



# NDIS Costs (Productivity Commission Transition Paper

June 2017

EarlyEd Early Childhood Intervention Service (Early Education (EarlyEd) Inc.) is pleased to have the opportunity to comment on the NDIS Costs (Productivity Commission Transition Paper June 2017).

EarlyEd has selected key 3 areas which address the cost benefits of and changes needed to ensure good planning.

1. Maintenance of the current approach to ECEI Providers who are actively practicing in the sector.
2. Transparency in planning.
3. Fact sheets/ videos that are appropriate for families of children accessing NDIS (as many documents are unhelpful eg. '*reasonable and necessary*'. The information at <https://www.ndis.gov.au/participants/reasonable-and-necessary-supports> is misleading for families of children.)

## Box 4.7 Why are good planning processes important?

### *Outcomes, benefits and equity*

The ECEI planning approach by ECEI Transition Providers in NSW, with expertise and experience in early child intervention and with children with delays in development or disability and their families, has provided a pathway for quality and appropriate NDIS planning for families of young children.

### Benefits:

Now that EarlyEd is at the point of starting service provision with families with NDIS plans that have come through the ECEI NDIS pathway ie prepared by experienced ECI staff, the benefits are noticeable compared to outcomes of former LAC planning. These include the

1. appropriateness of the plan for the needs of children
2. awareness of good practice in ECI by families when they start services
3. an increased awareness of taking a holistic approach to intervention
4. recognition of the value of planning by families
5. recognition of the value of inclusion activities in a plan by families
6. an understanding of "reasonable and necessary" supports by families

### Transparency in Planning:

P167: Consulting with participants about plan content

**ACTION REQUESTED:** Transparency in ECEI needs to be increased to ensure families feel listened to and respected and value the planning process and its outcome.

Under ECEI NDIS has instructed service providers not to show the final planning documents to families before sending them in to NDIS for approval. EarlyEd is concerned that this does not make the planning process transparent for families.

As a response to this EarlyEd has tried to engage families closely with the wording of the their plan at the planning session, added in wording that reflects their particular preferences, while following the guidelines from NDIS ECEI and only sharing the parts of the plan permitted by NDIS ie their goals and family background.

EarlyEd feels that it is important for families to feel confident that the story being presented on the family's behalf represents their needs. Confidence will lead to satisfaction with the outcome, an

Submitted by: Kerry Dominish, CEO, Early Education (EarlyEd) Inc.

11.7.2017

understanding of “reasonable and necessary supports”, and easier review in 12 months and reduction in appeals. Families are very anxious to ensure they complete the planning process effectively and feel that if they don’t get the right amount of funding for their child that they are failing them. Transparency will reduce stress levels and help them feel ownership of the plan.

Under ADHC funding services to families have been limited by the amount of services that could be shared under block funding. NDIS is offering families the opportunity for their child’s individual needs to be represented in their level of funding. Transparency will increase their confidence that their support is individualised and that their child’s needs can be met. Under Best Practices in Early Intervention families are used to choice and control over how their services are offered. Many ECI families understand and value choice and control and find the lack of transparency a mismatch with the philosophy of choice and control under NDIS. Families need to feel that they can request supports based on their individual need rather than feel that NDIS has formulaic expectations.

‘Reasonable and necessary’: INFORMATION REQUEST 4.1 P152

*Is the National Disability Insurance Scheme Act 2013 (Cwlth) sufficiently clear about how or whether the ‘reasonable and necessary’ criterion should be applied?*

In the case of supports for children the National Disability Insurance Scheme Act 2013 (Cwlth) is not sufficiently clear about what supports are ‘reasonable and necessary’. As ECEI Transition Providers we have avoided using any of the material provided by NDIS as it is misleading. The underlying approach is clear but examples are for adults and give families a false impression of what is acceptable for children.

#### ACTION REQUESTED:

A. NDIS to produce appropriate videos, web links and documents for families of children. Therapeutic Supports – NDIS is not promoting the Best Practices in Early Intervention i.e. through a *key model approach* or intervention through *inclusion activities* and promotes individual allied health services as its only examples of therapeutic supports. The long term insurance value and costs benefits of using the Best Practices in Early Intervention will not be realised until the language in these videos/ written examples is addressed.

B. Individualise approaches to funding and not be limited by benchmarking under NDIS.

The following areas are susceptible to inappropriate interpretations of *reasonable and necessary*:

1. No iPad’s - Through assessment by a speech pathologist iPad’s are sometimes selected as the appropriate communication device for children. It is to be used solely by the individual child as a communication device not a toy. NDIS is saying that no iPad’s will be approved. A child’s right to the full time use of this is being refused and therefore their right to communicate is denied. As a consequence of the denial of funding for this mainstream device of \$1000 device a substituted device for example a Liberator cost \$6,000.

2. Trialling and implementing of assistive technology is not being fully funded or individualised approaches being supported and is benchmarked and will cost more in the long run when devices fail. Careful selection, trialling, implementation and maintenance of equipment to match the needs of a child in the context of their environment and development will insure good outcomes and reduce long term costs. Benchmarking reduces individualisation and good outcomes.

3. “Daily personal activities” – NDIS has indicated that it is not likely to fund personal care for children as typically family members are responsible for their child’s care 24/7 or arrange for this to be covered. This does not acknowledge that children with a disability frequently need more than the typical level of care for their age group.

Families are requesting care. They need an indication for when it might be appropriate to request care support.

4. “Help with household tasks to allow the participant to maintain their home environment” Families are requesting cleaners and assistance to help them manage the demands of supporting their child with disability. Families need an indication of when it might be appropriate to request support and how much.

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NDIS has said that families of children should be able manage all their house work. This does not recognise that families who have a child with significant levels of disability require a great deal of their parent's time in care and that parents need help to maintain their home, support the needs of their other children and to maintain their own well-being. Without support how can families provide their child with the amount of intervention time they need? Funding families with care support will build resilient families and ensure better outcomes for the child with the disability.

#### 5. Social participation:

Families are not being funded to support social participation. They cannot manage to involve their child with a disability in social activities without support because the child with disability demands their full attention and they cannot care for the other children in their family at the same time. The siblings are missing out and so are they.

Eg. Families are requesting payment for individual swimming lessons because the child cannot learn alone. This has been knocked back.

Families need an indication for when it might be appropriate to request support for social participation.

#### Assessment:

P155 "Other study participants were critical of how certain tools were used, particularly in relation to early childhood and early intervention (chapter 3)."

**ACTION REQUESTED:** Replace the PEDICAT with an age appropriate assessment tool. The PEDICAT is inappropriately being used with young children as it poorly differentiates degree of disability for child aged 0 – 6yrs. It does not inspire confidence in families that it establishes their child's degree of need. It asks questions not designed to be appropriate for a child and doesn't identify the child's areas of need. It achieves scores that have to be countered by reports and other assessment tools. Families find these inaccurate scores very stressful and worry that they will affect their planning outcomes.

Streamlined entry for early intervention: *INFORMATION REQUEST 3.1: The Commission is seeking feedback on the advantages and disadvantages of maintaining 'List D — Permanent Impairment/Early Intervention, Under 7 years — No Further Assessment Required' in the National Disability Insurance Agency's operational guidelines on access.*

**ACTION REQUESTED:** Retain List D and fund supports to manage transition out of NDIS

• This list "*reduces the burden on families to demonstrate that their child will benefit from early intervention and/or provides certainty that support will be provided*" and is cost effective and will support good outcomes.

- This list is evidence based and recognises ongoing need for intervention.
- Families have the right to not ask for formal assessments on their child.

Asking families to prove eligibility may mean that they fall out of the system and don't support their child. This occurs when they want to avoid labelling or are stressed by the process.

This list is

- unlikely "*to contribute to supports being provided to children who are unlikely to benefit from such supports or*
- be "*discouraging or inhibiting exit from the scheme*".

Families will happily move to a more appropriate service if

1. there is appropriate assessment of the child's outcomes using quality tools
2. appropriate community services are available without long waiting periods eg speech therapy
3. ECEI providers can support families back into mainstream services
4. changes occur at transition points eg starting school

Do we really think families want to stay in NDIS? They will move if adequately supported to do so.