

Disability Royal Commission

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30 May 2022

Dear Commissioners,

Senate Select Committee on Autism's Report

Amaze works to build community understanding of autism, 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 Autistic community through our national help line Autism Connect, our peer support networks and community capacity building initiatives.

We are writing to highlight the evidence informed work of the Senate Select Committee on Autism ('Committee') and the findings and recommendations outlined in its final report, 'Services, support and life outcomes for Autistic Australians' ('Final Report'), tabled on 25 March 2022.

The Committee was established on 17 November 2019 to inquire into and report on the services, support and life outcomes for Autistic people in Australia, and the associated need for a National Autism Strategy. Over a period of approximately 2 years, it held 9 public hearings and received 168 submissions, including from Autistic people, their families and carers, the autism and wider disability sectors and health professionals.

This evidence received, and robust research conducted by the Committee, led to significant findings regarding the poor life outcomes for Autistic people and resulted in 81 targeted recommendations, centred around the urgent need for a **National Autism Strategy**. Echoing the call of the Disability Royal Commission ('Commission'), the Committee's recommendations also included the development of a **National Roadmap for Improving Health Services for Autistic people**.

We commend this report to the Commission, demonstrating the urgent need for autism specific reforms to improve the lives of autistic Australians.

Key findings: life outcomes for Autistic people are unacceptably poor.

The Committee found that life outcomes for Autistic Australians are unacceptably poor and that this comes at a significant personal, social and economic cost. It found that approximately 660,000 Australians are autistic, and that Autistic people and their families are often discriminated against and have difficulty accessing the services and supports they need.

It found that the drivers of poor outcomes for Autistic people are complex and interrelated, and that generic disability strategies have proven ineffective at improving life outcomes for Autistic people. Concluding that maintaining the status quo is simply not an option, the Committee stressed that meaningful 'autism specific' systemic change would be essential to improve the lives of Autistic Australians.

***"The headline statistics are stark.** Autistic people have a life expectancy more than 20 years shorter than the general population, with more than twice the mortality rate. Autistic people experience high rates of co-occurring mental health conditions and are more likely to attempt or commit suicide than other groups. Seventy-five per cent of autistic people do not complete more than a Year 12 education, while the unemployment rate for autistic people is almost eight times that of people without disability. Autistic people also appear to be overrepresented in the justice system and at higher risk of homelessness than the general population.*

Inclusion of autistic people in the community is also poor, with many experiencing loneliness, isolation, exclusion and discrimination. Significant numbers of autistic people report having no friends other than family or paid staff. Likewise, many families say they feel unwelcome at community events, or unable to leave the house due to negative public reactions to their child's autism.

***These are not simply statistics on a page.** Behind each set of numbers are thousands of autistic children and adults who have been denied the opportunity to fulfil their potential and live healthy, safe, and productive lives, as well as scores of families who have been pushed to breaking point." (Final Report, page v – vi)*

A National Autism Strategy is urgently needed.

Central to the Committee's recommendations is the establishment of a National Autism Strategy, to be co-designed with Autistic people and the autism community. The strategy would coordinate initiatives across government, address whole-of-life needs and contain clear and measurable goals by which progress could be tracked.

The committee envisages that the strategy would include targeted actions to support vulnerable cohorts of Autistic people, including: people from lower socio-economic backgrounds; people in regional and remote locations; First Nations people; people from culturally and linguistically diverse backgrounds; gender diverse and LGBTQI people; and people with complex support needs. It would also be complemented by a series of action plans and roadmaps for specific areas—such as health and mental health, advocacy, employment, research, and the service delivery workforce.

Further priority recommendations identified by the Committee in its Final Report include:

1. Developing a National Roadmap for Improving health and mental health services for Autistic people (echoing the Commission's call).
2. Lifting Medicare rebates and removing the age cap for autism assessment and diagnosis together with initiatives to drive timely and quality assessments.
3. Jobs initiatives to shift the dial on employment for Autistic people.
4. Reforms to markedly increase inclusion and attainment in education and training, and reduce bullying of autistic.
5. A National Autism Workforce plan to build autism capacity of key frontline workforces.
6. A national approach to disability advocacy, including a National Autism Advocacy Plan.
7. The effectiveness of the National Disability Insurance Scheme for Autistic Australians should be the focus of a separate inquiry.

We are pleased to advise that in response, the new Australian Government has committed to a suite of reforms, including:

- A National Autism Strategy, with \$1 million to be invested for the next year to develop a coordinated national approach between all levels of government and services.
- A National Roadmap to specifically target health and mental health outcomes, with a \$300,000 investment to begin work immediately.
- Lifting the age cap for people seeking autism assessment from 13 to 25 years of age so that young adults can access a diagnosis and support.

- A commitment to include an Autism lens in their pandemic response and NDIS workforce strategy.¹

Considering the stark evidence given by Autistic people and the autism community to the Commission, and its findings to date², we strongly urge the Commission to echo the Committee's recommendations and call for an accountable National Autism Strategy that is capable of meeting the needs of all autistic Australians, in all aspects of their lives, across their lifetime.

Amaze stands ready to assist the Commission.

Amaze played a key role in the Committee's Inquiry. We led advocacy through the Australian Autism Alliance (before the last Federal election) for the Inquiry to be established; helped design the terms of reference; developed a national wide survey (completed by almost 4,000 Autistic people and their families and carers to inform the Inquiry); drafted papers and submissions – including a comprehensive submission on behalf of the Australian Autism Alliance; appeared before the Inquiry; and participated in significant background work with individual Senators and Committee staff.

We now stand ready to assist the Commission. Please contact me by email at Nicole.rees@amaze.org.au if we can assist by presenting to the Commission on the need for a comprehensive National Autism Strategy with robust and measurable goals, and the report's further findings and recommendations. We would also be pleased to attend any future public hearings related to these matters.

Yours sincerely,



Nicole Rees

Deputy CEO | Executive Manager, Policy & Advocacy.

¹ For more information, please see the ALPs press releases detailing both its [Autism initiatives](#) and broader views on disability and the [NDIS](#).

² For more information, please see Amaze's '[Disability Royal Commission – Autism Hub](#)' website, What the DRC is hearing, finding and recommending on autism. <https://www.amaze.org.au/drc/>