



Building better futures
for children with disabilities

**Submission to the Joint
Standing Committee on
the National Disability
Insurance Scheme (NDIS)
Inquiry into: Provision of
services under the NDIS
Early Childhood Early
Intervention (ECEI)
Approach**

Submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Inquiry into: Provision of services under the NDIS Early Childhood Early Intervention (ECEI) Approach

Noah's Ark welcomes the opportunity to provide comment to the Joint Standing Committee on the NDIS Inquiry into the ECEC Approach.

Noah's Ark has been involved in the NDIS from its commencement, through our services for children in the Barwon and ACT trials. 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, as well as being active in the ACT. Last year these programs reached over 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 involvement 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 the Inclusion Professional Support Program. In addition, Noah's Ark provides training and resources nationally.

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

For further information about this submission contact:

John Forster
CEO
Noah's Ark Inc
Tel: +61 3 8823 8600
1283 Malvern Road, Malvern, Victoria 3144
john.forster@noahsarkinc.org.au

1. Introduction

The term Early Childhood Early Intervention (ECEI) Approach is used in a number of ways within the context of the National Disability Insurance Scheme (NDIS), including:

- An approach to providing early intervention
- A specific process providing access, or a gateway, to the NDIS
- The way in which the NDIS provides supports to young children in general.

This submission addresses the different meanings of the ECEI Approach by discussing:

- The rationale for early intervention for young children with disabilities
- The opportunities offered by the ECEI gateway
- The implementation of the NDIS for young children and their families
- The sustainability of early intervention for young children.

While Noah's Ark strongly supports the underlying direction being articulated by the NDIS through its ECEI Approach, we are deeply concerned about its implementation.

Firstly, there is a lack of publicly available policy articulating why the NDIS is implementing early intervention for young children in the way it is. The lack of policy, and a lack of publicly available guidelines articulating how initiatives like the ECEI Partners are to be implemented, is creating confusion and inconsistency. As the result of the lack of policy and guidelines, there is a lack of quality information available to families, services and the community. The lack of policy also means that the NDIS is not implementing an early intervention approach consistently.

Secondly, the implementation of supports for early intervention for young children, as is evident from the very limited data, suggests that the NDIS has not understood what early intervention is. The allocation of supports appears to be less than two thirds of what was expected for 0 – 6 year olds. At a utilisation rate for funding packages at an average of about 75%, then about half of what was expected is being spent on packages for children aged 0 – 6 years. Allocations of support to young children is the least of any age group. The population of 0 -4 year olds in the NDIS remains very narrow. The principle of early intervention is that investment should be made early. Currently the NDIS is not implementing this approach. If this situation is confirmed by more detailed analysis, the NDIS is not acting in the best interest of the child.

Thirdly, little attention appears to have been given to how to sustain high quality services for young children with a disability. The ongoing quality of services is dependent on a stable and highly skilled workforce. There is little indication that the NDIS costing has considered the recruitment and training of new staff or the need to provide careers for allied health professionals and teachers, who have other career opportunities in health and education. The NDIS does not appear to have a mechanism for considering how its business rules interact with its policy intentions and some of its business rules undermine a best practice ECEI Approach.

Noah's Ark acknowledges that the NDIS is a major reform which has been implemented very quickly, which has to address many diverse needs and which has not had the anticipated resources. Early Childhood Early Intervention should be regarded as the foundations for a sustainable NDIS. If the NDIS invests wisely in the early years then it should gain benefits over time. It is now a matter of priority that the necessary resources are allocated to develop policy and guidelines, review and repair the current poor levels of investment in supports for young children and consolidate strategies and business rules that support best practice.

2. The rationale for Early Childhood Early Intervention

Early childhood - a critical and distinct life stage

Services for children have generally been organised in ways that recognise that children go through distinct stages of development, for example early years services, primary school and secondary school. There is a professional and community understanding that the needs of children and families evolve over time. This is also the case for children with a disability and their families.

The early years is a distinct stage in any child's life. During the early years, particularly the first three years, children are almost entirely dependent on adults to look after their welfare and development. Children go through a profound period of development in which the foundations for future development and learning are created. It is now evident that children develop in a complex interaction with their environment, including their parents and other close adults. How parents interact with their child, and the developmental opportunities that the family provides, has a significant impact on a child's development¹. The developmental opportunities that a child has in the community and with their peers will also have an influence.

Families who have a child with a disability face all the complexities of raising a child, plus all the additional issues raised by the impact of a disability. Families may also have to live with uncertainty. Children's development during the early years is uneven and the presence of a disability is not always evident or certain. The impact of disabilities on individuals varies significantly and the long-term implications may be unclear for some time.

The identification of a developmental delay or disability creates additional stressors on families and family life. When a child is first identified as having issues, parents do not have the information they need to understand their situation or how to respond. The identification of a disability or developmental delay can put pressure on family relationships, as family members adapt to the situation, try and reconcile why this has happened, deal with reactions from their broader social network and, in some communities, address the stigma attached to a family having a child with a disability. There may be many additional demands made on family resources, both in time, (e.g. to attend appointments), and financially, (e.g. to meet the additional expenses for services and equipment). Families may also decide that one parent should stay at home to provide care, rather than both parents working. The fact that a child has a disability can also challenge people's confidence in their capacity to care for their child or support his or her development².

Due to the nature of this life stage, early childhood services are organised in ways that recognise the key role that families play in a young child's development, learning and wellbeing. Quality services place a priority on family centred practice and partnerships with families. They also recognise that it is important to seek out and engage all families in the best interest of the child's development³.

¹ Institute of Medicine. 2000. *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Washington, DC: The National Academies Press.; Centre for Community Child Health, (2007) Parenting young children. Policy Brief No 9, Melbourne: author.

² Guralnick M (2005) An Overview of the Developmental Systems Model for Early Intervention, in Guralnick M (ed) *The Developmental Systems Approach To Early Intervention*, International Issues in Early Intervention Series, Paul H. Brookes Publishing

³ For example, Department of Education and Training, (2016). *Victorian Early Years Learning and Development Framework*. Department of Education and Training, Melbourne.

There are important lessons from how these services engage with families in the early years.

Early intervention - an important strategy for the NDIS

The Productivity Commission identified that early intervention was an essential element in an insurance based approach, although determining the rationale for investment in a specific early intervention was not going to be straight forward⁴.

Early intervention is different from the reasonable and necessary supports provided to individuals through the NDIS where the impact of a disability is established. Early intervention includes both rehabilitative and habilitative interventions. Rehabilitation generally occurs after an individual has experienced a traumatic event and the purpose of early intervention is to assist with regaining abilities. In early childhood, most early intervention is habilitative, because the early intervention is designed to address the risks associated with the child's condition, as well as promoting the child's development. This means that in early childhood intervention there is uncertainty about what level of functional and participatory skills the child will achieve. The Convention on the Rights of Persons with a disability describes the aim of early intervention as assisting individuals to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life⁵.

In the early years, the term early intervention includes many activities such as:

- helping prevent or mitigate the effects of abuse and neglect;
- reducing the isolation and building the capacity of families to support children, for example through parenting skills;
- helping support families with specific issues, for example behaviour management; and
- supporting children's developmental, social, and educational outcomes.

While the primary focus of early intervention with young children with a disability is on children's outcomes, there is a higher incidence of abuse and family breakdown in families that have a child with a disability.

There is unambiguous evidence about the benefits of early intervention in the early years for individuals and the cost benefits of the investment for the society⁶. The recent major reforms to Early Childhood Education and Care in Australia, including Kindergarten and Child Care, were in recognition of these benefits⁷.

⁴ Productivity Commission (2011) *Disability Care and Support*, Report no. 54, Canberra.

⁵ The United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Treaty Series, 2515*, 3. Article 26

⁶ Institute of Medicine. 2000. *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Washington, DC: The National Academies Press; Heckman, J.J., & Masterov, D.V. (2004). The Productivity Argument for investing in Young Children. Invest in Kids Working Group. Working Paper No. 5, September 2004. Washington, DC: Committee on Economic Development

⁷ Ministerial Council on Education, Employment, Training and Youth Affairs, (2008). *Declaration on Educational Goals for Young Australians*. Author, Melbourne.

There are two academic literatures on early intervention for children with a disability. One literature is focused on the nature of the disability, is more likely to be related to a specific diagnosis, examines strategies to change the child's functioning and often involves intensive interventions. This has been a focus of early intervention strategies since the closure of institutions in the 1970s.

The second literature has a focus on what supports young children's development, combines multi-disciplinary perspectives to support a more holistic approach, and emphasises the need to adapt the environment to create regular developmental opportunities for the child within daily, family life. It engages the family, carers and peers as critical people influencing a young child's development⁸. This approach recognises the need for young children to continually practice new skills to gain mastery, for example in the acquisition of language.

The ECEI approach is broadly based on this second literature, which also incorporates specific methods to promote development and learning.

3. The ECEI approach as an early intervention strategy

The introduction of the NDIS requires the development of a national approach to early intervention for young children for the first time in Australia. The proposed ECEI approach draws on Australian literature, reflects international scientific evidence and is consistent with the views of the national peak, Early Childhood Intervention Australia. However, there is not a national consensus on the purpose of early intervention for young children with a disability.

The development of early intervention services for young children has been highly fragmented in Australia. Over the last 30 years each state and territory has developed its own approach. These approaches have included different eligibility criteria, different administrative arrangements and various levels of investment. The involvement of education, health and disability departments in providing early intervention services have led to different perspectives and priorities. There was no capacity for leadership in national policy development. When the Australian government became involved in this field recently, through the Helping Children with Autism and Better Start Initiative, it was as an alternative funder of services⁹.

⁸ KPMG, (2011). Reviewing the evidence on the effectiveness of early childhood intervention. Report to the Department of Families, Housing, Community Services and Indigenous Affairs.; Institute of Medicine. 2000. *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Washington, DC: The National Academies Press.; Centre for Community Child Health, (2010). DEECD Early Childhood Intervention Reform Project: Revised literature review, State of Victoria, Melbourne.; Dunst, C.J. (2017) Family systems early intervention. In H. Sukkar, C. J. Dunst, & J. Kirby (Eds.), *Early childhood intervention: working with families of young children with special needs* (1 ed., pp. 36 -58). Routledge, Taylor & Francis Group.

⁹ Kemp, C., & Hayes, A. (2005). Early intervention in Australia: The challenge of systems implementation. In M. J. Guralnick (Ed.), *The developmental systems approach to early intervention* (pp. 401-423). Paul H Brooks Publishing Co: Brookes; Sukkar, H. (2013). Early Childhood Intervention: An Australian Perspective. *Infant & Young Children: An Interdisciplinary Journal of Early Childhood Intervention*, 26 (2), 94-110; Forster, J. (2017). Development of community based services for children with disabilities and their families. In H. Sukkar, C. J. Dunst, & J. Kirby (Eds.), *Early childhood intervention: working with families of young children with special needs* (1 ed., pp. 36 -58). Routledge, Taylor & Francis Group.

The development of services for young children with a disability is not dissimilar to the development of services for young children in general. Services for young children in general were also highly fragmented until the recent national reform process that led to the adoption of consistent legislation, for Early Childhood Education and Care, and a National Quality Framework¹⁰.

The NDIS needs to be properly resourced to develop a national policy on early intervention for young children and lead a national engagement process.

This policy needs to articulate:

- An underlying rationale for early intervention for young children and the intended outcomes for children and families;
- The evidence on which this approach is based, and the process for the ongoing evaluation of evidence;
- How the early intervention provided by the NDIS interfaces with other community services for young children and their families and how the benefits of these services can be maximised; and
- The long-term benefits of the investment for children with a disability, as they continue to grow and become increasingly independent and make contributions, and for the community.

A process of engagement needs to build common understandings across jurisdictions and should include, amongst others:

- families,
- paediatricians,
- academics,
- early childhood intervention service providers, and
- early childhood service providers.

The implications of the direction being proposed by the ECEI Approach for best practice has been identified by Early Childhood Intervention Australia ¹¹(See Box 1). As part of a workforce strategy the NDIS needs to support the adoption of these practices nationally.

4. The ECEI Approach as a specialist access point or gateway.

ECEI Partners have been established to offer a specialised entry point for families coming into the NDIS and provide:

- Advice and support to families,
- Accurate advice on a child's development, and
- Linkages to other services and supports in the community.

¹⁰ Tayler, C. (2016) Reforming Australian early childhood education and care provision (2009–2015) in *Australasian Journal of Early Childhood*—Volume 41 Number 2 June 2016

¹¹ ECIA, (2016). *National Guidelines: Best Practice in Early Childhood Intervention*<https://www.ecia.org.au/documents/item/186>

BOX 1 KEY BEST PRACTICES IN EARLY CHILDHOOD INTERVENTION

Quality Area 1: Family

Family-Centred and Strengths-Based Practice: is a set of values, skills, behaviours and knowledge that recognises the central role of families in children's lives. Family-centred practice is a way of thinking and acting that ensures that professionals and families work in partnership and that family life, and family priorities and choices, drive what happens in planning and intervention. Family-centred practice builds on family strengths and assists families to develop their own networks of resources – both informal and formal.

Culturally Responsive Practice: creates welcoming and culturally inclusive environments where all families are encouraged to participate in and contribute to children's learning and development. Practitioners are knowledgeable and respectful of diversity and provide services and supports in flexible ways that are responsive to each family's cultural, ethnic, racial, language and socioeconomic characteristics.

Quality Area 2: Inclusion

3. Inclusive and Participatory Practice: recognises that every child regardless of their needs has the right to participate fully in their family and community life and to have the same choices, opportunities and experiences as other children. All children need to feel accepted and to have a real sense of belonging. Children with disability and/or developmental delay may require additional support to enable them to participate meaningfully in their families, community and early childhood settings.

4. Engaging the Child in Natural Environments: promotes children's inclusion through participation in daily routines, at home, in the community, and in early childhood settings. These natural learning environments contain many opportunities for all children to engage, participate, learn and practise skills, thus strengthening their sense of belonging.

Quality Area 3: Teamwork

5. Collaborative Teamwork Practice: is where the family and professionals work together as a collaborative and integrated team around the child, communicating and sharing information, knowledge and skills, with one team member nominated as a key worker and main person working with the family.

6. Capacity-Building Practice: encompasses building the capacity of the child, family, professionals and community through coaching and collaborative team work. The goal is to build the knowledge, skills and abilities of the individuals who will spend the most time with the child in order to have as great an impact as possible on the child's learning and development. Quality

Area 4: Universal Principles

7. Evidence Base, Standards, Accountability and Practice: ECI services comprise practitioners with appropriate expertise and qualifications who use intervention strategies that are grounded in research and sound clinical reasoning. Standards based on these ECI key best practices will ensure ECI practitioners and services are accountable to continuous improvement and high quality services.

8. Outcome Based Approach: focuses on outcomes that parents want for their child and family, and on identifying the skills needed to achieve these outcomes. ECI practitioners share their professional expertise and knowledge to enable families to make informed decisions. Outcomes focus on participation in meaningful activities in the home and community with outcomes measured and evaluated by ECI services from a child, family and community perspective.

Early Childhood Intervention Australia

The development of a specialised access point is warranted because families with young children may:

- continue to be confronted by the notion their child has a disability
- face a range of evolving issues while adjusting to having a child with a disability
- be inexperienced in engaging with disability services
- find dealing with services intimidating

Many families need to be encouraged to seek and start early intervention, which is in the best interest of the child.

The NDIS needs to be resourced to develop full, publicly available guidelines for the ECEI Partners. This will ensure families have consistent information, increase the consistency in how ECEI Partners are implemented and support other community services to understand the role of the ECEI Partner and its relationship with the community in which it is based.

The guidelines need to address the confusing number of roles that ECEI Partners are undertaking. The ECEI Partners are providers of information, a screening mechanism for eligibility, planners, the provider of short term services and the builders of community linkages.

Access to independent advice

Parents need access to independent advice about appropriate ways to support their child's development and the services available. Parents do not initially understand their child's situation or the services available. Parents are vulnerable to exploitation in their pursuit of a remedy for their child's condition. Parents may have their own needs for support as they adjust to having a family member who has a disability.

Parents should be able to get independent advice, including from someone who is not a service provider or who is not involved in determining eligibility for service. Parent's need to be able to gain advice if they are considering a challenge to decisions regarding eligibility or levels of support. If the ECEI Partner is determining eligibility, then families need another source of independent advice.

Eligibility and planning

There are significant advantages in having a specialised workforce managing access for young children to the NDIS. A successful early intervention gateway needs to be able to engage with a wide range of families. Staff need to understand the risks associated with developmental delays and the potential benefits of early intervention.

As a specialist access point or gateway, planners will often be one of the first professional's parents approach in relation to concerns about their child's development. In the initial meeting, planners need to have the skills and qualities to quickly establish trust and rapport, have the professional expertise to administer and interpret the required screening assessment/s, provide sensitive feedback about the assessment results and eligibility, and provide clear and accessible information about next steps. If this is done well, it sets the scene for families to continue to engage with services. This requires a skilled workforce.

In Victoria, several early NDIS implementation issues are now being addressed as the ECEI Partners start to become operational. This includes a shift away from an over reliance on telephone planning, which is inappropriate for families with young children. Some Partners are including a home visit as part of their planning. The quality of plans is improving and

inconsistencies arising from planner's lack of knowledge about the issues of young children and their families are decreasing.

To date the NDIS has relied on the disabilities compiled in List D in the NDIA Operational Guidelines to streamline entry to the NDIS. While diagnosis can predict risk factors, it cannot predict the extent of the impact of a disability on an individual. A public explanation for how List D has been determined should be provided.

A focus on diagnosis is not consistent with the principle of early intervention having a preventative role. Gaining a diagnosis can take time and be uncertain for some time. Good early intervention is triggered by a child's developmental issues, rather than waiting for a determination of the cause of the delays, and a specialised workforce can implement this approach.

The NDIS also needs to provide a public explanation about how it is making decisions in relation to levels of support provided to individuals, including the use of standardised reference packages and the use of screening tools in making determinations. The use of screening tools should be subject to ongoing academic review to ensure that they are fit for purpose (see Box 2).

Provider of short term services

The rationale for the NDIS becoming a provider of short term services for children deemed not eligible for the NDIS is not clear and needs to be explained through guidelines. It is not clear what the evidence base for this type of short term intervention is.

This initiative appears to be a response to the very uneven provision of services for children with developmental issues across the states and territories. Children who are not eligible for the NDIS should be eligible for other forms of support, for example through maternal and child health, community health or other health and educational services. These services are not available in some communities. However, a short-term response by the NDIS does not solve the problem that children will end up with no supports if they cannot be referred to an alternative service. The NDIS needs to work with state and territory governments to address this gap.

Community linkages

One of the underlying principles for early intervention for young children with a disability must be inclusion. The role of ECEI Partners in facilitating linkages for young children in their local community is critical. The ECEI Partners/ LACs provide one part of the NDIS Information, Linkages and Community building strategy to promote participants access to, and participation in, other opportunities in the community. Given its multiple roles, it is not clear how much of its time the ECEI Partners can dedicate to developing linkages.

The development of ILC functions focused on the early years is a matter of priority. The early years is primarily the responsibilities of states and territories. The NDIS is taking children with a disability out of the policy context of the state and territory children's services. Without strong linkages young children with a disability and their families are at risk of becoming more isolated from, and not getting the benefits of, general community services.

Box 2

The Pediatric Evaluation of Disability Inventory – Computer Adaptive Test (PEDI-CAT) is the assessment tool currently being used by ECEI Partners for screening and eligibility requirements. We have the following concerns about the current use of the PEDI-CAT:

- We understand that whilst the authors of the PEDI-CAT do not provide for a total score that sums across all four domains, the ECEI Partners are using an algorithm that has been developed to determine severity ratings. It has been reported that ECEI planners use the T-score (without referring to the standard area of measurement) on the algorithm to determine the level of severity, sometimes in isolation, and to determine subsequent funding. As this algorithm is not publicly available, we are unsure of its reliability and utility, if any.
- In our experience, the algorithm determines that the majority of children are in the 'mild' category, even though individual functional domain scores indicate that the child is below median in several areas of development.
- Due to the lack of transparency about the use of the PEDI-CAT, we also have concerns about whether recommendations made by the authors are being adhered to (e.g. When PEDI-CAT scores are used for service eligibility decisions, the authors strongly recommend that the child should be identified as eligible if EITHER the T-score OR the percentile range is below the criterion).
- The PEDI-CAT is being used by ECEI partners to measure change over time following a short-term intervention (3-6 months). There needs to be future research on the sensitivity and responsiveness of the PEDI-CAT for young children before it can be confidently used in this manner.
- We also remain concerned that results should be interpreted by a professional who has the necessary qualifications and training requirements to both administer the assessment and provide sensitive feedback to parents.

5. The implementation of early intervention for young children with disabilities

The NDIA releases little information about the implementation of services for young children, but what has been released is extremely concerning. It raises questions about whether the NDIS is committed to early intervention and suggests families do not have the information and supports they require to exercise choice and control as effective participants in the scheme. The level of supports being funded for young children, the length of time it is taking to activate plans and the significant underutilisation of funding packages are all unsatisfactory.

The NDIA continues to raise the issue that a greater number of children have entered the NDIS than anticipated¹². This certainly raises issues about how eligibility is being managed. It does not accurately reflect the situation for young children. The Productivity Commission reports that the number of 0 - 4 year olds in the sites it has information about represents about 2% of the population of that age group, which is slightly higher than anticipated¹³. This

¹² Productivity Commission, (2017). *National Disability Insurance Scheme (NDIS) Costs – Issues paper*. Australian Government, Canberra (p.11)

¹³ Productivity Commission, (2017). *National Disability Insurance Scheme (NDIS) Costs Position Paper*. Australian Government, Canberra (p. 102)

represents a low number of children with a disability, lower than the numbers previously discussed in Victoria. The NDIA's comments are accurate in relation to the number of older children.

While the number of children in the 0 - 4 age group is not significantly higher than expected, the supports being provided to this age group is significantly lower. The funding for early intervention for young children has been guided by evolving forms of standardised packages. This process has led to the NDIA reporting consistently that the annualised commitments for 0 - 6 year olds is less than two thirds of the amount that was expected¹⁴. According to the NDIA, the actual average annualised committed supports are higher than revenue received for older age groups (15 - 64 year olds) and less than revenue received for 0 - 14 year olds¹⁵. The low level of funding supports for children aged 0 - 6 years is at odds with the concept of early intervention, in which early investment is made to reduce the need for later supports. In the NDIS, funding levels appear to be based on shoe size.

The low level of supports allocated is being further impacted by delays in plan activation and underutilisation. The data for plan activation is not age specific, but there is anecdotal evidence that parent's confusion about the NDIS has contributed to delays. The NDIA reports that in Victoria, in the second quarter of 2016 -17, only 64% of plans had been activated after 90 days and there had been no payment on 32% of plans after 180 days. This was worse than for the previous quarter, when 76% of plans were activated after 90 days.¹⁶ The NDIA does note that more plans will have been activated than reported because in-kind support is not included and there can be delays between when support is provided and when it is invoiced¹⁷. Nonetheless, these delays suggest extended periods of time when children had no service.

Delays in the activation of plans is one factor contributing to unacceptable levels of underutilisation of committed supports across NDIS participants. The NDIA has reported underutilisation of committed supports of 26% in 2014 -15, 26% in 2015 -16 and it is predicting a similar result in 2017¹⁸. While the Productivity Commission¹⁹ recently noted that underutilisation had led to significant savings for the NDIS, underutilisation means participants in the NDIS are not getting the supports that they were funded to receive. If an individual service underspent 25% of its funding annually, it would be investigated for under servicing its clients.

The utilisation rates of funding packages by families of young children needs to be urgently reviewed. On the average of 75% utilisation, the supports being expended on young children is about half what was expected. There is anecdotal evidence that the situation is worse than this.

A situation in which half the expected supports, or less, is being utilised for services for young children with a disability is not in the best interest of the child. This situation raises questions about the supports being provided to families to manage the responsibilities being placed on them by the NDIS. If this limited information is confirmed by more detailed

¹⁴ National Disability Insurance Agency, (2017). *COAG Disability Reform Council Quarterly Report for Quarter 3 Year 4*. (March 2017) (p. 31)

¹⁵ Ibid p.31

¹⁶ Ibid p.68

¹⁷ Ibid p.22

¹⁸ Ibid p. 34

¹⁹ Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs Position Paper*. Australian Government, Canberra (p.53)

analysis, it raises fundamental issues about the design of the NDIS and its capacity to meet the needs of young children.

6. The sustainability of early intervention for young children

The design of the NDIS does not appear to have considered how to sustain early intervention services for young children.

The pricing structures being used by the NDIS is not realistic in a number of areas, including organisational overheads. There are significant new costs being introduced under the NDIS, including for marketing, administration (e.g. highly complex financial processes) and IT systems. A significant part of the overheads for services for young children in the past have supported the recruitment and professional development of staff. It is not clear how this can be sustained under the assumptions being made by the NDIA.

The NDIS needs to develop a workforce strategy for early intervention for young children as a matter of urgency. The provision of high quality services is dependent on a stable and skilled workforce. Consideration needs to be given to how the NDIS will provide attractive careers for health professionals and teachers, who have other career options in health and education. There is a general shortage of health professionals.

The NDIS workforce strategy needs to address:

- the lack of tertiary courses that prepare professionals specifically for working with young children with disabilities,
- the need for services to be able to provide student placements,
- the need for inexperienced staff to go through orientation,
- the costs of lost income during orientation, and
- the costs of ongoing professional development.

There is also a disconnection between business rules and the implementation of best practice services. For example, best practice under an Early Childhood Early Intervention Approach supports services working with families in their home and with children in the places they attend, like Kindergarten and Child Care.

During the trial phase, there was a recognition that reasonable and necessary travel was appropriate. Subsequently, the NDIS has introduced standardised business rules across all participants for travel which make assumptions that:

- it is possible to drive at 60 kms an hour throughout metropolitan and regional centres,
- it is appropriate to have annual limits, regardless of where a family lives.

These rules add costs to the provision of services. They were introduced retrospectively and without consideration of any arrangements previously in place. The new rules have led some service providers to decide to provide more affordable services, for example clinic based services to which the family travels, rather than best practice services.

Other examples of business rules which do not support early intervention for young children include cancellations and translators. The NDIS had a rule that service providers could not charge for any cancellations by participants. This has now been modified to allow for the charging for two hours of cancellations per year. Young children, as is generally understood in the community, become ill more quickly and more frequently than older children and

adults. As a result, the cancellations policy has a more adverse effect on service providers supporting young children. This is compounded when travel time is involved.

The NDIS has a rule that it will not support the cost of translators. This means that non English-speaking families cannot understand gain information from services about their child's condition or the supports they need to provide. This rule undermines the purpose of early intervention. The NDIS has asked service providers to meet the costs of translators.

The NDIS needs to develop a process for testing the impact of its business rules on different populations in the NDIS and how they interface with policy intentions.

It is also unclear what rules apply to Early Childhood Intervention Supports as opposed to rules for "therapy". Do rules that relate to "therapy" also relate to Early Childhood Intervention Supports? It is ambiguous. Service rule changes require providers to communicate these changes across their staff, implement new business rules, and test IT system changes, all of which add to the cost of providing the service. Changes are made without adequate notice to enable service providers to implement changes in a cost effective or timely way.

7. Conclusion: The cost of not providing effective ECEI services

The ultimate aim of the NDIS is for people with disabilities and their families to be able to make informed choices about the supports and services they need in order to participate meaningfully in the economic and social life of the community.

This goal is not achievable overnight. When families of young children with disabilities have the diagnosis confirmed and become eligible for ECEI services, they are likely to be in a state of some distress and disorientation. They will be unfamiliar with the ECEI service system and uncertain of their role in relation to professionals. They will also likely to be lacking in confidence in their own abilities to help the child, and tend to defer to the knowledge of professionals.

Thus, at this point in time, they are not well placed to be able to make sound decisions about their own needs or those of the child, or about what forms of service would best meet these needs. It is unreasonable and potentially harmful to expect them to be able do so, or to manage funds to purchase appropriate services. Even with professional help in deciding what they need and in choosing services, the additional burden of managing funds can be an unreasonable extra task that adds to the stress families are experiencing at this time.

One of the tasks of ECI services is to build the understanding, confidence and capabilities of parents in knowing how best to meet the needs of the child and family, and to work in partnership with service providers to ensure that these needs are met. When this is done effectively, by the time families leave the ECI service system, their personal circumstances and skills will have altered dramatically. By then, most parents should be familiar with the service system, confident in their ability to help their children, able to articulate their needs, and able to work with professionals as partners. Since ECI services can work with families over several years, this gives them the time to support families as they gradually gain the skills and confidence they need to manage their child and family needs into the future.

To achieve the goals of the NDIS, an outcomes-focused life cycle approach is needed. This means that, during the early childhood intervention phase in particular, the services that are funded by the NDIS to support families should always be seeking to progressively build the capacity of families (and ultimately of the young people with disabilities themselves) to

identify their own needs, build effective partnerships with professional services, and manage the funds allocated to them. These requirements should be clearly stated by the NDIA and providers that cannot demonstrate that they work in ways that achieve these goals should not be accredited.

Early intervention can be powerfully instrumental in giving children and families a strong foundation for later development and participation. What are the risks in not providing support early or not providing such support effectively?

Early childhood intervention has a dual focus – promoting the development and well-being of the child, as well that of the family. At the child level, the aim is to promote the child's development of functional skills that will enable them to participate meaningfully in family and community life. Not providing such support or not doing so effectively can incur costs in a number of ways:

- In some instances, early childhood intervention can address an emerging developmental problem so effectively that the problem is resolved and the child no longer needs more intensive levels of support. Without such support, the problems will escalate and become increasingly difficult (and costly) to manage, thereby incurring ongoing financial claims upon the NDIS.
- In most instances, however, the child's developmental disabilities are not transient and are sufficiently severe to require ongoing NDIS support. Here, the aim is to ameliorate the impact of the developmental disabilities on children's development and ability to participate meaningfully, thereby reducing the demands on the family and other services, and their associated costs.
- Children with developmental disabilities are at their most vulnerable when they are very young, which is when their relationship with their caregivers is just developing and most likely to be compromised.

Overall, the failure to provide effective early childhood intervention support for young children with disabilities can have long term consequences for their development and capacity to participate, and can result in them needing more costly forms of care and support across the life span.

Early childhood intervention services also seek to support family functioning and build parent capabilities. When this is not provided, then there are likely to be worse outcomes with associated costs for the family and the wider society. These can take a number of forms:

- The demands of parenting a young child with developmental disabilities often prevents one of the parents (usually the mother) from working, thereby reducing both the family income and the contribution that the family makes to social productivity as workers and tax payers
- Having a young child with developmental disabilities increases the level of stress on parents, leading to higher incidence of depression and other stress-related conditions, all of which have additional treatment costs that society has to bear
- These same stresses affect the relationship between parents, resulting in a higher than usual breakdown in parental relationships, with all the associated additional costs of divorce and single parenting

- Children with developmental disabilities are more likely to be neglected or abused, both having adverse effects upon their development and well-being, but also resulting in higher societal costs in the form of child protection and other services.

Overall, the failure to provide appropriate and effective support to families can lead to poorer outcomes for parents and families as a whole. These incur additional costs that have to be borne not only by the family, but also by the wider society in the form of support and treatment services to address mental health and family dysfunction. These personal and social problems also reduce the capacity of family members to contribute productively to society as active citizens, workers and tax payers.