

Developing a cohesive and unified strategy

Submission to the National Autism Strategy

May 2024



**Australian Advisory Board on
Autism Spectrum Disorders**

About the Australian Advisory Board on Autism

- Australia's first and longest running national autism collaboration, established in 2001.
- Consists of community driven autism associations and leading researchers from across Australia.
- Our autism associations were established by families and have long been working with and for the Autistic community, not for profit.
- Collectively, we serve and support Autistic people and their families across all life stages and in every State and Territory.
- We are trusted leaders in quality, innovation and neuro-affirming practice.
- We have deep insight into what works, how and why. We want to share and grow good practice in supporting Autistic people, their families and carers.
- We are proud to have established the Australian Autism Alliance in 2016 (bringing together a diverse range of autism interests).
- The AABA seeks to drive evidence-based improvements to policy, programs, practices and workforce so that Autistic people can access high quality, safe, respectful, inclusive and effective services and supports, wherever they are and whatever their circumstances.

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We acknowledge the First Nations and Traditional Owners of the land, sea and waterways and pay respects to Elders past and present

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STATEMENT ON LANGUAGE

Language is a powerful way to promote positivity and to influence perceptions, attitudes and beliefs. Language preferences are deeply individual. The AABA continues to review the use of language related to autism to ensure that current views are represented in our written and spoken presentations.

Some autistic people prefer to use identify-first language 'autistic person', some prefer to use person-first language 'person with autism', while others are fine using either. Throughout this response, we will use identify-first language in line with the language used by the Australian Government in the National Autism Strategy.

STRATEGY RESPONSE

The Australian Advisory Board on Autism (AABA) welcomes and strongly supports the *Draft – National Autism Strategy* (The Strategy). It is a significant step toward creating a more inclusive and supportive society for autistic individuals and their families.

The Strategy highlights the importance of raising awareness and reducing stigma. Promoting understanding and acceptance within the broader community is vital for fostering a more inclusive society where autistic individuals are valued and respected.

It is a welcome initiative that, if executed with national consistency and shared purpose, can bring about meaningful change. It represents a comprehensive commitment to supporting autistic individuals and their families, paving the way for a more inclusive future.

The AABA look forward to seeing a well-rounded, comprehensive National Autism Strategy that addresses the diverse needs of autistic people across their whole life span.

VISION, GOALS & GUIDING PRINCIPLES

The AABA welcomes the Vision, Goal, and Guiding Principles of *The Strategy*. While there is mention of a family-centred approach, it is recommended that the wider family unit is recognised in the Goal. Although not an exhaustive list, the wider family unit often encompasses parents, guardians, grandparents, aunts, uncles, cousins, and sometimes close family friends who are regularly involved in family activities, that provide emotional or financial support, and are considered integral members of the family dynamic. The wellbeing of the entire family unit, which we recognise varies among cultures, is critical in achieving the best outcomes for an autistic person.

Families of autistic individuals are crucial support networks, providing the foundational emotional, social, and practical assistance needed for their well-being. Families often assist with daily activities, health care management, and educational needs, ensuring that their autistic loved ones can lead fulfilling lives. Families navigate complex systems, such as healthcare and social services, advocating for appropriate resources and accommodations. This advocacy is essential in overcoming the barriers that autistic individuals often face in accessing necessary support.

Families facilitate inclusion and participation in community activities, reducing isolation. Moreover, families play a pivotal role in long-term planning, including financial security and future care arrangements. They provide stability and continuity, which is crucial for the long-term well-being of autistic individuals.

AUTISM AS A DISABILITY

The strategy is silent on autistic individuals who experience autism as a disability, and their families and carers.

Many autistic people experience autism as a disability. While we recognise autism can be a positive experience, at the other end of the autism spectrum, people with profound autism (i.e., a subset of autistic people who have a significant co-occurring intellectual disability or very limited language, or both) need 24-hour support and assistance with all aspects of everyday life. These individuals often have severe behavioural challenges, such as self-injurious behaviours that cause harm, which are often used to indicate pain or physical illness, express unmet needs, or help to reduce feelings of distress or anxiety related to overwhelming sensory experiences or environmental changes. Profound autism is often associated with other vulnerabilities, such as cultural and linguistic diversity, low socioeconomic status, or have medical conditions such as seizures. Even autistic people without a co-occurring intellectual disability have significant difficulties with adaptive functioning and face barriers to accessing education, healthcare, employment, and community activities. Mention of disability is a gaping hole in *The Strategy*. The failure to address disability associated with autism in *The Strategy* “others” people with high and complex support needs, and implies that they do not deserve the same inherent dignity, worth, and quality of life as other people in the autistic community.

Therefore, in its current form, *The Strategy* does a disservice to the broader autistic community by failing to recognise those people who experience autism as a disability. People with profound autism are some of the most vulnerable members of the autistic community, and those most likely to experience abuse and neglect at the hands of caregivers or fraudulent service providers. While tailored, high quality supports are vital for those people who experience disability because of their autistic characteristics, *The Strategy* is silent on the ways in which these community members will access housing, education, healthcare, community services, and opportunities for social inclusion, all of which are vital for ensuring good quality of life.

The AABA recommends that *The Strategy* outlines an approach to supporting people with autism who experience disability, with specific reference to the unique and complex needs of profoundly autistic people. Specifically, we would like to see a strategy for ensuring that all autistic people, including those with disability, can access the resources, accommodations and supports necessary to thrive and lead fulfilling lives. While profound disability remains the remit of the National Disability Insurance Scheme, *The Strategy* provides a unique and important opportunity to make recommendations about the safeguards and autism-specific approach to supports provided to all autistic people.

AGEING & ELDERLY AUTISTIC INDIVIDUALS

The strategy has limited detail on the approach for the ageing and elderly autistic community.

Elderly autistic individuals face a unique set of challenges as they age, stemming from the intersection of their neurodevelopmental condition and the typical aging process. Communication difficulties, sensory sensitivities, and social interactions can become more pronounced, exacerbating their challenges in navigating daily life.

One significant challenge is the increased risk of isolation and loneliness. Autistic individuals may struggle to form and maintain social connections throughout their lives, and as they age, changes in routine, living situations, or the loss of loved ones can further isolate them. This isolation can have detrimental effects on their mental health and well-being, highlighting the importance of creating inclusive communities and support networks.

Health care disparities also pose significant challenges for elderly autistic individuals. They may encounter barriers to accessing appropriate medical care due to communication difficulties, sensory sensitivities, or a lack of health care providers trained in understanding and accommodating their unique needs. As a result, their physical and mental health needs may go unaddressed, leading to poorer health outcomes and reduced quality of life.

Furthermore, aging can bring about additional sensory and motor difficulties, such as declining sensory processing abilities or mobility issues, which can further impact independence and daily functioning.

At present autistic individuals exit NDIS services at 65 years of age, despite autism being a lifelong condition. It is recommended that *The Strategy* addresses the challenges faced by elderly autistic individuals. It requires an holistic approach that considers their unique needs and experiences, including access to supportive services, healthcare, and social inclusion initiatives tailored to their specific requirements. Furthermore, there needs to be a commitment to supportive transition from NDIS to aged care initiatives.

EDUCATION AND SCHOOLING

Embedding education as a subset of social inclusion diminishes the importance and impact of education and schooling on autistic individuals.

Quality education in accessible and inclusive settings is a fundamental human right enshrined in the United Nations' Conventions on the Rights of the Child and the Rights of Persons with Disabilities. Nonetheless the overwhelming majority of autistic people report experiencing significant difficulties throughout their schooling, such that:

- Autistic students are suspended and expelled at a far higher rate than non-autistic students¹
- Autistic students are four times more likely to be bullied than other students².
- 9% of autistic children need more support or assistance in school than they are currently receiving³

Of critical importance are supports and adjustments within mainstream schools to ensure autistic students feel safe and supported to engage in learning. Where schools are unable to provide this, many parents of autistic students seek out education and schooling at specialist schools. The Disability Royal Commissioners were divided on the recommendations on education segregation.

Whilst education is primarily the responsibility of states and territories, the AABA recommends a nationally consistent approach in line with the Disability Royal Commission's report identifying the need for better data collection, analysis, and reporting to understand where additional supports are required at a school and student level. This can be done using existing mechanisms including the Disability Standards for Education, the Nationally Consistent Collection of Data on School Students with Disability, the Australian Curriculum, and an additional monitoring of progress through IEP reporting, with data on autistic students clearly identified.

UNIFIED & COHESIVE

The strategy fails to address how intersectionality will be cohesive and unified.

A cohesive and unified National Autism Strategy across states and territories is essential for ensuring consistent and equitable support for autistic individuals and their families. Disparities in services and resources between regions can lead to significant inequalities in access to care, education, and support.

¹ Cleary, M., West, S., McLean, L., Johnston-Devin, C., Kornhaber, R., & Hungerford, C. (2024). When the Education System and Autism Collide: An Australian Qualitative Study Exploring School Exclusion and the Impact on Parent Mental Health. *Issues in Mental Health Nursing*, 45(5), 468–476. <https://doi.org/10.1080/01612840.2024.2328251>

² Amaze, Talking About Autism: Guidelines for respectful and accurate reporting on autism and autistic people, 2019

³ Amaze, Talking About Autism: Guidelines for respectful and accurate reporting on autism and autistic people, 2019

A unified strategy ensures that all autistic people, regardless of where they live, have access to the same high standards of support and inclusion. This consistency is critical to prevent individuals and families from being forced to navigate varying and often confusing systems of care when between federal and state services.

Moreover, a cohesive approach allows for the effective sharing of best practices and resources, fostering collaboration and innovation. It ensures that successful programs and supports can be implemented nationally.

The AABA recommends the development and implementation of a unified, comprehensive framework that mandates regular collaboration and is applied consistently across the health, mental health, education, and justice sectors in all states and territories. This framework should ensure uniform standards of knowledge and attitudes toward autism, facilitating seamless service delivery and support for autistic individuals.

CONCLUSION

In conclusion, the AABA strongly supports the *Draft - National Autism Strategy*, and believes it is an important initiative. There is significant investment required to ensure that commitments are implemented, measured, evaluated and reported upon.

The AABA recommends the ongoing engagement of autistic individuals across the spectrum to highlight the importance of *The Strategy*.