

Submission to

**the inquiry into
the implementation, performance
and governance of the National
Disability Insurance Scheme
(NDIS)
in the ACT**

for the ACT
Standing Committee on Health, Ageing and Social Services

from

Speaking Out for Autism Spectrum Disorder (SOfASD)



and

Autism Aspergers Advocacy Australia (A4)



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Introduction

This submission responds to [the ACT Government web-page](#) that says ...

The Standing Committee on Health, Ageing and Social Services will inquire into and report on the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT. The Committee will consider:

- a. The relationship between the ACT Government and Australian Government in regard NDIS and National Disability Insurance Agency (NDIA) as it affects the ACT; particularly gaps or duplicate roles and responsibilities;
- b. Practical outcomes of implementation in relation to disability workforce development strategies; the Human Services Registrar; the availability of services for eligible NDIS participants; the availability of early childhood intervention services; the implementation of local area coordination; and supports for people with psycho-social disabilities; and
- c. Whether there are unique factors relating to the provision of disability services affected by the implementation of the NDIS in the ACT.

Autistic people and their support community in the ACT appreciate this opportunity to comment on the implementation, performance and governance of the *National Disability Insurance Scheme* (NDIS) in the Australian Capital Territory (ACT).

This submission focuses on the NDIS as it relates to and effects autistic people and the support they get now in the ACT.

Two systemic advocacy groups, *Speaking Out for Autism Spectrum Disorder* (SO_fASD) and *Autism Aspergers Advocacy Australia* (A4), developed this submission.

SO_fASD is the ACT organisation doing systemic advocacy specifically for autistic people, their families and those who support them in the ACT. SO_fASD has a history of advocacy for autism in the ACT. Previously, as *Action for Autism*, it played a significant part in the creation of the ACT's successful autism-specific Learning Support Units (LSU-As) in the late 1990s. For a time SO_fASD was part of (the now defunct) *Autism Asperger ACT* (AAACT) group, but SO_fASD separated from AAAC_T when it became impractical to function as systemic advocates from within an organisation whose goals were increasingly on service provision.

A4 is a national grassroots systemic advocacy group representing autistic people, their families and family carers. A4 formed in 2002. A4 is a member of the *Australian Federation of Disability Organisations* (AFDO), the Disability Australia consortium and the *Australian Autism Alliance* (AAA).

A4 recognises and represents the diverse views found in the ASD community. A4 appreciates that autistic people, their families and carers have diverse, and sometime conflicting, views about how best to support autistic people. A4 tries to help governments, policy makers and service providers appreciate the varied needs and expectations of autistic people in Australia.

Please note that SO_fASD and A4 have limited resources and capacity to develop a submission like this. While Commonwealth and state/territory governments have programs to fund systemic advocacy for a range of disability types, neither the Commonwealth nor the ACT Government has ever supported systemic advocacy for autism/ASD as a distinct disability.

Please appreciate that few autistic people can represent themselves effectively in a group setting. Those who can often represent the particular goals and aspirations of formerly autistic and higher functioning people; understandably, more-able people mostly do not represent the diverse spectrum of support that the wider (mostly severely or profoundly disabled) autistic population needs. Consequently, generic (non-specific) disability advocacy groups represent a fraction of autistic people who were/are mildly or moderately affected; they do not represent most autistic people, especially autistic people who do not or cannot represent themselves effectively in the discussion and debate of systemic advocacy and general policy development.

Autism Spectrum Disorder (ASD)

The DSM-5¹ classifies [Autism Spectrum Disorder \(ASD\)](#), sometimes called “autism”, as a neurological disorder of unknown aetiology (cause and nature). By definition, ASD is present in early childhood and most autistic people have severe or profound pervasive disability until they die. Mostly, ASD is life-long disability though research suggests 10-20% of autistic children lose² their need for disability support through effective early intervention.

Currently, around 4 in every 5 diagnosed autistic people are male. More young people are diagnosed with ASD (see the figures below).

ASD is distinct from Intellectual Disability; estimates suggest 30-50% of autistic people have Intellectual; Disability.

As ASD is a distinct disability, autistic people have service and support needs that are distinct from the needs of people with disability generally. This means that generic disability services and support rarely meet or even address the needs of autistic people.

Historically, autism was described as “rare”. Few services provide for autistic people. This is especially evident in the area of Mental Health.

In recent decades, the rate of ASD diagnosis among children has increased substantially in most parts of the world. Diagnosis rates for children exceeds 1% in many places. Some time ago, the US average was reported as 1 in 68 with substantial variability between the states where data was collected.

Outcome for autistic people are generally poor. The section on “development and course” in [the DSM-5](#) says:

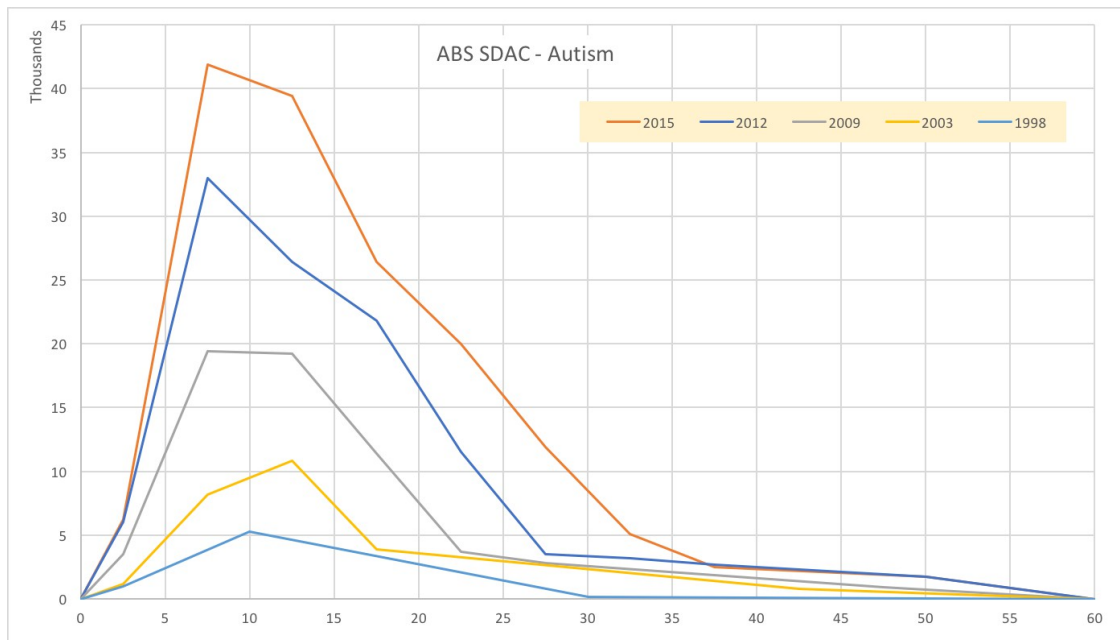
Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills. In general, individuals with lower levels of impairment may be better able to function independently. However, even these individuals may remain socially naive and vulnerable, have difficulties organizing practical demands without aid, and are prone to anxiety and depression.

ASD in Australia

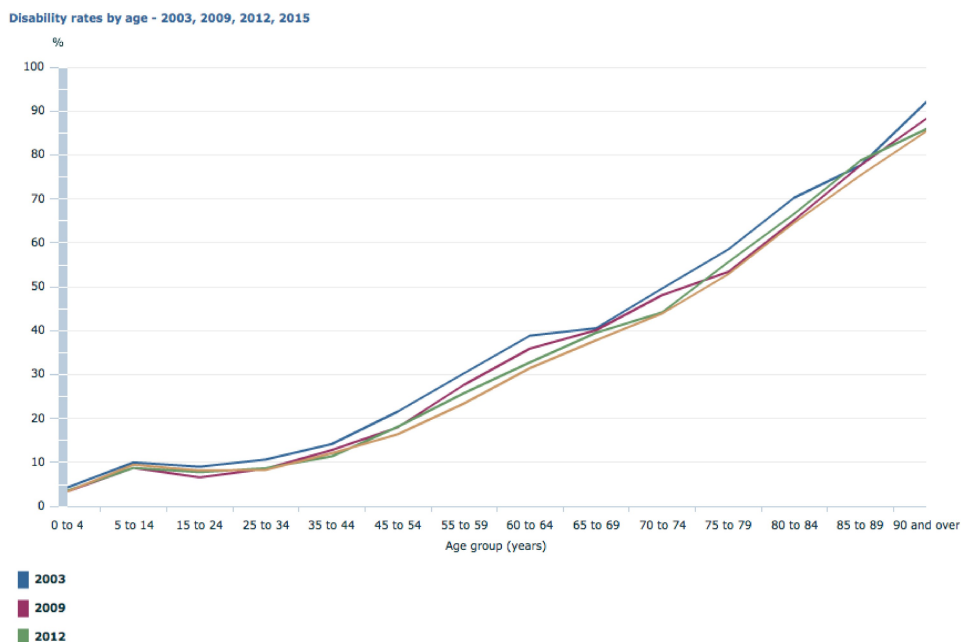
The Australian Bureau of Statistics (ABS) estimates (based on its [2015 Survey of Disability, Ageing and Carers](#)) that there were close to 164,000 autistic Australians in 2015 and 55% of those were aged under 15 years. The number of autistic Australian has increased substantially over the last two or three decades.

1 The American Psychiatric Association’s *Diagnostic and Statistical Manual of Mental Disorder*, 5th edition.

2 and most autistic children who get best-practice early intervention learn skills that improve their education outcomes, improve their quality of life and reduce their long-terms support needs (and consequent support cost) substantially.



The difference between the age profile of autistic people and people with disability shows that ASD is a quite distinct disability. Below is the ABS representation of the age profile for people with disability generally. It shows that generally the disability rate increases with age.



While it is very clear that there was significant under diagnosis previously, it is unlikely that under-diagnosis accounts for all of the increase being observed. In other words, it is likely that there is also a real increase in ASD in Australia.

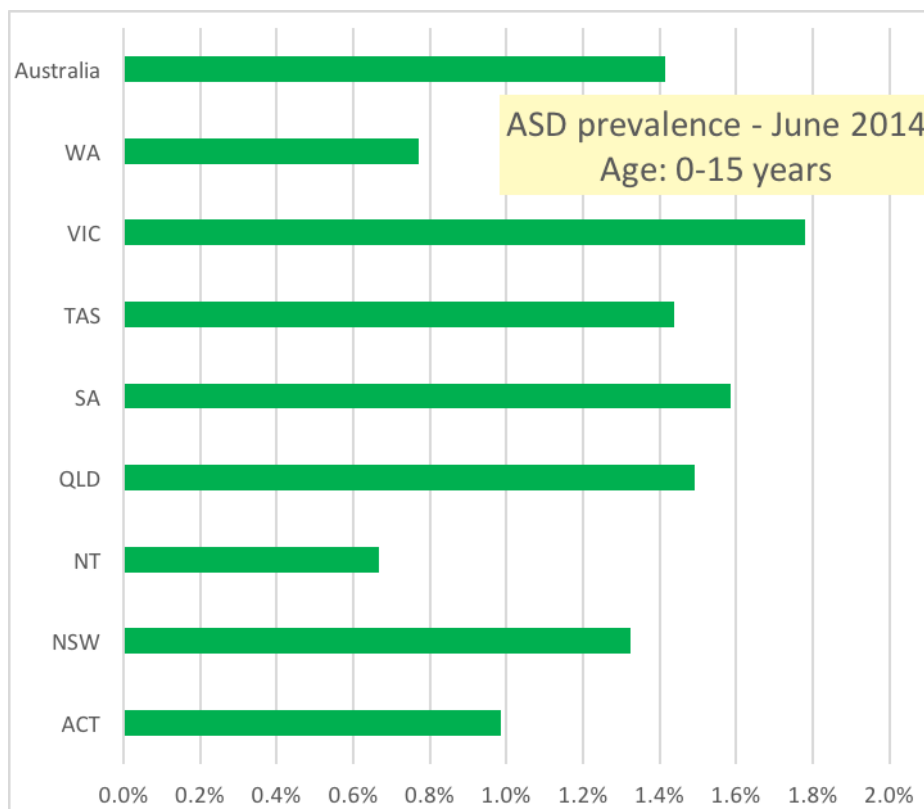
In recent times, the number of autistic children has overtaken the number of children with intellectual disability³. The diagnosis rate for “autism” observed in the ABS SDAC 2015 data was 2.8% of children aged 5-14 years.

To some degree, autistic children who are less severely affected are increasingly diagnosed. But autistic people with severe or profound disability remain the substantially larger proportion of formally autistic Australians. The image of autistic people being created in movies and television shows is not representative.

³ 1.8% to 2.2% of children have an intellectual disability, depending on the definition of intellectual disability.

Population data from the Commonwealth Government's Carer Allowance (child) scheme show similar growth in autism numbers in Australia. These data show variable diagnosis rates for ASD between states and territories, though not as variable as is observed in the USA.

Data from Commonwealth Carer Allowance (child) scheme shows ASD diagnosis rates in the ACT are well below the national average which suggests diagnostic services in the ACT do not function as well as they do in most Australian states.



Prior to the NDIS, supports for autistic people in the ACT were minimal. The ACT Government had a slow and unreliable diagnostic service and a mishmash of therapy services. The ACT Government had the Autism Intervention Units (AIUs) for some pre-school children. And there was funding and services via the Commonwealth Government's *Helping Children with Autism* (HCWA) package. Locally, there was Autism Asperger ACT (AAACT), a support organisation for autistic people, their families and carers in the ACT and surrounding regions.

The HCWA Autism Advisors and the AIUs were highly regarded and much appreciated services. The NDIS shut them down. There are no replacements for these essential services under the NDIS.

The ACT Government and the NDIS encourage AAACCT to transition to being more of a service provider and function as a business. But they provided no discernible support for such a transition and the organisation failed soon after the NDIS started its trial in the ACT.

The federal government's funding of ASD services through its HCWA early intervention package was minimal – HCWA's funding level was about 5% of what government was advised autistic children need for "best practice"⁴ – but HCWA funding was equitable,

4 See <http://a4.org.au/sites/default/files/2006PriorRobertsbooklet.pdf> that says "To be successful [early intervention for ASD] needs to be extensive and intensive. A minimum of 20 hours a week over two or more years ...". Effective EI is not a few hours of parent training, as NDIA bureaucrats would have us believe.

accessible and immediately available, unlike the NDIS's ECEI Approach. Regrettably, HCWA did not promote best practice or evidence-based delivery of early intervention for autistic children.

HCWA created an arbitrary cut-off at 6 years of age for early intervention. Around 30% of autistic children are diagnosed in Australia at an age they can access early intervention given this arbitrary barrier.

Few bureaucrats in Australia understand what autistic people and their families need. Bureaucrats who are responsible for the NDIS refuse to learn about autistic people and reject the available evidence. They insist that parents of autistic children are responsible for their child's autism and that programs that make "better parents" are needed. The idea that autism was due to poor/bad parenting was completely discredited in the 1950s and 1960s yet this prejudice persists with (or re-emerges through) uninformed bureaucrats, officials and sections of the community. Blaming parents⁵ for their child's ASD is derogatory of parents/families and detrimental to autistic people.

The research and clinical evidence tells a very different story.

Government policy and program development for autistic people is largely an evidence-free zone in Australia.

The ACT has a low diagnosis rate for ASD and diagnostic delay may be among the worst in the country.

Outcomes for autistic Australian

Under the heading, *development and course*, [the DSM-5 says](#) "Only a minority of individuals with autism spectrum disorder live and work independently in adulthood".

Outcomes for autistic Australian are abysmal. The [ABS reports](#) that:

- "Young people (aged 5 to 20 years) with autism may need a high level of support to participate in their education. In 2015, over half (55.8%) of young people with autism needed special tuition and 41.8% needed help from a counsellor or disability support person, while 20.7% didn't receive any additional assistance (excluding attending a special school or special classes in a mainstream school)" and "More than two out of five (44.1%) children indicated they needed more support or assistance at school than they were receiving."
- "People with autism are less likely than others to complete an educational qualification beyond school and have needs for support that differ from people with other disabilities. People with other disability were 2.3 times more likely to have a bachelor degree or higher than people with autism, while people with no disability were 4.4 times more likely to have one. All people with disability and those with no disability were 1.6 times more likely to have an Advanced Diploma, Diploma or Certificate III or IV than people with autism."
- "The labour force participation rate was 40.8% among the 75,200 people of working age (15-64 years), living with autism spectrum disorders. This is compared with 53.4% of working age people with disability and 83.2% of people without disability."
- "About two in five people (41.6%) needed assistance with cognitive and emotional tasks at least once a day, while three in ten needed assistance with self-care (29.9%), mobility (30.2%), and communication (30.5%)."

5 evident through the NDIA's mistaken belief that parent training is the most effective approach to addressing ASD.

- "many people with autism who required assistance did not receive some or all of the assistance they needed, with over half (56.8%) indicating they needed more help with at least one activity. The need for more assistance with the core activities of communication (39.1%), mobility (22.7%), and self-care (16.2%) are particularly noteworthy given the intensity of the support that can be associated with these activities."

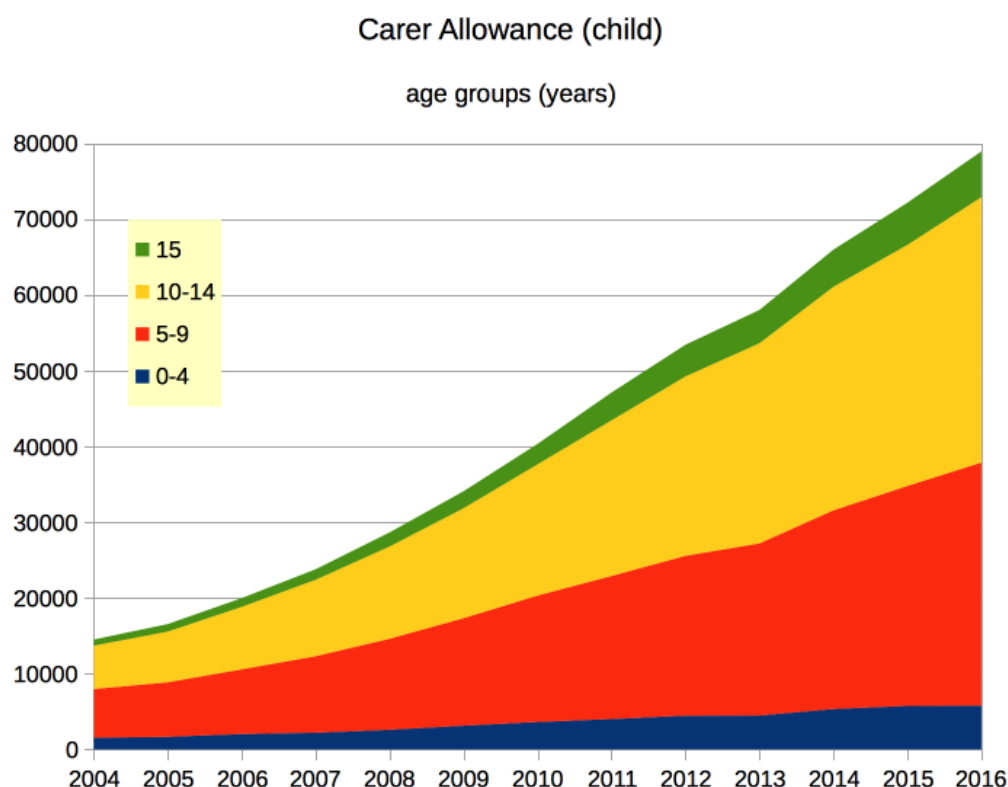
ASD and the NDIS

The NDIS had so much promise. It has some success but tragically, the NDIS is increasingly disappointing especially for autistic NDIS participants.

ASD is especially significant in the context of the NDIS: NDIS Quarterly Reports show repeatedly that around 28% of NDIS participants have ASD as their primary disability. So far, the NDIS has refused⁶ to show age breakdowns of NDIS participants. We have to rely on other data to try to understand how the NDIS affects autistic participants.

The Productivity Commission reported recently that over 50% on NDIS participants aged 0-14 years have ASD as their primary disability.

ABS data shows more young people are autistic than older people: the pattern of disability across the population is quite different for ASD compared to disability generally. While disability rates have generally decreased slightly, diagnosis rates for ASD increased substantially over the last several decades. Recent Australian data is depicted below:



Apparently, the high level of ASD among NDIS participants surprised the NDIS and Governments. In South Australia and in the ACT, the NDIA shutdown NDIS intake for periods due to higher than expected numbers of NDIS participants. It appears that intake of substantially more autistic people than the NDIS expected contributed significantly to or even caused those shutdowns.

⁶ A4 and others have repeatedly suggested that the NDIS should report on autistic NDIS participants separately for at least the early-intervention, school-age and post-school cohorts. The NDIA has not done this.

Before the NDIS trial started, the ASD community warned Government and the NDIS that their estimates were too low. The authorities chose to ignore warnings that came from sources that had previously predicted accurately the number of children who would access the Commonwealth Government's *Helping Children with Autism* package.

The NDIA created what it called a "stakeholder group" to review the latest review of research into early intervention for autistic children⁷. However, the NDIA disbanded the group without showing the NDIA's Early Childhood Early Intervention (ECEI) Approach to the group. The NDIA avoided feedback from its autism stakeholder group about its ECEI Approach even though autistic children are over 50% of the NDIS's early intervention participants⁸. The Productivity Commission reports that "the average annualised committed packages were about \$17 700" for an autistic child which is a long way short of adequate funding for good practice early intervention for ASD.

Increasingly, the NDIA is cutting funding for early intervention.

The immediate consequences of under-funding early intervention for ASD are that autistic children need more support in school and their education is substantially less effective – their education costs more and achieves less. In the longer term, autistic people:

1. live less independently;
2. are more likely to need supported accommodation;
3. are substantially less likely to be employed; and
4. experience high rates of severe (often untreated) mental illness.

Their informal carers are far less productive and have substantially reduced economic participation. Australian research shows the average financial burden of an autistic child on the whole family is \$35,000 per year (see <http://a4.org.au/node/881>).

NDIA refuses to engage with the ASD community. Despite repeated letters of concern and occasional meeting with NDIA minions, [the NDIA did not acknowledge a single issue that A4 raised about early intervention](#). Both Mr De Luca, NDIA CEO, and Ms Nugent, Chair of the Board, declined to meet with A4. And Mr De Luca declined to meet with the Australian Autism Alliance. Instead, they or their staff set up repeated meeting with a string on NDIA minions.

The eligibility of autistic people for the NDIS is an ongoing area of concern. A documented diagnosis of ASD is documentation that a clinician has determined that the person needs support. However, the NDIA then has officials with little or no knowledge or understanding of ASD nor relevant training or qualification, overrule expert assessments and advice. Too often, the result depends most on how strong the child's family is in standing up to NDIA bureaucrats. The process is less fair than the processes that the NDIS replaced.

When the NDIA feels that NDIS eligibility may be marginal for an autistic person, the NDIA is inclined to test eligibility using the [PEDI-CAT](#). Even the people who develop and sell the PEDI-CAT acknowledge that it is not suitable for autistic children which is why they hope to release [an assessment tool for autistic people](#). But the NDIA knows better – and refuses to discuss or review its use of PEDI-CAT assessments for autistic children.

7 See <https://www.ndis.gov.au/html/sites/default/files/Early%20Intervention%20for%20Autism%20research%20report.pdf> or <http://a4.org.au/sites/default/files/Autism%20Research%20Report%20final.pdf>

8 See Box 4.5, p164 in <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.docx> or <https://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf>

Early Intervention for autistic children

The best prospect for the NDIS to improve the lives of autistic people in the ACT relates to early intervention.

Since 2006, the Commonwealth Government has commissioned several reports on early intervention for autistic children. These are:

1. 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.

The Health Department removed this report from its website but it is available at <http://a4.org.au/sites/default/files/2006RobertsPriorreport.pdf> (a link is given on <http://a4.org.au/node/965>). The associated booklet can be downloaded from <http://a4.org.au/sites/default/files/2006PriorRobertsbooklet.pdf>.

2. The Australian Society for Autism Research (ASFAR) (2011), *A Review of the Research to Identify the Most Effective Models of Practice in Early Intervention for Children with Autism Spectrum Disorders*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA).

The main authors of this report are M. Prior, J. M. A. Roberts, S. Rodgers and K. Williams. Links to this [report](#), a [report summary](#), a “[good practice guidelines](#)” booklet and the [early interventions table](#) extracted from the main report are on the web-page <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/research-and-evaluation>.

3. Roberts, J. M. A., & Williams, K. (2016) *Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*, funded by National Disability Insurance Agency.

This report is available from <https://www.ndis.gov.au/html/sites/default/files/Early%20Intervention%20for%20Autism%20research%20report.pdf>, <https://www.ndis.gov.au/html/sites/default/files/Early%20Intervention%20for%20Autism%20research%20report%20FINAL.doc> or <http://a4.org.au/sites/default/files/Autism%20Research%20Report%20final.pdf>

These reports consistently say that autistic children need intensive individualised ASD-specific early intervention. This message is consistent with a plethora of reports from overseas that have the same conclusion.

The “findings” for Question 2 in Roberts & Williams (2016) says:

The level of early intervention support is a funding (or package) decision made prior to the commencement of a support program being implemented. Even if, as is ideal, detailed information about an individual child and family’s strengths and difficulties is available to those making this decision, there is not yet sufficient evidence upon which to base individualised decisions about the level of early intervention support for children with autism based on these characteristics.

Current best evidence to inform decisions about level of support is information about intensity and duration of interventions that have been shown to be effective. Reviews and guidelines that provide evidence about intensity (hours per week) and duration of interventions report that comprehensive programs that have been evaluated and shown to be effective are most commonly provided for between 15 and 25 hours a

week, suggesting a midpoint of 20 hours, and for at least 1 year. Children included in the studies that have been reviewed have a diagnosis of autism (research standard).

The NDIA rejects this advice. NDIA planners and decision makers insist on getting specific information about individual children and making decisions specific to the child. Some planners demand that families get expensive assessments of their child then simply ignore those assessments in their decision-making (families report that often the NDIA officials don't even read the extra reports). Some NDIA planners and decision-making delegates design individual plans with fewer than 10 hours of early intervention for an autistic child and insist that parents deliver specialist clinical intervention for their autistic child.

The 2012 "early intervention table" cited previously reports that Applied Behaviour Analysis (ABA - sometimes called Early Intensive Behavioural Intervention, EIBI) is the only early intervention approach for ASD that is rated as "evidence-based". But NDIA planners tell families that "ABA doesn't work" or "the NDIS does not fund ABA early intervention". It is clear that these NDIS planners are not qualified to give this advice; this is unprofessional conduct.

NDIA officials who say "ABA doesn't work" deny basic science.

The NDIA funds early intervention using ABA for some autistic children, so it cannot be said that "the NDIS does not fund ABA early intervention". However, it appears that the NDIA is increasingly reluctant to fund evidence-based early intervention for autistic children.

Some families prefer early intervention from a multi-disciplinary or trans-disciplinary "team" for their autistic child. The NDIA prefers this model because it is cheap; the "teams" of allied health professionals offering this style of intervention do not offer and are not trained to supervise or deliver intensive ASD-specific early intervention. These "teams" make parents responsible for most of their child's intervention. This approach is not known to deliver optimal outcomes. The 2011 Early Interventions Table rated these approaches as "evidence-informed" or as having "emerging evidence".

Some families of autistic children do not want early intervention for their child. Some autistic people believe that autistic people should be accepted, and not changed. This choice is available for them. Presumably, these people are not involved with nor affected personally by the NDIS.

The NDIS is meant to ensure families can choose for themselves, but the NDIA prevents many of them from choosing by denying them their preferred approach.

The [NDIA Early Childhood Early Intervention \(ECEI\) Approach document](#) says "the NDIA also commissioned Early Childhood Intervention Australia (ECIA) to develop best-practice guidelines for early childhood intervention". [This document](#)⁹ says:

The role of direct intervention by specific professionals

In addition to the body of evidence for the ECI sector there are also other bodies of evidence that suggest specific intervention for children with specific needs, such as cerebral palsy and autism spectrum disorder that lead to improvement in childhood development and skill development. This is particularly evident in disability-specific evidence. This evidence should be taken into account when providing services to young children. However, any specific intervention with young children should always be provided through the context of family centred principles, inclusive of coaching, and incorporated into everyday routines and settings. Therefore, providing ECI does not exclude the provision of specific targeted interventions, it is the way in

9 <https://www.ecia.org.au/documents/item/186>

which these interventions are provided and supported which is critical (ECIA, NSW Chapter, 2014).

Note that the “other bodies of evidence that suggest specific intervention for [autistic] children” relates to over 50% of NDIS participants who list ASD as their primary disability type. It is disappointing and inappropriate that the NDIA ignored the advice that “this evidence should be taken into account”. Instead, the NDIA insists that its ECEI Approach is entirely “via a family-centred approach that supports greater inclusion in mainstream settings and builds child and family capacity”, ignoring the specific needs of most (over 50%) of their early intervention cohort who are autistic.

Autistic children are diagnosed autistic because mainstream setting failed to ensure they achieved crucial milestones. The NDIA’s insistence on putting autistic children back in these settings without necessary preparation and with inadequate support is ineffective at best and outright dangerous at worst. This approach is certainly not good practice or evidence-based for autistic children. The NDIA says this approach is evidence-based but it has never produced evidence supporting this approach for autistic children.

NDIS planners and decision-making delegates with no relevant training, experience or qualifications are writing “early intervention plans” for autistic children. Mostly, the planners and delegates have not even met the child. The planners and delegates ignore advice from highly experienced clinicians; often, parents are told that they didn’t even read the expensive reports that the NDIA demanded parents provide.

Many planners require that a child’s early intervention plan explain how it will train parents to be expert clinicians and deliver most of the early intervention for their autistic child. This approach is founded on the long-disproved (and deeply prejudiced) view that a child’s ASD is due to deficient, dysfunctional or defective parenting hence many NDIA officials claim/believe parent training is the best intervention for ASD. Blaming parents of autistic children is very detrimental for everyone . The NDIA must stop this approach.

This does not mean parents should be excluded from early intervention for their autistic child. Most parents want to contribute, but the research is clear that their contribution should augment clinical intervention; parent contributed intervention does not replace early intervention provided by professionals.

Previously, A4 raised these concerns (see [here](#) or [Submission No. 18 here](#)) with the [Joint Parliamentary Committee on the NDIS](#) in their inquiry into early intervention. The inquiry’s [final report](#) (7/12/2017) lists numerous issues and make crucial recommendations. As yet (4 months on), there is no discernible response to the report from either the NDIA or the Commonwealth Government.

The NDIA cuts off early intervention for autistic children when they go to school or reach seven years of age¹⁰. This approach is not evidence-based.

Before the NDIS, a child diagnosed with ASD had immediate access to an Autism Advisor and HCWA funded services. Once the family decided what type of early intervention most suited their child they could immediately register for *Helping Children with Autism* (HCWA) funding and engage with clinicians (though the supply of trained clinicians was limited). Many autistic children also accessed an ACT Autism Intervention Unit (AIU) that provided ASD-specific early intervention for autistic children.

Prospects for improving outcomes for autistic people

Academics and clinicians advise that the best prospects for improving outcomes for autistic people are from:

¹⁰ Six years of age is an arbitrary/bureaucratic cut off that has no evidence base.

1. timely and accurate diagnosis of ASD – nationally, the median age of ASD diagnosis is after 9 years of age which is far too late for best outcomes.
2. effective early intervention that is intensive, individualised and ASD-specific provides the best prospect for substantially improved outcomes. Regrettably, few autistic children in Australia can access best practice early intervention.
3. appropriate and effective education increases prospects for best outcomes for autistic children. The ABS data above shows this rarely happens in Australia.
4. ensuring appropriate behaviour, health and mental health services and supports. Insufficient services are available to address and meet the needs of autistic Australians.

There are many prospects for improving outcomes for autistic Australians. However, outcomes will remain abysmal while governments in Australia refuse to recognise and address the unmet needs of autistic Australians.

Governments promised that no one would be worse off with the arrival of the NDIS. They lied. For example,

- Some people who could previously access HCWA cannot access the NDIS – in particular, the growing number of autistic children who are excluded from the NDIS because they have a Level Severity rating with their ASD diagnosis. Their diagnosis is an assessment by specialist clinicians who say these children need ASD-specific services and support. But the NDIS excludes them; they are left without the support they need.
- Most families of newly diagnosed autistic children need access to an Autism Advisor. The NDIS abolished this service. The NDIA refuses to discuss the matter.
- The ACT Government abolished the AIUs when the NDIS arrived. Few children can access an equivalent service with NDIS funding.
- Access to after school care for autistic children is substantially reduced.
- Many carers in the ACT report substantially difficulty accessing respite services for autistic school-age children. Without respite, carers experience “burn-out” and increased mental illness which impacts on the autistic people they care for.

The NDIA refuses to recognise and discuss issues and concerns raised by ASD related stakeholders.

Better and timely ASD diagnoses

Children’s ASD diagnoses are often delayed in Australia.

The NDIA and the Autism CRC are trying to create national guidelines. But A4 doubts that these will reduce the typical age of ASD diagnosis.

Many autistic children in the ACT see several clinicians and have to see a clinician privately to get their ASD diagnosis.

Early intervention for autistic children

Experts advise consistently that intensive individualised ASD-specific early intervention provides the best prospect for improved outcomes for autistic people.

Regrettably, fewer than 30% of Australian children are diagnosed with ASD in time to access early good/best practice early intervention for their ASD. Their families no longer have access to impartial advice about early intervention for ASD. And those who are informed face enormous barriers from the NDIS eligibility and planning process.

The NDIS cuts off early intervention as soon as it can: either when the child enters school or reaches 7 years of age.

The NDIS has destroyed most of the most valuable services in the ACT. The NDIS:

- abolished the HCWA Autism Advisors and refuses to even consider any sort of replacement service.
- took the AIU funding.
- refuses to ensure planners have clear guidelines about what is good or best practice early intervention for young autistic children. The planning process for young autistic children is substantially less fair than the previous HCWA approach.

Education for autistic students

Education for autistic students remains a problem. There are no discernible measures of education outcomes for autistic students in the ACT. Few improvements happen without regular outcome measurement and reporting.

The ABS has published results¹¹ showing education outcomes nationally for autistic students are abysmal. The ABS reported that in 2015 ...

... almost all children on the autism spectrum had some form of educational restriction (96.7%), including a small number who were unable to attend school because of their disability. Almost half (48.0%) the children attended a special class in a mainstream school or a special school.

Of the young people (aged 5 to 20 years) with autism who were attending school or another educational institution, 83.7% reported experiencing difficulty at their place of learning. Of those experiencing difficulties, the main problems encountered were fitting in socially (63.0%), learning difficulties (60.2%) and communication difficulties (51.1%).

There is no reason to believe the ACT is different from the national figures.

The NDIS often refuses to support school-age children in their life outside school. This lack of support also affects their education outcomes. NDIS planners seem to think that families just switch off their child's ASD when the child leaves the school grounds. This reflects the ignorance of ASD that the NDIA maintains in its staff.

Many autistic students experience "behaviours of concern" or "challenging behaviour". Families and autistic people cannot access registered behavioural clinicians because neither the Commonwealth nor the ACT Government (like other Australian state/territory governments) has a process for formally recognising or registering behavioural clinicians. Knowledge of and access to internationally registered behavioural clinicians is difficult in the ACT.

Apparently, neither the ACT Government nor the NDIS recognise internationally registered behavioural clinicians.

Employment for autistic people

Despite increased media interest in the employment of autistic people, the overall outcomes remain poor. Again, there are no measures for the ACT.

The ABS reported that nationally in 2015:

11 <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features752015>

The labour force participation rate was 40.8% among the 75,200 people of working age (15-64 years), living with autism spectrum disorders. This is compared with 53.4% of working age people with disability and 83.2% of people without disability.

The unemployment rate for people with autism spectrum disorders was 31.6%, more than three times the rate for people with disability (10.0%) and almost six times the rate of people without disability (5.3%).

Again, we expect that outcomes in the ACT resemble national averages.

Accommodation and independent living

The ACT has substantial gaps in supported accommodation for autistic people.

Relationship between ACT and Commonwealth Governments

This section addresses the following Term of Reference:

- a) The relationship between the ACT Government and Australian Government in regard NDIS and National Disability Insurance Agency (NDIA) as it affects the ACT; particularly gaps or duplicate roles and responsibilities;

SOofASD expects that the relationship between the ACT and Commonwealth Governments for the NDIS is described in a Bilateral Agreement. We hoped to find it via the ACT Government's website: it is listed on the ACT [Intergovernmental Agreements](#) page. When we try to follow the link to the agreement, the results is [here](#): a 404 page that says:

404

The COAG website was recently redeveloped and as such any existing hyperlinks to the website may no longer work.

You can use the Search tool in the top right to look for content.

A search of the COAG website for the "ACT NDIS bilateral agreement" did not succeed.

Commenting on this item is a challenge when we cannot access the required information. But never let it be said that the ASD community is not up for a challenge.

The NDIS and ASD in the ACT

We commend the ACT Government on being the first fully rolled-out NDIS jurisdiction. In our view, it is far better to be building practical solutions and trying to make the NDIS work rather than waiting for bureaucrats to design a perfect system.

We are disappointed that the NDIA squandered its trial period. The NDIS trial appears to have been designed to win over the disability sector as the initial plans were reasonable, however the scheme that the NDIS rolled out since the trial has involves substantial cuts people's plans in the trial period. This strategy brings enormous stress and distrust from the disability sector.

This is demonstrated by significant drops in client satisfaction, a measure that many in the disability sector simply don't believe is accurate.

It seems like the ACT Government now has very little influence over the NDIS, or may be reluctant or unwilling to use any influence that it may have.

We wrote above about ASD and the NDIS generally. Issues of particular concern in the ACT include:

- slow and unreliable diagnoses of ASD
- slow¹² NDIS eligibility, planning and plan review processes.
- the demise of valued services and supports including the AIUs (or any equivalent) and AAACCT.
- the lack of ASD expertise in this small jurisdiction, for example the lack of any registered behaviour support service in the ACT.
- the lack of mental health services and supports for people who have both ASD and mental illness.
- limited access to disability advocates: there are two agencies – ADACAS is severely over-stretched and the other one has no idea about nor little interest in ASD.

The ACT Minister for Disability, Children and Youth [wrote recently](#) that “The ACT Government is aware that there are a number of community concerns relating to the ECEI approach”. SOfASD and A4 suspect that the precise number is zero since that is the number of issues that they have discussed with SOfASD and A4 and also the number of issues that the Directorate has so far shown a discernible interest in.

She also wrote that “The Office for Disability is actively working with the NDIA both at a national and regional level to address these concerns and hopes to influence a positive outcome.” We are concerned that this “active working” cannot be discerned. Nor have the nature of any “positive outcomes” been discussed with ASD advocacy groups locally or nationally. Nor has the NDIA recognised or mentioned any of “these concerns” in its correspondence with A4.

A4 and SOfASD cannot discern the ACT’s role in COAG’s governance of the NDIS/NDIA.

ACT Government should be very concerned by the performance of the NDIS and the Commonwealth Government –

- the Commonwealth Minister for Social Security, the NDIA CEO and the Chair of the NDIA Board all decline to meet ASD advocates.
- Government at both federal and territory levels fund various a peak disability bodies but omit funding for ASD advocacy.
- The NDIA provides utterly hopeless responses to correspondence – see <http://a4.org.au/node/1588>

Gaps in roles and responsibilities

With the NDIS, the ACT has ongoing gaps in the complex services and supports that many autistic people need.

1. The ACT Government has a heavily overloaded services for pre-school age autistic children. It’s diagnostic service is slow with an unacceptable waiting list. There are still substantial delays getting ASD diagnoses privately.
2. The early intervention therapy service is extremely limited and does not provide what experts advise the Commonwealth Government is good or best practice for autistic children (see above). Early intervention service using multi-disciplinary or

12 SOfASD heard from one family in the ACT that they have experienced 18 months delay having their child’s NDIS eligibility assessed ... and they are still waiting.

- trans-disciplinary approaches for ASD in the ACT do not offer programs that are sufficiently intensive and ASD-specific for autistic children. Such services are not good or best practice nor evidence-based for autistic children. Programs using these approaches often dump responsibility for their child's clinical intervention on the parents, usually the mother. Research evidence contra-indicates these approaches.
3. The NDIS abolished the post-diagnosis service that previously was provided by the HCWA Autism Advisor service. The NDIS has no replacement for this essential service.
 4. With the arrival of the NDIS in the ACT, the ACT Government abolished its Autism Intervention units. Since the arrival of the NDIS, access to good/best practice or evidence-based early intervention for ASD is very difficult. It is very difficult to get the NDIS to fund good practice early intervention for an autistic child using any of the private services that offer good or best practice early intervention for ASD in the ACT. Increasingly, families have to take individual cases to the AAT ... where delays in AAT processes usually deny the child access to the early intervention that they need.
 5. The ACT has a massive gap in the area of behavioural services for autistic people. In Australia and in the ACT, there is no system/process for registering behavioural clinicians, that is clinicians who are trained and registered professionals in treating "behaviours of concern", unwanted, problem or challenging behaviour. Neither the ACT Government nor the NDIA recognise the international Behavior Analysis Certification Board (see <https://www.bacb.com/>). Despite the internationally infamous [boy-in-a-cage incident](#), the ACT Government has still not addressed this issue (see <http://sofasd.org.au/d7/node/194>).
 6. The NDIA's pricing does not recognise the varying levels of international certification in behavioural practice. This means that families cannot access some services, for example the BCaBA, with their NDIS funding.
 7. The NDIS tries to avoid funding disability supports for school age children. NDIS officials have told parents as their child enters school and has their NDIS early intervention funding cut, that they should re-apply for NDIS supports when the child leaves school. Apparently, NDIS officials think that school-age autistic children are only autistic during school hours; the NDIS avoids funding supports for school-age children outside school hours. The NDIS claims autistic children only need support while they are at school and they say that is the responsibility of the ACT Education Directorate.
 8. A particular example is the difficulty families report in getting after-school support for their autistic children. Many families try (and are often unable) to make complex work arrangements with their employer. Others drop back to part-time employment so that they can support their child after school when other (non-disabled) children access after-school care.
 9. as autistic people become teenagers and adults, the stress resulting from their ASD and the lack of appropriate support leads in increased levels of mental illness. The ACT lacks essential services for autistic people with mental illness. Autistic people are usually denied access to mental health services ... often because mental health staff are not trained to treat people who have both ASD and mental illness. The ASD community has repeatedly raised this issue with the ACT Government ... and the ACT Government continues to ignore it.
 10. Families report substantial difficulty accessing respite for carers of severely or profoundly autistic children and adults in the ACT.

11. Families report enormous difficulty accessing appropriate support for autistic students in education setting. Schools rarely if ever seek support from the ACT Education Directorate ... it is usually up to families to seek help for their autistic child from outside the school. Schools usually resist and resent (instead of supporting) such moves. The ABS reports abysmal education outcomes nationally for autistic students; we are not aware of any reporting for autistic students in the ACT.
12. Behaviour support services for autistic people, and in particular for school-age children, outside of school are largely non-existent in the ACT.
13. Access to psychiatry services, especially child psychiatry services, are very difficult in the ACT.
14. Recent reports state publicly that disability advocates are now turning away 50% of the requests for help with individual advocacy that they receive.
15. The ACT lack an autism association to apply for ILC funding for ASD-related projects in the ACT.

Governments and their health, education, and disability agencies have not grown supports for autistic people to keep pace with a) the growth in ASD diagnoses, and b) the evidence-based or best practice approaches that are documented in the research literature. Part of the problem is that 20-30 years ago, autism was considered a rare disorder. But since then, the number of people diagnoses has doubled every 5 years but services have not grown proportionally. The service that was available for one autistic person is now spread over about 20 autistic people.

Note: Politicians and bureaucrats believe that the “free market” will solve service supply and demand problems. But the NDIS sets the price of disability services and support. The “free market” is simply an ideological dream; it is not reality.

Part of the problem is that neither the ACT Government nor the NDIA is responsible for ensuring that necessary services actually exist. While access to necessary services and supports is a right according to treaties that Australia has signed, Australian Governments as usual refuse to enact laws that bring basic human rights into effect for their citizens. Australia’s disability discrimination law allows, even promotes, the exclusion of students from their education when their behaviour may be “unwanted” (see *Purvis vs NSW*) ... which impacts autistic students more than others.

duplication of roles and responsibilities

Bureaucrats and apparently politicians have a pathological fear of “duplication” ... yet you say that you understand that service efficiency is due to competition. Your simple ideology is profoundly confused.

Given the lack of essential services for autistic people, a level of service duplication would be a very good thing.

The service gaps documented above show a strong need for more duplicate services and responsibilities in the disability sector. The disability sector needs duplication during the initial stages of the NDIS. Now is not the time to be worrying about duplication. Bureaucrats will pare the NDIS back in coming years, until it breaks – don’t you worry about that.

NDIS implementation in the ACT

This section addresses the second section of the inquiry’s Terms of Reference.

- b) Practical outcomes of implementation in relation to disability workforce development strategies; the Human Services Registrar; the availability of services for eligible NDIS participants; the availability of early childhood intervention services; the implementation of local area coordination; and supports for people with psycho-social disabilities;

The NDIS implementation in the ACT has so far resulted in major service and support gaps for autistic people, as listed previously.

Despite the efforts of ASD stakeholders to engage the NDIA (see <http://a4.org.au/node/1690> and <http://a4.org.au/node/1664>) there has been no discernible progress. Despite holding occasional meetings, the NDIA does not recognise a single concern about early intervention (see <http://a4.org.au/node/1654>) ... and the process of meeting with the NDIA to *not discuss* issues has yet to move on to subsequent life-stages for autistic people.

disability workforce development strategies

The NDIS is meant to double spending on disability services and supports in Australia. So spending the NDIS funding means that people in the sector will either work more hours, charge more or more people will start charging for services and supports.

Many people working in the disability sector were already working close to or beyond their capacity, so few will increase their hours.

The NDIS is setting prices for services¹³ so providers cannot increase charges by much. Some providers find that the NDIA's prices combined with excessive paperwork and sometimes delays in payments make it impractical to accept NDIS funding.

The NDIS has no discernible strategy for growing a trained workforce to address the needs of the increasing number of autistic people. Quite the reverse, the NDIA prefers to develop generic services in mainstream settings whenever possible. But generic (non ASD-specific) services often fail to meet the needs of autistic people.

The NDIA just hopes that market forces will fix any workforce issues. This strategy never worked for autistic people in the past; instead, it attracts some misguided (or worse, unscrupulous and inappropriate) "services" to the sector. New service providers appear with no knowledge or experience of supporting autistic people. They have no understanding and many incorrect assumptions about services for autistic people. They don't last long and they often cause a lot of detriment through their inadequacies.

The NDIA and Governments need to recognise that a substantial effort is needed to improve the workforce for services and supports for the increasing number of autistic Australians.

the Human Services Registrar

We see from the Internet that the ACT has [a Human Services Registrar](#). This agency is unknown to the ASD community. It is not mentioned in communications with the NDIS. It is not mentioned in ASD-related or disability-related social media. We are not aware of any disability advocacy agencies that refer people to this office.

Searching on the NDIS website returns the results (29/3/2018) find a mention under "Pending State Approval" ... so it appears this is not yet operational.

13 see <https://www.ndis.gov.au/medias/bin/documents/h86/hcf/8805126144030/201718-ACT-NT-SA-WA-Price-Guide.docx>

This office has not contacted ASD stakeholders in the ACT about what such an office might do and what requirements it might have to register service providers for autistic people or to offer ASD-specific services and supports.

the availability of services for eligible NDIS participants

Some supports and services for autistic adults have improved with the arrival of the NDIS. But availability of services and supports still has a very long way to go before the needs of autistic adults are met.

The remaining challenges for the NDIS and governments, in relation to autistic adults include:

- developing appropriate accommodation services with effective supports
- addressing the behavioural needs of autistic people
- tertiary education
- employment.

Previously we have described an extensive list of service gaps where services are not available for autistic NDIS participants (who are 28% of all NDIS participants).

the availability of early childhood intervention services

Early intervention for autistic children remains a major challenge for the NDIS and for the ACT Government. The arrival of the NDIS ended the ACT's Autism Intervention Units (AIUs). Many people in the ACT's ASD community valued the AIUs and are deeply disappointed by their demise.

As yet, there is little or no centre-based early intervention for ASD in the ACT since the NDIS started here. And the NDIA opposes good/best practice and evidence-based early intervention for autistic children.

The ACT continues to miss out on the [Autism Specific Early Learning and Childcare Centres](#) (ASELCC) that Federal Labor created responding to Howard's HCWA package. The ACT is the only jurisdiction where the ASELCC model makes sense. ACT Labor Governments opposed or prevented the efforts of the late Steve Dozspot to bring an ASELCC to the ACT.

The [Joint Standing Committee on the National Disability Insurance Scheme](#) (JSC) published its final report from its Inquiry into [Provision of services under the NDIS Early Childhood Early Intervention Approach](#) 7/12/2017. The report identifies numerous issues and makes recommendations. So far (more than 3 months on), the ASD community have seen no discernible response from the NDIA or from the Federal Government.

The NDIA says [wrote to A4](#) (22/2/2018) that "the NDIA is currently undertaking a review to consider and identify enhancements to the ECEI tailored pathway". Recently, [A4 wrote to the NDIA CEO](#) pointing out ...

A4 is aware (of the ECIA Best Practice Review), but only because our contacts in the disability sector alerted us to this "review". It seems that the NDIA chose Early Childhood Intervention Australia (ECIA), the authors of the existing ECEI Approach that is quite problematic for autistic children, to conduct this review. Through this choice, the NDIA created a major conflict of interest. The concerns and recommendations of the Joint NDIS Committee were not mentioned/presented or discussed in the "consultation" (the brief ECIA Best Practice Project ACT Round Table – 22/2/2018) that A4 attended. While the significance of ASD in the early

intervention “space” was acknowledged, there was little or no awareness of the distinct nature of ASD and the need for ASD-specific strategies, services and approaches. The clear intent was to justify generic early intervention and avoid issues arising from the diversity and complexity of the disability sector especially in relation to autistic children. The review process limited/minimised input from the ASD community.

A4 wrote to the NDIA CEO expressing concern and disappointment with the NDIA’s especially poor stakeholder engagement with ASD-related stakeholders and requested a meeting. He declined.

the implementation of local area coordination

When SOfASD asks autistic people and their families about local area coordinators (LACs), a common response is “what is an LAC?”

Autistic people and their families have very little to say about LACs. LACs do not seem useful because:

1. generally, LACs lack knowledge and experience with autistic people, their families and their needs;
2. the LAC service is seriously deficient compared to the previous Autism Advisor service; and
3. there are few services for autistic people in the ACT that LACs can refer autistic people to.

supports for people with psycho-social disabilities

It is unclear whether ASD is, should or could be classed as a “psycho-social disability”. Generally it isn’t and many autistic people would not want it to be classed that way.

Many autistic people have comorbid psycho-social disability. Many autistic people have high levels of anxiety that prevent them from participating socially or even venturing from their home.

Unfortunately, mental health services often simply refuse to treat autistic people claiming they do not know how (or were not trained) to treat mental illness in the context of ASD. Autistic people are routinely denied access to mental health services because of their disability/ASD.

There is no discernible recognition of these issues in the ACT, and no effort to address them.

Long delays in ACT health systems combined with patient anxiety exacerbates psycho-social disability and the inability to access health services. There are similar issues for autistic people trying to access other supports.

Uniquely ACT

This section discusses the third term of reference:

- c. Whether there are unique factors relating to the provision of disability services affected by the implementation of the NDIS in the ACT.

The first unique aspect of the NDIS in the ACT is that the NDIS is fully rolled out. Supposedly, the NDIS is now available for everyone in the ACT who is eligible.

The ACT was the first jurisdiction to lose its Autism Advisors. The NDIS has no plan to replace this essential service. In fact, the NDIA is keen to avoid families learning about good/best practice or evidence-based early intervention for autistic children as knowledge and awareness lead to increased reviews of decisions both internally and in the AAT.

There are parents of school-age autistic children who still have not applied for the NDIS for their child. Some parents of school age children have not applied because they believe or expect, based on others' accounts, that the NDIS won't provide support for their child until the child finishes school. These parents feel that applying before their child leaves school is simply not worth their effort.

No choice of ECEI Access Partner

The NDIS has just one ECEI Access Partner in the ACT (see [EACH](#)), so families of autistic children in the ACT trying to access early intervention for ASD have no choice of NDIS Access Partner. Reports suggest that the NDIS Access Partner, who is the pathway to the NDIS Early Childhood Early Intervention (ECEI) Approach, has limited knowledge, training and experience in early intervention for autistic children.

ACT is the only state/territory without an autism association

The arrival of the NDIS resulted in the demise of *Autism Asperger ACT* (AAACT). Basically, with little or no support from the ACT Government AACT did not make the transition to becoming a service provider.

The types of supports that AACT provided were meant to be funded through the NDIS Tiers 1 & 2, now the ILC. But the NDIA delayed the ILC in the ACT and AACT did not have the reserves to bridge the extended funding gap. So now, autistic people in the ACT who are not accepted into the NDIS have few if any ASD-specific supports. The [Marymead Autism Centre](#), that absorbed some of AACT staff and activities provides a substantially reduced service.

Since the NDIS arrived, the ACT has been the only state/territory without an autism association. This is unique to the ACT.

As yet, the ACT Government has not recognised this substantial gap.

Few supports for autistic people who are not eligible for the NDIS

The NDIS was conceived originally as having Tiers 1 & 2 for people who were ineligible for an individualised NDIS plan in Tier 3.

The NDIA's ILC is meant to provide services for this group of people. The size of this group is very unclear ... and undefined for autistic people since NDIS eligibility for autistic people is very unclear.

Some essential supports for autistic people need to be ASD-specific; generic disability services do not meet all the essential needs of autistic people.

With the demise of AACT, there is now no viable organisation to seek ILC funding to support autistic people in the ACT. This means autistic people in the ACT miss out on ILC funding for ASD-specific supports. The NDIA and the ACT Government have yet to recognise and address this issue.

ACT's unique demographic

The ACT is Australia's most compact state/territory jurisdiction.

As such, it is the only state/territory where an ASELCC could serve most if not all the autistic population. And it is one of the two jurisdictions that does not have an ASELCC or equivalent.

The ACT is also relatively small. This maybe why there has been relatively little (less than hoped) growth in service provision for autistic people in the ACT since the NDIS arrived.

Other concerns

The NDIA has been unable so far to engage with ASD stakeholders. A4 has been trying to engage with NDIA officials about early intervention, but the record shows clearly that NDIA officials refuse to recognise the concerns of the ASD community (see <http://a4.org.au/node/1664>). A letter from NDIA officials (see <http://a4.org.au/node/1654>) that they promised would document *all* the issues raised in the latest meeting ostensibly to discuss early intervention for autistic children, omitted every issues that A4 raised.

A4 [asked](#) Mr Robert De Luca, CEO of the National Disability Insurance Agency, to meet to discuss the NDIA's lack of engagement with autism stakeholders. He declined (see <http://a4.org.au/node/1690>).

On the 7/12/2018, the Joint Standing Committee on the NDIS released its final report the NDIS and early intervention. The report makes numerous recommendation for improving early intervention under the NDIS. Some recommendations are especially relevant for autistic children. As yet, there is no discernible response from the NDIA or the Commonwealth Government.

Since the full NDIS roll out, NDIA officials have developed (or perhaps resumed) the usual public service disrespect and contempt for people with disability, their families, carers and clinicians/professionals. NDIS planners and decision making “delegates” expect that most requests for services and supports are a scam or a rort. NDIS staff routinely reject advice from clinicians and allied health professionals who know the needs of specific individuals. This disrespect is very noticeable in relation to autistic NDIS participants and the people associated with them.

[Many NDIS officials are badly misinformed](#) about ASD. NDIS planners in NSW and the ACT have misinformed many families of newly-diagnosed autistic children when they claimed that:

- good/best practice early intervention doesn't work which means the NDIS officials don't believe basic science and disregard actual evidence;
- the NDIS does not fund evidence-based early intervention for ASD; and
- parents just need to be better at parent=ing or become expert clinicians to overcome their child's ASD.

In relation to early intervention for ASD, the NDIA appears to be an evidence-free zone.

Since the Liberal Party won the federal election in 2013, successive Ministers who are responsible for the NDIS have declined all of A4's requests to meet. The Assistant Minister met A4 just once (and the commitments made were not honoured).

It is especially difficult to understand how the NDIS is supporting autistic people because the NDIA refuses to report separately on the numbers and costs of autistic people in the early intervention, school-age and post-school parts of the NDIS participants.

External review of decisions

Autistic people are experiencing substantial delays in accessing the NDIS and in their subsequent plan reviews.

The time taken in reviewing NDIS decisions, especially the delays experienced in the AAT, deny autistic children access to essential early intervention (see <http://a4.org.au/node/1669> and <http://a4.org.au/node/1670>). AAT processes often take in excess of a year and autistic children miss out on necessary early intervention through much of the process. The long-term cost to the community of denying young autistic children access to essential early intervention is enormous – usually millions of dollars per autistic individual over the individual's lifetime.

For most young autistic children who the NDIS decides to deny good practice or evidence-based early intervention, the external review process is hopeless. The process set up for external review of NDIS decisions is dysfunctional, especially in relation to the NDIS's ECEI Approach.

Repeated advice from clinicians and academics to government is that many autistic children need intensive, individualised ASD-specific early intervention for two years or more. The NDIS, like HCWA before it, cuts off early intervention for autistic children after 6 years of age. This means that any autistic child whose review process is before the AAT after the child is 4 years of age is missing out on necessary early intervention.

Unfortunately, the external review process via the AAT often deprives autistic children of necessary early intervention because of its excessive delays.

A4 is trying to help autistic children who were found to be eligible for the NDIS at age 3 or 4 years but who the NDIS denied good practice or evidence-based early intervention for their ASD. The NDIA takes many months¹⁴ to deliver an initial NDIS plan for these children. Once they get their initial NDIS plan, the family requests an internal review but the NDIS take 6 months of longer (sometime never) to do an internal review. By then, the child is at least 5 years old. The family has exhausted their savings and cannot increase their mortgage to pay for their child's early intervention.

At this point, the AAT concedes that they might conduct an external review of the NDIS's decision (although the NDIS has not yet documented its decision).

The NDIS tells the AAT that the family needs to provide more information in order to inform the NDIA's offers in conciliation ... although NDIA staff often admit they have not even read the material they have already received. The families are expected to fund expensive further assessments that they cannot afford and that, typically, NDIS officers dismiss or ignore.

Note that the request for additional information is an admission that the NDIS made its reviewable decisions up to this point, decisions that are the subject of the complaint, without all the information that it needed. The NDIS had not previously taken action to obtain information that is now tells the AAT is essential in making decisions properly. Sadly, the AAT does not notice the NDIA's admission that its decisions that are being reviewed were improper decisions. Instead, the AAT upholds the NDIA's delaying tactic.

The AAT process usually takes at least 12 months unless the family accepts the NDIA's unilateral offer in conciliation.

Often, the autistic child will be older than 6 years by the time the AAT process completes so the NDIS will not fund early intervention once the AAT review is done. The AAT review

14 A4 and SOfASD heard from families who are still over 18 months later.

process for NDIS decisions provides no prospect of a useful outcome for these young autistic children.

Conclusions and suggestions

The NDIS has enormous potential to improve the lives of Australians with disability and the whole community. But to achieve its goals, the NDIS needs to be so much better than it is now.

The NDIA seems to have issues particularly with autistic participants.

The NDIA needs to engage with ASD stakeholders. It needs to develop a culture of respect for people with disability, especially autistic people, and their associates.

NDIA staff must become properly informed about ASD. The NDIA's existing culture of misinformation and distrust is extremely detrimental.

Better reporting is needed. The NDIA should report separately on numbers, spending and outcomes for pre-school, school-age and post-school categories.

Governments and the NDIA need programs to develop a workforce to better support the NDIS and people with disability, especially autistic people whose numbers continue to increase well beyond the capacity of the existing workforce.

The ACT Government needs to address the non-NDIS support that people with disability need, especially in education, employment and accommodation.