (ECUs) or Centres (ECCs). These offerings fall well short of EBP or “best practice”: the group settings in the ACT lack the required intensity (falls short of 20 hours per week, is for only 40 weeks per year and cannot meet an individual’s needs for one-on-one intervention) and individual programming (since its programming is for a group setting). ASD is the only mental/clinical disorder that is “treated” in the ACT by early childhood teachers. The ACT Government has never explained why/how its early childhood teachers are qualified and prepared to treat a clinical disorder (on Axis I in the DSM).

The report says:

In addition to these specialised settings, in some schools, students may receive therapy services in the school setting from Therapy ACT. This may involve speech pathology, occupational therapy or physiotherapy. Therapy ACT’s Therapy Assistants Program was piloted in 2011-12 and \$1.31 million was allocated in the 2012-13 Budget to continue it for a further two years. The Government has pledged a further \$1.67 million to fund the program until 2016-17. The program supports up to five mainstream schools and two specialist schools each year, giving students with autism and other developmental delays and disabilities an opportunity to receive regular therapy sessions in their classroom.

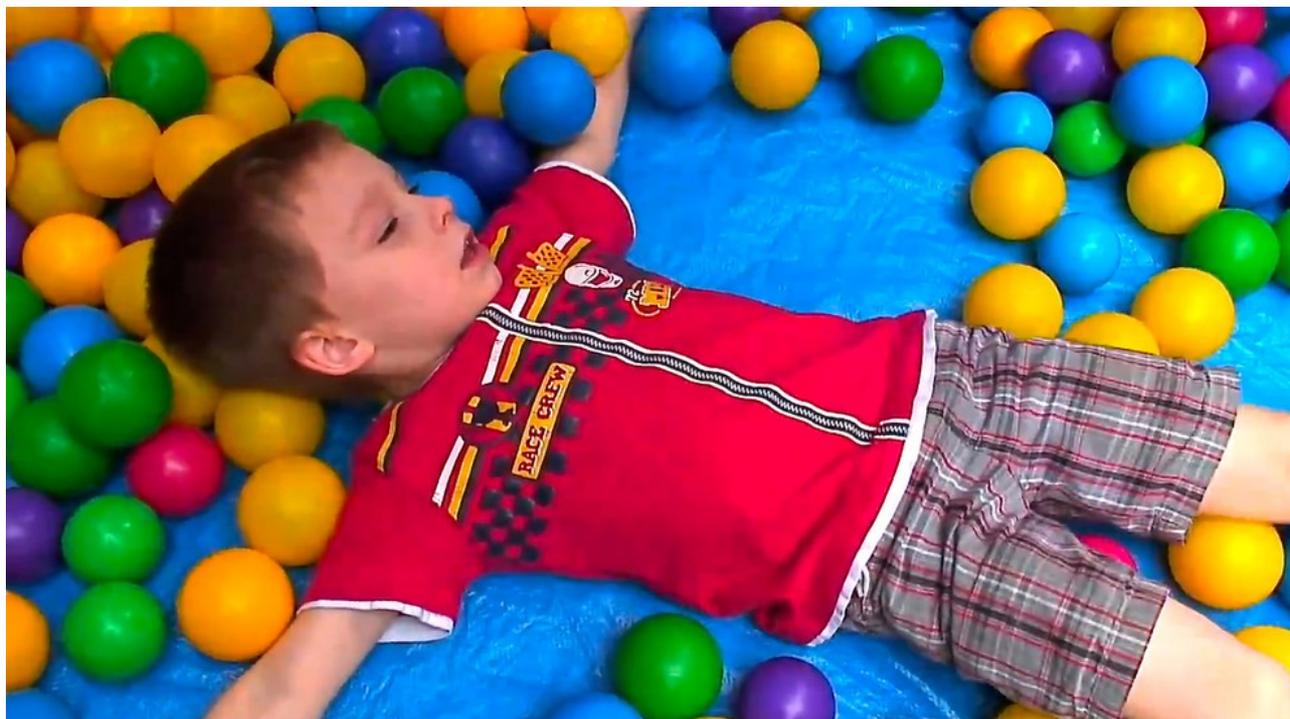
Page 12

A program that “supports up to five mainstream schools and two specialist schools each year” clearly falls well short of meeting the needs or ensuring equitable access to therapy for all students with a disability who need support in all schools. The ACT Government wilfully breaches Article 23 of the CRoC.

No child with ASD received therapy assistance when Therapy ACT piloted its Therapy Assistants Program in 2011-12. Notice that the Therapy Assistants Program does not involve (behavioural) psychology to address the behaviour issues that many students with ASD experience in schools.

The Therapy Assistants Program in ACT schools neglects/omits/excludes many students with ASD. No doubt the ACT Government will continue to neglect the behavioural needs of students with ASD (that relate to education goals) when the NDIS is implemented ... the ACT Government is responsible for services in schools since the NDIS does not support education goals of students with a disability in school education.

The ASD community will be interested to see whether school-age students with ASD can use NDIS funding to address their behavioural needs when they are not in school; and even more interested to see whether their needs across multiple settings including school can be supported through the NDIS (since their needs are not met through education services, and the High Court said, in *Purvis vs NSW*, anyone can exclude students completely from education – or discriminate generally – if they believe a student’s behaviour even *might* be “unacceptable”).



## Review of the report section on Post school options

This section does not really reflect the post-school situation that people with ASD experience in the ACT. Established service providers such as LEAD and Sharing Places provide incomplete services. For example, some of the people using these services simply do not access these services themselves; they are completely dependent on informal carers to transport them to and from their services. The ACT Government has a very limited perspective on what “access” means for people with a disability.

People who get an ISP, because established disability service providers cannot or do not provide the services they need, often cannot access any appropriate service ... either because no appropriate service exists or because the bureaucrats do not recognise services as appropriate.

The Government increased funding for some by \$5,000 per person ... but offers no justification for this amount. The amount is clearly inadequate since the NDIS indicates that significantly more funding is required.

The Government claims “The grants will help graduates with autism and other disability access services that support their participation and engagement in socially valued activities”; but it is clear from numerous Federal Budget speeches that employment is really the only “socially valued activity” ... and this does nothing to help people with ASD participate in the labour force.

The ACT Government *bangs on* about “social enterprises”. Sadly, recent local experience does not show small businesses that are centred on a single individual with high support needs is unlikely to be sustainable.



## **Review of the report section on supported accommodation and respite**

This section describes services that are being shut down with the introduction of the NDIS.

There is no transport service for people with ASD to access the ACT Government's respite services. Again, these services are inaccessible to clients with ASD unless their informal carers provide transport to and from the service.

## **Review of the report sections on Information services**

There are short sections on informations for:

1. people with ASD and their families
2. allied health and education professionals

The section on information for people with ASD and their families fails to mention either the Autism Advisor service or Autism Asperger ACT and its Family Support Officer. These are by far the most prolific and respected sources of information for people affected by ASD in the ACT.

## Review of Section 2

### Review of the section on the NDIS

The report says “People with disability have the same right of access to services as all Australians”. This Principle denies people with disability have different service *needs*; that their needs are not the same as people who don't have a disability. This is recognised and articulated clearly in the CRoC and the UN Convention on the [Rights of Persons with Disabilities](#) (CRPD).

We understand the Government’s “No wrong door” approach, but we usually include the missing punctuation.

The ASD community is aware and appreciative that the report says ...

The legislation does not place an age restriction on children accessing early intervention requirements under the scheme.

We also welcome significantly increased funding for disability services.

The report talks pretty pointedly about the *Better Start for Children with a Disability* initiative, which has little or nothing to do with autism, before it talks about the *Helping Children with Autism* (HCWA) package. This reflects the resentment that senior staff in Therapy ACT always held for the HCWA package.

Previously, Therapy ACT cut services to a child if the child’s families augmented the child’s profoundly inadequate therapy from Therapy ACT with services from another allied health professional. Therapy ACT claimed that having more than one allied health professional working with a child is contrary to professional service standards. But when the HCWA package was created to augment services provided by the Territory, the ACT Government suddenly decided to “adjust” its service model to allow a child to access services from multiple allied health professionals, contrary to the very “professional conduct” rule that Therapy ACT used previously to exclude children with ASD from its therapy services.

Originally, the NDIS was going to start on 1 July 2013 ... but it was deferred until 2014. The ACT Government decided to use some of the funds allocated for 2013 to make its Enhanced Service Offer (ESO). This was meant to help people transition to the NDIS model of individualised person-centred service access. In hind-sight, the ESO with its grant approval model and limited funding did not turn out as well as expected.

The report has a section on the *National Plan for School Improvement*. It is especially disappointing that this section contains **nothing** at all to improve education outcomes for students with ASD. We know already that *services for students with a disability* deliver abysmal outcomes for students with ASD. This report continues to ignore this critical issue.

This section of the report concludes

Individuals and families with autism have access to a range of supports and services in the ACT, including diagnostic, intervention, education and family support services, from referral to advocacy. While these services represent a significant investment in the wellbeing of people with autism, the ACT Government is committed to providing even greater choice and control to families who are the best judge of what support and services will suit their family member with a diagnosis of autism.

Over the past ten years, funding for disability services has doubled and with the transition to the full NDIS scheme in 2019-20, funding for disability services will have doubled again. For individuals and families with ASD this represents an opportunity to engage more fully in the community, to receive the supports and services they need to reach their potential and to choose the life they want to live.



Sadly, it simply isn't true to say that "these services represent a significant investment in the wellbeing of people with autism". The ACT Government has done little to enhance "even greater choice and control to families".

The report only mentions "advocacy" and "referral to advocacy" in its Introduction and its Conclusion. The ACT Government funds "Advocacy for Inclusion" (that is, advocacy with its own agenda) which is usually not the type of advocacy that people with ASD need. Claiming advocacy services are available for people with ASD without saying what those services are diminishes the report.

Note that the Commonwealth Government also *refuses* to fund systemic advocacy for people with ASD at a national level: the Commonwealth does not fund any national ASD-related peak body or systemic advocacy organisation ... and national ASD-related organisations, like several other disability types where a DPO is not particularly representative, are excluded from peak disability bodies.

Again, while disability funding may have doubled in raw dollar terms over ten years, this does not allow for inflation ... and the number of people diagnosed with ASD has more than quadrupled in the same time. Services from the ACT Government for each individual with ASD have decreased substantially ... already meagre services for people with ASD in the ACT are now spread much thinner than before.

This still left a system that the Productivity Commission said was not working. Much of the increased disability funding in the ACT went to improving access for people with a disability. This spending is of little or no benefit to people with ASD.

There is no guarantee that the further funding from the NDIS will get disability services and supports working effectively for people with ASD in the ACT.

In particular, the NDIS does not fund services and supports in education or employment ... and the ABS data shows major deficits in both these areas for people with ASD.



## Review of National Plan for School Improvement

Again, the ACT Government fails to recognise that a plan to help student with a disability, that is a generic disability service, does not recognise nor address the needs of student with ASD. This section offers no discernible prospect for better education outcomes for students with ASD.

## Omission: Health Services and ASD is missing

One of the more remarkable features of the report is the absence of any health services for people with ASD. There is no mention of any role for the public paediatricians in relation to ASD. There are no mental health services or supports for people with ASD. While there are a range of services for people with dual diagnosis, that is intellectual disability and mental illness, these services do not exist, despite an obvious need, for people mental illness and ASD.

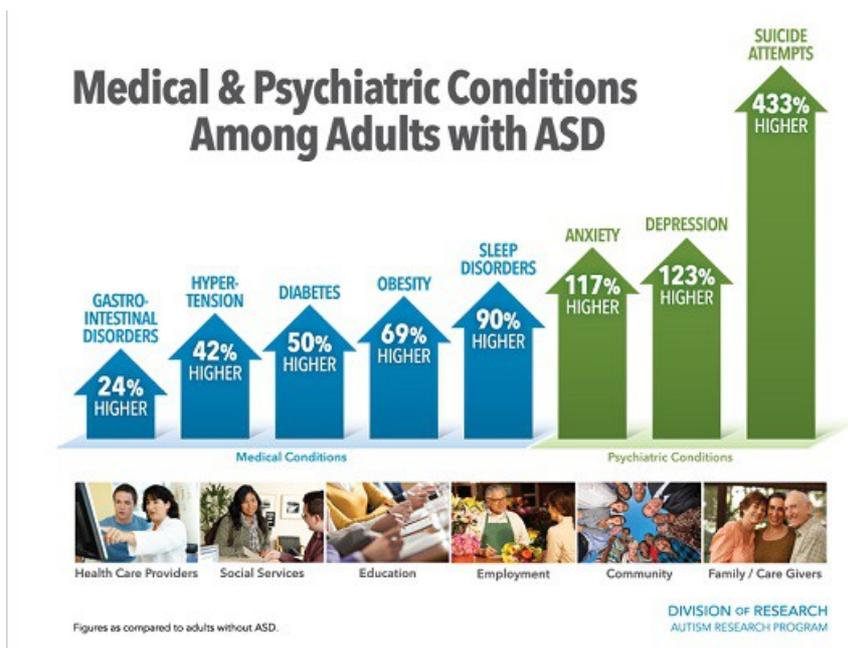
The World Health Organisation says

Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.

The positive dimension of mental health is stressed in WHO's definition of health as contained in its constitution: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

[http://www.who.int/features/factfiles/mental\\_health/en/](http://www.who.int/features/factfiles/mental_health/en/)

The ACT Government's report on "autism diagnosis and services" reviewed above shows that there is a long way to go before it recognises, let alone addresses, the mental health needs of people with ASD in the ACT.



The lack of awareness of and provisions for ASD in the ACT's health sector is contrary to the Government's alleged goal of meeting the needs of people with disability in mainstreams service settings.

## Conclusion

The information that the Government provided in its report on ASD for the ACT Legislative Assembly is quite inaccurate. It is a poor foundation for policy and service planning.

The ACT Government does not know

- how many people in the ACT are severely affected by their ASD or how many children have been diagnosed with ASD.
- What best practice for ASD is, how to deliver it or even how to recruit appropriate staff.
- How to monitor and report outcomes appropriately.

Without effective plans, there will be little or no improved outcomes in education, employment, community access or supported accommodation for people with ASD in the ACT.

*Really?*

Is this *really* the best the ACT Government can do? Does the ACT Government *really* think their report to the ACT Legislative Assembly, their policy and their programs are anywhere near good enough?



- i [http://www.health.gov.au/internet/main/publishing.nsf/Content/19A99E0084110A31CA257BF0001E74DB/\\$File/autbro.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/19A99E0084110A31CA257BF0001E74DB/$File/autbro.pdf)
- ii For example, see the Commonwealth Government’s advice where ABA/EIBI is the **only** program for ASD in young children that rates their top *evidence* rating ... see [http://www.dss.gov.au/sites/default/files/files/disability-and-carers/hcwa\\_tables.doc](http://www.dss.gov.au/sites/default/files/files/disability-and-carers/hcwa_tables.doc) (links to download PDF or MS Word are [here](#)).  
The Cochrane Collaboration reports says “The evidence supports the use of EIBI for some children with ASD”, see <http://summaries.cochrane.org/CD009260/early-intensive-behavioral-intervention-eibi-for-increasing-functional-behaviors-and-skills-in-young-children-with-autism-spectrum-disorders-asd>.
- iii See <http://summaries.cochrane.org/CD003496/early-intervention-delivered-by-parents-to-young-children-with-autism-spectrum-disorder> ... now withdrawn; it’s replacement is slightly more supportive but remains inconclusive – see <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009774.pub2/abstract;jsessionid=ACFAF53C7B13DC4F67C8317418D88AC3.f01t02>