Submission to the Productivity Commission Inquiry into the National Disability Insurance Scheme (NDIS) Costs

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Response to the Productivity Commission Review of National Disability Insurance Scheme (NDIS) Costs

1. Background

Noah’s Ark welcomes the opportunity to provide comment in relation to the Productivity Commission’s Issues Paper on the Review of NDIS Costs.

Noah’s Ark has been involved in the NDIS from its commencement through our services for children in the Barwon and ACT trials and currently we are involved in the roll out in North East Metropolitan Melbourne and other areas of Victoria.

Noah’s Ark is a non-government organisation providing early childhood intervention (ECI) services to children with disabilities and other additional needs and their families and carers. We are the largest early childhood intervention service in Victoria operating from 19 centres across metropolitan and regional Victoria. Last year these programs reached 1,800 families. Noah’s Ark currently receives funding from the Victorian Government (Department of Education and Training) for the delivery of ECI services, and has regional involvements in the Kindergarten Inclusion Support, Pre-School Field Officer and Parent to Parent Programs. Noah’s Ark was previously funded by the Australian Government (Department of Education) as an Inclusion Support Agency as part of their Inclusion Professional Support Program. Noah’s Ark also provides training and resources.

Noah’s Ark has been active in the development of services for young children with a disability both in Victoria and nationally and links to the early childhood intervention field internationally.

2. Scheme costs

It is our view that the model of early intervention being implemented by the NDIS is not clear. There is no clarifying policy document. The lack of a theory of change, clarity of evidence base or clarity of the intended outcomes means that the NDIS may not implement early intervention for young children and their families in the most beneficial or cost effective way or avoid unintended consequences.

As the Productivity Commission noted in its report of Disability Care and Support, the NDIS will inevitably face difficulties in choosing or targeting any early interventions to be funded or purchased, because it is easier to identify interventions that are safe and work and that are likely to yield the highest benefits or have lowest costs than to put these measures into practice. The Commission suggested clarification would be needed to decide:

- The standard of evidence required to decide on whether to adopt a particular intervention
- How evidence be obtained
- How particular interventions sit with the funding of other disability supports

Developing a uniform approach to early intervention services for young children with a disability presents difficulties in the Australian context. Each jurisdiction has developed different approaches to services for children with a disability. Some services have been more educationally orientated and others more focused on allied health services. Some have been

focused on the child, while others have broadened their focus to include the family. Some have been influenced by evolving knowledge of child development while others have not.

3. Scheme Boundaries

The need for clarity about the model of early intervention is evident in developments in Victoria. The NDIS in Victoria practically combined two different programs for children with a disability and their families. The Victorian State funded early childhood intervention services were integrated into the State’s early childhood policy and service network. It viewed the development of children with a disability as consistent with the development of all children. The Australian government’s Helping Children With Autism and Better Start Initiative primarily provided grants to families to purchase allied health therapy. These services were independent of other services.

The difference between these two approaches is apparent in the differences in their intended outcomes. The Victorian services promoted outcomes for the child, for their family and for engagement in the community. This approach included both outcomes and participatory outcomes, consistent with the World Health Organisation’s International Classification of Health and Disability. The Australian government programs, by contrast, primarily focused on the development of the child’s skills.

The evidence behind the Victorian government’s approach has been extensively reviewed and published. The Australian government has only published in detail in relation to children with autism.

3.1 The two ‘literatures’ related to services for young children with a disability

A KPMG report commissioned by FaHCSIA, Reviewing the evidence on the effectiveness of Early Childhood Intervention (2011) observed that there are two literatures about early intervention in early childhood. While both can be seen to share a common starting point, that “early intervention refers to the strategies, practices and therapies designed to help

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3 Department of Education and Training (n.d) Early Childhood Intervention Services


6 Centre For Community Child Health (2010) DEECD Early Childhood Intervention Reform Project: Revised literature review, State of Victoria, Melbourne


children with a disability or developmental delay to participate as fully as they are able in social, educational and economic life”, the approaches taken to how this is achieved are different. One approach is “a service system that mobilises to support children and families with emerging needs relating to a child’s disability or developmental delay”. The second approach is a “process, where intervention modifies the natural environments in which children develop – that is, the environments that children inhabit and experience in their everyday lives – to improve the functioning of both children and their families”.

The Centre for Community Child Health (2010)\(^9\) observed: If early childhood intervention is defined in terms of providing children with experiences and opportunities that promote competencies that enable them to participate meaningfully in home and community environments, then the focus will be on ensuring that families and other carers are able to provide children with such experiences and opportunities. In other words, the aim will be to ensure that the child’s everyday learning environments are optimal. If early childhood intervention is defined in terms of providing children and families with services, then the emphasis will be on the nature and quality of those services, and on changing the child’s behaviour directly rather than on changing the child’s learning environments. (p 32)

Clarity about the purpose and intended outcomes of services is essential because it leads to quite different service responses. Approaches aimed at changing children’s behaviour have typically been provided by a therapist in a clinical setting and based on professionally identified deficits in the child development. The parent may or may not be present and there is no expectation for external communication, although that may happen. Approaches designed for the child, family and community typically have had a strong focus on the family's goals, address real life problems, occur in the home environment and intentionally reach out to other adults who spent time with the child, including an early childhood services like childcare. While both approaches are informed by allied health understandings, they offer very different opportunities to the child and their family, are also based on very different models of service and require different types of workforce development.

3.2 The value of early childhood early intervention

The value of early intervention in early childhood more broadly has gained greater recognition in both the research and government policies in recent decades. For example, From neurons to neighborhoods: The science of early childhood development (National Research Council and Institute of Medicine, 2000), provided a compelling description of the importance of early life experiences to a child’s later development. It highlighted the critical influence that positive relationships with adults had on a child and the highly interactive interplay between a child’s innate drive to develop and the environment in which he or she lived. This greater understanding of what supports children’s development linked with research into the economic benefits of early intervention for children. The human capital argument proposed that as children’s skill development built on earlier skill acquisition, it was more efficient to support a child’s early development. There was also evidence of a cost benefits in early intervention for later expenditure, such as on the criminal justice system, poorer health outcomes and special education\(^10\). Two key policy areas to emerge are the

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9 Centre For Community Child Health (2010) DEECD Early Childhood Intervention Reform Project: Revised literature review, State of Victoria, Melbourne
importance of support for positive parent-child interactions\textsuperscript{11} and the potential of services for young children to improve the opportunities of children at risk of poor developmental outcomes \textsuperscript{12}.

A contemporary example of an early intervention approach that directly includes children with a disability is the Children and Families Act (2014) in the UK\textsuperscript{13}. This Act addresses similar issues to those raised by families and family advocates in Australia. It is designed to reduce the complexities and inconsistencies of the services that families and young people deal with. Its purpose is to drive the development of more holistic plans of support for children. The Children and Families Act has been developed specifically from the perspective of the needs of children and young people.

The core propositions in the new Children and Families Act are that:

- Families and young people are to be the centre of the planning process
- There is a focus on supporting children and young people from 0 - 25 years
- Local Authorities advertise their core offer of services for children and young people
- Children with significant needs are to have one combined education, health and care plan
- There will be individual budgets available to those who choose them

The development of a focus across the 0 - 25 years age range is significant. Its purpose is to facilitate the development of a cohesive set of services that support children with disabilities into adulthood. The coordination of services throughout the 0 -25 years period will enable young people to develop the skills and have the experiences that will enable them to enter adulthood with the greatest potential for independence and capacity to participate in the community. The economic rationale for the reforms is if young adults with disabilities achieve greater independence and participation they will be less dependent on services and more able to make their own contribution.

3.3 A holistic approach to children

In its submission to the Productivity Commission Inquiry into Disability and Care, Early Childhood Intervention Australia (ECIA)\textsuperscript{14} proposed that the principles of the NDIS should include:

1. Recognition that each child and all families as unique
2. Outcomes for children with disabilities align with desired outcomes for all children

\textbf{The importance of the early years.} Evidence into Action Topical Paper, for the Australian Research Alliance for Children & Youth. Parkville, Victoria: Centre for Community Child Health
\textsuperscript{14} Early Childhood Intervention Australia (ECIA) (2010) Submission to the Disability Care and Support inquiry.
3. Recognition that the child, the family and their participation within community settings need to be supported.

The ECIA submission noted that the NDIS should have a holistic view that recognised that disability does not only affect an individual, but also the whole family. It should support the education and development of the child and the social participation of the child and his or her family. This approach is consistent with the United Nations Convention on the Rights of The Child (1989), in which the child is the subject of rights and full membership of society.

Early intervention was regarded as essential to:

- minimise the effects of disability, potential ongoing dependency and the need for more costly services throughout life
- support families to provide optimal family life and avoid increased risk of poor mental health, family distress and breakdown
- support children with disabilities to benefit from greater participation in universal early childhood education and care settings, allowing them to make friends, play, learn with others and achieve alongside their peers.

3.4 Segregation

There is not a universal recognition that children with disabilities should be full participants in the community. Building on a history of 80 years of the institutional segregation, there are still strong tendencies towards the community segregation of children with disabilities. The routine institutionalisation of children with disabilities during the first half of the twentieth century meant they were excluded from the community during the period in which many community based services for children were developed. In the 1970s, when institutionalisation ceased, the new services set up for children with disabilities were segregated services. Ongoing segregation continues through disability specific services and special schools as well as through discrimination and barriers to participation in the community services and the community more broadly. Children with disabilities and their families face discrimination every day in ECEC services across Australia. Children are redirected to “more suitable” services where other children with disabilities may be present and services may “scare” parents away by questioning their own capacity to cope, or by overdramatising the amount they will need to do for the child to participate.

3.5 The purpose of the NDIS involvement in services for young children with a disability and their families

The NDIS appeared to adopting a holistic approach to early intervention during its establishment phase. This is evident from various documents rather than a cohesive public statement.

At the broadest level, the General Principles from the Act indicate that any supports for children need to consider the best interests of the child as paramount and any decision or action should consider the need to:

- Protect the child from harm
- Promote the child’s development, and
- Strengthen, preserve and promote positive relationships between the child and the child’s parents, family members and other people who are significant in the life of the child.  

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15 Operational Guideline – Children – Overview
More detail is given in the Guidelines on Planning and Assessment. These variously refer to the intention of services for young children and their families as:

- optimising learning, development and social participation
- facilitating the development of the functional domains of self-care, language, cognition and motor development
- supporting families, within the context of their values, priorities and aspirations, to enhance their children’s learning and development
- enhancing a child’s functioning to undertake activities of daily living.\(^{16}\)

These guidelines go on to identify practices which are regarded as effective and beneficial, including those that:

- Link to mainstream programs of support, where specialist providers build the capacity of those programs to support the child and family’s inclusion and participation,
- Are coordinated by a Key Worker using a trans-disciplinary approach where there are multiple interventions delivered across a range of different environments,
- Use a “routines based” approach which facilitates meaningful daily activities in a child’s natural environment, and
- Enable a family to support their child’s development and learning.\(^{17}\)

Most recently this approach has been reinforced by the NDIS Early Childhood Early Intervention approach, with its focus on:

- achieving the best outcome via a family-centred approach
- supporting greater inclusion in mainstream settings
- building child and family capacity.\(^{18}\)

The Guidelines on Planning and Assessment also reference a document developed for the USA Office of Special Education Programs to identify good practice which is called: Seven Key Principles: Looks Like / Doesn’t Look Like. The seven principles include that:

- Infants and toddlers learn best through everyday experiences and interactions with familiar people in familiar contexts.
- All families, with the necessary supports and resources, can enhance their children’s learning and development.
- The primary role of a service provider in early intervention is to work with and support family members and caregivers in children’s lives.
- The early intervention process, from initial contacts through transition, must be dynamic and individualized to reflect the child’s and family members’ preferences, learning styles and cultural beliefs.
- ‘Plan’ outcomes must be functional and based on children’s and families’ needs and family-identified priorities.
- The family’s priorities, needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support.

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\(^{16}\) Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Early Childhood

\(^{17}\) Ibid

\(^{18}\) Early Childhood Early Intervention Approach
• Interventions with young children and family members must be based on explicit principles, validated practices, best available research, and relevant laws and regulations.\(^{19}\)

The themes of children developing functional skills and the ability to participate in daily family life and families developing the capacity to understand, support and advocate for their child is evident in a pilot undertaken to develop an outcomes framework for the NDIS. The areas considered for children and families were:

- Children gain functional, developmental and coping skills that are appropriate to their ability and circumstances
- Children show evidence of self-determination in their everyday lives
- Children participate meaningfully in family life
- Children participate meaningfully in community life
- Specialist services assist children to be included in families and community

The areas considered relevant to families were:

- Families understand their children’s strengths, abilities and special needs
- Families know their rights and advocate effectively for their children with disability
- Families help their children develop and learn
- Families feel supported
- Families are able to gain access to desired services, programs, and activities in their community
- Families enjoy health and wellbeing\(^{20}\)

While these references might be seen as representing purpose, principles, beneficial practices and potential outcomes for providing services for children with a disability and their families, they are not in a format suited to provide guidance in the context of a major initiative being introduced across very different State and Territory contexts.

3.6 The NDIS in practice

The NDIS appears to have commenced with an approach that supported a holistic approach to early childhood early intervention during trial. It is less clear it is maintaining that focus in rollout.

3.6.1 The lack of independent advice for families

Young children with disabilities and their families present specific challenges to the introduction of a National Disability Insurance Scheme (NDIS). At the time that families first seek assistance for their child they are least clear about what they need, the services available and what services offer. Many families also experience considerable stress, as the result of not having sufficient information to take control of their situation, potential differences in family members’ reactions to a child having a disability, the additional


demands on time and resources that a child’s disability may give rise to and challenges to their confidence in parenting.\textsuperscript{21}

Providing clarity to families about the purpose of early intervention services for children with a disability is very important if they are to be informed consumers. To date the NDIS has not provided families with independent advice in a systematic way. Families are largely dependent on services which have a vested interest in providing advice. When services act in an ethical way they cannot provide advice in within the context of a clearly articulated purpose because that purpose has not been published in sufficient detail or disseminated. Service to specifically provide advice have not been funded. The best opportunity to promote independent advice has been through the proposed appointment of ECEI Partners. This process has not had the outcome it intended, as discussed below.

\subsection*{3.6.2 ECEI partners}

The Early Childhood Early Intervention (ECEI) Approach was introduced to manage access to early childhood intervention for children aged 0-6 years. Its aim was to ensure that parents or primary caregivers can provide young children who have developmental delay or disabilities with experiences and opportunities that help children gain and use the functional skills they need to participate meaningfully in their environment.

The NDIA were to engage Early Childhood Providers around Australia as Early Childhood Partners who would use their expertise in Early Childhood Intervention to work with families to understand the child’s developmental delay or disability, identify goals and discuss evidence based supports that can help meet the goals of the child and family.

The brief called for Early Childhood Partners who were suitably experienced and qualified, had strong local knowledge and an understanding of the needs of children and their families.

The activities of the Early Childhood Partners were to include:

- Providing information
- Referring the family to a mainstream service like a Community Health Service, playgroups or peer support group
- Identifying if a child may benefit from some short-term intervention and provide those services to inform the child’s longer term support needs
- Identifying that a child requires long-term specialised early childhood intervention supports then assist the family to request access to the NDIS, submitting the required information and evidence to the National Access team.
- Undertaking the planning process with families who receive access to the NDIS
- Coordinating a combination of the options above\textsuperscript{22}.

This approach was based on a successful trail in the Blue Mountains.

In practice the NDIA decided that it would not appoint registered service providers, or potential registered providers, to these roles as the involvement in the being the point of access and in the planning process was a conflict of interest with being a service provider.


\textsuperscript{22} NDIA website (n.d.) Early Childhood Early Intervention Approach https://www.ndis.gov.au/ecei.html
The result has been the appointment of services which do not have a background in early childhood intervention or who are from out of area.

For example, Latrobe Community Health Service, which is based in Gippsland and which has an involvement in allied health services for young children not eligible for early childhood intervention, has been appointed as the Partner in the Central Highlands (Ballarat) region and the Western District (Warrnambool) region. The Merri Community Health Service, which is based in norther metropolitan Melbourne and does have a small early intervention program, has been appointed the partner in Ovens Murray (Wodonga / Wangaratta) region. The Brotherhood of St Laurence has been appointed in the North East Metropolitan Melbourne. Except for The Brotherhood of St Laurence these partners have no local knowledge. Except for Merri Community Health, they have no knowledge of Early Childhood Intervention.

These services are expected to be the entry point for families and to refer ineligible families to other local services. The outcome of this process contradicts the stated aims of the ECEI Partners. Further partners are to be announced.

3.6.3 ILC

Whilst the range and type of service proposed to be funded under the ILC program appear consistent with the overall goals of the program, there is a lack of clarity in the ILC Commissioning Framework to be clear about this. What is clear, is that there is not enough ILC funding to meet the needs of the current market; particularly considering the needs of ATSI, CALD, rural and remote communities and the specific needs of young children with, or at risk of, developmental delay and/or disability and their families.

In relation to young children, the current structures rest on the need for a solid foundation of universal supports and services (e.g. Community Health, Maternal and Child Health, Early Childhood Education and Care). Whilst some states have a strong universal early childhood system based on an educational policy context, others do not.

4. Planning Processes

4.1 Planning

*It should be noted that while the PC asks for comment about the planning process, there is no information about the planning process and how it is supported in the public domain.*

There has been a significant change in how plans have been written. These changes have not been documented or an explanation provided.

During the trial plans were written as Transdisciplinary Packages. These offered a flexible way to providing services. Since the roll out the plans have changed to being constructed from line items. Plans now indicate specific hours of therapy for the child. This can be put as a total of therapy hours or it can be directive, such as indicating the number of hours for Occupational Therapy and Speech Pathology. These plans appear to be directing families to seek specific therapies rather than a holistic approach. The new plans are also stipulating limits to travel costs. If a service is to be holistic and home based, then the cost of working in homes needs to be addressed at a policy level rather than by the introduction of limits.

Based on our understanding through talking with families, the planning process that families and providers are currently trying to navigate is unhelpfully cumbersome. For example,
implementation in North East Metropolitan Melbourne (NEMA) is currently requiring families to:

a) meet with the ECEI Access Partner to assess eligibility and receive referral to the LAC if eligible,
b) talk with the LAC to complete their plan and receive referral to a Service Coordinator,
c) meet with the Service Coordinator, and then;
d) contact their provider/s of choice.

It is only at the first point of contact, with the ECEI partner, that there is any requirement that the staff have any expertise in understanding the discrete needs of young children with a disability and their families.

Rather than provide a soft entry point for families of young children with a disability, this layered system provides unnecessary hurdles that increases the burden on families and the likelihood that the most vulnerable and marginalised families will not persist and receive the supports they need. Our anecdotal evidence is that those that do persist, but do not have the advocacy skills required to articulate the needs of their child and family, are at risk of receiving less funding.

Further to this, the planning process is not reliable, clear nor accessible. We can report that currently:

- Families are being provided with a financial intermediary without informed consent and are later appealing that component of the plan (which is taking several months).
- Service coordination is being provided as a standard item, even when parents indicate that they do not want, nor require it.
- Calls to the 1800 NDIA number have an extremely long wait-time. Emails and requests to return calls are very rarely followed up. Those participants who can talk to a NDIA representative, or navigate the website, are receiving conflicting advice about implementation of the scheme. This is adding to our concern that we do not currently have well-informed consumers that can exercise the choice and control that is one of the pillars of the Scheme.
- The review process is flawed, with review plans being extended for six month blocks due to the workforce shortage of Planners and a rush to meet planning targets. (add Barwon details)

### 4.2 Assessment

The Paediatric Evaluation of Disability Inventory – Computer Adaptive Test (PEDI-CAT) is the assessment tool currently being used by ECEI Partners for screening and eligibility requirements. It is our understanding that there are issues relating to the use of this test and the necessary qualifications and training requirements of the Interviewer/Examiner.

The authors of the PEDI-CAT indicate that although parents/caregivers can complete the PEDI-CAT independently, results should be interpreted by a professional:

- with a background in education, early childhood education, paediatrics and/or rehabilitation,
- with an understanding of functional assessments and scoring to be able to understand and explain the intent of the individual items and meaning of different types of scores, and:
- training in PEDI-CAT Administration.

It is our understanding that these requirements are not met by all current professionals conducting the test and consequently there is varied use, and at times misuse, of the tool. For example, while the PEDI-CAT has been designed to tailor the items to the individual child and avoid irrelevant items, parents of children with a significant disability have reported
being asked questions related to much older children and/or higher functioning children. This is causing unnecessary distress to families and is setting the scene for mistrust with professionals from the beginning of their interactions with the scheme.

We also have concerns that PEDI-CAT ‘Responsibility’ domain requires children to use several functional skills in combination to carry out life tasks and is therefore not suitable for children before the age of 3 years as indicated by the authors.\(^{23}\)

5. **Market readiness**

The NDIA’s priority on developing a market with many service providers may be in conflict with best practice approaches to services for young children.

The market for early childhood disability services is very small, as the following example from Barwon demonstrates. At the end of the June quarter the number of NDIA plans for children aged 0 – 4 years in Barwon was 325, or approximately 2% of this age group. As services for young children include 5 year olds, the number of young children with plans would have been approximately 400 children. If the number of families a professional need to work with to be financially viable is 20, then the market in Barwon can support 20 full time practitioners.

One of the foundation principles of best practice in early childhood early intervention has been the development of teams of therapist and educators with different backgrounds who can support families and each other to develop a more holistic understanding of a child’s developmental needs. This replaced an approach where individual therapists approached a child through the prism of their own discipline and families had to manage the competing priorities and advice from professionals.

There are a wide range of professions relevant to child development. A minimal team might include Speech Pathology, Occupational Therapy and Special Education. A large team might also include a Physiotherapist, Psychologist and Social Worker. In Barwon, the number of families means that that can be three large teams of professionals or 6 small teams of professionals with interdisciplinary expertise. If more than 20 practitioners are involved, then it would no longer be viable to specialise in early childhood. This is in a context in which university courses do not provide specific training in working in the early years and practitioners have been supported to develop their expertise in early childhood on the job with support from their organisation and peers.

An approach by the NDIA to prioritise as many providers over specialisation is contrary to building a workforce that has expertise in early childhood. Services for young children with a disability and their families should be managed in a context in which values specialisation in early childhood and can deliver best practice.

6. **Conclusion**

The Productivity Commission reports that the NDIA has identified cost pressures including higher than expected numbers of children (especially in South Australia, Victoria and the ACT trial sites). We request that the Productivity Commission investigate this. According to the NDIA’s quarterly reports from the last year of the trial the number of 0-4 year olds supported by the NDIS in the Barwon trial site varied between 319 in September 30, 2015,

282 in March 31, 2016 and 325 in June 2016. The 325 children aged 0 – 4 years with plans at the end of the June quarter represents just under 2% of this age group in the region, lower than the number supported by Victorian services, in our understanding, and less than the number proposed by the Productivity Commission. The variation over the year means a much lower percentage at times. It is also our understanding that there are significant variations in the size of the population accessing the NDIS in different States and Territories.

The most recent NDIA quarterly report Quarterly Report (Dec 2016; p75) indicates that the overall level of funding for children is significantly lower than anticipated and has not increased significantly, taking into consideration the State Government funding, HCWA and Best Start Initiatives. This means that children receiving large funding packages are being offset by children receiving small funding packages.

The most recent Quarterly Report (Dec 2016) indicates that of those 0-6-year-old children currently in the scheme, 58% are participating in age appropriate activities in their community and of these 65% feel welcome. This means that only 38% of this age group both participate and feel welcome.