



## Submission: a new National Disability Strategy and Autism

The Australian Autism Alliance (the Alliance) is pleased to provide input to the development of a new National Disability Strategy (the Strategy). The Alliance consists of 12 autism-led organisations from across Australia, which together reach more than 170,000 people and provide direct service support to 30,000 autistic people.

### There is a high prevalence of autism

Autism is a high prevalence condition. Improved recognition of autism and the reclassification of Asperger's Syndrome has contributed to a dramatic increase (217%) of people diagnosed with autism in Australia over the last decade. In 2018 the ABS reported that 1.3% of males, 0.4% of females and 3.2% of children aged 5-14 years have an autism diagnosis. Actual prevalence in the community is likely to be much higher as many adults have not been diagnosed.

In the context of the National Disability Insurance Scheme, 31% of participants have a primary autism diagnosis, and an additional 5% of participants have autism as a secondary disability – the largest diagnostic group within the Scheme. In the younger age groups, the lion's share of participants are autistic: 65% of those aged 7-14 years and 54% of 15-18 year olds.

### The National Disability Strategy is not delivering for Autistic people

Notwithstanding the existence of the National Disability Strategy over the last ten years, and the high prevalence of autism across Australia, critical life outcomes for autistic people remain substantially worse than for most other disability and vulnerable population groups.

Autistic people are more likely to be unemployed, have shorter life expectancy, experience higher rates of mental illness, higher rates of social isolation and are less likely to attain a vocational qualification or university degree than all people with disability.

The following statistics illustrate the stark gap in outcomes:

- Approximately 33% of autistic students leave school by year 10, compared to 19% of students with disability.
- Autistic people are underrepresented in Vocational Education and Training, with 17.9% having a Certificate III, diploma or advanced diploma as their highest qualification, compared with 29.4% of all people with disability.
- Autistic people are half as likely to attain a bachelor degree or higher as all people with disability.
- As recently as 2018, unemployment among autistic people was at 34.1%. More than three times the rate for people with disability, and almost eight times the rate of people without disability.<sup>1</sup>
- Social isolation is a continuing challenge, with more than 66% of respondents to an Alliance survey reporting feeling socially isolated, compared with 32% of people with disability<sup>2</sup>.
- Autistic people have a life expectancy of 20-36 years shorter than the general population,<sup>3</sup> compared to a life expectancy of 10 years shorter for people with disability.<sup>4</sup>

Importantly, these outcomes are not primarily caused by the ‘disability’ of autism itself, but rather by a lack of an enabling and supportive environment. The statistics reflect the myriad ways that key systems and structures in our communities are not accessible to autistic people.

There is high aspiration and huge untapped talent in the autistic community, which can be unleashed if systemic barriers are knocked down and replaced with enablers proven to assist autistic people.

A National Autism Strategy is needed to complement the National Disability Strategy  
 There is a clear need for a specific National Autism Strategy to complement the next iteration of the National Disability Strategy.

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<sup>1</sup> Australian Bureau of Statistics, 2018. *4430.0 Disability, Ageing and Carers, Australia: Summary of Findings 2018*. Available at: <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features102018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=>

<sup>2</sup> Australian Federation of Disability Organisations. Available at: <https://www.afdo.org.au/about-australians-with-disability/community-and-social-participation/>

<sup>3</sup> Hirvikoski T et al 2015. *Premature mortality in autism spectrum disorder*. Available at: <https://pubmed.ncbi.nlm.nih.gov/26541693/>; Guan J, Li G. *Injury mortality in individuals with autism*. Available at: <https://pubmed.ncbi.nlm.nih.gov/28323463/>

<sup>4</sup> Majer M et al 2011. *Mortality Risk Associated With Disability: A Population-Based Record Linkage Study*. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3222426/>

A National Autism Strategy would build on the ambitions and measures of the general Strategy, and buttress it with specific and targeted measures to address the distinct challenges and enablers of autistic people.

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*The large numbers of people with autism, the distinct challenges faced, and the opportunity to make significant gains with a well targeted and tailored response make an autism-specific strategy a national imperative*

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A National Autism Strategy would create an intentional and coherent approach to shifting the dial on outcomes for autistic people. It would provide an overarching and bi-partisan framework to drive coordinated and mutually reinforcing policy, research, service, and program responses across different domains and jurisdictions. It would cover autistic people across the life course – including through key life transitions – and across the spectrum.

Such a tailored approach cannot be delivered through a generalist disability strategy. The Victorian approach is instructive, with a general disability strategy providing the overarching architecture that other cohort-specific strategies hang off. [‘Absolutely Everyone’](#) is Victoria’s state disability plan. It guides action against key outcome indicators across all Victorian Government departments and offers the overarching governance and policy framework for the Victorian Government. A discrete autism strategy – the [Victorian Autism Plan](#) - has been developed within that frame. The two strategies are designed to fit together. For example, strategic themes and outcomes under the Victorian Autism Plan are linked to those in the overarching disability strategy (Absolutely Everyone).

The Alliance submits that situating a National Autism Strategy to be a complementary component of the next National Disability Strategy is both possible and preferable.

While there are some that will contend that a revamped National Disability Strategy is sufficient to cover all disabilities, the Alliance respectfully disagrees. We acknowledge the excellent work that has been done in cross-disability policy, leading to major gains in support and resourcing for the disability community. However, despite all this work, key indicators and outcomes for autistic people have not advanced. This is unacceptable.

The call for a National Autism Strategy is not coming exclusively from the autism community, rather there is a broad consensus about the need. A range of organisations including The Royal Australasian College of Physicians, the Autism Cooperative Research Centre, Scope and the University of Melbourne, and the Australian Association of Social Workers recommend an autism specific strategy in their submissions to the current Senate Inquiry into Autism.

There are significant opportunities to strengthen the next iteration of the National Disability Strategy

The Alliance supports the high level vision, outcome areas and guiding principles proposed for the new Strategy. We also support the proposal that the Strategy include a greater emphasis on improving community attitudes towards disability.

**Strong and transparent measures are critical – including comparisons between jurisdictions and disability groups**

A fundamental flaw of the current National Disability Strategy is the absence of an outcomes framework. This has made it challenging to learn about what is working, or to track change or to hold governments and mainstream service providers to account.

The Alliance welcomes the clear intent to enhance measures and accountability in the refreshed National Disability Strategy.

We support the inclusion of an outcomes framework and see this as an essential element in tracking whether the National Disability Strategy is delivering actual change for people with disability.

Principles and ambitions need to be matched with formal accountabilities for performance against targets, coupled with a structured public reporting mechanism.

Proposed options for reporting against the outcomes framework do not go far enough. A higher degree of accountability is needed to ensure governments at all levels continue to drive change within their remits. This would include each state, territory and federal minister with portfolio responsibility reporting to their respective parliaments about actions taken during the preceding 12-month period and progress against key outcome indicators.

Comparison of outcomes across Australia’s different jurisdictions, across different disabilities, and for key population groups including females, culturally and linguistically diverse people, and First Nations peoples will be crucial to understanding challenges and tailoring responses. Such transparent reporting is an essential means of supporting a culture of continuous improvement.

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*The opportunity to make meaningful in-roads into the priority areas proposed in the Strategy cannot be missed and must be reflected with a sincere approach to transparent reporting and public accountability.*

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**The Strategy needs to be backed by resourcing to support meaningful change**

The challenges posed by the response to the pandemic are significant, however the long-term engagement and uplift of people with disability in Australia is a commitment and priority that will continue and pay dividends into the future.

Targeted and ongoing investment from governments and other key stakeholders is foundational to improving the quality of life for people with disability generally and autistic people specifically.

Public expenditure on the National Disability Strategy and its measures represents an investment not only in people with disability, but in the broader Australian community and economy. Ensuring that this investment represents good value is an important consideration. Funding allocated to initiatives in support of the National Disability Strategy need to be reported on transparently and be linked to the outcomes framework.

**Co-design and shared governance is critical**

Reflecting the principle of “nothing about us without us,” the next National Disability Strategy needs to be co-produced from end to end with people with disability – including autistic people.

Shared governance would support continued attention and accountability, even as political leaders come and go and governments change.

Inspiration can be drawn from the recent refresh of Closing the Gap which has seen processes and governance overhauled to embed the voice, aspirations and experience of First Nations peoples.

[We stand ready to assist with development and implementation of the refreshed NDS](#)

The Autism Alliance is committed to supporting development of an improved National Disability Strategy and a complementary National Autism Strategy.

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[Alliance partners include:](#)

- AEIOU Foundation
- Amaze
- Australasian Society for Autism Research
- Autism Aspergers Advocacy Australia
- Autism Queensland
- Autism SA
- Autism Spectrum Australia
- Autism Tasmania
- I CAN Network
- Autism Self Advocacy Network
- Autism Association of Western Australia
- The Sycamore School

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