

# A4 response to the Draft National Autism Strategy

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Abundant opportunity for improvement

*We all need people who will give us feedback. That's how we improve.*  
Bill Gates



**Autism Aspergers Advocacy Australia**

2 June 2024





## Preface

*Autism Asperger Advocacy Australia*, known as A4, appreciates the opportunity to suggest improvements to Australia's National Autism Strategy.

A4 was created in 2002 as a national grassroots organisation to provide systemic advocacy for Autistic Australians and others affected by autism.

The Department of Social Services recognise A4 as a disability representative organisation (DRO) for autism on its [DRO webpage](#).

A4 is proudly a member of:

- the Australian Federation of Disability Organisations (AFDO),
- the Disability Australian Consortium, and
- the Australian Autism Alliance (the Alliance).

### Content warning

If it is fully understood, government official, employees, politicians and their apologists will find the information in the following document confronting and distressing. Should you need support after reading this response to the Draft National Autism Strategy, a free service may help.

#### *Beyond Blue Support Service*

- Telephone 1300 224 636, 24 hours a day, 7 days a week.
- Chat online 24 hours a day, 7 days a week.
- Email for free, short-term counselling, advice and referral services.
- Website: [Beyond Blue Support Service](#).

#### *Lifeline Crisis Support*

- This confidential service may provide support when you are adversely affected.
- Speak to support by telephone on 13 11 14, 24 hours a day, 7 days a week.
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- Website: [Lifeline Crisis Support](#).

### Cover picture

There is no silver bullet; silver buckshot may be a more effective approach.

## **Proud member of**



**AUSTRALIAN  
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## Introduction

The first draft National Autism Strategy is primarily a policy/plan/approach to have strategies in the four areas that the Department of Social Services initially created.

A National Autism Strategy must identify the problems and challenges it is meant to address. The next stage of the strategy must refine and enhance the strategy. There is abundant opportunity for improvement.

While the draft strategy recognises the NAS is a key recommendation of the Select Committee on Autism's report, omission of autism from Australia's Disability Strategy and from the recommendations of both the Disability Royal Commission and the NDIS Review demand a NAS.

From the outset, the strategy needs to recognise, respect and address all areas of concern. It must be comprehensive and ambitious.

## Understanding the problems and challenges

Initially, the strategy needs to understand autism. Autism is complex; the "spectrum" analogy is used to indicate its heterogeneity. Few people encounter the range of the spectrum and come to appreciate its full diversity.

An effective strategy for autism needs a spectrum of solutions. As John Mendoza said recently (at [the National Press Club](#) in the relevant context of youth crime<sup>1</sup>), government must stop looking for a silver bullet, instead we need metaphorical silver buckshot to vanquish the inequities. Strategies, policies and programs for autistic people must:

1. be designed and implemented with and for the autistic people and their families being affected, not by people with other types of disability and no relevant lived experience; and
2. fully address the diversity and individual needs of all Autistic Australians, not just selected self-advocates.

The NAS must recognise and overcome a collection of challenges that Autistic Australians currently endure, the many unaddressed challenges relating to particularly poor outcomes. Some of those challenges are:

- Ending government's (and their media allies') *War on Autism*<sup>2</sup> in Australia.
- Diagnosis of autism for Autistic Australians takes too long and lacks quality/consistency.
- Behaviour services and supports is a chronic issue that governments refuse to address.

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<sup>1</sup> So much of what John Mendoza and Matt Noffs here say relates to autistic youth ... but autism goes mostly unmentioned.

<sup>2</sup> The government's *War on Autism* is an ongoing issue for systemic advocacy for autistic Australians – see <https://a4.org.au/index.php/node/2419>

- Few autistic children in Australia access evidence-based or effective early investment/intervention for their autism.
- ABS SDAC data and much other data show
  - Substantial and sustained growth in the number of Australians being diagnosed autistic
  - autistic children in Australia have especially poor education outcomes. Too many do not even attend school.
  - Autistic Australians have especially poor employment outcomes – the strategy must recognise and address this as an autism problem, it cannot be restricted to “intersectional” issues.
- Growth in support capacity and capability do not match increasing diagnoses so accessing services is getting more difficult.
- the health and well-being of autistic Australians needs serious improvement.

Other data shows Autistic Australians have exceedingly poor life outcomes that must be addressed.

The National Autism Strategy must:

- emphasise that autism is a distinct disability – not based on intersectional aspects.
- ensure government and its agencies recognise and respect that autism is not just a subset of intellectual disability, cognitive disability, psycho-social disability or neurodiversity.
- treat and value autism as a spectrum that needs multiple perspectives and solutions – cannot rely on common factors, back to the basics of individualised supports – no silver bullet, we need silver buckshot (thanks John Mendosa) to target every aspect of the autism challenges in Australia
- meet the needs of *all* Autistic Australians – it must not cater to any majority or more communicative (or articulate) subsection of the autistic population.
- Respond fully to the needs of autistic people with more severe or profound disability due to their autism.

## Goals of the NAS

The NAS need specific goals in a long list of areas mentioned below.

A simple over-arching goal ensures essential elements of a NAS will be ignored. The risk is far too great.

## DDS-devised strategy

A4 understands that DSS officials led the development of the draft NAS. A4’s view is that DSS officials and their work would benefit from:

- better understanding of how autism impacts the lives of Autistic Australians,
- improved engagement with all areas of the autism sector,

- more understanding and appreciation of the available evidence and what policies and programs are likely to benefit the sector, and
- recognising that research is required where evidence and understanding are insufficient or absent.

DSS officials partitioned work on the NAS into four areas. Discussion of the draft strategy under those four categories follows.

## Social inclusion

The section on social inclusion in the draft strategy missed the point almost totally.

Families of children with severe or profound autism often stop socialising because it is just too hard, or maybe their autistic child requires their constant and undivided attention – they have little/no capacity for social activities.

Families of autistic children are often extremely isolated. Their focus is on their autistic child or children. They are socially isolated ... or their social network changes radically, often away from family connections (who often fail to support them or worse). Those who do socialise often do so within other autistic groups/communities.

An autism strategy needs to recognise that autistic people are often less “social” than non-autistic people. Many prefer to be less social than the rest of the community. They may need to be encouraged to increase their social participation, but autistic people who prefer less social engagement/participation must have their choices respected.

A strategy aimed at providing opportunities to do something, like participate, are not credible strategies. Mostly, people already have *an opportunity* to participate. They fail to do so because there is some form of barrier. A strategy is more likely to succeed if it identifies and addresses the barriers.

Bureaucrats love the *opportunity* strategy: the Social Inclusion part of the strategy starts with

Social inclusion is about ensuring everyone has the opportunity to participate fully in our society.

Apparently, the bureaucrats who wrote the draft strategy believe autistic people can be fixed just with opportunities to be neurotypical. This is consistent with the NDIS that supports developmental goals for most autistic children saying the child (NDIS participant) will be *given the opportunity* to do the things they can't do. That means autistic children will be encouraged or required to practice the dysfunctional aspects of their disability: letting autistic kids just be (autistic) kids means allowing them to practice social avoidance, disengagement, etc.

This strategy is known to not work with autism.

Perhaps bureaucrats regard this strategy as having worked for Jesus: he said “Rise, take up thy bed and walk”, thus giving the man the opportunity

to be whole again. Bureaucrats just can't see why this technique would not work when they do it.

On this basis, they might regard turning the light on when a blind person enters the room as giving a blind person an equal opportunity to see.

The issue is more nuanced than this. We face deaf people to give them an opportunity to lip read. Or even better, we use AUSLAN. And some of them have technology to enhance hearing. This means they are *prepared* for opportunities to communicate ... and there are other options for communicating.

Toilet training is modified behaviour. Few children are toilet trained through simply having opportunities to use a toilet<sup>3</sup>. However, the NDIS is now denying some young autistic NDIS participants evidence-based toilet training (as their parents request and clinicians advise), choosing instead to fund continence products. This is not choice and control. It has long-term consequences that limit the participants' social and economic participation over their lifetime.

The more extreme example is the NDIA's policy on one type of evidence-based intensive early intervention – see <https://a4.org.au/node/2567>. The life-long negative impact of these policies is immeasurable. Clearly, the NDIS is not in the least concerned about its sustainability; instead it's intent on perpetuating the government's ongoing *War on Autism*.

If the opportunity strategy really worked our education system would not need teachers – schools could just provide opportunities for children to spontaneously discover chemistry, invent calculus, etm.

More severely autistic people typically need to be taught skills before they can benefit from being given opportunities. TV shows like *Employable Me*, *Love on the Spectrum* and *Better Date than Never* show how relatively moderately affected autistic people still need support, more than just opportunity, in order to participate economically and socially.

The key message here is “do what works” or use evidence-based practices. Government must work with, not against, the autism sector and individuals to know what works for different parts of the autism spectrum and for autistic individuals.

Originally, the NDIS was meant to meet individual needs but the bureaucrats (and politicians) running it have been unable so far to achieve that outcome.

The first paragraph in the Social Inclusion section also says, “When people are equally included, they can participate”. That is not how it works; in practice when people can participate equally, they are included.

Basically, the draft strategy fails to understand autism.

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<sup>3</sup> Maybe spontaneous toilet training would be more frequent if children saw toileting modelled by more adults.



## Economic inclusion

While the section in the draft strategy on economic inclusion recognises that poor outcomes in education delivers poor outcomes in employment and economic participation, it understates the challenge. The draft strategy says,

School education outcomes for Autistic people are poorer than those of the general population.

“Poorer” is a gross understatement of the challenge facing a NAS. ABS reporting on autism and education from the SDAC shows that outcomes for autistic students are utterly abysmal. Apparently, the government contemplated tackling this problem by stopping the reporting. That was not an acceptable strategy<sup>4</sup>.

The draft strategy has a scattered approach to employment. The employment section under the About Autism heading recognises the abysmal employment outcomes that Autistic Australians experience.

The *Employment and income support* section under consultation is remarkably brief and would be improved with better identification of the problems/challenges and preferred outcomes. It would be better to separate employment from income support as those are quite different issues.

The Economic Inclusion section omits serious discussion of the issue.

Self-esteem and self-confidence are not mentioned in the draft strategy. Good employment brings these additional benefits. They are among the best protections from mental illness. The need for achieving secure employment must be recognised and addressed so the strategy can improve well-fare outcomes.

Again, the draft strategy proposes opportunities, not outcomes. Opportunities that are unachievable are not real opportunities.

## Diagnosis & services

The draft strategy claims

The average age of diagnosis in children in Australia is about 3-4 years of age, with the most frequent age for diagnosis being 5.9 years.

This may be the case for children up to age 6 years, but that is not helpful. Figures 13 & 14 in the *ASD in Australia* report that A4 gave to the NAS (but apparently not circulated to members of the Oversight Committee and the working groups) shows average age of diagnosis for children up to 16 years of age is 8-9 years of age. Most autistic children are diagnosed too late to benefit from early intervention programs in Australia.

The NDIS ignores the functional information about people’s diagnoses that clinicians provide with most diagnoses.

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<sup>4</sup> The ABS since informed A4 that a report on autism from the latest ABS SDAC data (initial publications due 4/7/2023) will be published in October 2024.

The NDIS ignore many service and support recommendations that clinicians provide with an ASD diagnosis, especially for the most severely affected (see <https://a4.org.au/node/2567>).

The fact that the NDIS has created a situation where many children are first diagnosed with Developmental Delay or Global Developmental Delay before getting their ASD diagnosis (see <https://a4.org.au/node/2626>). This means that they miss out of ASD-specific early intervention. The personal, social and economic cost of this Roadmap for autistic Australians is unaffordable; it needs urgent attention in the strategy.

## Health and mental health

The draft strategy cites Soke G et al 2018. (see Endnote 2 in the draft strategy). However, it omits to mention the following detail about some more frequently co-occurring conditions among autistic 8-year-olds in the USA.

<i><b>co-occurring condition</b></i>	<i><b>%</b></i>
Self-injurious behaviours	25.02
ADHD	26.05
Aggression	54.26
Language disorder	34.83
Sleep abnormalities	37.12
Developmental disability-motor	26.86
Mood disorder	74.80
Developmental disability-adaptive	20.81
Abnormalities in eating, drinking	56.74
Temper tantrums	55.27

Four of these conditions are reported at over 50%. Clearly, most autistic children have multiple co-occurring conditions; they have complex needs.

The list of co-occurring conditions in Appendix D of the draft strategy is different, though there is some overlap. Its origin is not cited. Even combined, these lists are far from complete.

The strategy needs commitment to understanding better the association of these conditions with autism. In particular, we need to understand whether the conditions are part of a person's ASD, caused by ASD, or whether they co-occur independently. The answers are needed across the autism spectrum and are likely to help improve overall outcomes for autistic people.

Most likely, autistic children in Australia have similar co-occurring conditions. However, health and disability services in Australia are not designed nor intended to address these conditions for autistic people.

The NAS needs to recognise, address, and hopefully meet the service and support challenge that autism usually with these co-occurring conditions presents for service and support delivery.

## Issues and gaps

A National Autism Strategy needs to be clearer about what it means by “autism” and “autistic”, or at least whose lives the Strategy is meant to address.

The opening section of the About Autism section in the draft strategy must be less vague. Presumably, it currently aims to satisfy people whose view is along the lines of “I’m autistic but I just need you to be aware and accommodate my differences”. A4 accepts and supports these autistic people – their needs and aspirations must be respected and achieved. The strategy must require mainstream settings to be more accepting, accommodating, and affirming.

However, those people are only part of the autism spectrum. The ABS SDAC reported that in 2018, 68.9% of Autistic Australians had severe or profound disability (down from 87% in 2003)<sup>5</sup> and their life outcomes in all areas were unsatisfactory. Their needs will not be met by saying their challenging and dysfunctional behaviour should be affirmed. Or that their difficulty acquiring life skills (e.g. toilet training) is just an inherent part of their condition and should simply be accepted as is.

It is important to appreciate that autistic people can have their own ways of doing things, just like deaf people learn to function in the world without hearing. Autistic people do not need to be normal to participate, but they can learn many functional skills.

Many autistic people need specific help in managing their stress, anxiety, mood disorders, etc. Behaviour and mental health services for Autistic Australians are in complete disarray. They need immediate and enormous improvement. The NDIS needs to recognise and require proper professional registration for behavioural clinicians. Behaviour services and supports need actual measurement and monitoring of quality. The existing approach does not work. Everyone needs to stop blaming autistic people for the failures, and government must take responsibility. This is an essential part of the National Autism Strategy.

The commitments in the draft strategy are too vague to have real utility. The NAS needs commitments that stand solidly on measured baselines and commitments to measured improvements.

For example, in education the ABS SDAC education outcomes measures might be an initial attempt at setting a baseline. The strategy needs to set qualitative and quantitative goals for improving the outcomes. Even better would be to properly capture standard measures like NAPLAN for autistic students ... and set clear targets for better results in defined and agreed (with the autism sector) timeframes.

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<sup>5</sup> Data from the ABS SDAC series is summarised in Table 1 in [A4's ASD in Australia report](#) that was provided to inform the NAS development process.

Issues on A4's list for inclusion in the National Autism Strategy include (but are not limited to):

- ending governments' *war on autism*, abolishing their anti-autism culture -  
- respect - the NDIS's particular war on autism especially some autistic children with the highest needs
- behaviour support is a massive problem – the NAS must comprehensively address this key issue
- supported decision making for autistic Australians
- the NAS must be built on a strong foundation of research, data, and evidence.
- The NDIS needs to develop real expertise in autism in conjunction with the whole of the autism sector.
- major areas for improvement that involve government agencies other than DSS (some at a state/territory or local government level) are:
  - education – both mainstream and alternatives – pre-school, primary, secondary, and tertiary, ...
  - employment
  - health and well-being
- autism must be recognised as its own issue - if the NAS wants to discuss intersectional complications, there are a bunch of others than those in the draft strategy's initial list that deserve specific mention ASD+ID, ASD+EDS, associated genetic, ...
- autistic children need a better introductory pathway that the increasingly frequent detour via Developmental Delay or Global Developmental Delay.
- the NAS must be clear that “ASD with high needs” does not always mean complex combined with other conditions - autism alone can be high needs.
- Australia's Injustice System is especially problematic for Autistic Australians
- Autistic Australians need an effective service that provides autism/ASD-specific individual advocacy for them.
- the capacity and capability of the health, allied health and disability support workforces
- improving every aspect of diagnosis: clearer diagnosis criteria and practices, workforce training and capacity, timeliness, recording and data collection, ...
- a full review of Medicare provision relating to ASD.
- the NAS needs to review DRC recommendations in relation to Autistic Australians – the DRC largely left Autistic Australian out of their conclusions and recommendations.
- Improved approaches from first responders
- Major revision of how so-called “child protection” services approach autistic Australians (children and parents/carers)
- Expectations of and support for carers of Autistic Australians of all ages
- Recognition and support for autistic peer supports
- Review and recommendation of autism research in Australia – how was the head of the Melbourne Disability Institute going round the country asking, “why are there so many (autistic?) children in the NDIS?” when he was the person who was most responsible for answering that question.

- How the strategy overall meets the needs of all Autistic Australians right across the spectrum – it must ensure some of the “silver buckshot” targets *all* the challenges for *every* part of the autism spectrum.
- What happens when strategies fail, and people and organisations just don’t do their jobs – what are the consequences?
- Policy and program developers and implementers must access the expertise needed ... and respected by government and the autism sector alike. There needs to be an end to autism policy by political expediency.
- Which recommendations of the Senate Autism Committee will be implemented?

## Monitoring outcomes

How will ongoing monitoring of outcomes ensure that goals are achieved? Mostly government measures (just observes) the passing of time – we gave people some money and they seemed to spend it within the time allowed<sup>6</sup>.

What are the baselines, what are the goals – e.g. the ABS SDAC reports education & employment outcomes for autistic Australians. Will it continue to do so? What is reasonable to expect – maybe start with autistic people have comparable outcomes to people with other disability. But how does that help severely/profoundly autistic Australians.

## About solutions

Bureaucrats and politicians usually complain that we do not provide solutions. There are several reasons for that.

1. There is no point at all in offering solutions before the parties have agreed on the problem they will solve. Picking a solution then building a problem around it simply does not work.
2. Giving a solution to someone else to implement means the implementors do not own the problem – and their goal becomes ensuring that the solution they were given does not work better than what they would have done themselves.
3. Experience indicates that any solution that is likely to work will have been developed with both government and the autism sector together, so all parties feel full ownership and commitment to delivering outcomes fully and effectively.

The process needed for all the issues raised is to first agree the nature and extent of the challenges that the strategy must overcome. That will be followed with collaborative design and implementation of solutions.

For example, with the issue of behaviour supports we first need to understand:

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<sup>6</sup> For example, funding that was allocated for autism supports in the 2021-22 federal budget have minimal discernible outcomes for autistic Australians. The outcome reports from the government’s *Helping Children with Autism* program were completely inadequate.

1. How many autistic people (and non-autistic people) need what level and type of behaviour support, with mutually agreed outcome targets.
2. What the evidence tells us about effective behaviour support at each level and type of need.
3. How effective (and evidence-based) behaviour support is delivered for each level and type, including who is responsible.
4. Whether there is a workforce that can deliver the behaviour support required at each level and type, both in terms of quantity and quality.
5. How the required quality and quantity of behaviour support outcomes that are required will be monitored.
6. What will be done if the required quality and quantity are not achieved.

Then implementation progresses with strong commitment to proper *continuous improvement*.

A similar approach is required for each issue/challenge in the NAS.

## Conclusion

Revision of the National Autism Strategy is an enormous opportunity for improvement. The review above offers ample material.