



Making an effective National Autism Strategy

Sector expectations and
requirements

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Preface

Bob Buckley wrote this document quickly in response, especially to the draft Health Roadmap. However, it deals with issues for both the overall National Autism Strategy and the Health Roadmap for Autism.

The views expressed are Bob Buckley's views after having provided a summary numbered list of issues to the A4 Management Group for feedback.

Contents

Preface	1
Contents	2
Introduction	3
Essential components of a National Autism Strategy	3
1 Autism Recognition and Awareness	4
1.1 Autism as a distinct or separate disability type	4
1.2 Autism affirming ideology	4
1.3 Severe and profound autism	5
2 Mental health	5
2.1 Suicide prevention and treatment	5
2.2 General mental health with comorbid ASD	5
2.3 Lack of child psychiatry services	6
3 General Health and Autism	6
3.1 Autism experts say early intervention as essential	6
3.2 Autism Visitor Scheme	7
4 Health workforce	7
4.1 Capacity	7
4.2 Capability	7
4.3 Culture	8
4.4 Quality controls	9
5 Behaviour support	9
6 Measurement, monitoring and reporting	9
6.1 Baseline data	10
7 Autism Research	10
Conclusions	11

Introduction

Autism Aspergers Advocacy Australia (A4) expects the National Autism Strategy (NAS) and the Autism Health Roadmap (The Roadmap) currently being developed need to recognise and respect the expressed interests of Autistic Australians and their representatives.

The NAS and the Roadmap will fail unless they recognise, respect, and incorporate fully the expressed needs of the whole autism sector in Australia. This means that addressing diverse and sometime opposing expectations and needs so that all people's needs are met. The NAS must be for all, not for a majority of the autism sector or for the loudest voices.

Australian governments, both federal and state/territory, have histories of failing or refusing to recognise the autism as a growing challenge for the nation.

Since 1998, the Australian Bureau of Statistic (ABS) has repeatedly reported that the number of autistic Australians has been increasing rapidly (41.8% from 2018 to 2022, around 9% p.a.) – see <https://www.abs.gov.au/articles/autism-australia-2022>. Similar increases have been reported overseas¹.

However, when asked in 2011 the Department of Health advised Senate Estimates (see <https://a4.org.au/node/359>) that

The Department does not collect data on autism prevalence. The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia.

The Department of Social Services (or its pre-cursor) created the National Disability Strategy 2010-20 and Australia's Disability Strategy 2021-30 without proper reference to the autism sector. This repeated failure of governments in Australia to recognise the significance of autism is a primary reason why Australia now needs a National Autism Strategy.

The NDIA's Scheme Actuary has indicated that the NDIS has sustainability issues and problems because autism numbers have not "stabilised". From the outset, the NDIS rejected advice from the autism sector that their estimates of numbers and support needs for autistic NDIS participants was not based of the available evidence, advice and expertise from the autism sector. The NDIA has continued as it started, ignoring crucial information about autistic Australians and their support needs.

Increasing autism diagnosis rates are definitely a serious problem for governments in Australia (and the rest of the world), but ignoring persistently the evidence, advice, and lived experience from the autism sector is always an especially ineffective strategy.

Essential components of a National Autism Strategy

Following is a list of components/elements that A4 regards as essential in a National Autism Strategy. If any are missing from the NAS, then the NAS is incomplete.

There may be essential elements that A4 has not identified in the short time available to prepare this document.

¹ See <https://acamh.onlinelibrary.wiley.com/doi/10.1111/jcpp.13505> for UK or <https://www.cdc.gov/media/releases/2023/p0323-autism.html> for the USA.

1 Autism Recognition and Awareness

A properly developed NAS recognises autism as a distinct disability. Autism not a type of intellectual or psycho-social disability.

1.1 Autism as a distinct or separate disability type

The DSM-5 classified autism as a neuro-logical disorder with unknown aetiology. As yet, there are no known physical markers for autism; there is no blood test, or even genetic test for autism. Autism is diagnosed based on behaviour and is defined as being present from birth (or very soon after).

Government needs to recognise and treat autism as a distinct disability type.

The NDIS (and [its legislation](#) - see s32BA(3)) came up with 6 disability categories. Those categories do not include the areas of dysfunction directly associate with (required for) a DSM-5 or ICD-11 autism diagnosis. But these are the functional areas that the NDIS (and its legislation) dictate are the only areas relevant to the NDIS; the NDIS now ignores dysfunction in communication, social engagement/interaction or behaviour - these are not considered to be disability (needing NDIS support) anymore. Consequently, the health sector, especially those involved in diagnosis and assessment, need to be completely re-educated about how to report autistic disability so the NDIS can understand it and deal with it legally.

All government agencies and instrumentalities must recognise the whole autism spectrum and its diverse (and conflicting) needs. All autism-related support needs must be recognised and addressed. This includes recognition that people with severe and profound autism were under-represented, and possibly ignored, in the NAS consultation. In particular, so-called autism affirming ideology is not inclusive of the whole autism spectrum ... it is an essential aspect of a NAS but must not be an *exclusive* aspect of the strategy as it appears (to many) in the draft.

As indicated above, governments in Australia need to recognise and address the substantial growth in autism diagnosis rates. Before the start of the current millennium, there was already a severe shortage of trained clinicians and autism services & supports. The massive gaps in supports have only become substantially worse since then. This is a major issue for the allied health workforce (see below) - with timeliness of diagnosis, access to services, service quality (and outcomes measures), etc.

As well as timing, the NAS must address the cost of ASD diagnosis.

1.2 Autism affirming ideology

The latest draft versions of the NAS and the Roadmap emphasise “autism affirming” while avoiding the central issue that any and every DSM-5 or DSM-5-TR diagnosis indicates that the diagnosed person at least “needs support” in relation to Parts A and B of their ASD diagnosis.

Both documents fail to describe adequately what they mean by “autism affirming”. And the description that is gives is not what many in the autism sector understand it to mean. That aspect of the draft strategy and roadmap is confusing if not misleading.

Basically, “autism affirming” ideology is the ontological elimination of the concept of autistic dysfunction. It espouses the view that autism and autistic behaviour is entirely positive hence it should be affirmed. At its extreme, it regards challenging behaviour, absconding

and/or elopement, incontinence & pooh-smearing, pica, etc. as positive traits to be encouraged and respected.

A4 and its members regard many of the traits and characteristics of autistic and neurodivergent people as positives ... and very deserving of being affirmed. Often, a neurodivergent approach is superior to a neurotypical approach.

It is not clear how the positive aspects of neurodivergence intersect with autistic dysfunction ... or even if they do at all. This issue will divide the autism sector until there is agreement about what autism means beyond the DSM-5 and ICD-11 diagnostic criteria.

1.3 Severe and profound autism

A4 and others have expressed concern that the voices supporting people with severe or profound disability due to autism have not been heard and had their issues and concerns considered sufficiently. These are the people who often have the highest (in terms of cost and intensity) needs.

Representative of people in this category feel strongly that they are not heard. And the issues they raise are dismissed and ignored.

2 Mental health

Many autistic people report enormous difficulty accessing mental health services. Autism needs to be a priority in mental health.

2.1 Suicide prevention and treatment

The National Autism Strategy needs actions to prevent suicide & suicidal ideation, which is a particular concern due to the high prevalence of suicidal ideation among Autistic people and their carers. Considering that the draft National Suicide Prevention Strategy (<https://haveyoursay.mentalhealthcommission.gov.au/draft-advice-national-suicide-prevention-strategy%E2%80%AF>) doesn't even mention autism or Autistic people, I would encourage the Roadmap to explicitly mention the National Suicide Prevention Strategy — and would include an action to harmonise with the work of the National Suicide Prevention Office ('NSPO').

The omissions — about autism — on the side of the National Suicide Prevention Strategy are regrettable; the Health & Mental Health Roadmap for Autism must close these policy gaps.

2.2 General mental health with comorbid ASD

Autistic people often report that mental health services deny them the help they need.

It seems that mental health clinicians believe that because they cannot cure a person's autism then they cannot help autistic people. They do not consider the possibility that they can treat anxiety, depression, and other mental health conditions effectively in the context of a person's autism. This is an uninformed, erroneous, and prejudiced belief. It often denies autistic people mental health essential treatment for their comorbid mental health conditions.

2.3 Lack of child psychiatry services

Access to child psychiatry is limited generally. This lack of services is especially problematic for autistic children and teenagers.

The National Autism Strategy need specific actions to target and address this issue.

3 General Health and Autism

The National Autism Strategy and the Autism Health Roadmap should be recognised explicitly as part of [the Treasurer's overall government well-being initiative](#).

Health workers (and clinicians) need to better appreciate that family and carers mostly know their autistic relatives best; so, they need to be listened to and respected. The NAS must espouse a pro-active approach to changing the culture of people who work in the health sector.

The Health Roadmap fails to mention that the AIHW reported autism as the greatest *burden of disease* for boys aged 5-14 years – see <https://www.aihw.gov.au/reports/children-youth/health-of-children>. This is likely to be a substantial under-estimate of the impact of autism.

The health sector needs greater awareness and respect for the significance of autism in patient's lives.

3.1 Autism experts say early intervention as essential

Research indicates that children can have their autism reliably diagnosed by age 3 years. The NAS needs to recognise this research outcome.

Most expert advice in relation to autism regards early intervention for autism as essential.

Early intervention is easiest (cheapest and requires least effort) in early childhood taking advantage of brain plasticity.

As a results of a Labor election promise in 2007, the Australian government created 6 ASELCCs, one in each state, to spearhead good practice early intervention for autistic children in Australia. The NDIS's approach to early intervention supports close most of these, and those that are still operating are about to close.

NDIS planners with little or no training refuse to include evidence-based early intervention for young autistic NDIS participants in those participants' *Statement of Participant Supports*. Numerous AAT decisions said the evidence-based interventions requested satisfy s34(1) of the NDIS Act and therefore the AAT's decisions include those supports in the autistic participants' SOPs. The NDIS has not learned from this experience.

Non-clinical staff in the NDIS created [a cruel case management guide](#) that sends many of the most vulnerable autistic children into the slow, complex, traumatic and demeaning AAT process if they want to access evidence-based early intervention. [The CM Guide](#) was created without advice from or consultation with the wider autism sector; it was meant to be reviewed every six months but it has not been reviewed yet. The CM Guide says "The NDIA is likely to fund up to 20 hours per week of ABA therapy where it is considered likely to be effective and beneficial" but the NDIS sends other cases, such as [DRXK v NDIA](#) where the Applicant sought fewer than 20 hours of EIBI per week, to hearing anyway. This approach is contrary to Article 2 of the UNCRPD; it make it most difficult for the most severely autistic children to access the supports they most need.

The NAS needs to create better way to create and monitor good practice and evidence-based supports for autistic Australians generally.

A recent discussion of varied expert opinion and autistic voices on early intervention for autistic children is found here: <https://link.springer.com/article/10.1007/s11920-024-01552-x>

3.2 Autism Visitor Scheme

Some people in the autism sector, especially in relation to severe and profound autism, have suggested that the disability sector needs a Visitor Scheme for severely autistic adults. At least once each year, there should be an unscheduled and unannounced visit to each autistic adult to check on their health and wellbeing.

4 Health workforce

The health workforce needs major change in terms of capacity, capability and culture if it has any chance of improving outcomes for Autistic Australians.

4.1 Capacity

As indicated above, by the years 2000 the clinical workforce relevant to autism had substantial gaps; people were waiting extended periods to access diagnosis services. Even after getting an autism diagnosis, many autistic Australians are unable to access evidence-based clinical services because there were far too few trained clinicians. Psychiatry and psychology are areas of specific concern, but the whole allied health sector has substantial service gaps for autistic Australians.

Autism diagnosis rates are continuing to increase substantially but the number of trained clinicians is falling further behind. The workforce lacks the capacity (and growth) to meet growing demand for autism-related services.

Australian governments refuse to recognise this capacity problem. Until they recognise it, they will not even attempt to address it.

4.2 Capability

Much of the allied health workforce simply lacks the training, skill and experience they need to support autistic Australians.

For example, data from the NDIS shows clearly that increasingly autistic children are being first diagnosed with Developmental Delay (DD) or Global Developmental Delay (GDD). They are later diagnosed with Autism Spectrum Disorder ... which they had all along, but the clinician who gave their initial diagnosis lacked the skills to diagnoses ASD in a timely manner. but too late to access early intervention for their autism.

Many clinicians diagnose children with both ASD and DD (or GDD). The DSM-5 says the ASD diagnosis should be given instead of GDD ... but the ASD diagnosis can specify “with intellectual impairment” and/or “with language delay”.

Some of these children who are diagnosed (incorrectly) with both ASD and GDD/DD have the clinical attention focused on the GDD/DD rather than ASD. They miss out on the substantial benefits that are often achieved through evidence-based (best practice) early intervention for ASD.

Both DD and GDD have age limits under 7 years of age. After that, they are expected to be given a more permanent diagnosis (though the NDIS currently spends over \$400 million p.a. illegally on children aged over 6 years with primary disabilities of DD or GDD).

Some health and allied health workers and officials describe autistic adults has also having DD or GDD. This shows that they simply do not have adequate training or skills.

A4 has seen examples of

- a speech therapist providing an autistic child with a full and successful program for stuttering; successful because in the end the child was not stuttering. Treatment of stuttering is a very famous skill for speech therapists. In this case, the child didn't stutter at when he started the program. There was no change in the child's echolalia (which should probably be affirmed as functional neurodivergence that helps his language processing).
- an occupational therapist whose highest priority was the creation of a sensory garden for the patient ... but after two years of weekly treatment not one plant had been planted.

Most autistic children are provided regular generic speech and occupational therapy as central to their early intervention for their autism. While the NDIS, many academics, and clinicians regard eclectic, multi- or trans-disciplinary treatment/therapy as being best-practice for autistic children, none of the research reviews of early intervention for autistic children advise that generic speech and/or occupational therapy is evidence-based for autistic children. It lacks in tensivity; it is "treatment as usual" in the research and shows little or no benefit for autistic children.

Few allied health professionals in Australia are trained in evidence-based practice for early intervention for autistic children. Most of them have no idea how little they know.

Clinicians in Australia who treat autistic children need to be educated and practiced in evidence-based methods for autistic children.

The NDIS has not provided any evidence that generic speech and occupational therapies, so-called *treatment as usual* (TAU) for autistic children, are effective and value for money; they may be illegal under s34(1) of the NDIS Act.

Hopefully, the coming Foundational Supports will offer much more than generic allied health (TAU) with its poor outcomes reported in the research literature for autistic children.

The situation for behaviour support is far worse (as discussed below).

4.3 Culture

The health workforce perpetuates spectacularly ableist and elitist culture. This is dysfunctional and produces quite poor outcomes for both patients and the workforce itself throughout Australia's health systems.

This culture starts with the selection and training of workforce members. And persists through education and training into the whole of working life.

The health workforce and government bureaucrats need massive re-education; they need to develop respect for patients and their carers (who typically know their care-ees best). This respect needs to be an essential part of professional standards and service conduct. It needs to pervade the entire health, education, and mainstreams service settings.

4.4 Quality controls

The clinical workforce for autistic Australians needs far better oversight than it currently gets. While it's tempting to call for a punitive approach to failure, it is more important that the workforce is well educated and delivers effective services. An educative but firm approach may suffice.

5 Behaviour support

Behaviour support for autistic Australians is a major issue. Many behaviour support clinicians and workers need much more training and experience than they get.

Governments need to ensure behavioural clinicians are properly trained, experienced and registered. The Q&SC's current self-assessment approach where unsatisfactory behaviour support plans are handed to unsupervised often marginally literate support workers to implement was never likely to work.

Meanwhile, NDIS planners who have no idea about behaviour support now² make unreviewable planning decisions believing that the NDIS will not fund Applied Behaviour Analysis in any form.

This means that the NDIS chooses to deny funding for evidence-based practices and therapy approaches to autistic dysfunction including challenging & unwanted behaviours, incontinence (and poo smearing), absconding/elopement, pica, etc..

It will be a very long time before state/territory government can develop and deploy a workforce to implement behaviour support for autistic Australians as part of Foundational Supports. State implementation will vary. They have never been successful in the past which is why we first got *Helping Children with Autism* (HCWA) and then the NDIS.

6 Measurement, monitoring and reporting

While various government agencies provide some valuable data about autism, much more is needed. Currently, major sources of relevant data include:

- Published research
- ABS SDAC autism reports
- NDIS participant reporting
- MEDICARE diagnosis data
- DSS Carer Allowance data is available on request

[A report](#) based on some of this information was provided to the NAS Oversight Committee.

While the Health Department chooses to downplay the value of the ABS's SDAC reporting, it needs to appreciate that other data sources support those findings.

The NAS should reference the ABS SDAC data, including the latest reporting from its 2022 data collection.

² Due to the recent changes to the NDIS legislation.

The NDIS provides limited standard reporting on autistic NDIS participants. The NDIA is slow to delivery on data requests to A4 and some data requests are simply ignored.

So far, the much-anticipated National Disability Data Asset (NDDA) has not yet emerged. Unfortunately, its pilot/trial was not especially successful in relation to autism: see <https://a4.org.au/node/2499>. A4 observed that:

In its *Education to Employment test case*, the NDDA Pilot used data on South Australian (SA) school students; it reported that there were 1,704 autistic students (see Table 4). NDIS data shows there were 9,783 autistic NDIS participants in South Australia at 30/6/2022 aged 7 to 14 years whose autism was severe enough to warrant NDIS supports. We expect there are a number of autistic students who are not NDIS participants in SA's schools as well as a number of autistic children who cannot attend school.

There are many more school-age autistic students (and non-students) than the NDDA found in its test case. This does not bode well for the success of the NDDA.

The NDDA project told the disability sector that “The first results from [the National Disability Data Asset](#) (NDDA) will be available in 2024”³. This does not appear likely.

6.1 Baseline data

The NAS needs to collect baseline data as the foundation for progress reporting as the NAS gets underway.

The NAS must start by deciding what outcomes it will measure & report, and the steps required to establish baseline data to be used to report progress ... and who will be responsible for ensure the outcomes are measures and reported.

Outcomes are what happens in autistic Australians lives; they are not ticking boxes showing bits of money were spent.

7 Autism Research

Australia needs a properly resources autism research effort.

During the NDIS Review, we saw the head of the Melbourne Disability Institute running around the country asking why there are so many autistic children in the NDIS. He is the person who should have answered that; he should not have been asking the question.

The NDIS has an internal research section that is driven more by ideology, bureaucratic practice and financial expectations than it is by evidence.

There are too many basic questions that are not being researched, including:

- Which early intervention approaches best suit particular children (and how good are parents and families with choosing)?
- Can and should we standardise the DSM-5 severity levels?
- How cost effective are various supports for autistic Australians?
- Why are education systems delivering such abysmal outcomes for autistic Australians?
- What specific health outcomes do autistic Australians experience?

³ See <https://www.ndda.gov.au/faq/>

Conclusions

A4 is concerned that the National Autism Strategy (NAS) and the Autism Health Roadmap (The Roadmap) are underdeveloped given that they will soon be sent for Ministerial approval.

Australia needs a comprehensive National Autism Strategy. The above material aims to identify most of the issues that the strategy needs to have addressed. It was prepared in haste so it may not be complete.

Please feel free to contact A4 if you have any questions or concerns about the content, suggestions, and issues raised.