

## SUBMISSION TO THE NDIS REVIEW – AUGUST 2023

### 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.<sup>1</sup> 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.

PRECI board 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.

***Our submission responds directly to the Review's areas for improvement questions.***

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

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

### How can we empower you through the planning process?

*You have told us that applying for the scheme is not easy. Once you are in, getting a plan is no different. This means dealing with the scheme is negative, confusing and stressful from the get go.*

#### **PRECI'S comments and recommendations:**

There are two issues here: how to make access to the scheme simpler and how to make planning a more positive experience.

##### *Re gaining access to the scheme:*

- All parents who might be eligible for the NDIS would benefit from having access to a skilled community-based worker whose fundamental task is to support service navigation, provide information, and help the parents determine an optimal service pathway. A national framework that describes the role of such workers should be developed, but local adaptations will be needed and where they are based will vary from community to community.
- We recommend that funds be redistributed to services in the community that have been commissioned to provide ECI navigator services for children with developmental concerns (e.g., community health services), and that the role of Early Childhood Partners be revised accordingly.

##### *Re developing ECI plans:*

- Helping new parents identify their priorities and goals is a skilled task. Those involved in the planning role should have explicit training and support in the relational skills needed to engage parents effectively, and the specific skills in facilitating parental decision-making. They also need to know how to learn about family strengths, resource and circumstances, and how to promote family wellbeing and capacity building.
- To make this task easier, we recommend that the service plans should be reframed so that they focus on the needs of parents / caregivers, the family as a whole, as well as those of the child. The formulation of short-term and long-term goals are essential components of this process.

### What is the best way to provide supports for those not in the NDIS?

*You've told us that disability supports are not planned, funded or governed as part of a whole ecosystem. This means that you are pushed to join the scheme to get supports that should be delivered in the community.*

#### **PRECI'S comments and recommendations:**

In considering this question, there are two key issues to keep in mind. First, In the early years, the nature and extent of the children's developmental problems are emerging and it may be unclear whether the child has a developmental problem or not. The second issue is that there are no absolute cut-off points for any disability: every disability is a continuum.

- Parents are usually the first to raise concerns, and their concerns should be taken seriously and support provided at this point. This can take the form of an augmented universal service such as a facilitated playgroup or other forms of community-based supports. The aim is to provide the parent with initial but comprehensive developmental guidance and support without waiting for a formal diagnosis or eligibility determination while also enabling the child's development to be monitored.
- We need a service system that can cater for every gradation of child functioning, not one that only caters for those who are at one end of the continuum and neglects the rest, some of whom will be only marginally less impaired than those deemed eligible for the NDIS. This would involve strengthening the capacity of mainstream ECEC and other services to support children with varying degrees of developmental delays and other developmental challenges.
- It would also mean providing additional support for those who are experiencing significant developmental challenges, temporary or otherwise, including children who may eventually need NDIS support. The Productivity Commission's original vision for the NDIS was that it would be complemented by a Tier 2 level of services catering for those who had developmental challenges but were not deemed to need NDIS support. This was not made clear to the States and Territories, who responded to the advent of the NDIS by withdrawing many of their ECI-related services, leaving the NDIS as the only source of support.
- This situation needs to be rectified. DSS/NDIA need to 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 fund national technical assistance to the workforce delivering ECI services, whether through the NDIS or at Tier 2 level.
- The provision of universal and Tier 2 early childhood development services is best managed by States and Territories and delivered by expert ECEC and ECI practitioners. Rather than the federal government continuing to manage the Tier 3 ECI services, consideration should be given to returning responsibility for the early years / ECI service segment of the NDIS to the States and Territories.

### How would you define reasonable and necessary?

*We have heard that no-one understands what 'reasonable and necessary' really means. The definitions are too broad and confusing. This means that it's impossible to know what to expect from the scheme.*

#### **PRECI'S comments and recommendations:**

- *Reasonable* and *necessary* are vague terms that will always be contested. To make access to the scheme as smooth as possible, the number of such contestable sticking points should be kept to a minimum.
- Rather than using the *reasonable* and *necessary* criteria as a basis for funding and planning, it would be better to focus on the *outcomes* that are being sought in ECI service, e.g, building the capability of families / caregivers, ECEC services providers and communities to provide young children with the experiences and opportunities they need to become fully participating members of their families and communities.

- Funding and planning should be based on providing families with the *support and resources* they need in order to achieve the ultimate outcomes of ECI, namely, to build their capacity to meet their children's needs and to build the child's capacity to participate meaningfully in all aspects of family and community life.

### **What is the best way to support children with disability... and those with emerging developmental concerns?**

*We've heard that early intervention for young children is not working. It means that you aren't getting the supports you need and it's not helping children or their families.*

#### **PRECI'S comments and recommendations:**

There are three issues to consider here: the relationship between ECI and mainstream services, the pathway to obtaining ECI support; and the effectiveness of the services being provided.

*Re the relationship between ECI and mainstream services:*

- The transfer of ECI services to the NDIS meant that they are no longer as closely linked to the mainstream ECEC, education, health and recreational services, and instead have become part of a disability service system. This has meant that NDIS services for children have less contact with ECEC and other services, and many providers are unclear about their role in inclusion and their relationship with inclusion support services.
- Young children with disabilities and their families need the specialist support of ECI practitioners, but they also need to be fully involved in community activities and ECEC services that are used by all other children and families. These constitute crucial learning environments and should be recognised as a form of early childhood intervention complementing the support provided by ECI teams.
- The relationship between the NDIS services and community-based services (e.g., schools, playgroups, social welfare organisations, recreational, community health services) that work with children with developmental disabilities was never established, is ad-hoc, and is currently causing much confusion. These services are not getting the degree of support from ECI providers that they had before; many sole, ECI providers do not know how to provide effective team-based supports to mainstream ECEC services and may not be aware of best practice in ECI.
- There is an urgent need to clarify the relationship between ECI services on the one hand, and mainstream ECEC, education, health and community services on the other. Provision of inclusion support should be recognised as an essential part of ECI.
- 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. This needs to take into account the current inequities in the availability of ECI resources across the country – there are large areas that do not have EC Partners and have few or no ECI providers.

*Re the pathway to obtaining ECI support:*

- What is currently lacking is a clearly articulated pathway that describes how parents can gain access to appropriate developmental support services (Tier 2 services) and hence to NDIS (Tier 3) services. The problem lies in the early and middle parts of this pathway – what parents do when they have concerns about their child’s development, how the child’s development is then monitored – rather than the final stages – referral to the NDIA.
- Articulating the full pathway should be part of the process of negotiating with the jurisdictions to develop a national, but locally focussed, approach to the provision of a continuum of services (as discussed earlier).

*Re the effectiveness of services being provided*

- Under the NDIS there is such poor oversight of what forms of ECI support are being provided to parents of young children that there should be serious concerns about the quality and effectiveness of much of this support. What is clear that that there has been a widespread shift away from home-based family capacity-building service models to the provision of clinic-based child-focussed therapy services, despite the fact that the latter approach is not appropriate with young children, is not in line with best practice recommendations, and is less effective.
- To ensure that the services provided to parents of young children with developmental disabilities, three actions are needed. First, the existing set of Best Practice Principles need to be expanded to become a fully-fledged practice framework with tools, examples and resources. Second, the NDIS needs to introduce a quality assurance mechanism to ensure that these best practices are being observed. Third, technical assistance for the ECI sector needs to be provided, with a credible organisation engaged to provide resources and training to the practitioners.

**How can the market be better designed, structured and supported?**

*You've told us the 'market' for getting your supports isn't working. This means it's hard for you to find supports that meet your needs or good providers.*

**PRECI’S comments and recommendations:**

There are three problems with the market for ECI services: the shortage of services in some areas, the overall workforce shortages, and the limited capacity of many services to provide comprehensive best practice services to families and support for staff.

*Re the service shortages*

- Where there are few or no services available (such as in rural and remote areas), the NDIS should commission appropriate registered ECI organisations to provide services in these areas. To ensure that the services offered are suitable for the particular region or community, planning and delivery should be done in collaboration with the local mainstream and community services.

### Re *workforce shortages*

- A national plan to expand the ECI workforce and ensure appropriate pre-service and in-service training and support should be developed. This should address both pre-service and in-service postgraduate training needs. At the pre-service level, tertiary training institutions need to be engaged to ensure that they provide preservice training that focuses on ECI evidence-based practices and to inform them of the work opportunities and requirements in the ECI sector. At the in-service level, there needs to be a range of options, ranging from micro-credentialling to Masters-level courses and doctoral qualifications.
- Attracting and retaining suitably qualified staff has become a major challenge for ECI organisations since the advent of the NDIS. Under the current billable hours model, many services cannot afford to release their staff for professional development and team building activities that would make the working in the organisation more satisfying and there retain more staff. To meet this challenge, we recommend that ways of supporting organisations to provide such support be explored.
- At present, ECI organisations are often in the position of spending time inducting and training new ECI practitioners only to see them branch out on their own as soon as that is finished. We recommend 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).
- Under the NDIS, there has been a great reduction in the employment of early childhood teachers in ECI services in some jurisdictions. This is despite the fact that they are specifically trained in working with young children, which is not the case with some of the other disciplines involved in ECI services. The pricing arrangements and price limits guide should be revised to encourage services to employ early childhood teachers.

### Re the *capacity of service providers*

- Many young children with developmental disabilities need the support of more than one specialist, but coordinating these specialists is difficult if they all work for different agencies. To be able to provide parents with access to interdisciplinary teams of ECI professionals, ECI provider organisations need to be large enough to employ a full range of discipline specialists and be able to effectively deploy them when required.
- The same question of size applies to the ability of organisations to support ECI staff. Only service organisations of a certain size are able to run induction programs for new staff (particularly those newly graduated) and to provide ongoing professional training and guidance for existing staff.
- Our long experience in this field suggests that organisations cannot ensure access to interdisciplinary teams when required or support staff adequately unless they are catering for at least 100 children. The majority of early childhood service providers in the NDIS cater for less than 10 clients.

### How should outcomes and performance be measured and shared?

*You have told us that you don't have enough information to make informed choices. This means that there is not enough evidence to make good decisions.*

**PRECI'S comments and recommendations:**

There are two issues here: how to ensure that parents can make informed choices, and how to measure and share outcomes and performance.

*Re informed choices:*

- The NDIS seeks to give parents choice and control over what goals they want to achieve and what services they receive. Such choices are meaningless and may even be harmful if the parents are not provided with the conditions they need to make informed choices.
- The conditions needed for making informed choices include:
  - The parents are clear about what ECI services are, how they work and what best practice is
  - The parents are clear about the goals they want and the most effective ways of achieving these
  - There are not too many or too few choices
  - All services meet approved standards
  - The parents are protected from predatory marketing from services providers who want parents to choose their services
  - The parents are protected from misleading or false claims about what interventions are most effective or the outcomes that particular services claim they can achieve
- Parents need skilled guidance to help them identify goals and choose how these can best be met.
- The NDIS planning process needs to be reconfigured to ensure that families have the conditions they need to make informed choices and that they are supported by skilled staff in making decisions about the services they need.

*Re measuring outcomes and performance:*

- In order to know if the ECI services being provided are effective, we need to be clear about what these services are trying to achieve. According to the ECI Best Practice Principles, the aim of ECI services is to build the capabilities of parents and caregivers to provide children with the experiences and opportunities needed to develop the functional skills that will enable them to fully participate in family, community and ECEC environments. That is what should be measured and monitored.
- The best way to do this is to get feedback from parents about the extent to which these goals are being met. Parent feedback measures that include the following questions should be developed and used regularly:
  - Is the service being provided addressing the issues that are of most importance to families?
  - Are the service providers respectful of the family beliefs and circumstances?
  - Are the parents and caregivers developing their capacity to meet the child's needs more effectively?

- Is the child developing the functional skills they need to be able to participate in family and community-related activities?
- Are the needs of all family members being considered?

### How would you build better outcomes or goals into your plan?

*We have heard that there is a lack of focus on long term outcomes. This means you are missing out on supports that enrich your life and future.*

#### **PRECI'S comments and recommendations:**

There are two issues to be considered here: how the ECI plans are structured, and what the current price guide funds.

##### *Re the structure of the ECI plans*

- We know that the developmental progress and functioning of young children with disabilities is dependent upon the functioning of the family as a whole, yet ECI plans are largely focused on goals for the child and neglect those of parents and other family members.
- We also know that parents benefit from having positive and realistic expectations for their child's long-term future, as well as having goals that will contribute to these long-term goals but can be achieved in the short term.
- The current ECI plans do not clearly identify goals for parents and family as well as the child, nor do they clearly identify long-term goals. The service plans need to be reframed so they include goals for parents and for the family as a whole, as well as long-term as well as short-term goals.

##### *Re the services funded by the NDIS*

- What ECI services are provided is largely determined by what the NDIS funds. As the NDIS is currently structured and funded, there are perverse incentives for families to choose services that provide supports that are not in line with the Best Practice Guidelines, and for service providers to adopt business models to match. As a result, there has been a widespread swing back to clinic-based therapy services, even though these are less effective and appropriate with this age group than home-based capacity-building services.
- The simplest way to rectify these regrettable developments is to change the pricing arrangements and price limits guide to encourage use of funding within the Best Practice Guidelines (e.g., create separate funding streams for travel, key workers, family capacity building and wellbeing, so that parents do not feel they are sacrificing services for their child when they are choosing support for themselves as well).

### What does good service from someone helping you navigate the NDIS look like?

*You've told us that the people who are supposed to help you navigate the scheme aren't doing this. This means that you aren't clear how to get the best out of the scheme.*



**PRECI'S comments and recommendations:**

- To be able to support and empower parents effectively, those who help them navigate the system and those who work directly with them need knowledge of the service system, training and experience in the provision of ECI services, and training in the relationship skills needed to build effective partnerships with parents. The ultimate goal is to build the capacity of the parents and caregivers to be able to provide the conditions that will benefit all family members, and will give the child with developmental disabilities the experiences and exposures they need to become fully participating members of the family and the wider society.
- As part of the process of developing and fully fledged best practice framework for ECI, the knowledge and competencies of ECI navigators and providers should be identified. The relevant undergraduate training institutions should be engaged to ensure that these knowledge and skills are introduced to all practitioners who might be eligible to work with young children and their families. For practitioners, evidence-based training should be provided by credible training organisations and a peak body with technical skills. knowledge and evidence.
- One feature of good service is the availability of a Key Worker. They play a critical role in simplifying and coordinating the demands on the family. A Key Worker is a primary point of contact for a family and is the conduit to their team, 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.
- Good service involves being considerate of cultural and linguistic diversity and supportive of Aboriginal and Torres Strait Islander people. We should be seeking to employ practitioners that represent the ethnic and Aboriginal and Torres Strait Islander communities that we work with.

**How should the safeguarding system be improved for a better NDIS?**

*We have heard that the NDIS has not done enough to safeguard you. This means that you don't get the support and safeguards you need in a way that works for you.*

**PRECI'S comments and recommendations:**

- Our main concern is not with safeguarding so much as with NDIA's lack of oversight of the nature and quality of the ECI services being provided to young children and their families. It is unconscionable that the government should be paying for services and not have any way of knowing what is being offered and how effective it is.
- As noted earlier, we recommend that feedback and other processes and outcome measures be developed and deployed to ensure that services are genuinely family-centred, build parental/caregiver capabilities, and are evidence-informed so optimal child and family outcomes are achieved.
- The ECI sector lacks clear guidance on what constitutes best practice and what they are expected to provide young children with developmental disabilities and their families.

Therefore we recommend that the existing Best Practice Principles be expanded to become a full practice framework that offers detailed guidance on how to deliver services that are consistent with the Principles.

- The ECI sector lacks an authoritative source of technical advice and resources on best ECI practices. We recommend that funding be provided for a national technical assistance body to ensure ECI practitioners receive high quality training and coaching in order to deliver services in line with the Best Practice Guidelines.

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

***We would also like to point out that we can see various ways in which PRECI could play a role in implementing many of the recommendations made in our submission, both in the short and long terms. PRECI board members would be happy to explore these with the NDIS Review panel.***

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Kind regards,

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

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

Dr Kerry Bull: *ECI consultant*

Paula Buttigieg: *Executive Director Wize Therapy*

Kerry Dominish: *CEO EarlyEd*

Mel Farrell: *Early childhood special educator*

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, RMIT University*

Assoc Prof Christine Johnston: *School of Education Western Sydney University*

Denise Luscombe: *ECI Consultant, Director Postural Care Australia*

Ros McAulay: *Senior Speech Pathologist*

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