

# SUBMISSION TO THE NDIS REVIEW

# **About Professionals and Researchers in Early Childhood Intervention**

Professionals and Researchers in Early Childhood Intervention (PRECI) is an Australian research-to-practice network focussed on outcomes for young children with developmental disabilities. PRECI was established as a not-for-profit public company limited by guarantee in June 2022.

**Our vision** is excellence and equity in services for young children with developmental disabilities and at risk of developmental delay in Australia.

**Our purpose** is to lead Australian early childhood intervention<sup>2</sup> (ECI) research, knowledge translation, quality practice, and policy for young children with developmental disabilities.

#### PRECI has been formed to:

- provide a national network connecting ECI practitioners<sup>3</sup> and researchers with a focus on supporting collaborative research, knowledge sharing and peer support.
- provide ECI professionals, community organisations, researchers, higher education institutions and policymakers with an authoritative source of information about best practice in ECI.
- identify, develop, promote, and raise awareness of advances in effective models of service delivery to ensure consistent implementation of best practice for young children and families.
- promote a national approach to coordinated and comprehensive pre-service, in-service, and
  post-graduate training opportunities for professionals working with children with developmental
  delay and disability, and their families and related mainstream services, on contemporary and
  evidence-informed practices.
- develop a national research framework and conduct research projects to advance and inform ECI within Australia.
- promote interdisciplinary collaborations to ensure advances in research and translation of research into practice.
- provide nationally coordinated and timely responses to federal policy, funding, and service delivery guidelines to support consistent contemporary practice in ECI.

On the basis of the expert knowledge and collective experience of its members across Australia, PRECI is in a strong position to provide substantial commentary and advice about the delivery of NDIS services to young children with disabilities and their families.

PRECI members<sup>4</sup> hold leadership positions across various professional and research organisations across Australia. Their views are based on Australian and international research and practice and have been continuously sought by Federal and State governments for the last 30 years.

<sup>&</sup>lt;sup>1</sup> The term 'developmental disabilities' in this document encompasses children with disability, developmental delays, and developmental concerns.

<sup>&</sup>lt;sup>2</sup> Early Childhood Intervention (ECI) is described as "the process of providing specialised support and services for infants and young children with disability and/or developmental delay, and their families in order to promote development, well-being and community participation". (ECIA Vic/Tas, 2023)

<sup>&</sup>lt;sup>3</sup> ECI practitioners are minimum bachelor qualified members of a collaborative team (e.g., speech pathologists, occupational therapists, psychologists, physiotherapists, specialist teachers, social workers...)

<sup>&</sup>lt;sup>4</sup> See below for current PRECI Board members.



# **Background**

PRECI welcomes the introduction of the NDIS, particularly the additional resources it provides and the potential changes to the lives of people with disability. We welcome the increased support for young children with disabilities and their families.

The views of PRECI are based on our understanding of what needs to be implemented to achieve best practice services and outcomes for children and their families. The implementation of the NDIS for children with disabilities and their families has been unusual in the lack of a specific focus on early childhood development.

PRECI supports the description of best practices identified in the National Guidelines for Best Practice in Early Childhood Intervention.<sup>5</sup> The identification of these practices included a review of the Australian and international literatures, drawing on findings across the health and education fields. PRECI members were active in the development of these guidelines and look forward to any opportunity to participate in the guidelines review.

To be successful for children and their families, the NDIS needs to deliver particular types of services that are in line with these guidelines, which include:

- Family-centred and Strengths-based Practices
- Culturally Responsive Practice
- Inclusive and Participatory Practices
- Engaging the Child in Natural Environments
- Collaborative Teamwork Practice
- Capacity-Building Practice
- Evidence Base, Standards, and Accountability and Practice
- Outcomes-Based Approach

It is our view that the NDIS for children and their families has not been implemented in a way that ensures all services are based on the delivery of best practice. There are three main reasons for this:

- 1) The design of the NDIS was developed for adults, rather than designed with children in mind.
- 2) The NDIS services for children were designed in the absence of a disability policy for children, which would have provided the necessary context for these services.
- 3) The NDIS services for children were designed with inadequate involvement by educational experts, education departments or the early childhood sector, which would have provided expert knowledge of child development and the integration of NDIS services with the broader services for children.

Many of the issues identified below are a consequence of the design of the implementation of the NDIS for children, the inadequate consideration of the role of families, and the importance of children's participation in the community and early childhood settings.

<sup>&</sup>lt;sup>5</sup> Early Childhood Intervention Australia (2016). *National Guidelines for Best Practice in Early Childhood Intervention*. Retrieved from: https://www.eciavic.org.au/resources/eci-best-practice-guidelines



Our children are our most valued resource. They are the future of the nation, but in order for them to be able to flourish as adults, we need to provide children with the conditions they need to flourish.

Right now, we are failing to do this for young children with developmental disabilities and their families. As a result, many children with developmental disabilities are less well prepared to take advantage of future learning and social opportunities and will need more support and resources than they would otherwise require.

According to available evidence:

- Parents are not able to exercise true choice and control under the current arrangements.
- The well-being of families of children with developmental disabilities has been worsening.
- Children with emerging developmental concerns are not receiving the support they need in the community.
- The age at which children are being deemed eligible for ECI has risen significantly under the NDIS.
- Fewer infants and toddlers are accessing ECI services.
- The strong and guiding commitment to prevention that informed the State and Territory-funded services has been abandoned.
- Best practice in ECI support has been compromised by funding drivers (e.g., pricing arrangements and price limits guide) and administrative arrangements.
- There is inadequate regulation or oversight of the quality of the ECI services provided through the NDIS.
- Access to ECI services and funding is inequitable, with those in rural and remote areas receiving fewer services.

Federal and State Governments and the wider society they represent are not getting value for the investment they are making in ECI services. We need to rethink the nature of these investments, and reconfigure the supports and services provided to children with developmental disabilities and their families to yield better results for everyone.

A new approach is needed, one that reconfigures not only the NDIS, but also the contexts within which the NDIS supports children with disabilities and their families. This means the active involvement of services in the community at large, including early childhood education and care (ECEC), community health, social welfare systems as well as other related mainstream early childhood supports.

In the first instance, this requires appropriate governance and leadership that addresses the lack of early childhood and early intervention expertise on the NDIS Board and the need for a children's portfolio within the NDIA to enable better and consistent oversight of this area.



## **Issues and recommendations**

We welcome the Government's review of the NDIS. The focus of our response is children aged 0-8 years.

Our response is in two sections, one addressing the broader context and identifying long term actions, the other describing actions that the NDIS can undertake immediately.

### Section 1. The broader context and long-term actions

Develop a	continuum of services for children with developmental concerns
Best Practice	<ul> <li>Children with developmental concerns or delays are supported through collaboration and referral between health, early childhood, and community services to receive a level of additional support that addresses their needs and the needs of their families.</li> </ul>
Issue Action	<ul> <li>Families who have concerns about their children's development do not have a clear and consistent pathway during the phase before they might become eligible for the NDIS.</li> <li>There is no standard Tier 2 form of support for children who may or may not have long-term developmental disabilities.</li> <li>As a result, many children and their families are not receiving timely support during the most sensitive developmental phase.</li> <li>In the absence of valued alternative Tier 2 services, the NDIS is experiencing an unprecedented growth in demand for ECI services.</li> <li>Redistribute funds to services in the community that have been commissioned to provide services for children with developmental concerns (e.g., community health services) and revise the role of Early Childhood Partners.</li> <li>Ensure all children eligible for the NDIS have access to a skilled community-based key worker<sup>6</sup> whose fundamental task is to support service navigation and determine an optimal service pathway which includes information provision,</li> </ul>
Duild cou	planning and goal development.  nected and inclusive early childhood services
Best practice	<ul> <li>Children with developmental disabilities can learn and develop alongside their peers in early childhood services, with additional support when required.</li> </ul>
Issue	<ul> <li>The transfer of ECI services to the NDIS meant that they are no longer embedded in the mainstream ECEC service system, but instead have become part of a disability services system.</li> <li>This has meant that NDIS services for children are disconnected from ECEC services</li> </ul>
	and are unclear about their role in inclusion and their relationship with inclusion support services.

<sup>&</sup>lt;sup>6</sup> A Key Worker is a primary point of contact for a family and includes family-centred and strength-based provision of emotional support, information and advice, identifying and addressing needs, supporting skills in advocacy and service coordination. (Alexander & Forster, 2012)



Action	<ul> <li>Clarify the role of ECI services and the current disconnect between ECI and ECEC services in providing inclusion support.</li> <li>Develop cross-jurisdiction policies that support the creation of clear service pathways between ECI and ECEC, so children benefit from smooth access to mainstream services.</li> </ul>
Building co	onnected and inclusive communities
Best Practice	<ul> <li>Children with disabilities and their families can access and participate in community-based services which are well informed and confident in the support that children and families are getting from NDIS services.</li> </ul>
Issue	<ul> <li>The relationship between community-based services (e.g., schools, playgroups, social welfare organisations, community health services) that work with children with developmental disabilities was never established, is ad-hoc, and is currently causing much confusion.</li> <li>These services are not getting the degree of support from ECI providers that they</li> </ul>
	had before, and many sole, unregistered ECI providers do not know how to provide effective team-based supports to mainstream ECEC services.
Action	<ul> <li>All States and Territories that hold historical and current ECI knowledge need to develop a consistent approach that addresses the needs of community-based services in the establishment of coordinated interactions with the NDIS, a revised role of the EC partners, and ECI providers.</li> </ul>
	<ul> <li>Ensure States and Territories engage in ongoing capacity building to support children's access to mainstream, community-based supports.</li> </ul>
Improve d	ata gathering and use
Best practice	<ul> <li>There is consistent data collection reporting and monitoring across State and Territory services and the NDIS so that children with developmental concerns or delays are being identified early and are able to access appropriate supports quickly.</li> </ul>
Issue	<ul> <li>Neither the States and Territories nor the NDIS knows how many young children there are with developmental concerns or delays or what services or supports they are receiving.</li> </ul>
	<ul> <li>The number of young children needing but not receiving some form of ECI support has grown due to growing delays in identifying children with developmental disabilities as well as long delays in eligible children receiving NDIS services.</li> <li>Lack of data on these children is hampering the development of services to meet</li> </ul>
	their needs and creating entrenched inequities in service provision.
Action	<ul> <li>All States and Territories need to develop monitoring and reporting systems for identifying children with developmental concerns or disabilities and collecting data on where they are, what services they receive, and how effective these services are in achieving child and family outcomes.</li> <li>This data should be used for quality improvement of the ECI services system.</li> </ul>
	Data on workforce also needs to be collected and published.



Section 2. Actions that the NDIA can undertake immediately within the NDIS. These are matters that can be addressed through the design of the NDIS itself.

Improve	access to NDIS services for children
Best practice	Children with developmental disabilities and their families are able to access NDIS services regardless of where they live.
Issue	<ul> <li>There is inequitable access to the NDIS for young children.</li> <li>Thin markets are evident throughout Australia, but particularly in rural and remote communities.</li> </ul>
Action	In areas where there are few or no ECI services, the NDIS should commission appropriate registered organisations to provide these services.
Improve	adherence to best practice in NDIS services for children
Best practice	The NDIS services for children are designed to ensure services deliver Best     Practices in ECI and that children and families benefit from the intended outcomes     of high-quality services.
Issue	<ul> <li>There are perverse incentives for families to choose services that provide supports that are not in line with the Best Practice Guidelines.</li> <li>There are a lack of sufficient technical assistance supports for providers to</li> </ul>
	implement best practices.
Action	<ul> <li>Ensure that DSS/NDIA work with State and Territory jurisdictions to develop a national approach to the provision of a continuum of services, with DSS's role being to provide national technical assistance.</li> </ul>
	<ul> <li>Ensure there is a national approach that is responsive to the local context across</li> <li>States and Territories.</li> </ul>
	<ul> <li>Make changes to the pricing arrangements and price limits guide to encourage use of funding within the Best Practice Guidelines (e.g., restructure with separate components of funding for travel, key workers, family capacity building and wellbeing).</li> </ul>
	<ul> <li>Provide funding for technical assistance to ensure ECI practitioners receive high quality training and coaching in order to deliver services in line with the Best Practice Guidelines.</li> </ul>
	• Continue with the action identified in Australia's Disability Strategy (2021-2031) Early Childhood Targeted Action Plan to update guidance for best practice in ECI.
Build wo	rkforce capacity
Best practice	Best practice services for children with disabilities and their families are delivered by a skilled and stable workforce.
Issue	<ul> <li>There is an acute shortage of appropriately qualified and experienced ECI practitioners. Recruiting and retaining staff is a major problem for ECI service organisations.</li> </ul>
	• This is contributing to long waiting lists for ECI services and is compromising access, quality, and choice for families.
	The latest national workforce plan for the NDIS does not address ECI workforce issues.



	There are disincentives for services to employ specialist early childhood teachers,
	who are the professionals most equipped to understand the learning and
	development needs of young children and their families.
Action	<ul> <li>Develop a national plan to expand the ECI workforce and ensure appropriate preservice and in-service training.</li> <li>Work with tertiary institutions to promote preservice training that focuses on ECI</li> </ul>
	evidence-based practices and to link them to work options.
	Develop strategies for providing technical assistance and induction services for new ECI practitioners, and career support for existing workforce. (e.g., financial subsidies for services employing new graduates).
	<ul> <li>Develop strategies to retain expertise in the sector (e.g., further study incentives)</li> </ul>
	<ul> <li>Review the pricing arrangements and price limits guide to encourage services to</li> </ul>
	employ early childhood teachers.
Support f	amilies of young children with developmental disabilities
Best	A child development approach which recognises the critical role of families in
practice	supporting the development of young children, including the additional challenges
	experienced by families who are raising a child with disabilities, is core to services.
Issue	<ul> <li>The specific needs of families for capacity building and well-being are not addressed under the NDIS.</li> </ul>
	Families, particularly in disadvantaged areas, are lacking in resources (e.g.,
	technological, in-home support) and social connections.
Action	<ul> <li>Conduct a review of supports and services currently available to families of young children with developmental disability.</li> </ul>
	Develop and implement a family-centred system of supports for families from the outset when children are first identified as having a developmental concern or delay.
	Ensure support plans address parent and family needs in addition to those of the child and include parent and family goals.

We recommend that these limitations would be best addressed through the development of an overarching **national policy plan for children with developmental disabilities**. This should complement existing policy frameworks governing children's health, education, child protection, and mental health. We also recommend that an ECI **Guarantee** be developed, specifying what children with developmental disabilities and their families will receive through State and Territory services and the NDIS.

Develop an overarching national policy plan for young children with developmental disabilities.			
Best practice	<ul> <li>All stakeholders – families of young children with disabilities, ECI service providers, and governments – are clear what outcomes are being sought for children with disabilities and their families.</li> </ul>		
Issue	<ul> <li>The Federal Government has not yet articulated an overall policy regarding how the needs of young children with disabilities and their families can best be met.</li> <li>With the advent of the NDIS, there has been a loss of policy coherence and direction.</li> <li>The lack of policy means that there is a lack of clarity about outcomes, and no way of evaluating State and Territory investment.</li> </ul>		



# Action DSS to lead the development of an overarching policy plan for young children with developmental disabilities to complement the Australian Disability Plan. The development of this policy framework and associated guidelines to be done in collaboration with the ECI sector, including families, service providers and peak bodies. Strengthen mechanisms for clear communication, planning, local coordination, and policy development between federal and state governments, with a focus on young children with developmental disabilities. The policy plan should not focus exclusively on young children's needs but should also include measures to address the wellbeing of families of young children with developmental disabilities. Develop an ECI Guarantee for children with developmental disabilities and their families. All families who have concerns about their child's development or who have a Best practice child with a developmental disability have immediate access to a package of ECI services and supports as part of the universal service system. There is no consistent provision of additional services and support for families Issue who have concerns about their child's development or are awaiting clarification regarding their child's needs and possible access to the NDIS within the universal early childhood and family support service system. The NDIS lacks a clear statement written for families and community members working with children about the support it provides to children with developmental disabilities and their families and what each family will receive, and how this relates to the services and supports they receive prior to accessing The NDIS pricing arrangements and price limits guide is adult-centric and does not reflect the use of ECI evidence-based practices. Action Ensure that every family who has concerns about their child's development has consistent access to funding of services and supports within the universal early childhood and family support service system (i.e. Tier 2) Ensure that every child with developmental delay or disability and their family is guaranteed a package of ECI services and supports that includes, but is not limited to: Dedicated funding for the first 12 months regardless of the characteristics of the child's developmental delay or disability. Access to a skilled community-based key worker whose fundamental task is to support service navigation and determine an optimal service pathway which includes information provision, planning and goal development. Provision of timely and effective short-term ECI services by registered local providers. Focus on both child and family outcomes on the basis of ECI Best Practice Guidelines. Change the structure of the pricing arrangements and price limits guide to foster the implementation of ECI Best Practice Guidelines, including funding for travel, key workers, family capacity building and well-being.



We believe that developing and implementing a plan that includes all these elements will have a number of direct **immediate and long-term benefits**.

#### Immediate outcomes

- Young children with developmental disabilities will be identified early and provided with timely evidence-based services and supports.
- Families who have concerns about their child's development will have a clear pathway to services that will provide them with support and guidance while their concerns are being explored.
- Workforce shortages will be better understood and there will be strategies in place to address these
- Services will provide ECI supports based on the Best Practice Guidelines.
- All key stakeholders will have an increased understanding of the extent to which all children with developmental disabilities (NDIS participants or not) are receiving the services they need and of how effective these are in meeting their needs and those of their families.



These direct impacts will contribute to longer-term positive outcomes for children with developmental disabilities and their families.

### **Long-term outcomes**

- Young children with developmental disabilities will make greater developmental progress and be better able to participate meaningfully in family, community, and educational settings.
- Families of young children with developmental disabilities will be supported and be better able to meet the needs of their child(ren).
- Early childhood services will be better able to meet the needs of all children, including those with developmental disabilities.
- The States and Territories and the NDIS will get better value for the money they are investing in ECI services.
- Clear service pathways across jurisdictions will be established.



PRECI members would welcome the opportunity to meet and discuss our recommendations with the NDIS Review Panel.

In addition, we would like an opportunity to discuss with the panel the evidence base for community based ECI. As indicated above, PRECI includes a number of key long-term researchers and professionals in the Australian field of ECI.

Kind regards, Kerry Bull (Secretary)

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### **Inaugural PRECI Board Members (in alphabetical order)**

Dr Anoo Bhopti: Senior Lecturer, Monash University, Dept of Occupational Therapy

Dr Kerry Bull: ECI consultant

Paula Buttigieg: Executive Director Wize Therapy

Leigh Dix: Senior Occupational Therapist

Kerry Dominish: CEO EarlyEd John Forster: CEO Noah's Ark Inc.

Megan Fox: National Early Childhood Specialist, Mission Australia

Dr Susana Gavidia-Payne: Adjunct Associate Professor, Educational and Developmental Psychology,

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Assoc Prof Christine Johnston: School of Education Western Sydney University

Denise Luscombe: ECI Consultant, Director Postural Care Australia

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Dr Tim Moore: Senior Research Fellow, The Centre for Community Child Health, The Royal Children's

Hospital