

Lessons learnt

for an Australian National Autism Strategy

"Those who cannot learn from history are doomed to repeat it."
George Santayana



Autism Aspergers Advocacy Australia

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Preface

Autism Asperger Advocacy Australia, known as A4, appreciates the opportunity to bring some initial material to the development of Australia’s National Autism Strategy (NAS). A4 prepared the following brief for the NAS Oversight Committee and its Working Groups.

The Australian Autism Alliance (the Alliance) is providing a separate brief to the NAS Oversight Committee that includes a “stakeholder mapping” describing Australia’s autism sector, and other pertinent information.

The following brief aims to outline issues and tries not to deliver conclusions. That is the task of the NAS Oversight Committee and its Working Groups.

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 a member of:

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

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Contents

Preface	i
Introduction	1
What is “autism”?	2
Autism is a distinct disability	3
Senate Inquiry	4
A National Autism Strategy for Australia	5
International experience.....	6
Behaviour science and autism	6
Australian experiences of autism strategies and plans.....	6
National.....	6
State level plans & strategies	9
Victoria's Autism Plan	9
South Australia’s Autism Strategy	11
ACT – autism abandoned.	11
Lessons from Intellectual Disability	12
General Lessons	13
What doesn’t work	13
What works	13
Conclusion	14
Annex A. List of Lessons Learnt	15
Annex B. A4’s suggestion on terminology.....	16
Annex C. Senate Autism Review Recommendations	19
Annex D. Autism in the NDS 2010-20	23
NDS 2010-20	23
ADS 2021-31	24

Lessons Learnt

Introduction

The Australian Bureau of Statistics (ABS) estimates that there were:

- 13,200 Autistic Australians¹ in 1998, and the estimate grew to
- 205,200 Autistic Australians² in 2018.

The 15-fold increase in the number of people diagnosed with Autism Spectrum Disorder (ASD) over 20 years needs to be recognised and addressed; this substantial increase in the number of autistic people needs serious attention from government at all levels.

The following material aims to help Australia's National Autism Strategy (NAS) Oversight Committee and its working groups hit the ground running. It brings together some of the available information.

Reasons for having a NAS include:

- Autistic Australians need substantially improved life outcomes, and
- the [Senate Select Committee on Autism inquiry recommended](#) “that the Australian Government develop a National Autism Strategy”.

As [the government's NAS webpage](#) says, “People within the autistic community have called for a dedicated National Autism Strategy.” The website recognises reasons that include:

- “For many autistic people life outcomes in education, vocation, health and family functioning continue are worse than they should be.
- “There is a 20-year gap in life expectancy compared with the general population.
- “Autistic people are also around 7 times more likely to be unemployed than people without disability, and they have a higher risk of homelessness.”

Life outcomes for Autistic Australians are significantly worse than is acceptable. There are issues specific to autism that need particular attention.

While the NAS must identify issues that particularly affect Autistic Australians, its development is likely to inform government about some issues that go beyond Autistic Australians. The development process should inform some aspects of policy, strategy, and programs in ways that benefit all Australians with Disability (AwD), not just Autistic Australians.

¹ https://a4.org.au/sites/default/files/buckley_prevalence_2004.pdf

² <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia>

What is “autism”?

Autism is a complex subject – the simple terminology that is often used is unclear.

[The South Australian Autism Strategy Discussion Paper](#) collects most of the descriptions of “autism” used in Australia. But only ASD has diagnostic criteria.

There is no clear definition of “autism”. **Error! Reference source not found.: Error! Reference source not found. Error! Reference source not found.** promotes the use of the terms *Autism Spectrum Condition* (ASC), possibly abbreviated to “autism”, for the broader spectrum. And *Autism Spectrum Disorder* (ASD) for a subgroup of autistic people who need support in both Parts A & B of the formal diagnostic criteria, where the term “disability” relates to an autistic person’s support needs.

A recent paper³ said:

Autism Spectrum Condition (ASC) is a neurodevelopmental condition that causes anatomical and functional differences in the brain, resulting in difficulties in social communication, repetitive behaviours, and restricted interests (Hadjikhani 2014). The definition of autism historically focused on deficits. Neurodiversity is an emerging term that moves away from a focus on deficit to a focus on neurological differences (Zolyomi and Tennis 2017). This model views [Autistic] disability as being caused by the failures of the environment to accommodate the autistic person’s needs (den Houting 2018), and recognises that autism is also associated with strengths, particularly in the areas of attention to, and memory for, detail and a strong drive to detect patterns (Baron-Cohen 2017).

There are no agreed criteria for ASC but that may not be an issue if there are not resources or support needs tied to the term.

The DSM-5, that describes formal diagnostic criteria for Autism Spectrum Disorder (ASD), is a manual of “mental disorders”. Clearly, this is a deficits and medical perspective.

Historically, “autism” was regarded as a rare and severely debilitating condition.

More recently, the terms “autistic” and ASC encompasses a much broader spectrum of conditions or differences extending beyond “disability”. Many more people are now described as Autistic than was the case in the past.

There is a risk that people who are severely disabled by their autism, who need substantial or constant support, can be forgotten as they are unable to speak up for themselves. Too often, their absence and lack of voice or participation in Autistic conversations is forgotten, un-noted.

³ Jones, S.C., Akram, M., Gordon, C.S. *et al.* Autism in Australia: Community Knowledge and Autistic People’s Experiences. *J Autism Dev Disord* **51**, 3677–3689 (2021). <https://doi.org/10.1007/s10803-020-04819-3>

Lesson 1. To be effective, a National Autism Strategy must recognise and respect the whole autism spectrum; it must deliver a spectrum of strategy that matches the heterogeneous Autistic population it aims to support.

Autism is a distinct disability

What follows in this report is based on the view that Autism Spectrum Disorder (ASD) means a person has an Autism Spectrum Condition (ASC, or autism in short) and needs support for both Part A and Part B of their DSM-5 diagnosis.

Many Autistic Australians would like the National Autism Strategy to recognise and promote ASC as a distinct condition. Government and the community generally should:

- Recognise that ASC is a distinct neuro-logical difference,
- Appreciate that autistic neurology has a spectrum of functioning at the individual level that aspects of autism vary from beneficial or advantageous to disabling or debilitating,
- Accept that increased “autism awareness” results in increasing recognition and diagnoses. There may also be other reasons contributing to increasing ASC numbers.
- Understand that ASC is not a type (nor subtype⁴) of intellectual disability or mental illness.
- Know ASC often co-occurs (and interacts) with other conditions; often resulting complex presentation.

“Autism” is not as a type of Intellectual Disability (ID) or mental illness. Many people in the health sector believe “70% of autistic people have an intellectual disability”. Apparently, they also think that addressing the needs of people with intellectual disability will “solve” the problem for the 70% of autistic people with ID ... and the other 30% don’t matter as they *only* have “autism”.

More recent data indicates that currently 25-35% of autistic people have an intellectual disability.

Both the DSM-5 and the ICD-11 treat ASD as a primary disability; they ask that the diagnostic report for ASD also indicate *with/without ID*. The DSM-IV put PDDs on Axis I, while ID (then called Mental Retardation) was on Axis II. Clearly, the authors of those diagnostic criteria regard ASD as distinct from ID.

ASD is also distinct in that it is a disability with increasing diagnoses as a proportion of the population. Most other disability types have a stable or decreasing proportion of the population.

⁴ The DSM-5 says ASD with two severity rankings, with or without IT, with or without language delay, etc. The DSM-IV had PDD (including autism, Asperger’s and PDD-NOS) on Axis I while ID was on Axis II.

Senate Inquiry

[The Senate Select Committee on Autism Inquiry report \(March 2022\)](#)

executive summary says:

Life outcomes for autistic Australians are unacceptably poor. This comes at an enormous personal, social and economic cost.

Meaningful systemic changes would have an enormous impact, with instances of good practice demonstrating how this can be achieved.

The drivers of poor outcomes for autistic people are complex and interrelated.

Generic disability strategies have proven ineffective at improving life outcomes for autistic people.

A National Autism Strategy should form the centrepiece of efforts to improve outcomes for autistic Australians.

The National Autism Strategy should be person and family-centred, address whole-of-life needs for all autistic people, and include targeted actions to support vulnerable cohorts.

The National Autism Strategy should be co-designed by the autism community.

Accountability will be critical to delivering genuine change.

Key priorities for the National Autism Strategy should be guided by the recommendations of this inquiry.

The effectiveness of the National Disability Insurance Scheme for autistic Australians should be the focus of a separate inquiry.

The Inquiry's report motivates a National Autism Strategy and includes 81 recommendations.

Senate Autism Review Recommendations below suggests how responsibility for the Inquiry's recommendation might be assigned to the NAS's four main working groups.

A National Autism Strategy for Australia

[The Government's webpage on the National Autism Strategy](#) says:

There is a growing number of Australians on the autism spectrum and with other neurodevelopmental conditions. For many autistic people life outcomes in education, vocation, health and family functioning continue are worse than they should be.

There is a 20-year gap in life expectancy compared with the general population.

Autistic people are also around 7 times more likely to be unemployed than people without disability, and they have a higher risk of homelessness.

People within the autistic community have called for a dedicated National Autism Strategy.

A National Autism Strategy will improve life outcomes for all autistic people in Australia. It will provide, for the first time, a coordinated national approach to services and supports for autistic

The overall problem, or challenge, for the National Autism Strategy is to deliver increasing and lasting improvement in life outcomes, well-being, health, social and economic/financial participation, etc. for all Autistic people in Australia.

Government interest in a National Autism Strategy may be due mostly to autism now being the most numerous primary disability type in the innovative National Disability Insurance Scheme, a development that was unanticipated when the Scheme was conceived. The Productivity Commission's initial report said that it expected 9% of Australians with profound disability were autistic. In 2018, the NDIA told Senate Estimates that it expected the level Autistic NDIS participants would decrease from 28% of NDIS participants to around 20% at full scheme roll-out, but instead Autistic participants increased to 35% at this time.

Reports⁵ from the Australian Bureau of Statistics (ABS) series of [Surveys of Disability, Ageing, and Carers \(SDACs\)](#) indicate repeatedly that Autistic Australians have especially poor outcomes in education, employment, life, etc. These indicators provide a possible starting point for creating Australia's National Autism Strategy.

Development of an effective strategy is a major challenge as it has not been done before. While it will not be cheap, it is likely that it can be achieved through redeploying existing funds, but targeting them better at delivering substantially improved outcomes for Autistic Australians in their diverse settings and needs.

⁵ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia>

International experience

There are two reports on Autism plans, strategies, and programs from overseas. They are reports:

1. from Amaze, a member of the Alliance.
2. prepared with A4 by the [Global Consulting Group](#).

The summary of, and lessons learnt from, these reports are:

Lesson 2. Autism is a problem elsewhere, not just in Australia.

Lesson 3. Others have not solved the problems yet ... it's difficult (a wicked problem, no easy answers). This means that expecting "a complete solution" is unreasonable, unachievable ... but substantially better outcomes for everyone are achievable.

Lesson 4. Experience suggests outcomes are better realised when autism is better defined/understood, and the rights of Autistic people are recognised and respected.

Lesson 5. The autism spectrum needs a spectrum of responses, strategies, policies, and programs across most areas of government to achieve equitable outcomes for Autistic people.

Lesson 6. Better outcomes need serious effort and money.

Behaviour science and autism

The role of behaviour science in services and supports for autistic people is perhaps the most challenging and contentious subject for Australia's National Autism Strategy. The subject is usually ignored in government strategies and plans, especially outside the USA.

A4 was not asked to address it in this document but we believe that the issue needs to be on the agenda for the NAS.

Australian experiences of autism strategies and plans

"We learn from history that we learn nothing from history."

George Bernard Shaw

"We spend a great deal of time studying history, which, let's face it, is mostly the history of stupidity."

Stephen Hawking

National

A4 is optimistic that the National Autism Strategy will make positive steps for the autism sector in Australia.

The previous experience of the autism sector in relation to government policy and programs is mostly negative. We observe that the current position results from repeated and frequent failure.

- The *Helping Children with Autism* package (HCWA, 2007) was a substantial step forward, but it was under-funded. At the start, the PM of the day told the autism sector that HCWA was “just a beginning for autism”, but the follow-up, the Better Start program, had nothing to do with autism.
The final report on HCWA⁶ contains 34 recommendations. There was no discernible action on any of them. Australia *dropped the ball* on autism.
The HCWA package lacked a review process and resilience.
- The National Disability Insurance Scheme (NDIS, 2013) has so far, after 10 years of operation, failed to appreciate the need for an autism-specific response despite “autism” having surprisingly (for the NDIA) emerged as the most numerous primary disability type in the Scheme. The NDIS experience so far shows governments have difficulty getting disability strategy, policy, and programs to work effectively. And autism is an especially challenging part of the disability landscape.
- While health sector may recognise ID occasionally, autism is mostly ignored or avoided. For example, the Department of Health and Ageing created a national Health Roadmap for Intellectual Disability without any reference to autism. The impact of the widely held misconception in the health sector of 70% autism co-occurrence with ID (see *The DSM-5, that describes formal diagnostic criteria for Autism Spectrum Disorder (ASD)*, is a manual of “mental disorders”. Clearly, this is a deficits and medical perspective.

Historically, “autism” was regarded as a rare and severely debilitating condition.

More recently, the terms “autistic” and ASC encompasses a much broader spectrum of conditions or differences extending beyond “disability”. Many more people are now described as Autistic than was the case in the past.

There is a risk that people who are severely disabled by their autism, who need substantial or constant support, can be forgotten as they are unable to speak up for themselves. Too often, their absence and lack of voice or participation in Autistic conversations is forgotten, un-noted.

Lesson 7. To be effective, a National Autism Strategy must recognise and respect the whole autism spectrum; it must deliver a spectrum of strategy that matches the heterogeneous Autistic population it aims to support.

- Autism is a distinct disability above), is enormous and disappointing.
- For more than a decade, the ABS SDAC has been reporting abysmal employment and education outcomes for Autistic Australians yet little or nothing was done.

⁶ ARTD Consultants, *Evaluation of the Helping Children with Autism Package (FaHCSIA components)*, Technical report, FaHCSIA (27 January 2012).
https://www.dss.gov.au/sites/default/files/documents/10_2014/hcwa_technical_report.pdf

- Australia’s refusal to develop a meaning approach to clinical practice standards or professional registration relating to behavioural supports⁷ continues.

Lesson 8. An effective National Autism Strategy needs to be:

- a. Resilient, robust and effective – safe and protected from bureaucratic erosion.
- b. Reviewed formally and regularly (at least bi-annually)

General disability programs and policy usually ignore autism, or at least trivialise autism.

The National Disability Strategy 2010-20 (NDS, see *Annex D. Autism in the NDS 2010-20* below) cited HCWA and claimed there were 8 ASELCS – when there were only ever 6 of them. The NDIS abolished HCWA and few of the ASELCS survived their transition to the NDIS. These autism-specific programs did not survive bureaucratic and political review processes. They were not resilient.

Australia's Disability Strategy 2021-31 (ADS), the successor of the NDS, did not adequately address the need of Autistic Australians ADS. Despite the emergence of “autism” as the most numerous primary disability type in the NDIS, the only mention of “autism” in the ADS 2021-31 (see *Annex D. Autism in the NDS 2010-20* below) is the final add-on in a list of disability types that warrant consideration for built and natural environment. The many other priorities for Autistic Australians did not rate mention.

The National Disability Data Asset has yet to properly validate data relating to Autistic Australians. The [test cases](#) for the developing National Disability Data Asset (NDDA) do not inspire confidence.

- Incredibly, the *Early Childhood Supports in NSW* test case does not mention autism or autistic at all. It does refer to “intellectual/learning” and “psychosocial” disability.
- The *NDDA Pilot - South Australian Test Case: Education to Employment* test case mentions autism/autistic and Asperger’s disorder together. It reports (Table 3) that there are 2,107 students with Autistic/Asperger’s disorder in contained in the Department of Education data, or (Table 4) that there are 1,704 students in the DSNMDS data with autism. NDIS data indicates there were 9,243 NDIS participants with autism as their primary disability aged 7 to 14

⁷ See <https://a4.org.au/node/1071>, <https://www.policyforum.net/policy-needs-of-autistic-australians-must-be-met/> also published in Fairfax papers: <https://www.canberratimes.com.au/comment/behavioural-needs-of-autistic-australians-must-be-met-20151023-gkhark>, <https://www.brisbanetimes.com.au/comment/behavioural-needs-of-autistic-australians-must-be-met-20151023-gkhark>, <https://www.theage.com.au/comment/behavioural-needs-of-autistic-australians-must-be-met-20151023-gkhark>, <https://www.watoday.com.au/comment/behavioural-needs-of-autistic-australians-must-be-met-20151023-gkhark> and <https://www.smh.com.au/comment/behavioural-needs-of-autistic-australians-must-be-met-20151023-gkhark>

years (and 2,734 more aged 15 to 18 years) in South Australia in December 2021. It seems that the NDDA only found about 1 in 5 autistic students ... and didn't notice that there was an issue with the result.

- Figure 5 in the *Services and supports used by people with disability and mental illness/psychological distress in Victoria* test case seems very much at odds with other reports of the mental health of Autistic people.
- The other two NDDA test cases do not even mention Autistic people.

Clearly, the NDDA will need to do far better than this if it is to have any prospect of supporting a National Autism Strategy.

The NDDA will need financial and economic data in addition to the data that it is already planning to incorporate.

The NDIS *could* become a key element of Australia's National Autism Strategy as it is well funded compared to overseas attempts provide equitable outcomes for Autistic citizens, but:

- the NDIS needs to recognise ASD as a distinct disability that needs ASD-specific responses; and
- major commitment is needed beyond the boundaries of the NDIS⁸.

The 2021-22 Federal Budget provided mental health funding for autistic people.

https://archive.budget.gov.au/2021-22/bp2/download/bp2_2021-22.pdf

Supporting the Vulnerable

- ...
- \$11.1 million over two years from 2021-22 to improve outcomes for people with complex mental health needs including people with cognitive disabilities and autism spectrum disorder.

The autism sector awaits the outcomes.

State level plans & strategies

Several state level plans and activities are discussed below.

- [Victoria's Autism Plan](#)
- [South Australia's Autism Strategy](#)
- The ACT's response to its Health Ministers review request.

Other states have shown interests in autism, but time limits A4's ability to report on these here.

⁸ The NDIS cannot be "the only lifeboat in the ocean" – see <https://www.abc.net.au/news/2023-05-10/ndis-eligibility-disability-services-bill-shorten/102326822> and many other reports.

Victoria's Autism Plan

The Victoria's former Department of Health and Human Services has [a webpage for the Victorian Autism Plan](#). It says:

The Victorian Government is developing an autism plan to better support people with autism, which will include short, medium and long-term actions over five years.

The plan is a key commitment from [Victoria's response to the Parliamentary Inquiry into Services for People with Autism Spectrum Disorder](#), which made 101 recommendations to improve supports, services and inclusion for people with autism.

[The Inquiry into services for people with Autism Spectrum Disorder Final Report](#) (June 2017) says (p252):

It is also anticipated that not all children who access early intervention services under the NDIS will require a funded package once they are adults. This is in line with emerging research on early intervention, which affirms that it can reduce ongoing health care, social and economic costs associated with ASD, and improve an individual's ability to participate in the mainstream. In terms of national guidelines for early childhood intervention, the early childhood intervention sector has produced its own set of national guidelines following industry and workshop consultations.⁹³⁹ Recent research commissioned by the NDIS has critically evaluated the effectiveness of different therapies for children with ASD.⁹⁴⁰ ...

⁹³⁹ See Early Childhood Intervention Australia, 'National Guidelines – Best Practice in Early Childhood Intervention', ECIA, accessed 12 April 2017, <www.ecia.org.au/resources/best-practice-guidelines>⁹.

⁹⁴⁰ J Roberts and K Williams, Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers, 2016, accessed 27 April 2017, <www.ndis.gov.au/html/sites/default/files/Early%20Intervention%20for%20Autism%20research%20report.pdf>¹⁰.

Note that the ECIA Guidelines referenced above have limited relevance for autistic children. The only mention of autism in the Guidelines says:

The role of direct intervention by specific professionals

In addition to the body of evidence for the ECI sector there are also other bodies of evidence that suggest specific intervention for children with specific needs, such as ... autism spectrum disorder that lead to improvement in childhood development and skill development.

While the Guidelines mention “other bodies of evidence” for autism, they do not reference any specific evidence. It is not clear what evidence they mean.

⁹ Now available at <https://www.eciavic.org.au/documents/item/1419>

¹⁰ The link to this document is now <https://www.ndis.gov.au/media/863/download>

Basically, this means that the ECIA Guidelines are largely irrelevant for autistic children.

In practice, all the NDIA's internal reviews of NDIS Plans relating to early intervention for young autistic NDIS participants, that A4 has seen, show that the NDIA's internal reviewers referred to the ECIA Guidelines but ignored the autism-specific “research commissioned by the NDIS [that] critically evaluated the effectiveness of different therapies for children with ASD”.

In matters before the AAT, the NDIA contests vigorously¹¹ the “other bodies of evidence” for autism and the advice Roberts & Williams (2016) provided to the NDIA.

What the NDIS offers for autistic children is not what the Victorian government assumes. The Vic. government really needs to check up on their expectation; it should not rely on assumptions.

Lesson 9. Assumption is the father of the greatest f**k-ups.

A recent commentary, [*Opportunity Autism: Next Steps for Victorian Autism Policy*](#) (June 2022), does not indicate much progress. Most of the reporting relies on data collected in 2018 (which is a long time ago in relation to autism data). It provides little or no evidence of progress.

Perhaps a major part of the problem is the lack of whole-of-government commitment. Autism is not mentioned in Victorian budgets; this is a sign that Victorian treasury and finance departments are not on board with Victoria's Autism Plan. There is no discernible financial commitment nor reporting requirement from the plan.

These are the same issues as are identified above in relation to strategies and plans from overseas.

South Australia's Autism Strategy

South Australia's government has embarked on creating its first Autism Strategy and Charter.

The initial focus seems to be in diagnosis and education.

In the past, South Australia appeared to have one of the most comprehensive and reliable diagnostic services in the country.

More recently, the NDDA used SA data for one of its *NDDA Pilot - South Australian Test Case: Education to Employment* test case. A4 does not consider the pilot test case to have been a success in its data reporting in this instance (see above). It seems A4 disagrees with the NDDA team on this.

The webpage for SA's Autism Strategy (see <https://autismstrategy.sa.gov.au/>) appears to be a pseudonym for a page on the more generic disability site (see <https://inclusive.sa.gov.au/have-your-say/autismstrategy>). SA's autism sector needs to be wary of this approach; the needs of Autistic people usually

¹¹ so far, without success at hearing in matters relating to preschool-age children.

disappear whenever governments fail to recognise autism as a specific disability and deliver specific services and supports for Autistics.

ACT – autism abandoned.

In 2018, the ACT Health Minister asked his department to review health services, including mental health services, for people with either (or both) intellectual disability or autism.

[The record](#) shows that the ACT Health Department responded by setting up a *Mental Health Services for People with Intellectual Disability Working Group*. It ignored autism.

It seems that ACT Health, like much of Australia’s health service sector, believed that

"The majority of people identified with autism spectrum disorder also have an intellectual disability (about 70%), group advised it would be appropriate to address these groups within this strategy."

It seems that this misbelief justifies ACT Health’s ignoring the distinct autism-related need of Autistic Canberrans; they only recognised intellectual disability.

Subsequent discussion with officials and politicians delivered various promises and commitments ... but no progress. No doubt COVID-19 is their excuse.

The ACT has a poor track record in disability-related issues. The ACT government’s response to its [Board of Inquiry into Disability Services](#) (the Gallop Report) was to defend its officials, who were described as “unreliable witnesses”, instead of responding properly to the Inquiry findings. There is a strong lesson in that experience.

Lessons from Intellectual Disability

Repeatedly, Australian governments had been told about especially poor health, well-being, and life outcomes for Australians with Intellectual Disability. The Burdekin Report (1993)¹² is an example: it described “dual diagnosis”¹³ as intellectual disability and mental illness.

Various services were set up in response to the Burdekin Report, but it is hard to find them now. The processes of government and bureaucracy has left most of the services created in response to the Burdekin Report in ruins or barely in existence.

Apparently, neither [the Victorian Dual Disability Service](#) nor the [ACT Mental Health Service for People with Intellectual Disability](#) had even the resources to mention COVID on their webpages.

¹² B. Burdekin (1993), *National inquiry into the human rights of people with mental illness*, <https://humanrights.gov.au/about/news/speeches/burdekin-national-inquiry>

¹³ More recently, the term “dual disability” seems to have emerged.

Lesson 10. An effective National Autism Strategy needs protection from the processes of government and bureaucracy; it needs to be resilient.

The ACT service on its webpages says:

Our Mental Health Service for People with Intellectual Disability provides assessment and treatment to people with a known or suspected intellectual disability and a known or suspected mental illness/disorder, including Autism Spectrum Disorder.

Autism is a neurological disorder/difference, not a mental illness. Some people have autism (with/without ID) and mental illness.

Now that most Autistic people do not have intellectual disability, this leaves autistic people without ID but with mental illness unable to access ACT mental health services.

Building services that cater for specific combinations of mental illness and disability simply will not meet the needs. Some combinations of co-occurrent health and disability conditions will always be left out in that approach.

Lesson 11. Australia's health system needs to be *inclusive of AwD*. Health services should observe the education sector's *Inclusion* attempts and learn from their successes (and avoid their failures). Successful health services for AwD will also need substantially improved autism-specific expertise.

Surely, no one is surprised that the part of the mental health system that is meant to support people with co-occurring mental illness and intellectual disability is under-resourced when the mental health sector generally is struggling.

General Lessons

To be successful, a National Autism Strategy needs to be modelled on other successful government strategies and programs. Unfortunately, there are relatively few models for success in the disability sector. We need to look elsewhere.

What doesn't work

In recent time, government policy is to operate as close to the brink of disaster as possible. Recently, this seems to have been tested by stressors like COVID-19 and climate change. Areas of government like disability, aged care, veteran's affairs, land & water management, education, early childhood, employment, health (especially mental health), transport, energy, etc. struggle.

Government in Australia usually asks for solutions in its consultations. Politicians and government officials are keen to rush to implement "solutions" before they properly understand the problem.

Many people suggest that we need more data about autism (or disability more generally) to properly understand the problem.

A4 argues that before getting more data, government needs to show that it can use properly the data it already has. The ABS SDAC data has described outcomes for Autistic Australians since 2006. However, governments (state/territory and federal), the Productivity Commission and the NDIA ignored these data that showed:

- autism numbers increasing substantially, and
- especially poor education and employment outcomes.

The NDDA did not validate the results that it got in its pilot test cases.

Lesson 12. Ignoring data and other evidence does not work.

What works

A4 suggests that we need to look beyond the disability sector for examples of successful and relevant strategies. As indicated above, successful strategies rely on evidence.

Understanding of a problem depends on good data. So far, the NDIA has failed abysmally in its understanding of autism which is the reason for many of its current problems.

NDDA didn't understand the problem sufficiently and didn't check its results.

Creating an effective NAS for Australia will depend on developing and maintaining real autism expertise to create and sustain the NAS.

An effective strategy:

- has both an Inclusive approach that integrates services and support within the mainstream whenever that can be made to work successfully.
- will recognise autism as a distinct neurology that needs specific services that are different from other disability services. There must be a clear understanding that autism is not the same as, or a subtype of, intellectual disability ... though the two often co-occur, and need to be addressed in combination.
- is resilient and sustained through entrenched commitment with strong monitoring, reporting, and accountability for positive outcomes.

The National Agreement on Closing the Gap, although it has yet to solve the problems, it appears to have the resilience and accountability needed to deliver outcomes in the long term. Notably, it has annual reporting to parliament with consequent annual debate.

Australia's NAS could entrench parliamentary reporting World Autism Day (2nd April each year).

Key indicators of success will include improved well-being and employment outcomes for Autistic Australians. Well-being outcomes stand on health and

accommodation outcomes. Employment outcomes rely on education outcomes.

Conclusion

The development of a National Autism Strategy, done well, is a major task. The above material is intended as initial food for thought.

An effective National Autism Strategy needs:

- Whole-of-government commitment and Funding
- Comprehensive coverage of all the challenges relating to all Autistic Australians.
- Longevity and resilience of outcomes.

A4 is available to comment further on the issues raised above, or on anything we missed in this quick introductory scan.

On behalf of the autism sector, A4 wishes the Oversight Committee and its Working Groups every success in this endeavour.

Annex A. List of Lessons Learnt

- Lesson 1. To be effective, a National Autism Strategy must recognise and respect the whole autism spectrum; it must deliver a spectrum of strategy that matches the heterogeneous Autistic population it aims to support.
- Lesson 2. Autism is a problem elsewhere, not just in Australia.
- Lesson 3. Others have not solved the problems yet ... it's difficult (a wicked problem, no easy answers). This means that expecting "a complete solution" is unreasonable, unachievable ... but substantially better outcomes for everyone are achievable.
- Lesson 4. Experience suggests outcomes are better realised when autism is better defined/understood, and the rights of Autistic people are recognised and respected.
- Lesson 5. The autism spectrum needs a spectrum of responses, strategies, policies, and programs across most areas of government to achieve equitable outcomes for Autistic people.
- Lesson 6. Better outcomes need serious effort and money.
- Lesson 7. An effective National Autism Strategy needs to be:
 - a. Resilient, robust and effective – safe and protected from bureaucratic erosion.
 - b. Reviewed formally and regularly (at least bi-annually)
- Lesson 8. Assumption is the father of the greatest f**k-ups.
- Lesson 9. An effective National Autism Strategy needs protection from the processes of government and bureaucracy; it needs to be resilient.
- Lesson 10. Australia's health system needs to be inclusive of AwD. Health services should observe the education sector's Inclusion attempts and learn from their successes (and avoid their failures). Successful health services for AwD will also need substantially improved autism-specific expertise.
- Lesson 11. Ignoring data and other evidence does not work.

Annex B.A4's suggestion on terminology

A proposal from A4 on language around autism

Terminology issues arising in the autism sector include:

- identity-first vs person-first language; and
- the disorder vs condition debate.

Paul Micallef explains the identity- vs person-first language issue well at <https://www.youtube.com/watch?v=RpRhgfRfXBM>. As we understand it, more autistic people who express an opinion on the issue indicate that they prefer identity-first language. They prefer “autistic person” over “person with autism”¹⁴. Preferences vary, and the individual preference and context should be used as guidance.

Perhaps the wise approach is to use personal preference when known, otherwise assume identity-first is more often preferred.

The main point of this note is the *disorder vs condition* debate.

Current use of the term “autism” is unclear: some people mean Autism Spectrum Disorder (ASD), some mean Autism Spectrum Condition (ASC), and some are less specific as to what they mean. Briefly, the origin and meaning of some terms are:

- *Autism Spectrum Disorder* (ASD) – is the name used in the DSM-5 and the ICD-11. These are a medical model diagnostic with diagnostic criteria ... that include “needs support” in relation to parts A & B of the diagnosis.
- *Autism Spectrum Condition* (ASC) – substituting “condition” (for “disorder”) thereby indicating that the autism spectrum broader than just “disorder”. [Wikipedia says](#) some people “see autism as part of [neurodiversity](#), the natural diversity in human thinking and experience, with strengths, differences, and weaknesses. From this point of view, autistic people often still have a disability, but need to be accommodated, rather than cured. This perspective has led to significant controversy among those who are autistic alongside advocates, practitioners, and charities.”

Regrettably, the controversy is increasingly divisive: as discussed [in the Washington Post](#) and elsewhere.

Over the past two decades, as the autism spectrum has broadened to include those with milder traits, this fight has flared into an all-out war that plays out online and in person.

Many autistic people prefer the term Autism Spectrum Condition (ASC) over Autism Spectrum Disorder (ASD). They prefer “condition” rather than “disorder”. S. Baron-Cohen said (14/5/2015) that “the term ‘disorder’ (not just

¹⁴ I'm told that many deaf people feel very much the same way.

for autism but for any atypical behaviour), but that word may be a legacy from an earlier period in the history of psychiatry”¹⁵. He says that:

- “condition’ is a less hard-hitting and more respectful concept”; and
- “whether we opt for ASD vs. ASC, it should not affect insurance cover”.

Some people say that they are autistic but, rather than needing support, they need “acceptance”, “accommodation”, and/or “awareness”. They can function effectively in inclusive environments with “accommodations” and respect for (appreciation of) their difference. They regard their autism as a condition that is just part of their nature, not a disorder.

A4 is also aware that *being functional* certainly does not require/expect being *normal* (whatever people think that means). Most autistic people *function differently* in many respects without being disordered or dysfunctional. The emerging terms, neurodiversity-affirming, neuro-affirming, or neuro-nurturing can be used to label this approach.

A4 accepts the argument that “autism” is broader than “disorder”. For some autistic people, perceptions of “disorder” can be due more to unsatisfactory, inappropriate, unsupportive, or disorder environments than to the person’s *differences*.

On the other hand, some advocates argue that adopting ASC terminology hides the impact of severe or profound autism. They suggest that ASC omits the extremely serious impact of autism on those who most severely affected.

The challenge with using the broader term, ASC, is that there are no accepted criteria as the basis for diagnosis.

At the same time, A4 recognises that some autistic people need help, even therapy, to learn to function *effectively* in their environments.

Some autistic people need supports.

Whitehouse discusses the issue of creating/introducing a “profound autism” term [here](#). [A recent article](#) cites some data. You can google “profound autism” to see numerous articles on the subject.

A4’s suggestion is that both terms, Autism Spectrum Condition (ASC) and Autism Spectrum Disorder (ASD), be used intentionally to describe all or part of the autism spectrum respectively.

A4’s suggests that, rather than *replace* the ASD term with ASC, we use ASC more broadly to include people whose condition is mitigated through awareness, acceptance and accommodation, and restrict ASD terminology to situations where disability support is essential, where disability cannot be mitigated through external (social and environmental) accommodations. *Both* terms are required.

¹⁵ <https://insar.confex.com/imfar/2015/webprogram/Paper19861.html>

And the word “autism” or the phrase “autism spectrum” mean ASC; they have the less specific, less medicalised, meaning. Basically, “disorder” relates essentially to “needs support”¹⁶.

A4 proposes that through using both terms, ASD and ASC, we avoid wanting/needing to introduce the term “profound autism”. This is like avoiding the term *high-functioning autism*.

The proposal works best if we understand that there are no hard borders between ASC & ASD, or between ASC & neurodivergent.

Bob Buckley, A4 Co-convenor

1/6/2023

¹⁶ though the boundaries for that are also unclear.

Annex C.Senate Autism Review Recommendations

The [Senate Select Committee into Autism](#) handed down [its report](#) in March 2022. It made [81 recommendations](#) to be considered for the implementation of a National Autism Strategy. The NAS Oversight Council and Working Groups will co-design and develop the strategy, with working groups in four key areas.

- Social inclusion
- Economic inclusion
- Diagnosis, supports and services
- Health and Mental Health

Members of the Oversight Committee and Working Groups are comprised of representatives of the autism community, researchers, and government representatives. The recommendations from the Senate Select Committee into Autism will be distributed between the working groups to compile data and other information into the four areas. The recommendations from the autism inquiry are listed below and have been dispersed amongst the working group topics below in the table. Green represents a recommendation that spans across all 4 working groups, orange across 3 working groups, yellow across 2 working groups and no colour across 1 working group. Responses to recommendations relevant to multiple working groups will need coordination; they need more attention from the Oversight Committee.

	Social inclusion working group	Economic inclusion working group	Diagnosis, supports and services working group	Health working group
1	X	X	X	X
2	X			
3			X	
4			X	
5	X	X	X	X
6			X	
7			X	
8			X	
9	X		X	
10	X			
11	X		X	
12			X	
13		X		

14		X		
15	X			
16	X			
17	X		X	
18	X	X	X	X
19			X	X
20	X		X	
21	X	X	X	
22	X		X	
23	X		X	
24			X	
25			X	
26	X	X	X	X
27	X	X	X	
28			X	
29	X			
30			X	
31	X			
32			X	
33	X		X	
34			X	
35	X		X	
36		X		
37	X	X		
38			X	
39			X	
40			X	
41			X	
42			X	
43			X	
44			X	
45	X		X	
46		X		X

47	X			
48	X			
49	X			
50	X		X	
51		X		
52		X		
53		X		
54		X		
55		X		
56		X	X	
57		X		
58		X		
59		X		
60		X		
61			X	X
62			X	X
63			X	X
64			X	X
65				X
66				X
67	X			
68	X		X	
69	X			
70		X	X	
71	X		X	
72	X		X	
73			X	
74			X	
75		X		
76			X	
77	X		X	
78	X		X	
79	X		X	

80	X		X
81	X		X

Education and justice issues are major topics deserving specific attention. These topics were not assigned to specific working groups. The table below suggests which of the recommendations may relate to education or justice.

Social inclusion and Diagnosis, supports and services		
	Education	Justice
14	X	
39	X	
46	X	
47	X	
48	X	
49	X	
50	X	
51	X	
52	X	
53	X	
54	X	
55	X	
56	X	
73		X
74		X
75	X	
76		X
77		X
78		X
81		X

Annex D. Autism in the NDS 2010-20

NDS 2010-20

See

https://www.dss.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf

5 Learning and Skills

...

POLICY DIRECTION 4

Improve pathways for students with disability from school to further education, employment and lifelong learning.

...

Current commitments 2010

...

Commonwealth, State and Territory governments are committed to improving early intervention and support for children with autism. The Commonwealth helping Children with Autism initiative (\$190 million) includes:

- establishing eight Autism Specific Early Learning Centres across Australia
- funding for early intervention therapies
- PlayConnect Playgroups (autism-specific playgroups)
- Early Days family workshops
- professional development for teachers, school leaders and other school staff
- workshops and information sessions for parents and carers.

New Medicare items are also available for children aged under 13 years (for diagnosis and treatment planning) and under 15 years (for treatment).

A number of States and Territories have introduced autism plans designed to help children with autism and their families get the specialised support they need, and to make the community more welcoming and inclusive. plans include measures designed to strengthen the capacity of the workforce to respond to children with autism, provide greater support to children and families, especially at times of transition, improve access to educational opportunities, and improve our understanding of autism.

...

6 Health and wellbeing

...

POLICY DIRECTION 2

timely, comprehensive and effective prevention and early intervention health services for people with disability.

...

Intensive educational and behavioural interventions have produced positive outcomes for children with autism (Commonwealth Department of health and Ageing, 2006).¹⁷

...

Current commitments 2010

- Improved access to health services for people with disability through new Medicare Benefits Schedule items including Intellectual Disability health Check and Chronic Disease management; and new items under the helping Children with Autism initiative and the Better Access initiative for mental health services.

ADS 2021-31

Policy Priority 4:

The built and natural environment is accessible

...

“[U]niversal design and built environment accessibility often needs to go beyond access for people with physical impairments and should include design for other issues such as hearing impairment, cognitive impairment, psychosocial disability, or autism” (Senate Community Affairs References Committee 2017)

¹⁷ M Prior & J Roberts, *Early intervention for Children with Autism Spectrum Disorders: guidelines for best practice*, Department of health and Ageing – Commonwealth Government, 2006, p. 2

Note: this document is no longer available on the <https://health.gov.au> website. The full report and the associated booklet can be downloaded from <https://a4.org.au/node/965>