



Interim Submission on Current Scheme Implementation and Forecasting for the NDIS

to the Joint Standing Committee on the
National Disability Insurance Scheme

“The general public still expects a lot more forecasting accuracy than any of us can deliver.”

— Edgar Fiedler

31/10/2021



Introduction

Autism Aspergers Advocacy Australia (A4) appreciates this opportunity to comment on the implementation and forecasting for Australia's *National Disability Insurance Scheme* (NDIS), and on the operation of the *National Disability Insurance Agency* (NDIA) that is responsible for the operation of the NDIS.

From the outset, government was advised that "from an economic perspective, the benefits of the NDIS will exceed the costs" (Productivity Commission 2011). The government and the NDIA appear to have lost sight of this fundamental feature of the scheme.

The NDIS is novel, a world first approach to disability services and support. There are bound to be some glitches.

For most NDIS participants, people who benefiting from a funded NDIS individual plan, the scheme improves their life, even if their plan and its administration are less than ideal.

Regrettably, the NDIA's NDIS implementation dismantled or abolished some crucial disability services. Many people who do not receive individualised funding have missed out.

This submission focusses on autistic people and their service and support needs. Before the NDIS, there were many autistic people who got little or no service. There are still some autistics who get little or no disability support now.

Before the NDIS, every child diagnosed autistic under age 6 years could get advice from an Autism Advisor and access a small amount of early intervention via the *Helping Children with Autism* (HCWA) package. The replacement of HCWA with the NDIS promised that no one would be worse off. But the NDIS abolished *HCWA Autism Advisors* and the NDIA's eligibility requirements exclude some autistic children. An autistic child who is ineligible for the NDIS will be worse off than under the previous HCWA provisions. The NDIA does not report how many autistic children are found to be ineligible for the NDIS and we do not know how many children simply don't bother applying for NDIS support.

Autism is a challenge for governments.

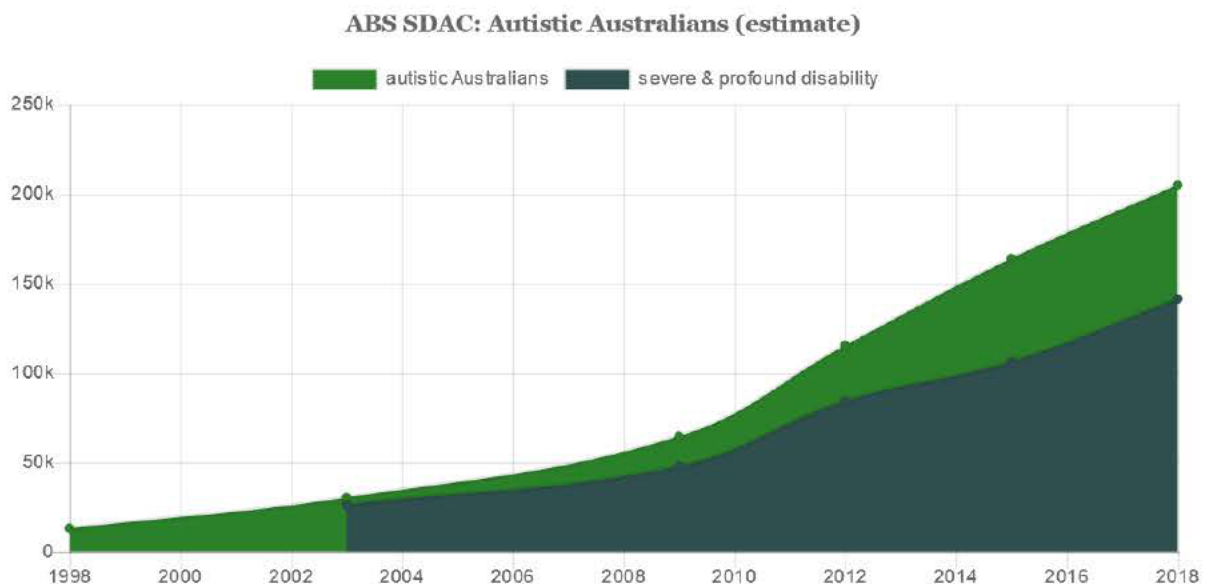
Several decades ago, autism was considered a rare disorder, thought to affect 4-10 per 10,000 people. Since the early 1990s, the number of people diagnosed autistic in Australia has increased substantially.

Now, 2% to 6% of school-age children are diagnosed autistic (see Annex A below) and most of them have severe or profound disability.

The Australian Bureau of Statistics (ABS) has run its Survey of Disability, Ageing and Carers (SDAC) for more than two decades. The following table and chart show substantially increasing estimates of the number of autistic Australians over 20 years (1998 to 2018).

year	1998	2003	2009	2012	2015	2018
autistic Australians '000s	13.2	30.4	64.6	115.4	164.0	205.2
increase		130.0%	112.5%	78.6%	42.1%	25.1%
annual increase		18.6%	13.4%	21.34%	12.43%	7.75%
severe or profound disability		87%	74%	73%	64.8%	68.9%
0-14 years old	80.3%	66.4%	65.2%	56.7%	53.4%	60.0%
female	n.p.	16.8%	17.8%	21.9%	19.6%	22.7%

A4 expects the ABS SDAC data for 2021 will show that people diagnosed with ASD has increased by around 20% since 2018, and that women and girls are around 25% of people diagnosed with ASD.



Few other disability types show this type of increase. Generally, disability rates decrease rather than increase.

Australia's Health Department said (23/2/2011):

The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia.

See <https://a4.org.au/node/359>

To our knowledge, the federal government's Health Department has still not recognised increasing autism diagnoses in Australia.

Also, the age profile for autistic Australians is distinct: most people diagnosed with autism are young people. And their disability is expected to be lifelong.

The following table, from ABS SDAC data, shows the number of Australians with disability in the age range 0 to 64 years has decreased. The decrease is more significant when expressed as a fraction of Australia's increasing population.

Age group (years)	2003	2009	2012	2015	2018
ESTIMATE ('000)					
total 0-64	2566.8	2474.4	2513.5	2489.2	2427.6
severe & profound disability	683.1	680.3	729.8	714.3	728.8
percentage	26.6%	27.5%	29.0%	28.7%	30.0%

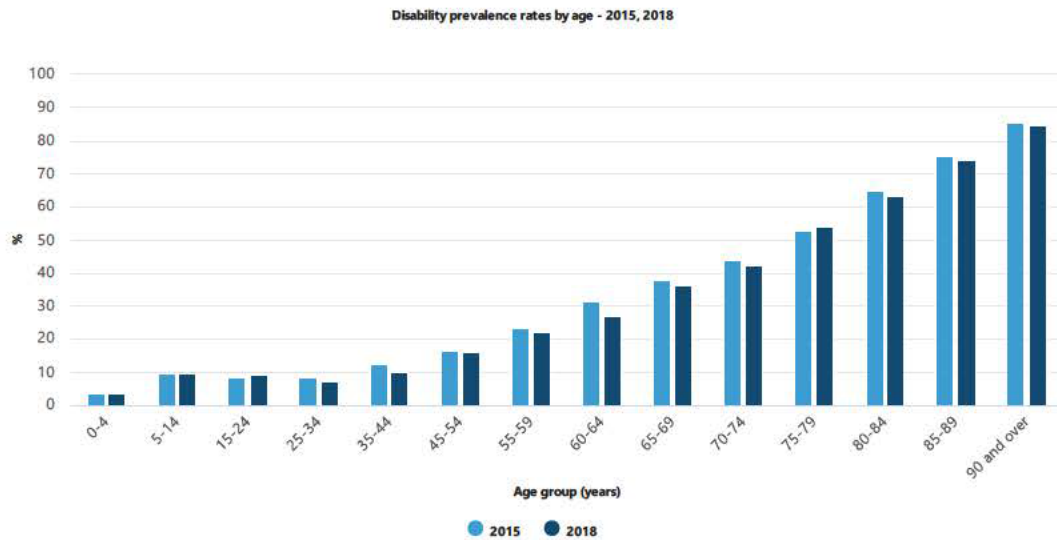
However, the Australians with severe and profound disability increased (by 6.7% in raw numbers over 15 years). A4 is not aware that the NDIA or the Productivity Commission took this increasing disability severity into account in its initial modelling and planning for the NDIS, or in its financial sustainability reporting.

In recent times, Minister Reynold has mentioned, presumably on advice from the NDIA, increasing NDIS plan costs ... that are assumed to be associated with increasing disability. She is concerned about the NDIS appearing to increase disability, rather than a pre-existing phenomenon of disability severity increasing for people aged the 0 to 64 year-old age group. The significance of shifting disability severity is discussed in the context of the financial sustainability of the NDIS below.

While the number of people with disability overall is decreasing, the number of people diagnosed with autism is increasing.

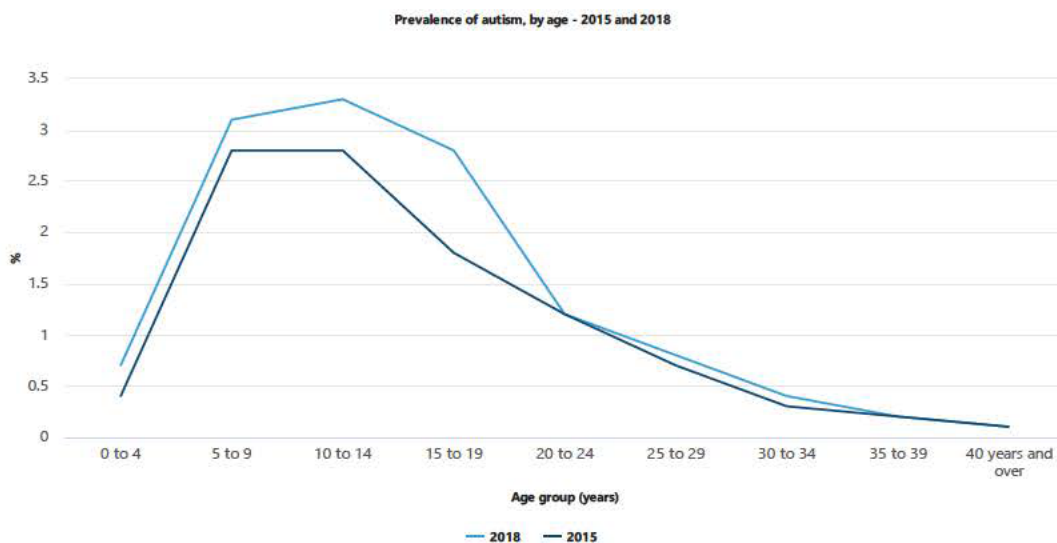
Also, comparing the rate of severe and profound disability for people with disability in general with the data for autistic Australians in the previous table shows that autism involves more severe and profound disability (68.9%) than disability generally (30%).

In general, disability increases with age. The following figure shows people with disability by age from [ABS SDAC 2018 data](#).



Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings 2018

This age distribution is completely different from autistic people. The following figure from the same website shows there are lots of autistic children and few autistic adults. We anticipate that the coming 2021 ABS SDAC data will show a higher and fatter peak.



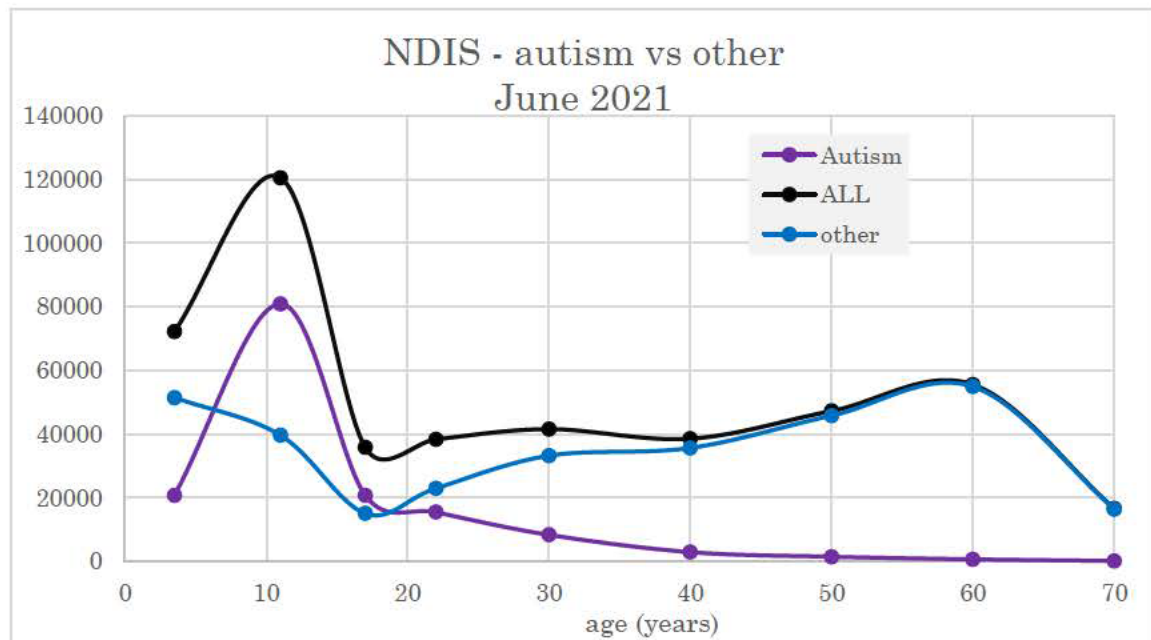
Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings 2018

Nationally, the autism diagnosis rate for children is ten times the diagnosis rate for adults. The reason for this is not known, though we expect under-diagnosis of ASD in adults, especially women, is a significant factor.

We expect that the peak will keep getting wider over time: autism is usually life-long so autistic children will become autistic adults, and more autistic children will be diagnosed. There are also be more autistic adults being diagnosed so autistic people will increase over time as a proportion of people with disability,

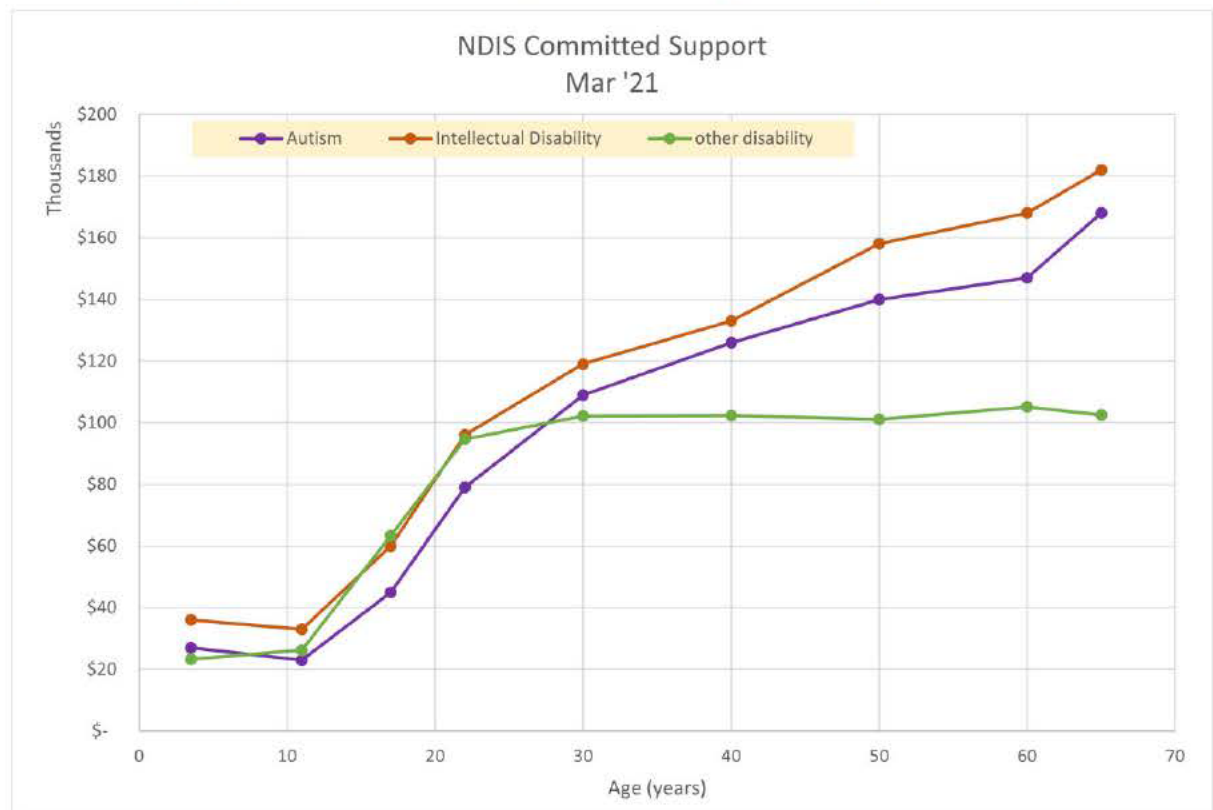
their needs will be recognised and the NDIS will be expected to address their needs.

The following chart shows the number of autistic NDIS participants (primary disability), compared to NDIS participants with other disabilities.



Note that in the 0 to 6 years age group, many children are diagnosed with a developmental delay before they are diagnosed with ASD at an older age. The NDIS does not report the rate of conversion for developmental delays to ASD.

The following figure shows the average cost of NDIS plans by age.

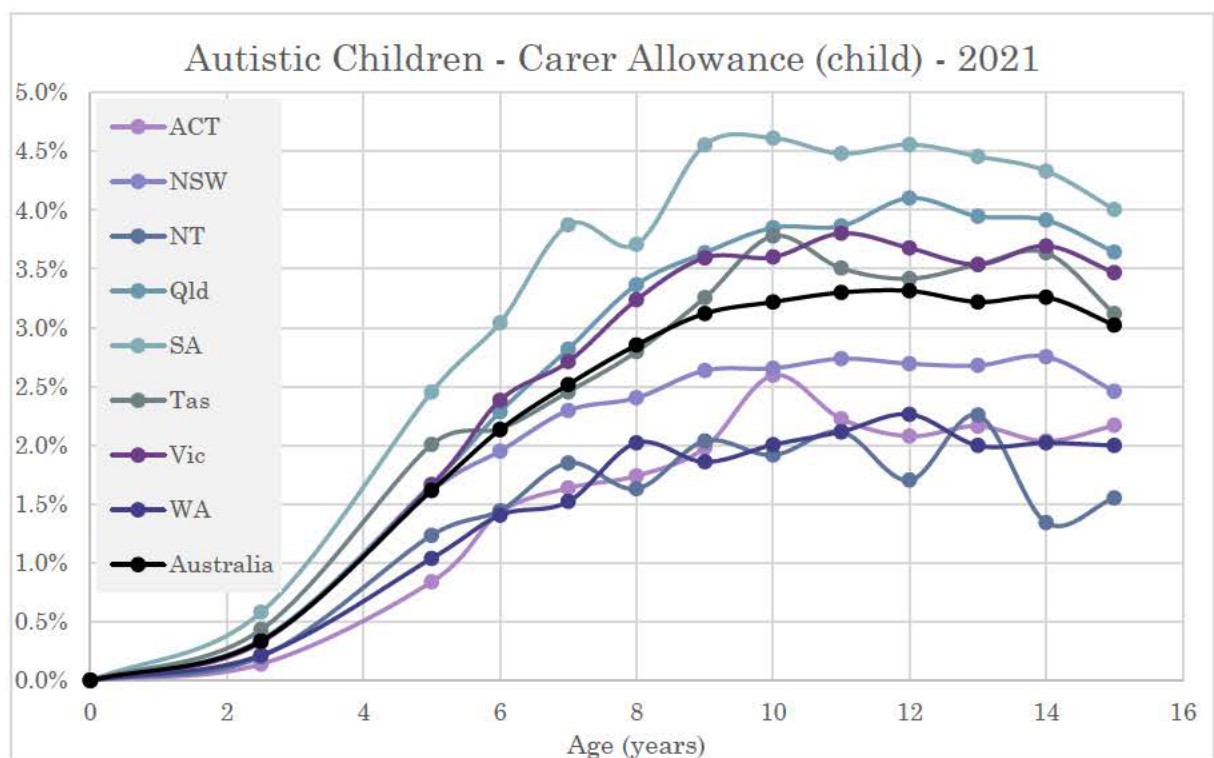


Basically, the biggest increase is expected to be in the more expensive age ranges.

The preceding two charts suggest the cost of a plan for an autistic NDIS participant increases with age and the number of autistic NDIS participants will also increase as the autistic cohort ages. In the context of the whole NDIS, the relationship between age and NDIS plan cost for autistic people is complex.

The average life-long cost of an autistic NDIS participant is over \$7million in 2021 dollars. Note that the breakeven point for early intervention that achieves a very modest 5% saving over a lifetime is \$350,000 but the NDIA refuses to spend anything like that. Clearly, the NDIA does not operate its early intervention for autistic children on “insurance principles”.

The following shows the varied autism diagnosis rates in Australia’s states and territories.



The variation between states (2 to 3 times) suggests substantially different diagnostic practice in different states.

Annex A below shows the number of autistic children aged 0 to 15 years who are a) NDIS participants with a primary diagnosis of autism, and b) Carer Allowance (child) recipients with autism as their primary disability.

Currently, over 3% of Australian children aged 7 to 14 years are autistic (primary disability) and have an NDIS plan. Rates are above 5% and 6% in South Australia and Victoria respectively.

Response to Terms of Reference

- a. *The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:*

- i. *the availability of support outside the NDIS for people with disability (e.g. community-based or 'Tier 2' supports), and*
- ii. *the future of the Information, Linkages and Capacity Building grants program;*

Unclear NDIS boundaries is a challenge. There are plenty of places where NDIS boundaries are unclear for autistic people.

1. Basic eligibility for autistic people is unclear. Apparently, the NDIS considers autistic people whose severity rating is 2 or 3 to be eligible for the NDIS. A DSM-5 autism diagnosis has two severity ratings for two parts of the diagnostic criteria. The DSM-5 requires the diagnosing clinician to identify that every person getting an ASD diagnosis “needs support” in two major aspects of their lives. The NDIA discards proper diagnosis information and discourages DSM-5 diagnosis reporting; if two severity ratings are given, it often complains, then records just the higher of the two. People with level 1 severity are accepted into the NDIS if they provide evidence of functional capacity limitation that satisfies the NDIA's gatekeepers.

With the arrival of the NDIS, many children are diagnosed with Developmental Delay, a new condition defined in Section 9 of the *NDIS Act 2013*. There is a condition called Global Developmental Delay described briefly in the DSM-5 to be used when a child clearly is not achieving developmental milestones, but diagnosis is difficult or incomplete. Both diagnoses are for children up to (and including) age 5 years, but some children are reported in the NDIS with these diagnoses beyond age 5 years. The NDIA should ensure children are fully diagnosed by age 6 years so they can access best practice early intervention for their disability.

The NDIA and its Minister perceive clinicians in Australia as having a “conflict of interest” and as trying to exploit the NDIS through overdiagnosis or exaggerating participants' disability. But the NDIA set up its ECEI Approach and Early Childhood partner scheme with a thorough conflict of interest. The unprecedented levels of Developmental Delay diagnoses in the 0-6 age group for NDIS participants is likely due to this approach.

The NDIA abolished the Autism Advisor element of the Howard government's *Helping Children with Autism* package that ensured the families of newly diagnosed autistic children had access to quality impartial advice.

The NDIA's ECEI Approach gives its Early Childhood partners preferential access to prospective and newly diagnosed young children. Regrettably, the NDIA's approach provides many families of autistic children with biased, unprofessional, incomplete, and inaccurate advice.

The NDIA's current scheme can delay a child's ASD diagnosis. Such a delay is a barrier to the child accessing the ASD-specific early

intervention that they need, and that the NDIS is meant to provide via its “insurance principles”.

2. Currently, autism is the most numerous distinct primary disability in the NDIS (over 32% of NDIS participants) and most of them enter the Scheme in their school years. A massive 67% of NDIS participants aged 7 to 14 years, and 58% aged 15 to 18 years, have autism as their primary disability. This group also has a low average for plan funding.

Many NDIS planners expect schools will meet most or all the disability support and service needs, including the clinical services, of a child with disability even when the child is only in school for a maximum of 30 hours per week.

Reporting from the Australian Bureau of Statistics shows that Australian schools are mostly failing to educate autistic students, so there is even less prospect that they will meet the student’s more general disability-related needs.

Similarly, autistic students have high rates of mental illness but mental health services in Australia often provide little or no mental health services for autistic children and adolescents. Annex B below shows how dysfunctional ACT political process has been in relation to health and especially mental health services in the ACT. So the NDIS needs to fund behaviour support as a safety-net service for these students. Regrettably, few NDIS planners understand the needs or include appropriate supports in the plans of autistic participants.

3. Mental health issues for autistic people extend well beyond their school years. Supports for autistic people in Australia’s health systems are substandard. Again, the burden of support ends up with the NDIS, usually after people leave hospital.
4. Employment rates for autistic people are unacceptable. The National Disability Employment Strategy (NDES) does not adequately recognise the problem and certainly does not address it. Basically, the NDES is doing the same thing it did last decade while expecting a different result. We judge it accordingly.
5. Recognition and support for autistic people in Australia’s various legal systems¹ is seriously deficient.

Encounters between autistic people and police often go awry.

6. The National Disability Advocacy Program (NDAP) does not fund any ASD-specific advocacy services. Few, if any, of the funded advocacy services understand the needs of autistic people adequately; too often, their ideological agenda is contrary to the interests of autistic individuals they have as clients, so their advocacy is unsatisfactory (at the very least) or misdirected.

¹ Australia lacks a Justice System because Australian law does not provide rights, which are the foundation for justice. Australia has a legal & penal system ... inline with its colonial past.

And so, it goes on ... so many issues.

The NDIA failed to deliver a credible ILC. In particular, the NDIA's misunderstanding of autistic Australia means that they leave autistic people with seeking NDIS Tier 3 support as their only option.

People in the NDIA disrespect anyone with an interest in autism. They disrespect clinicians, most researchers, parents, representatives, and advocates. They are interested in a select group of people who say they are autistic but claim they don't need support: they just need acceptance. If they don't need support, then they are not autistic, by definition ... and they should not be NDIS participants. Clearly, these people are not representative of adult autistic NDIS participants (whose average NDIS plan costs over \$100K p.a.). The NDIA needs to hear the spectrum of autistic voices, not the select few whose voice suits [the NDIA's anti-autism agenda](#).

The ABS reports repeatedly that education systems in Australia fail autistic students. Autistic students leave school unprepared for employment, often unprepared for disability support. After school their behaviour is seen as an escalating problem and their support costs rise. Australia lack trained, qualified and effective behaviour supports. The NDIA has no discernible plan to address this massive deficiency: worse, whenever possible, they oppose the application of behaviour science in support services.

b. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;

In most states, disability diagnostic services for children with autism have long waiting lists. In some instances, they are distinctly unreliable – people often get their ASD diagnosis via a “second” professional opinion. Delayed diagnosis means delayed or denied access to the most beneficial early intervention for ASD.

Diagnostic service rarely follows [the national guidelines](#) or provide reports using the template associated with the guideline. As a result, diagnostic practice is inconsistent and substandard (we showed previously that diagnosis rates vary by 2 or 3 times between states).

The NDIS could easily reduce the variability in autism diagnosis. It could contact every clinician whose diagnostic reports do not use the autism diagnosis template from the guidelines and require them to complete one for the child. Even better, would be to get them to complete the template for an ASD diagnosis online (on the NDIS website). Use of the template would quickly become standard practice. Diagnostic practice and standards would improve. It might provide better initial assessment information reducing the need for some of the NDIA's disability assessment for children.

In relation to autism, education is the major state/territory non-NDIS service. As indicated above, all levels of education are failing autistic students. At the same time, NDIS planners have utterly unrealistic ideas about what supports education can provide for autistic people.

As yet, few autistic people entering the aged care system. However, as their numbers increase, they are likely to be an increasing challenge for behaviour support services in aged care.

Health systems around the country avoid supporting autistic people. We saw this demonstrated with COVID-19 vaccination. No credible attempt was made to vaccinate autistic Australians even though the disability sector was initially given a high priority.

Currently, problems in Australia's aged care system mean that people with an NDIS plan will be substantially worse off if they move to aged care. The aged care system should do better for ageing clients than the NDIS does.

Australia does not have "justice services", it has a legal & penal system. The legal & penal system does not recognise autistic people adequately so their encounters with it are rarely constructive.

The one counterexample is that the AAT has functioned relatively well for autistic people who sought independent reviews of their NDIS plans. It would work much better if the NDAP provided ASD-specific advocacy support and properly resources legal aid was available.

- c. The reasons for variations in plan funding between NDIS participants with similar needs, including:*
- i. the drivers of inequity between NDIS participants living in different parts of Australia,*
 - ii. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and*
 - iii. measures that could address any inequitable variation in plan funding;*

The government does not wish to understand "variations in plan funding"; it prefers that bureaucrats use this variation as an excuse for under-funding many NDIS participants, especially autistic NDIS participants.

A4 justifies this claim through the observation that the government and the NDIA refuse to discuss the nature of the problem or how it might be addressed with representatives of the ASD community.

However, you did ask so we'll answer.

Various datasets show autism diagnosis rates vary between locations. Carer Allowance (child) (CAc) data shows that the ASD diagnosis rate in South Australia is double the rate in ACT, WA and NT. These data were previously shown to be consistent with separate datasets: the Autism SA client database and WA's autism register. The CAc dataset has been relatively consistent with

ABS SDAC estimates, even if the reliability of Carers Allowance (child) as an autism prevalence indicator is declining.

NDIS planning starts with diagnostic assessments whose outcome rates varies by 100% between states.

When a child is diagnosed autistic, their parents have a lot to learn. A4 feels parents who want the best for their child do the equivalent of a university degree in their first six months post-diagnosis. Their understanding depends a lot on who they meet in that period. Most clinicians know about one type of therapy; few understand the range of therapies that are available, so it is unlikely that families get comprehensive and impartial advice about how best to proceed.

Families take the advice they get to the NDIS and ask for an NDIS plan for their child. NDIS planners have varied understandings of autistic children and their needs. Many planners lack essential knowledge.

For example, A4 gets regular reports that NDIS planners advised families that the “NDIS does not fund ABA”. This is incorrect: the NDIA can and does fund ABA, more accurately called Early Intensive Behavioural Intervention (EIBI) for autistic children when parents advocate effectively.

The NDIS is meant to provide evidence-based early intervention for autistic children. EIBI/ABA is the only intervention (therapy approach) that the reviews of autism interventions for the government have ever rates as “evidence-based” – see various reports from [DSS’s HCWA Disability and Carers page](#), especially [the Early Intervention Table](#) extracted from the reports. The next best rating achieved was rated as having “emerging evidence”, but the anticipated evidence has still not “emerged”. It should not be up to NDIS planners with little or no expertise in early intervention for autistic children to decide, especially when their decisions are based on insufficient and incorrect information.

NDIS planner have many misconceptions, including that EIBI’s intensity is too expensive. The average lifelong cost of an autistic NDIS participant is currently around \$7million. If best practice early intervention for autistic children achieved only a modest 5% improvement (cost reduction), the break-even cost for early intervention for autistic children is \$350,000. This is a very conservative average saving from best-practice early intervention. Few NDIS planners would consider approving NDIS plans that go anywhere near this level of funding. Clearly, in relation to autistic children, the NDIS does not operate using the “insurance principles” that it claims underpin its decisions.

Whatever principles and processes the NDIS uses in planning for autistic children, it is very likely to deliver inequitable planning outcomes.

A4 has written to the NDIA about its planners telling participant’s families that “the NDIS does not fund ABA (evidence-based early intervention)”. The NDIA has repeatedly ignored A4’s concerns. We can only conclude that the NDIA prefers that planning for autistic children delivers inadequate funding for autistic children resulting inequitable outcomes for them in both the short- and long-term. Despite its claims, the NDIA does not use “insurance principles” in relation to autistic children.

Families who challenge the NDIA's decisions, which means challenging a government agency through the AAT, usually get funding for evidence-based interventions. But few families are willing or able to do this.

Some of the variation between plan funding and supports for participants with similar needs is due to a family's willingness or ability to a) articulate need, and b) advocate for supports.

Autistic people have limited access to advocacy services since there is no NDAP-funded ASD-informed advocacy service. Many autistic NDIS participants cannot get the advocacy support they need.

The AAT is not friendly and informal as Government and the NDIS Minister believe. Relatively few families are brave enough to challenge a government agency like the NDIA in Australia's legal system.

d. How the NDIS is funded, including:

- i. the current and future funding sources for the NDIS,*
- ii. the division of funding between the Commonwealth, States and Territories, and*
- iii. the need for a pool of reserve funding;*

A4 does not have expertise in how governments in Australia fund their compliance with international human rights obligations.

A4 does expect both state and federal government to put on the *big boy pants* and sort it out: stop bickering, finger-pointing and name-calling over their responsibilities to people with disability and their associates.

Federal and state/territory governments need to meet all their responsibilities including essential and equitable outcomes for people with disability in education, health, employment, etc. If governments use the NDIS as their disability safety net, then they need to redirect funding from the sectors that fail people with disability – that is, health, education, employment, etc.

It looks to us that the federal government is trying to transfer 50% of the responsibility for disability supports for Australians 65 years of age and older to state and territory governments. Hopefully, few Australians will be convinced to blame people with disability for increasing aged care costs.

e. Financial and actuarial modelling and forecasting of the scheme, including:

- i. the role of insurance-based principles in scheme modelling, and*

- ii. *assumptions, measures, and methodologies used to forecast and make projections about the scheme, participants, and long-term financial modelling;*

From the outset, the autistic community told the NDIA that it's projected numbers for autistic participants were wrong. The NDIA chose to ignore advice from people who had previously helped predict relatively accurately the number of participants in the national *Helping Children with Autism* package.

Annex C shows a transcript from 1/6/2018 where the NDIA advised that they expected the number of autistic NDIS participants would drop to 20% by full NDIS roll-out. We now know that was also wrong. Their estimates were out by 60-80%, depending on how you calculate it. This is a large error.

Their "financial and actuarial modelling" for autistic NDIS participants, the biggest primary disability type in the NDIS has been consistently wrong. The scientific method suggests that we should expect their latest modelling will also be wrong.

A4 has severe doubts about the NDIA's latest modelling of autistic participants. Our concerns include that:

1. the NDIS is only just reaching its expected roll-out numbers – it was slow in rolling out which may have been due to NDIS intake limitation. It is likely that the NDIS is still in roll-out mode for autistic participants.
2. Other data sources indicate that diagnosis rates for ASD are still growing, contrary to the NDIA's initial assumptions. It is unlikely that future growth in autistic diagnoses will match the NDIS intake rate for autistic participants. The NDIS needs better modelling than this for autistic participants.
3. The age distribution of autistic NDIS participants means that the increasing age of autistic NDIS participants is associated with increased cost, unless support for autistic participants is substantially improved ... especially behaviour supports.
4. The NDIS is providing a safety net for the failure of education, health, employment, and other sectors for autistic people. The NDIS should not be considered in isolation.

Previously, we indicated that the NDIA is not using "insurance principles" in relation to early intervention for autistic children. They are extremely reluctant to properly fund evidence-based early intervention.

None of the modelling considers more complex aspect of the NDIS.

1. The contribution of parents continuing to care for autistic adults is not mentioned.
2. The economics, social and health benefits of supporting caring parents to continue working is not accounted for.
3. The overall cost of underfunding education, health and employment form autistic Australians is ignored.

The Productivity Commission advised that the benefits of the NDIS out-weigh its costs. But the reasons for their saying this are not addressed in the latest modelling and sustainability reporting.

- f. *The measures intended to ensure the financial sustainability of the NDIS (e.g. governance, oversight and administrative measures), including:*
- i. *the role of state and territory governments, and the Disability Reform Ministers Meetings,*
 - ii. *the arrangements for providing actuarial and prudential advice about the scheme, and*
 - iii. *the way data, modelling, and forecasting is presented in public documents about the NDIS, (e.g. NDIS Quarterly Reports and Reports by the Scheme Actuary), and*
 - iv. *measures to ensure transparency of data and information about the NDIS;*

At this stage, it is unclear what measures are intended to ensure the financial sustainability of the NDIS.

Governments have agreed to abandon their plans to impose so-called Independent Assessments. The process [exacerbated the autistic community's already chronic mistrust of the government and the NDIA.](#)

A4 recognises that supporting autistic people in Australia is a growing challenge for governments of all levels. In June 2021, over 3% of children aged 9 to 15 years were formally diagnosed with autism and receiving Carer Allowance (child).

Autistic participants are the majority of school-age NDIS participants.

Most autistic children will remain autistic for life². Most likely, the number of autistic adults will increase at least 10-fold over the next 30-50 years. The average lifelong cost of an autistic NDIS participant is around \$7million. A ten-fold increase in plans costing \$7million over a lifetime is a substantial cost to the NDIS and may be a challenge to perceived sustainability.

If governments continue their *strong resistance* to actions aiming to improve health, education and employment outcomes for autistic Australians, the ensuing cost of autistic participants in the NDIS will increase substantially.

It does not matter whether or not actuarial modelling and reporting predicts these outcomes, or whether the predictions are accurate.

The challenge is for government and the NDIA to obtain and implement advice that improves outcomes for autistic people, and to promote action beyond the

² A4 accepts that some autistic children learn to function without needing disability supports, so they no longer meet DSM-5 diagnostic criteria for ASD. They lose their autistic diagnosis.

NDIS to achieve these outcomes. Initial advice said “from an economic perspective, the benefits of the NDIS will exceed the costs” (Productivity Commission 2011), and that “the cost to governments of disability support without reform would be two to three times the cost of the NDIS” (PriceWaterhouseCooper 2011). Unfortunately, recent reporting omits key information about this aspect of the NDIS.

The NDIA has very little idea about “transparency of data and information about the NDIS”. The NDIA does not give us access to percentiles, even quartiles, for NDIS plan values for autistic people divided by age, state, etc. Very little information about plan utilisation is provided. They do not provide data about autistic participants: diagnoses (severity ratings), comorbid diagnoses, etc. They provide very little information about ASD as a secondary or comorbid diagnosis.

NDIA staff regard participants as liars, rorters and scammers. The NDIA has no respect for the people they are meant to help. For example, a participant’s parents told the AAT that they did not receive transport funds from their son’s plan until recently. The NDIA told the AAT that the parents were lying: the NDIA claimed it made regular fortnightly payments. The parents produced a bank statement showing a recent large sum was paid into their account and one small (fortnightly) amount. About six months later, the NDIS made another payment ... and fortnightly payments started. The NDIA told the AAT that the family lied but apparently did not even check the truth of their version of events. The NDIA’s statement to the AAT was incorrect. The NDIA did not fix the issue for an extended period.

There is no justification for the NDIA’s culture of disrespecting and denigrating its clients ... and much of the disability sector generally.

It is very likely that the NDIA’s culture and attitude to participants impedes its ability to function effectively.

Currently, the NDIA’s reporting, and the government’s focus is entirely on costs. Genuine consideration of sustainability reviews both benefits and costs, not just the cost side.

g. The ongoing measures to reform the scheme including:

- i. the new early childhood approach, including whether or how early intervention and other supports intended to improve a participant’s functional capacity could reduce their need for NDIS funding, and*
- ii. planning policy for personalised budgets and plan flexibility; and*

The NDIA’s proposed approach to early intervention for autistic children was shelved. It was not developed in consultation (as a co-design) with the autistic community. In fact, the NDIA has an extended track record of ignoring expert

advice on early intervention for autistic children and avoiding providing evidence-based practice³.

Personalised budgets and planning for autistic people is challenging.

The NDIA seems to prefer functional assessment tools, but such tools are not evidence-based for autistic people. The spectrum nature of autism means that needs of individuals vary substantially. The NDIA keeps secret the range of plan costs. A4 knows 30 year-old severely autistic males whose functional assessments rate them similarly, yet their NDIS plans vary from average for autistic people that age to 3 or 4 times that amount of funding.

As yet, no one has developed a standardised assessment tool for autistic people that covers reliably their spectrum of service and support needs. Either ...

- a. a few general questions are asked, and respondents are likely to miss important issues in their response, or
- b. lots of specific questions are needed many of which are less important in each specific case ... there are too many questions, and the process often fails.

A more reliable strategy for planning services and supports for autistic people is to discuss specific needs ... and to ensure that issues that arise subsequently can be addressed as they arise. NDIS procedures could manage such an approach.

A4 is concerned that the NDIA may be using a secret scheme of *typical support packages* (TSPs). Such a practice would be contrary to their existing Participant Service Charter and any future Participant Service Guarantee.

The NDIA's Early Childhood Approach seems to have caused a Developmental Delay epidemic, and a decline in timely diagnoses of ASD.

h. Any other related matters.

1. The NDIA's culture of distrusting and denigrating NDIS participants impeded the functioning of the NDIS.
2. [The NDIA's war on autistic Australians](#) is inappropriate and unproductive.
3. lip-service to co-design will not appease the autistic community.
4. Even with co-design, the NDIA is unlikely to deliver a planned outcome – they will just do things their way anyway.
5. The AAT is being overwhelmed.
6. The timescale government gave the disability sector to respond to proposed legislative changes to the NDIS Act 2013 are discriminatory.

³ The NDIA funds groups who oppose and denigrate evidence-based practice for young autistic children: see https://reframingautism.org.au/wp-content/uploads/2021/10/20314_Reframing-Autism-Position-Statement_web.pdf

Financial Sustainability of the NDIS

The first challenge for this discussion is that it is unclear what people mean by the “financial sustainability” of the NDIS. It is impossible to discuss it meaningfully without a definition.

From the outset, there were concerns that there would be more NDIS participants than the Productivity Commission initially estimated. The autism sector or the disability community certainly raised their concerns on numerous occasions. The NDIA ignored the autism and disability sector’s concerns. It is unacceptable that the people who ignored those concerns now seek to weaponise their miscalculations against the NDIS.

A major part of the problem is that other parts of government are ignoring their responsibilities. The education sector is not meeting the education needs of people with disability. Education outcomes for autistic Australians are abysmal – far worse than they should be. Similar and consequently, employment outcomes are also abysmal (and the National Disability Employment Strategy is a ten-year plan to perpetuate those abysmal outcomes).

The health sector, especially mental health, largely ignore the needs and rights of autistic Australians. They expect the NDIS will make up for Health’s deficiencies.

Governments need to ensure mainstream services meet the needs of people with disability in most cases. Quality and safeguard measures are needed in all sectors, not just the NDIS.

Next, they need to think about the Productivity Commissions original Tier 1 & 2.

And the NDIA needs to make its Tier 3 NDIS work better.

The NDIA need to be more proactive about the disability workforce.

One of the biggest impediments to a more sustainable NDIS is the NDIA’s culture. There are too many problems to name them all.

The data presented above suggests that a high percentage of autistic children are being accepted into the NDIS even when more rigorous checks of “level 1” autism is applied. A4 questions whether additional testing, beyond diagnosis is justified. It may be better to improve diagnostic practice. This might result in more uniform diagnosis rates between states (and socio-economic indicators), and reduction of anti-autism prejudice in the NDIA culture.

The greatest improvement to the financial sustainability fo the NDIS will come from the NDIA recognising, respecting and utilising existing expertise in the disability sector.

The growing number of autistic Australians is a major challenge for governments. Australia needs a distinct National Autism Plan.

Terms of Reference

As part of the committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee has decided to conduct an inquiry into current scheme implementation and forecasting for the NDIS, with a focus on how the NDIS is implemented and funded, and what supports are or should be available for people with disability in addition to the NDIS.

Terms of reference

As part of the committee's role to inquire into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS), the committee will inquire into and report on current scheme implementation and forecasting for the NDIS, with particular reference to:

- a. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding, including:
 - i. the availability of support outside the NDIS for people with disability (e.g. community-based or 'Tier 2' supports), and
 - ii. the future of the Information, Linkages and Capacity Building grants program;
- b. The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth, particularly aged care, health, education and justice services;
- c. The reasons for variations in plan funding between NDIS participants with similar needs, including:
 - i. the drivers of inequity between NDIS participants living in different parts of Australia,
 - ii. whether inconsistent decision-making by the NDIA is leading to inequitable variations in plan funding, and
 - iii. measures that could address any inequitable variation in plan funding;
- d. How the NDIS is funded, including:
 - i. the current and future funding sources for the NDIS,
 - ii. the division of funding between the Commonwealth, States and Territories, and
 - iii. the need for a pool of reserve funding;
- e. Financial and actuarial modelling and forecasting of the scheme, including:
 - i. the role of insurance-based principles in scheme modelling, and
 - ii. assumptions, measures, and methodologies used to forecast and make projections about the scheme, participants, and long-term financial modelling;
- f. The measures intended to ensure the financial sustainability of the NDIS (e.g. governance, oversight and administrative measures), including:
 - i. the role of state and territory governments, and the Disability Reform Ministers Meetings,
 - ii. the arrangements for providing actuarial and prudential advice about the scheme, and
 - iii. the way data, modelling, and forecasting is presented in public documents about the NDIS, (e.g. NDIS Quarterly Reports and Reports by the Scheme Actuary), and
 - iv. measures to ensure transparency of data and information about the NDIS;
- g. The ongoing measures to reform the scheme including:

- i. the new early childhood approach, including whether or how early intervention and other supports intended to improve a participant's functional capacity could reduce their need for NDIS funding, and
- ii. planning policy for personalised budgets and plan flexibility; and
- h. Any other related matters.

Committee Secretariat contact:

Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

Phone: [+61 2 6277 3083](tel:+61262773083)

Fax: +61 2 6277 5829

ndis.sen@aph.gov.au

See

[https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National Disability Insurance Scheme/ImplementationForecast](https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/ImplementationForecast)

Annex A. Australia’s autistic children 2021

	NDIS - autism			NDIS rates		Carer Allowance (child)			NDIS/Cac increase		
	0 to 6	7 to 14	15 to 18	0 to 6	7 to 14	0 to 6	7 to 14	15 to 18	0 to 6	7 to 14	15 to 18
ACT	248	1325	398	0.63%	2.97%	171	917	306	45.0%	44.5%	30.1%
NSW	7124	23869	6100	1.03%	2.90%	5300	21438	7020	34.4%	11.3%	
NT	148	568	102	0.61%	2.03%	126	517	141	17.5%	9.9%	
QLD	4257	17125	4267	0.96%	3.05%	3712	20707	7215	14.7%		
SA	1795	8622	2406	1.29%	5.01%	1708	7433	2430	5.1%	16.0%	
TAS	431	1513	469	1.04%	2.87%	383	1744	612	12.5%		
VIC	5197	21159	4707	0.93%	6.23%	4668	22964	7701	11.3%		
WA	1587	6782	2301	0.66%	2.41%	1229	5547	1911	29.1%	22.3%	20.4%
<i>Australia</i>	<i>20788</i>	<i>80972</i>	<i>20752</i>	<i>0.95%</i>	<i>3.09%</i>	<i>17301</i>	<i>81285</i>	<i>27351</i>	<i>20.2%</i>		

In all states and territories, more children aged 0 to 6 years are NDIS participants than get Carer Allowance (child) even though the eligibility criteria for the NDIS are meant to be more rigorous. This indicates that families of autistic children are more interested in getting support for their child (via the NDIS) than in getting cash-in-hand (via Carer Allowance). This contradicts the NDIA and government

culture that families of autistic children just want to port the system.

The ACT (with no ASD-specific support) has 1 in 3 autistic children *not* getting Carer Allowance (child).

Both datasets have diagnosis rate variations as high as a factor of 2 in the 7 to 15 years age range. Nationally, diagnosis rates are over 3% and some states are 5-6% of children diagnosed autistic.

These data suggest that most autistic children become NDIS participants. The NDIA’s additional functional assessments accept most autistic children as eligible. This confirms that an ASD diagnosis accurately identifies a child diagnosed with ASD as “needing support”. This infers that further NDIA functional assessment is unnecessary, that is redundant and time-wasting.

Annex B. ACT Mental Health & autism timeline

ACT Health avoids services and support for autistic people as much as possible. This is just the state/territory that A4 (and SOfASD in the ACT) knows most about. We expect other states and territories have similar responses to their autistic citizens.

Following is some of the correspondence and inactivity relating to mental health service and support for autistic youth in the ACT.

July 2018	parents, advocates and a psychiatrist wrote to ACT Minister for Mental Health about autistic patients needing mental health service and supports. See https://sofasd.org.au/d7/sites/default/files/20180715StatementofIntent.pdf	No direct response.
15/11/2018	First Working Group Meeting see FoI result below.	Working group decided to ignore autism; to only consider Intellectual Disability
24/12/2019	SOfASD Freedom of Information request.	See https://sofasd.org.au/d7/node/232
March 2020	Review of Children and Young People in the ACT Office for Mental Health and Wellbeing	The words “autism” or “autistic” do not appear anywhere in the document.
5/7/2020	Letter from Minister Rattenbury quoting “additional work is required to address issues for people on the Autism Spectrum more specifically” to complement this Position Statement	
August 2020	ACT Standing Committee on Education, Employment and Youth Affairs: report on Youth Mental Health in the ACT	The report says “Routinely, autistic youth who present with anxiety, trauma or depression are denied mental health services for those conditions because of their autism. In the past, CAMHS had a strong interest in autism but now the service excludes many, possibly all known, patients known to be autistic. Many autistic youths with mental illness have

		nowhere else to go to get the mental health services they need. It seems this is a staff decision rather than an actual policy”
13/4/2021	<u>SOofASD Correspondence</u> : “We will be commencing this body of work in this quarter, rather than earlier in the calendar year, due to competing work priorities.”	By 29/10/2021 – there is no discernible progress.

Annex C: Evidence to Community Affairs Legislation Committee, 1/6/2018

The following is from a transcript available at

<https://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;db=COMMITTEE;id=committees%2Festimate%2Fc0730a81-3382-47c0-9bce-8920288dad41%2F0002;orderBy=customrank;page=0;query=autism%20lve%20ru ndle%20community%20affairs%20estimates%20ndis;rec=2;resCount=Default>

Senator WATT: Does the NDIA have concerns about the number of people with autism entering the scheme?

Mr De Luca : Does it have any concerns with it? Our focus is to make sure that those eligible for the scheme get into the scheme. At the moment, 29 per cent of our active participants have a primary disability of autism. The Productivity Commission's expectation at full scheme was around 20 per cent. So it's not materially different to what the Productivity Commission's expectations were.

Senator WATT: I would have thought 10 per cent is a pretty big—

Mr De Luca : Yes, and the slight difference is that the way the bilateral agreements were put in place was based on different participants across the country getting in at different times. In South Australia, for example, children were first. A large proportion of the children in the scheme have autism. So it really depends on where we are in the phase of the rollouts. Over time, we would expect the numbers to be broadly in line with what the Productivity Commission estimated, but we continue to monitor that to understand any variances and differences to those assumptions.

Senator WATT: Do you think that the number of people entering the scheme with autism poses a risk to the sustainability of the scheme?

Mr De Luca : In itself?

Senator WATT: Yes.

Mr De Luca : I think the key focus for us from a sustainability perspective is a number of things we need to continue to monitor, including making sure we've got the right people in the scheme with the right packages. That's really core to what we need to focus our attention on. Whether it's autism or other disabilities, we monitor that in line with the expectations.

Senator WATT: So autism numbers are no greater threat to the sustainability of the scheme than many other factors?

Mr De Luca : Well, I think each of them is different in its own situation. Depending, obviously, on the total number of people in the scheme, if you have a large proportion of one cohort, you need to have a look at whether that cohort's cost of their packages varies from the expectations. So it's not just about the number; it's about the package

and then the tenure of how long they would be in the scheme based on exit assumptions as well.

Ms Rundle : It's also important to make the point here that we've been within budget every single year of operation and remain within budget. Whilst we monitor carefully, as Mr De Luca has just said, we haven't exceeded our scheme envelope year on year.

Mr Lye : The intention here is not based around concern that autism is out of control or is that it's too high a proportion of scheme costs. The concern here is around an area of disability which, relative to other areas, is not as well understood. The interventions that work aren't as well documented, and I think we have a lot of work to do in policy terms to say, 'Okay, what's a fair way—what's the best way—to work out who comes into the scheme, what they might need and what's the most effective intervention?' For autism, relative to other areas, we don't know as much, and we have to pay attention to that—most importantly because it's an insurance based scheme, and we want to actually get better at devising interventions that work and then maximise the outcomes for people who have the benefit of the scheme. This isn't coming at it from a view that it's a problem that we need to contain or where we need to restrict access. It's around understanding better what the needs of people are out there in the community and how we can help them.