



5 September 2024

Australia's Disability Strategy review.
Department of Social Services
71 Athllon Drive
Greenway ACT 2900

Submitted via email: ADSReview@dss.gov.au

Dear Review Team,

Amaze submission to review of Australia's Disability Strategy.

Amaze works to build acceptance and understanding of autism in communities, educational settings, organisations and businesses, and wider society. Informed by evidence, experts and lived experience, we influence policy change for Autistic people and provide independent, credible information and resources to individuals, families, professionals, government, and the wider community. We are closely connected with the community through our national Autism Connect helpline, peer support networks and capacity building initiatives.

We welcome your findings and recommendations to strengthen *Australia's Disability Strategy 2021 - 2031* ("ADS"). Our submission focusses on the importance of ensuring the ADS complements the National Autism Strategy, currently under development, and meets the needs of all Autistic people (including intersectional cohorts and Autistic people with high and complex support needs). It also highlights the importance of a co-designed Community Engagement Plan to ensure the diverse experiences and perspectives of all people with disability, including Autistic people continue to help shape the ADS and all policies and programs that impact them.

We recommend:

1. Ensure the ADS links to, and compliments the National Autism Strategy, driving a comprehensive, transparent and accountable whole of governments approach to improving the lives of Autistic people.
2. Include an additional policy priority under Health and Wellbeing: All people with disability can access timely and reliable assessment and diagnosis.
3. Co-design an ADS Community Engagement Plan that drives the co-design of, and community engagement in, the design, implementation and evaluation of the ADS, and all other government policies, programs and initiatives that impact people with disability.
4. Co-design an Associated Plan to the ADS to improve the accessibility of information and communications for people with disability.
5. Extend ADS data and reporting by improving the visibility of intersectional experiences, and by disaggregating data by disability type (including autism) and support needs levels, across the Outcomes Framework and other ADS reporting.
6. Create a National Roadmap for Inclusive Education (including safe and quality education) that is aligned with the ADS and linked to achieving the outcomes of the Strategy (but not as a Targeted Action Plan).

1. Link the ADS to the National Autism Strategy, ensuring the ADS complements the Strategy and addresses the needs of all Autistic people.

We welcome your commitment to reviewing the ADS. To enhance inclusion and improve the outcomes of people with disability, the ADS must drive a national, integrated approach to the entire disability ecosystem, ensuring strong collaboration and co-ordination, clear ownership and responsibilities, and well targeted accountability measures for all aspects of the ecosystem and policy reform. This is particularly important in the current climate of NDIS reform and where urgent, whole of governments action is required to progress the many Disability Royal Commission recommendations accepted in principle or in part by Australian governments.

The ADS, and its predecessor the *National Disability Strategy 2010-2020* have progressed positive change for people with disability. However, as found by the Senate Select Committee on Autism in its [Final Report](#) (2022), the ADS and NDS have failed to close the gap between Autistic and non-Autistic people, with many Autistic people continuing to have some of the poorest experiences and outcomes across multiple domains, including education, employment and community inclusion. The Committee concluded that the ADS alone cannot deliver the change needed to improve outcomes for Autistic people (or their families and carers) and that a National Autism Strategy (“NAS”) is required.

We have since welcomed the development of a National Autism Strategy and are continuing to engage with the Australian Government (see for example, our most recent [submission](#) to the draft NAS) to ensure it can address the whole of life needs of all Autistic people and improve their life outcomes. However, the development of a NAS cannot lead to a siloed national approach to improving the lives of Autistic people. The NAS is not a whole of governments initiative with state and territory commitment or investment.

As emphasised by the Senate Select Committee on autism, the ADS and NAS must “complement each other, rather than work in parallel” to meet the needs of all Autistic people, with an autism lens applied to all areas of policy and policy reform. It is vital that the ADS link to the NAS across all outcome areas, and its outcomes framework must measure outcomes for all Autistic people, including those with high and complex support needs and those experiencing intersectional disadvantage (see further discussion below). The ADS must also ensure that the needs of Autistic people are considered and addressed across the areas not covered by the NAS, including transport, justice and housing.

Recommendation 1

Ensure the ADS links to, and compliments the NAS, driving a comprehensive, transparent and accountable whole of governments approach to improving the lives of Autistic people.

2. Include a policy priority to improve access to assessment and diagnosis.

We support the ADS outcome areas and policy priorities. However, we are concerned that there is little focus on improving access to reliable and robust assessments and diagnosis.

The benefits to accessing an early assessment and diagnosis are well understood. There is clear evidence that for Autistic children, it ensures evidence-based supports can be accessed as early as possible, maximizing outcomes for children, adolescents and adults, and increasing their independence, quality of life, understanding of self and developmental trajectory across their lifetime. For some Autistic people, it can also reduce the level of supports they need across their lifetime. The failure to diagnose early, and misdiagnosis, can lead to many years of anxiety, learning and social difficulties, struggling to understand oneself and challenges entering and maintaining employment and independent living. For further information, please see the Senate Select Committee on autism’s [Final Report](#) and the Victorian Inquiry into services for people with autism spectrum disorder’s [Final Report](#).

Further to these reports, recent [evidence](#) from Autism CRC demonstrates that considerable barriers remain to accessing an assessment and diagnosis. These include:

- Before the diagnostic process starts, including getting referrals, knowing how to navigate the diagnosis process, getting hold of services or professionals who can initiate the diagnosis process, and the long wait time associated with accessing them.
- During the diagnosis process, including securing the funds required for assessments and services, deficit-based manuals for diagnosis, health professionals not being specialised in diagnosing autism, not following the Autism CRC best practice National Guideline for Assessment and Diagnosis of Autism, not acknowledging a person or family's concerns, and a very lengthy unclear process that is very taxing for the person or family pursuing a diagnosis
- After the diagnosis process, including misdiagnosis/over/under-diagnosis of autism, lack of support and information for those who receive a diagnosis and those who do not.

For adults seeking a diagnosis in Victoria, there are no publicly funded adult assessment clinics, and the Medicare rebate can only be claimed up to age 25. Autistic adults report that high assessment costs (more than \$2000), long wait lists and workforce understanding of autism and capability remain significant barriers.

While the NAS will address autism assessment and diagnosis at the National level, complimentary actions are required under the ADS to drive a whole of governments approach to holistically improving access to assessment and diagnosis. These actions should include endorsing the National Guideline for Assessment and Diagnosis of ASD, expanding the availability of publicly funded assessment clinics (including for adults), removing the Medicare age cap, increasing the diagnostician workforce, funding comprehensive education and training and increasing the availability of accessible information and resources for Autistic people and families/carers navigating the system.

Recommendation 2

Include an additional policy priority under Health and Wellbeing: All people with disability can access timely and reliable assessment and diagnosis.

3. Attach a co-designed ADS Community Engagement Plan to the ADS.

While positive steps were taken to ensure the experiences and perspectives of Autistic people were heard during the design of the ADS, we strongly support your recommendation to develop an ADS Community Engagement Plan (CEP), in addition to existing ADS community engagement commitments. This plan should be attached to and form an integral part of the ADS going forward.

Meaningful co-design is essential to ensure that decision making rests with those most likely to be impacted by those decisions. It strengthens public policy by drawing on diverse perspectives and ways of thinking, increasing stakeholder ownership and trust, enhancing transparency and accountability, providing for the early identification and mitigation of gaps or issues, and ensuring solutions are fit for purpose and do not exclude or marginalize people. It also upholds the rights of people with disability, under the UN Convention on the Rights of Persons with Disabilities, to be actively involved in policy related decision making.

Building on the existing [Engagement Plan](#), the CEP should be co-designed with people with disability, their families and carers and representative organisations. It should ensure stakeholders are able to provide advice, and exercise shared decision making power and responsibility over decisions that impact them. Most importantly, it should ensure that people with disability, with a diversity of lived experiences, perspectives and expertise are heard. This must include Autistic people of diverse age, backgrounds, identities and experiences, and ensure that cohorts most at risk and/or hardest to reach are

engaged. These cohorts can include First Nations Autistic people and Autistic people from culturally and linguistically diverse backgrounds, as well as Autistic people with complex and high support needs (and their families and carers).

Drawing on the [Guide on Co-Design with People living with disability \(Purple Orange, 2021\)](#), [Disability Royal Commission Final Report – Executive Summary \(2021\)](#) and [Co-design approach \(NDIA, 2024\)](#), the CEP should embody the following key principles of policy co-design:

- **Diversity, equality and respect:** A wide range of participants, with a rich diversity of age, backgrounds, experiences and identities are involved. Participants are treated equally, with dignity and respect. Co-design and community engagement opportunities are well promoted (including through targeted channels), with clear and accessible recruitment information, to ensure a diversity of people are reached and can be involved.
- **Timeliness:** Stakeholders, including people with lived experience, are involved as early as possible to help shape the accessibility, workings and vision of the co-design process. Throughout the co-design process, participants have adequate time to review and process information, and contribute their thoughts and ideas (with adjustments/extra time available to those who may require it).
- **Safety:** Participants feel safe and supported. Confidentiality is assured and participants can speak freely, without fear of retribution. Cultural safety, that acknowledges and respects the cultural identities, beliefs, values and practices of all individuals, is embedded throughout the co-design process to ensure all participants are respected and can fully participate without fear of discrimination or marginalisation.
- **Accessibility:** The co-design process is inclusive and accessible to all participants, with adjustments made to ensure participants can contribute to the fullest extent possible. Flexibility is embedded to meet the changing needs of participants and address any prior learnings from incidents of inaccessibility or exclusion. Participants are involved in identifying the multiple ways that they may engage in the co-design process. For example, these may include co-design workshops, focus groups, interviews, webinars, surveys and targeted approaches to engage hard to reach groups. Adjustments are embedded to support meeting preparation, engagement and follow up, with information provided in a multitude of accessible ways.
- **Commitment to authenticity and transparency:** There is a genuine commitment to shared decision making through co-design for the life of the policy. The roles and expectations of participations are mutually understood and mechanisms are engaged to ensure transparency throughout the co-design process. All contributions are valued and contribute to decision making, with contributions acknowledged, and participants continually informed of how their contributions have impacted policy decisions. Where contributions have not been incorporated, an explanation is given as to why.
- **Acknowledgement:** The skills, experiences and ideas shared by participants are recognised and valued. Participants are appropriately reimbursed for their time and contributions.

The CEP should also drive a whole of governments commitment to developing co-design and community engagement plans for all policy, programs and initiatives that impact people with disability. These plans should apply to all stages, including the design, implementation and evaluation stages, and ensure the diverse perspectives and experiences of people with disability help shape actions and reforms across all sectors.

Recommendation 3

Co-design an ADS Community Engagement Plan that drives the co-design of, and community engagement in, the design, implementation and evaluation of the ADS, and all other government policies, programs and initiatives impacting people with disability.



4. Create a comprehensive Associated Plan to improve the accessibility of information and communications for people with disability

We agree that accessible communications is a priority for long-term action, and we support your recommendation to identify ways to support best practice approaches on accessible communications. However, we encourage you to take a step further and echo Recommendation 6.1 of the Disability Royal Commission, that an Associated Plan to the ADS be agreed to improve the accessibility of information and communications for people with disability (with the Plan co-designed by people with disability and their representative organisations).

As recommended by the DRC, the Associated Plan should:

- consolidate and build on existing initiatives and commitments by governments
- recognise the diversity of people with disability and the many formats and languages that people may require information to be provided in
- consider the roles of various stakeholders, including the Australian Government, state and territory governments, disability service providers, disability representative organisations and organisations representing people from culturally and linguistically diverse backgrounds
- focus, in the first instance, on information and communications about preparing for and responding to emergencies and natural disasters, and public health
- include targeted actions to ensure access to information and communications for people with disability in the criminal justice system; supported accommodation, including group homes; Australian Disability Enterprises; and day programs
- identify and allocate appropriate funding and resources for delivery
- include mechanisms for review and public reporting of progress made against the Associated Plan.

It is important to highlight that this Associated Plan alone will not satisfy international human rights obligations to ensure access to information and communication. For more information on the comprehensive actions required, please see [AFDO Briefing Paper – Access to Information and Communications for People with Disability Across the Public Service \(March 2024\)](#)

Recommendation 4

Co-design an Associated Plan to the ADS to improve the accessibility of information and communications for people with disability.

5. Extend ADS data and reporting to improve the visibility of intersectional experiences and outcomes for different disability types and levels of support need.

We support your recommendations to extend ADS data and reporting to improve visibility of intersectional experiences, and to embed mechanisms that will support the early identification of delayed and undelivered Targeted Action Plan actions.

We also recommend, to the extent possible, that data consistently and transparently be disaggregated by disability type, including autism, as well as support need levels, across the Outcomes Framework and other ADS reporting. This data is urgently needed to measure the impact of the ADS, NAS and other policy and policy reform on Autistic people, including the most vulnerable and at risk cohorts, and inform change.

Autism is the most prevalent primary disability type among [NDIS participants](#), and as highlighted above, Autistic people continue to experience some of the worst outcomes of all people with disability across multiple domains, including in education and employment. The Senate Select Committee on Autism found that outcomes are particularly poor for some

cohorts of Autistic people, including intersectional cohorts and people with high and complex support needs. The outcomes of these cohorts must be measured and transparently reported to drive targeted reforms.

Recommendation 5

Extend ADS data and reporting to improve the visibility of intersectional experiences, as well as by disaggregating data by disability type (including autism) and support needs levels, across the Outcomes Framework and other ADS reporting.

6. Develop a National Roadmap to Inclusive, Safe and Quality Education that is linked to achieving the outcomes of the ADS.

We strongly support the development of a National Roadmap for Inclusive Education (including safe and quality education) that:

- prioritizes a pathway for building a skilled workforce and infrastructure capable of supporting meaningful and rights-based inclusion;
- drives implementation and evaluation of consistent state and territory education reforms (including the Disability Royal Commission's unanimously agreed recommendations, agreed by governments in principle or in part); and
- drives research, data collection and modelling to inform appropriate reforms to mainstream and specialist schools across Australia.

This Roadmap should be aligned with the ADS and linked to achieving the outcomes of the Strategy. However, it should not be developed as a Targeted Action Plan (TAP). As highlighted by the [Disability Royal Commission](#), TAPs have a shorter term focus and tend to focus on particular jurisdictions. They are not appropriate where a longer-term roadmap and national co-ordination is required. Consideration may be given to whether the Roadmap should form an Associated Plan. As highlighted in the ADS, Associated Plans (including roadmaps) can be sector specific and generally run for three to ten years, providing a more co-coordinated, long-term approach, and identifying how they contribute to achieving the outcomes of the ADS. However, given the roadmap envisaged by the Disability Royal Commission may be longer term than 10 years, careful consideration should also be given to whether this is an appropriate pathway.

Recommendation 6.

Create a National Roadmap for Inclusive Education (including safe and quality education) that is aligned with the ADS and linked to achieving the outcomes of the Strategy (but not as a Targeted Action Plan).

Please contact me by email at david.tonge@amaze.org.au or by phone on [03 9657 1600](tel:0396571600) if we can assist by providing further information or answering any questions you may have.

Yours sincerely,



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