

# Response to NDIS Interventions for Children on the Autism Spectrum 2021



**MISSION  
AUSTRALIA**

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## About Mission Australia

Mission Australia has been serving Australia for more than 160 years. Our vision is an Australia where all of us have a safe home and can thrive. In the 2019-20 financial year, we supported close to 170,000 individuals through almost 500 programs and services across Australia.<sup>1</sup> Mission Australia's integrated nationwide services help people find safe and affordable housing, support children and families experiencing disadvantage, empower young people, assist people with disability, and much more. Early intervention, prevention and collaboration are at the heart of our work. We support people through a range of services, including housing and homelessness services, strengthening communities services, employment and skills services and Partner in the Community ECEI and LAC services.

## Introduction

Mission Australia broadly agrees with the direction of the NDIS' *Interventions for Children on the Autism Spectrum*. Our response to this paper outlines our position in each of the paper's areas of questioning:

- Promoting best practice
- Reasonable and necessary
- Supporting parents to exercise choice and control
- Addressing conflict of interest

We support the principles and standards outlined in the paper; however, we believe that these should be universal and applied to interventions for all children, regardless of disability or developmental delay. We agree that funded supports should be evidence-based and best practice and constitute reasonable and necessary supports. We welcome investment to support using peak bodies and specialised agencies to support the NDIA with information provision and decision-making support. We would like to see further involvement of the Early Childhood Intervention sector and specialists in this process.

The intent and purpose of the ECEI pathway is to recognise individual needs and support based on functional assessment and information gathering. We are concerned that developing specific guidance for the cohort of children with a diagnosis of autism could lead to confusion among families and the sector. The separate guidance and funding may ultimately place pressure on practitioners to find a diagnosis of ASD so that families can attract a higher level of funding; we have seen this on the ground in previous iterations of support, such as in the Department of Social Services' Helping Children with Autism (HCWA) Packages rollout.

Maintaining a different set of standards and support levels for children and families on the autism spectrum could exacerbate existing vulnerability and disadvantage, especially given the concerning pattern of misdiagnoses or missed diagnoses of Aboriginal and Torres Strait Islander people, and people living in remote areas, who are experiencing signs and symptoms of autism<sup>2</sup>. Aboriginal children, children in remote areas, and children from socioeconomically disadvantaged backgrounds have less access to diagnostic services, reducing the likelihood of diagnosis. A review using data from

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<sup>1</sup> Mission Australia, Annual Report, 2020, accessible at: <https://www.missionaustralia.com.au/publications/annual-reports/annual-report-2020>

<sup>2</sup> "We Look After Our Own Mob": Aboriginal and Torres Strait Islander Experiences of Autism. Lilley, R., Sedgwick, M., & Pellicano, E. (2019). Sydney, Australia: Macquarie University

the HCWA package found that Aboriginal and Torres Strait Islander children with a less severe clinical presentation were underrepresented, suggesting that they might be missing out on diagnosis or early intervention support, thereby increasing the risk of more support required later in life.

### **Promoting best practice**

Prior to the NDIS implementation, families connected with trusted peak bodies and early childhood services to source accurate information about their developmental delay or disability and best-practice interventions. Since the introduction of the NDIS, the peak bodies continue to hold the expert information, but what constitutes reasonable and necessary support and best practice is determined by the NDIA. The connection between best-practice and plan funding has been disrupted.

This means that families now go through a Partner to access information and support so it is logical that the Agency is also the first place to look for information about autism or other diagnosed disability. There is tremendous value in the Agency replicating the process of consultation with peak bodies for all disability types so that the information available through the NDIA reflects best-practice interventions. We believe the Agency needs to develop stronger relationships with peak bodies to ensure there is consistency in the provision of accurate, best practice information for the community and families. This would also empower families to recognise and understand best practice as it relates to their child, and improve outcomes.

We also encourage the Agency to continue to seek information from outside the Agency, and also directly commission research and evaluation that contributes to the evidence base. The commissioning of the Autism CRC is one example of this, and we would like to see the role of research and evaluation expanded further.

### **We need to prioritise research and evaluation**

The paper refers to a lack of evidence of what works in interventions and outcomes. The Agency has a comprehensive data set relating to children and young people with disability, and interventions and their outcomes, which has grown over many years and continues to grow. This paper is a step towards strengthening evidenced informed information and approaches, but we need to recognise that its methodology simply synthesizes information that already exists, rather than producing new information.

In referring to operationalising the science, the paper proposes that the missing element is incorporating the voices of consumers and experienced clinicians and professionals. While we agree and strongly support the inclusion of consumer and clinician voices in research, we would support the Agency's engagement in collaborative research partnerships so that we can develop a stronger applied evidence base that addresses more practice-related questions. These partnerships would draw on the existing data held by the Agency to establish what has worked for children with disability or developmental delay, and what interventions or approaches have not worked. Doing so would start to link plan funding amounts with outcomes, rather than the level of impairment so that we can determine whether the plan funding amount is sufficient to achieve sustainable long-term outcomes.

The NDIA has piloted a series of approaches and releasing the findings of these pilots would further help us to develop and support best practice approaches. There is also an opportunity to look at the

systemic factors contributing to the successful outcomes of early childhood approaches, and how these factors interact.

As an ECEI Partner in the Community, we strive to link families with community and mainstream supports, but in regional areas, these can be extremely limited. While we recognise that the lack of community and mainstream supports is not the sole responsibility of the NDIA to address, we would encourage the Agency to leverage its profile and influence with state and local governments to address these limitations. The National Disability Strategy has committed all governments in Australia to a unified and national approach to improving the lives of people with disability, their families and carers, and providing leadership for a community-wide shift in attitudes. We have seen the benefits of grants to support and facilitate peer and parent groups funded through the Agency.

## **Reasonable and necessary**

While we agree with the overarching principles and standards, any standards and principles need to be co-designed with children and families who are working with all NDIS Services including ECEI, LAC and all ILC-related activities.

Previous specific support packages such as HCWA saw a dramatic increase in referrals from GPs and other non-specialist providers for families seeking support for their child, but the child did not always have a diagnosed disability. This has perhaps led to the conclusion that short-term early intervention may reduce the likelihood that children with autism will require funded plans. However, a diagnosis of autism (as with other disabilities) can present in different ways throughout person's life. The benefit of the NDIS is that the diagnosis is less important than a child's functional capacity. These considerations need to account for the functional impact of a disability and the supports that exist in the community.

We are aware of community concern relating to some of the statements in the paper that imply that short-term early intervention will address a child's needs for life. Developing and communicating a strong research evidence base that relates interventions to outcomes will maintain trust and broader community support for changes to the NDIS.

## **Supporting parents and carers to exercise choice and control**

### **We need to prioritise the 'how' over the 'why'**

The recent NDIS consultations have sought feedback on the rationale and basis for proposed changes, but there has been little opportunity to provide meaningful feedback on the proposed implementation of these changes, and on the refreshed operating model.

While the consultation paper sees the role of incorporating the voices of consumers and experienced clinicians into the process of developing the funding framework, it is the way processes and changes are implemented – the how – that shapes a person's experience of the NDIS, more so than the rationale underpinning the changes. We would welcome the opportunity to be further involved in developing the operational elements and support the inclusion of participant and stakeholder feedback in co-designing a system and operational model that includes the voices of people with disability.

## **We need to look at how the approach shapes both the LAC and ECEI models**

The consultation refers children aged under 13 years, which has implications for both ECEI and LAC practice. The role of the Partner in the Community differs significantly between ECEI and LAC, and many of the proposed strategies may not apply directly to LAC delivery. For example, the paper references access to short-term early intervention (STEI) by an ECEI Partner but this option is only available through ECEI and it is not yet clear how this will affect children aged 7-13.

## **Addressing conflict of interest**

Regional areas have a thin labour market, and removing all potential conflicts of interest is likely to be challenging. Children and families want to work with someone who understands their individual journey, and we need to ensure that managing the conflict of interest does not negatively affect the families, or reduce their choice and control. Instead, the onus needs to remain on the NDIS Quality and Safeguard Commission in partnership with the Agency to develop and implement robust processes to ensure providers are adhering to best-practice principles and mitigating conflicts of interest.

The paper highlights the unique needs of children on the autism spectrum, and stratifies the levels of support based on areas of high, medium and low support. These classifications are driven by the frequency, regularity and sustained effort of supports over the duration of a plan, but they assume that these supports are available in the community and accessible by families. As an ECEI Partner in regional areas, we see the impact of a lack of specialist supports and therapeutic options on children and families and we need to understand further how the high and medium support levels will be implemented in regional areas where providers are scant. At present, there is significant underutilisation of plan funding and supports, and many providers of funded supports have waiting lists to access support. Underutilisation of plan funding is tied to a lack of access to support <sup>3</sup>.

We are encouraged by the development of the landmark National Disability Strategy, and we see that greater collaboration at all levels of government to identify and incentivise the opportunities in the sector and promote inclusion in mainstream services will realise the benefits of the Scheme. We believe that people with disability, and their families and carers, need a voice in access and inclusion across governments.

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<sup>3</sup> Lowitja Institute (2019) Understanding disability through the lens of Aboriginal and/or Torres Strait Islander people – challenges and opportunities. [Lowitja\\_UnderstandingDisability\\_291019\\_D4\\_WEB.pdf](#)