



## Responses to questions on notice – Australian Autism Alliance

### International evidence in favour of a national autism strategy – including in jurisdictions with federal/state levels of government

While a strategy in and of itself is no silver bullet, analysis by Autism Europe<sup>1</sup> highlights that countries with a national autism strategy bring about positive impact and change for autistic people, even if they do not achieve all their objectives. Likewise, a UK Parliamentary Report undertaken ten years after their *Autism Act* was introduced found that while there has been small improvements in some areas, including healthcare and social services, there is still a long way to go. They underscore the need for an enabling framework – such as a national strategy – to be underpinned by strategic actions, measureable outcomes, accountabilities for delivery and co-ordinated funding.

We draw the Committee's attention to the necessity of including clear incentives and accountabilities to ensure recommendations are funded, implemented and progress and results publicly reported. Feedback from key stakeholders with direct experience in the design and implementation of the UK's National Autism Strategy was that a strategy without sufficient incentives and deterrents risked being ineffective in meeting its goals.

How have autistic people fared during the pandemic? Do you have any case studies or examples you would like to share with the committee about the impact the pandemic has had on people with autism?

Our submission has been developed with the vital and fervent input of autistic people and their families, by way of a detailed consultation survey that included opportunities for respondents to provide open responses on issues linked to the Inquiry's terms of reference.

Many respondents detailed their challenges with social isolation, mental health needs and the compounding effects of social restrictions during the pandemic, impacting significantly on both autistic people and carers and guardians.

In terms of more focused research into the effects of the pandemic on autistic people, we draw the Committee's attention to early work being conducted by Claire Brown and Associate Professor Mark Stokes out of Deakin University, which will track the impacts on participants' mental health as the pandemic progresses. The study began in June, so broad results are not yet available, but will be of interest to the Committee as it progresses.<sup>2</sup>

<sup>1</sup> Available at [https://www.autismeurope.org/wp-content/uploads/2018/02/ASDEU\\_State-of-the-art-autism-policies.pdf](https://www.autismeurope.org/wp-content/uploads/2018/02/ASDEU_State-of-the-art-autism-policies.pdf)

<sup>2</sup> Available at: [https://researchsurveys.deakin.edu.au/jfe/form/SV\\_00eZqA4Yf5RaNVP](https://researchsurveys.deakin.edu.au/jfe/form/SV_00eZqA4Yf5RaNVP)

Findings from detailed interviews and a survey conducted by Dr Liz Pellicano and colleagues that looked into the impact of the COVID-19 pandemic on autistic people have recently been published. The findings indicated that many autistic people felt worryingly unsupported during the pandemic.<sup>3</sup>

The Alliance is particularly concerned about the impact of schooling disruptions on autistic students. While we accept that rapidly changing circumstances are presenting challenges for many students and teachers, we note that remote and digital learning environments have disproportionately impacted autistic students and their families. Papers prepared by Alliance member Amaze (together with the Associate for Children with Disabilities) summarises the impact on Victorian students with autism.<sup>4</sup>

In general, we are concerned that any gains made by autistic people will go backwards on account of the pandemic. It is essential that autistic people – who as a cohort already experience far worse health, mental health, social, education, justice and employment outcomes than the general population AND those experienced by other disability groups – are considered and special measures put in place as part of the recovery process. Autistic people have disproportionate disadvantage and thus will require disproportionate responses.

Are there any risks that you foresee in developing and implementing a National Autism Strategy? Why do you think that a strategy hasn't already been developed?

A risk that the Committee should be cognisant of when considering our recommendation to develop and implement a National Autism Strategy relates to the measures of success and accountability, and in particular the necessity to ensure that key initiatives are resourced appropriately.

International comparators, in particular the United Kingdom's Autism Act, can be considered relevant case studies when defining the scope and ambition of an Australian Autism Strategy. When reviewing the Autism Act at its 10-year mark, the UK Parliament's All-Party Parliamentary Group on Autism noted that much of the lack of progress for autistic people could be linked to the lack of strategic actions, measurable outcomes, accountabilities for delivery and coordinated funding.

A consideration raised in our submission is that the Committee may hear arguments that a diagnosis-specific autism strategy is unnecessary given the existing National Disability Strategy. Given the stubbornly poor outcomes experienced by autistic people, and the need for well targeted measures, the Alliance respectfully disagrees with this assertion. Instead, we believe that a National Autism Strategy and its commensurate activities and accountabilities will likely have flow-on benefits for other social, economic and disability

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<sup>3</sup> Available at: <https://www.amaze.org.au/wp-content/uploads/2020/08/Reflections-on-learnings-on-schooling-during-COVID-19-Amaze-and-ACD-Aug-2020.pdf> and <https://www.sydney.edu.au/content/dam/corporate/documents/sydney-policy-lab/everyday-experiences-of-autistic-people-during-covid-19---report---july-2020.pdf>

<sup>4</sup> Available at <https://www.amaze.org.au/wp-content/uploads/2020/07/Reflections-on-remote-flexible-schooling-during-COVID-19-Amaze-and-ACD-June-2020.pdf>

groups. For example, we have seen that when schools implement strategies to support autistic learners, other groups benefit, including those with learning difficulties, CALD students and First Nations learners.

What kind of supports are autistic children missing out on under the ECEI pathway?

There is significant concern that participation in ECEI can delay access to diagnosis and support at the most critical time of intervention.

Further, the light touch and short-term approach of short-term Early Intervention Plans can postpone autistic children accessing the intensity of supports that evidence shows makes a real difference to their trajectory. Systematic reviews clearly demonstrate that intensive and comprehensive early intervention support for autistic children, starting as young as possible (i.e. 18 months-2 years), is key to improving their life outcomes, enabling them to be as independent as possible and participate to their full potential in education, employment and their community.<sup>5</sup> The upcoming report from Autism CRC (commissioned by NDIA) on the evidence base for early interventions should provide an important contribution.

Providing autistic children with automatic access to the NDIS as scheme participants with an individually funded plan will provide the best return on investment for the NDIS in the long run.

The Tune Review made important recommendations that if implemented will improve supports available through ECEI. These include provision for funding in advance of a plan so that supports can be immediately accessed, and greater flexibility for families to access in-home supports and respite.<sup>6</sup>

When working well, ECEI enables access to comprehensive supports, strengthens family capacity including within natural settings, uses family centred practice and a key worker model (subject to worker caseloads).

We are hopeful that the ECEI Reset process will deliver a strengthened ECEI offering. Consideration should be given to stretching the pathway to age 8, bringing it into alignment with the early years' transition to school (generally understood to be 0-8 years). This would enable stronger transition to school support, easier interface with early years services, extended support for families, a focus on building capabilities in natural settings and continuation of a key worker model in a developmentally appropriate setting.

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<sup>5</sup> Prior, M et al., 2011. *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Available at: [https://www.dss.gov.au/sites/default/files/documents/10\\_2014/review\\_of\\_the\\_research\\_report\\_2011\\_0.pdf](https://www.dss.gov.au/sites/default/files/documents/10_2014/review_of_the_research_report_2011_0.pdf); Roberts J, Williams K., 2016. *Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*. Available at: <https://webcache.googleusercontent.com/search?q=cache:kVtO3NLKyIJ:https://www.aph.gov.au/DocumentStore.ashx%3Fid%3Db203535f-060d-48f5-bcf6-276ce828aa19%26subld%3D670195+&cd=3&hl=en&ct=clnk&gl=au>

<sup>6</sup> Tune AO PSM, D., 2019. *Review of the National Disability Insurance Scheme. Removing Red Tape and Implementing the NDIS Participant Service Guarantee*. Available at: [https://www.dss.gov.au/sites/default/files/documents/01\\_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf](https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf)