**EARLY CHILDHOOD INTERVENTION AUSTRALIA (ECIA)**

**SUBMISSION**

**Productivity Commission Position Paper**

**NDIS Costs Review**

7 July 2017

**Early Childhood Intervention Australia**

**Who we are**

Early Childhood Intervention Australia (ECIA) is the national professional association that promotes and supports the interests of young children with developmental delay and/or disability, and their families.  Its members are early childhood intervention (ECI) professionals and service providers, including private practitioners, mainstream and early childhood sector organisations. ECI Services are based in metropolitan, rural and remote centres throughout Australia and include small community organisations, large disability and children’s services agencies and various government departments, reflecting the diverse ways in which services are provided nationally to young children with developmental delays and disabilities and their families.

**What we support**

ECIA endorses a framework of evidence-based practices that promote, encourage and support principles that drive positive outcomes for children and families. These practices include:

* **Family centred and culturally responsive practice**, which creates culturally inclusive environments for families from all backgrounds, and recognises the central role of families in children’s lives.
* **Inclusive and participatory practice**, which recognises that, children regardless of their needs have the right to participate fully in their family and community life.
* **Engaging the child in natural environments,** to promote inclusion through participation in daily routines, at home, in the community, and in early childhood settings.
* **Collaborative teamwork and capacity building practice**, where the family and professionals work together as a collaborative and integrated team around the child, to build the capacity of the child, family, professionals and community.
* **Evidence base, standards, accountability**, to ensure ECI services comprise practitioners with appropriate expertise and qualifications who use intervention strategies that are grounded in research and sound clinical reasoning.
* **Outcome based approach**, which focuses on outcomes that parents want for their child and family, and on identifying the skills needed to achieve these outcomes.
* These practices lay the foundation for each individual’s successful participation as a valued member within our diverse community. This has been articulated in our *National Guidelines of Best Practice in Early Childhood Intervention*.

**What we do**

ECIA leads and strengthens the sector by influencing policy, promoting quality services and building shared understanding of best practice to ensure that ECI practitioners and service providers are able to best support young children with developmental delay and/or disability and their families.

We support practitioners and service providers in their work with families to ensure that families are engaged and gain the skills and confidence in caring for their child and all members of the family.

We promote providing support to children and their families while they are waiting for services to ensure children and their families get support right from the start. We promote best practice principles and provide resources and materials to our ECIA members that assist them to provide quality services when working with children and families.

**RESPONSE TO PC REQUESTS FOR INFORMATION**

**INFORMATION REQUEST 3.1**

*Scheme Eligibility*

 Early Childhood Intervention Australia (ECIA) does not support maintaining ‘List D — Permanent Impairment/Early Intervention, Under 7 years.  *Diagnosis based eligibility* is in contradiction to the principles of the Insurance Scheme and Early Childhood Intervention principles, both of which focus on the functional impact of the developmental delay or disability on areas of major life activity.

 There is a positive impact on dispensing with List D as, under the *ECEI Approach*, families are able to access supports without formal diagnosis. Access to supports at any point in the ECEI Approach pathway, is based on functional need. There is no preconceived belief that a particular diagnosis will result in access to a full package of supports. If the family proceeds to the planning stage and ultimately to a plan, their plan will be reviewed at the plan cessation date against functional goals stated in the plan.  At this stage, the child’s functional needs and subsequent goals are reviewed to determine if a further individualised funding support plan is required. The extent of the child’s delay may have decreased such that it is no longer considered significant, and the child may exit from the full Scheme as they no longer require that level of support.

To date, the Nepean Blue Mountains ECEI Partners use their specialist expertise to determine whether a child would benefit from a funded package of supports. With a decision based on functional need, rather than diagnosis, this process has supported approximately 40- 50% of all children who have accessed the pathway, to be deemed eligible for a funding package. Approximately 50-60% of children of this cohort are being supported to participate in community and mainstream supports. This is a positive outcome of the ECEI Approach using functional needs to determine full scheme eligibility. No diagnosis is required to support access.

If diagnosis alone is used to determine access to a funding package, there is the risk that children with a diagnosis, who could be supported in community and mainstream services, would be entering into the scheme. Parents/Carers, of all children with a formal diagnosis, can then reasonably expect that once in the full scheme, there is no other pathway for their child. The strength and diversity of community and mainstream supports ultimately determine whether a child can be adequately supported without requiring access to a funding package. It is acknowledged that this will vary across jurisdictions.

The Agency’s preferred tool for measuring outcomes is called the Paediatric Evaluation of Disability Inventory (PEDI), (originally published in 1992) which has been revised as a Computer Adaptive Test (CAT) – the PEDI-CAT.

The PEDI-CAT has proven through consistent use in the NBM pilot and currently with NSW ECEI Transition Providers to be significantly inaccurate in determining the level of function, in particular, for children with an Autism Spectrum Disorder.

The majority of children assessed come up as mild on the final PEDI-CAT score due to the scoring system implemented by Scheme Actuaries, even though individual functional domain scores within the PEDI-CAT show that the child is below median range for a child the same age.

Some planners, it has been reported, are using the level, as determined by the T-score, to determine the level of funding for a child’s individual funding package. In some instances the planners are not reading the supporting evidence in the Family Service and Support Information form which is supplied as part of the pre planning documentation by the ECEI Partners and Transition Providers.

*Definition of Developmental Delay*

We affirm the adequacy of the *definition of Developmental Delay* as set out in section 9 of the NDIS Act 2013 and note that the ECEI Approach sits within the Scheme as a pathway approach to providing timely support to children who are at risk of delayed development.

The ECEI Approach does not have eligibility requirements other than a concern that a child age 0-6 years is not meeting their developmental milestones. The ECEI Partner would use tools such as the ‘Ages and Stages’, to assess the child’s functional developmental needs and work with the family to:

•  Explain the nature of the delay and how to support the child at home and in the community;

•  Refer to relevant community and mainstream supports such as Community Health and Child Care;

•  Provide interim therapeutic support services and monitor the child’s development – these supports are provided in a best practice approach of working with and through the key people in the child’s life and in the places where the family/child spend time.[[1]](#endnote-1)

If the ECEI Partner’s professional opinion determines that the child requires longer term funded supports and the child meets the eligibility requirements for Developmental Delay, then they would start the NDIS access process.

**INFORMATION REQUEST 4.1**

*Scheme Supports*

 The definition of *Reasonable and Necessary* as set out in section 34 of the NDIS Act 2013 and the NDIS Operation Guidelines gives sufficient clarity.  There continues to be some issues around apportioning responsibility between the NDIS/mainstream support systems which can hold up approval of individual plans.  There needs to be greater specificity on a State level about funding responsibility between governments’ funded systems than what is currently in the *Principles to Determine the Responsibilities of the NDIS and other Service Systems* as many of these systems are in fact state-based.

**DRAFT RECOMMENDATION 4.1**

*Plan review*

ECIA agrees that the NDIA should implement a process for allowing minor amendments or adjustments to plans without triggering a full plan review. Currently, where there have been minor errors such as plan management choice, a full review is required. As well, when Assistive Technology needs have been determined after assessment, trials and prescription, a full review is required rather than a determination that the request is reasonable and necessary and subsequently approved.

In some instances for young children where continence aids have been requested at the planning stage, the planner has only approved a continence assessment without the supply of nappies. This then needs to be completed and a full review triggered to have the continence aids included in the package. This is unreasonable and unnecessary. Due to growth spurts, children can outgrow a piece of equipment such as a wheelchair or orthotics that should be replaced as needed without the full review process.

ECIA does not support the use of phone planning for young children. While the ECEI Approach is operated by specialist practitioners, there is no need for phone planning. For older children, aged 7 – 10 years, it is suggested that they would best be supported through a face to face meeting.

**DRAFT RECOMMENDATION 5.1**

*Information, Linkages and Capacity Building*

ECIA fully supports the recommendation that the ILC funding be increased to the full scheme amount of $131 million for each year during transition and form part of the next COAG review in five years time. The development of these service systems is critical to the success of the ECEI Approach being able to support children to participate in their community and mainstream activities.

Given the specialist nature of ECI service provision, we recommend quarantining a portion of ILC funding commensurate with the projected number of children per state.  Doing this would ensure that children 0-6 years have access to capacity building activities, and their parents have support from informal peer networks outside the formal NDIS system.

**INFORMATION REQUEST 7.1**

*Workforce Strategy*

The best way to develop a holistic workforce strategy to meet the workforce needs of the National Disability Insurance Scheme is to consult with the representatives from different parts of the disability sector and relevant professional accreditation bodies.

 Early Childhood Intervention is a specialist area of expertise employing early childhood practitioners that specialise in development of children age 0-6 such as Early Childhood Educators, Psychologists, Social Workers and Allied Health professionals. As such solutions to workforce challenges in the Early Childhood Intervention sector require tailored solutions informed by the ECI sector.

**GENERAL COMMENT**

*Numbers of Children in the Scheme and exiting the Scheme*

ECIA believes in the cost benefits of Early Childhood Intervention, both in terms of the Early Childhood Early Intervention Approach, and early childhood intervention supports available through a full package of supports from the scheme. This review should not be about costs or cost savings.

 Possible reasons for the numbers of children in scheme could also relate to the following:

* There are 10,450 children 0-6 with approved NDIS Individual Support Plans in Australia, which comprises 14 per cent of the total NDIS population.[[2]](#endnote-2)
* The Dyson, Cutter and Moore’s estimate of 11,600 children is not a good predictor of *future* numbers if the ECEI Approach has time to mature and develop across Australia.
* 7-14 group is 44 per cent of the Scheme.  More needs to be done at an earlier stage.

ECIA looks forward to the continuing release of the data that is being analysed by the Scheme actuaries that tracks over time, the pathway for young children with developmental delay or disability.

1. *NDIS Early Childhood Early Intervention (ECEI) Approach*, National Disability Insurance Agency, 26 February 2016, page 4 [↑](#endnote-ref-1)
2. *NDIS National Public Dashboard,* 31 March 2017, National Disability Insurance Agency, page 2 [↑](#endnote-ref-2)