Think
Insight & Advice

Protecting Best Practice: An evaluation of the transition to the ECEI Approach under the National Disability Insurance Scheme in NSW

ecia
NSW / ACT

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insight, integrity, independence

The plane is being built in flight and sometimes it feels like nobody knows what it'll look like once it's finished. There is almost nothing providers can do about this, it's just where we are in the roll-out.

Rob Wooley
Disability Services Consulting

Everything can look like a failure in the middle.

'Kanter's Law'
Rosabeth Moss Kanter
Harvard Business School

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Executive Summary

Early Childhood Early Intervention (ECEI) is an evidence-based approach to addressing disability and global developmental delay in children aged 0-6. Early Childhood Educators (ECEs) in New South Wales have been national leaders in both the development and uptake of ECEI in Australia. In 2016, Early Childhood Intervention Australia (ECIA) developed the *National Guidelines: Best practice in early childhood intervention* in consultation with sector representatives and more than sixty academics and experts drawn from areas relevant to ECI.

The ECEI Approach as developed by NDIA was trialled by four services in the Nepean Blue Mountains region of NSW in 2016/17 and an evaluation found it to be an effective way to support children with disability and/or global developmental delay. The approach was then formally adopted by the National Disability Insurance Agency (NDIA) to guide its approach to early childhood intervention under the National Disability Insurance Scheme (NDIS). Given the large number of children currently receiving early intervention services under the previous NSW State-based program, a decision was made to use a two-year Transition Period to transfer 'defined children' to the new federal insurance scheme and to give ECI providers an opportunity to gain experience with the new service system. 56 Transition Providers were appointed by the Department of Family and Community Services (Aged, Disability and Home Care - ADHC) NSW and divided into two cohorts. This study is an evaluation of the experience of the Transition Providers and seeks to investigate whether it is possible to implement best practice ECI under the ECEI Approach of the NDIS in NSW.

This study revolves around two key research questions. First, 'Can a system designed for adults accommodate the special needs of children and their families? Second, 'Can a social insurance scheme serve the needs of the children who meet its access requirements and those who don't?' Related questions include, 'How can a child aged 0 to 6 exercise independent 'choice'? and, 'Can the needs of parents ever be separated from those of their young children?'

The NDIS is composed of two components: individualised funding packages (otherwise known as IFPs or NDIS plans) and support for Information, Linkages and Capacity Building (ILC). While the limited data that has been released to date would indicate that IFPs are being funded generously, the NDIA has yet to release further details on the form and structure of the ILC. In particular, it is unknown how these important supports will be delivered and if they will be funded adequately.

In order to ensure that children living with disadvantage are given the best start in life, vulnerable families need to engage with early intervention services. However, it is the experience of the ECI sector that many vulnerable families are challenged by socio-economic and cultural pressures that affect their awareness and ability to access ECI. One way to help would be to combine the roles of early linkers with that of family workers and to incorporate their function into the ECEI Approach under the NDIS.

Building parental capacity is acutely needed under a best practise approach that requires early childhood supports be extended and reinforced in the home. If the definition of 'insured party' under the NDIS were changed from child to parent, the services could then cascade from the parents to their dependent children, ensuring support for the entire family along their journey through early childhood intervention services. While other systemic reforms will be needed to protect best practice, this single change could have a transformative effect on the lives of hundreds of thousands of families all across Australia.

Otherwise, ECIA can help protect best practice through its manifold roles.

First and foremost, as a thought-leadership organisation, it could review the National Guidelines to reinforce the need for 'soft-entry' and 'interim supports'. The National Guidelines represent the one objective, evidence-based approach the government and the NDIA has endorsed to date and it is through these Guidelines that the public can hold the government to account.

As a non-provider, ECIA could play an important role in providing unbiased, evidence-based, advice to parents on best practice early childhood intervention. Helping parents to understand the value of non-standard, therapeutic approaches is important to ensure that Australia does not revert to a diagnosis-driven model and to avoid setting the ECI approach in Australia back by decades.

Finally, as a peak body, ECIA can communicate openly and regularly with the NDIA, the federal *Joint Standing Committee on the National Disability Insurance Scheme* and the NSW government on what further changes are required.

This is a point-in-time process evaluation which was conducted during a period of unprecedented change for the ECI sector and for thousands of NSW families. Hopefully, some quick process improvements can be made immediately. Indeed, at least one of the findings of this study has already been overtaken by changes introduced by the NDIA during the study period. The proposed changes may put the ECIA on a long-term advocacy journey but with a federal general election approaching in 2018, change could come sooner. If the sector is able to mobilise an effective pre-election contact program with the major parties, it could achieve legislative change during the term of the next federal Parliament.

Best practice should be protected for children with disability and/or global developmental delay *and* their parents. There are challenges ahead including funding arrangements, workforce pressures and data management issues. There are outstanding issues requiring more work including, how to effectively re-define global developmental delay without denying service to disadvantaged children and how to engage and contact vulnerable families. While a number of community-based local services are not expected to succeed in their bids to become ongoing Community Partners, the sector is more prepared than ever to extend and refine the ECEI Approach and to help the NDIA evolve in line with the latest best practice.

Randall Pearce, BA, MPA
Managing Director
THINK: Insight & Advice Pty Ltd
October 2017

Conclusions

Transition Provider Arrangements

1. The Transitional Arrangements have given 56 early childhood intervention providers in NSW invaluable experience in trialling the NDIS gateway function for young children and their families. This experience will undoubtedly ensure a smoother transition when the NDIS goes 'full-scheme' in July 2018.

2. ECIA NSW/ACT effectively supported its members through the transitional period. ECIA members widely praised its efforts.

3. Department of Family and Community Services NSW, Ageing, Disability and Home Care (ADHC) achieved two of its four stated goals. First, providers were able to provide information and short-term support to children and families during the transition period. Second, the sector now has clarity on the changes to the service system.

4. Some families currently supported in the NSW system reportedly experienced more than 'minimal disruption' and some 'new children' waited for referral to support in parts of the State. However, there was no discernible pattern in the client experience across the entire group of 56 Transition Providers.

5. Local referral pathways have been preserved for the time being but the future will be unknown until the ECEI Community Partners are selected later in 2017.

6. Poor communication between the NSW government and the NDIA was blamed for a delay in providing the names of 'defined children' to the Year One cohort of Transition Providers by six months and to the Year Two Cohort by six weeks. These delays caused 'new children' and their families to wait to enter the service system for varying periods.

7. The NDIA said that it struggled to deal with the total number of Transition Providers in NSW. However, the appointment of Transition Advisors alleviated some of the delay and difficulties for both the NDIA and Transition Providers alike.

National Best Practice ECEI

8. *Family-centred and strengths-based practice* is difficult to implement under a social insurance scheme such as the NDIS. As an insurance scheme, the service system focuses solely on the individual needs of the insured child. However, dependent children are dependent and cannot exercise self-determination or 'choice' without parental support. The current approach does not adequately consider the needs of the family along with those of the child.

9. While therapy should be delivered in familiar surroundings, it is more important that they be practised and reinforced in the home and other natural environments. Travel arrangements will need to be flexible to ensure that children and families can benefit from *inclusive and participatory practice* wherever they live.

10. Families need to be educated about the role of key workers in *collaborative teamwork practice* because the model has been found to come into direct conflict with 'deeply held cultural

assumptions' about what is 'real therapy'. There is a role for an independent third party to educate parents about the value of the various approaches to early childhood intervention.

11. Supporting parents is essential to supporting children. However, the limited information regarding the ILC component of the NDIS released to date does not give readers confidence that *capacity-building practice* will be structured or funded appropriately.

12. While it is important that the Early Childhood Early Intervention (ECEI) Approach be grounded in *evidence base, standards and accountability practice*, parents need help interpreting evidence and information to guide choice-making. Expert observers believe this educational role is one that ECIA could play in future.

13. It will be difficult to maintain *outcomes based practice* under the NDIS if the ECEI approach reverts to a diagnosis-driven model. Functional needs, not a diagnosis, must determine access to early childhood intervention services.

14. The National Best Practice Guidelines don't sufficiently call out the need for 'soft supports' for families awaiting a diagnosis and 'interim supports' for 'new children' entering the service system under the NDIS.

Funding

15. Although initial IFPs have been funded generously, there are concerns that funding could be reduced upon review or renewal. Some say that a reduced funding allocation would be proof that the intervention was effective and that the children no longer need intensive support. Others say that it will be important to monitor funding levels as cost pressures on the NDIS increase over time and affordability becomes a concern.

16. The exact structure and funding of the ILC component of the NDIS is still unknown, leading providers to look for critical supports not funded under an individualised approach to funded by other levels of government to make up the shortfall once block funding ends.

Workforce

17. Workforce pressures threaten the availability of therapeutic supports in some parts of the State. Providers are concerned parents and the NDIA tend to preference therapists over early childhood educators and that the NDIA guidelines do not support the role that educators can play.

Data

18. Data is needed to demonstrate the effectiveness of the ECEI Approach but the NDIA has been uncommunicative about what data needs to be collected, why it needs to be collected, how it will be used or if and when the data will be made available for sector development.

19. The need for the PEDI-CAT Assessment Tool is poorly understood and providers say that it is inappropriate for use with young children in an Australian context. There is a widespread perception among users of the tool that it does not adequately detect global developmental delay and can understate autism spectrum disorder in young children.

Transitional Issues

20. The NDIA funding of the Nepean Blue Mountains Trial was assessed to be adequate for a short-term trial but not sustainable on the long-term.

21. ADHC residual funding for Year One and Two Transition Providers was found to be insufficient to serve the volume of 'new' and 'defined' children processed through the gateway. However, it should be noted that this funded was 'topped up' in early 2017.

22. Many community-based services said that they had no option but to support their communities with their own funds, effectively subsidising government to provide public services through the Transition Period.

23. Transition Advisors helped Transition Providers navigate the system and provided much needed help to the NDIA to expedite access determinations through Year Two of the Transition Period.

24. Plans do run out and Year One Providers are uncertain about how they will balance the competing demands of writing plans for 'new children' while also renewing plans for 'defined children'. A failure to renew a plan could mean that a child's intervention is interrupted at a crucial time.[1] Transition Providers found it necessary to innovate to balance the needs of 'defined children' with those of 'new children'.

Outstanding Issues

25. While many of the people who participated in this study said that 'tight definitions' are necessary to ensure the overall viability of the Scheme, they were just as likely to say that 'too tight a definition' could mean that some children and families are denied early intervention services. As a result, they say that global developmental delay needs to be carefully redefined so as not to exclude children living with disadvantage from the service system.

26. Transition providers blamed poor communication between the NDIA and FACS for the delay in providing lists of 'defined children' to ECEI providers. The process for contacting families will need to be redesigned to ensure that families, including vulnerable families, engage in a timely manner.

27. Engaging with families experiencing disadvantage and vulnerability takes time and there are concerns there may be insufficient funding for 'soft entry' supports and family workers.

28. In a multicultural country like Australia, multi-lingual interpretation is essential to getting culturally and linguistically diverse (CALD) families to connect to needed early intervention services. Without compensation for the additional time needed to work through interpreters, providers had to either absorb the costs or reduce the number of hours available to non-English speaking children and families.

29. The perceived overlap between early linkers, key workers and ECEI professionals will be eliminated when the AbilityLinks NSW program closes next year. However, it will be important to ensure that the important function of that role is incorporated into the ECEI Approach under the NDIS so that families can be adequately supported through the grief process and transition into school.

Competitive Sourcing Process

30. Conflict of interest provisions regarding the ability of a single organisation to serve as an ECEI partner and an ECI provider have been controversial and will only be clarified through the upcoming

[1] The terms 'review' and 'renew' are used interchangeably when describing the process which follows the end date of an NDIS plan. We prefer 'renew' because it implies that a plan will not remain in force if it is not 'renewed'. A plan might be 'reviewed' but may continue in force until its end date.

competitive sourcing process. However, based on the results of the Queensland and Victoria funding rounds, NDIA is expected to adopt a narrow interpretation of conflict of interest.

31. The NDIA has expressed frustration at having had to work with so many providers through the transition period. It has explicitly demonstrated a preference to work with a small number of large providers despite sector concerns about a single non-specialist agency taking control of the state.

32. Even though 56 services have gained experience with the NDIS gateway function, it appears that very few providers will qualify to submit a tender to be a Community Partner because of the multiple and overlapping conflict-of-interest provisions.

Recommendations

To protect best practice in Early Childhood Early Intervention, we recommend the following options for consideration by ECIA NSW/ACT and, its federal counterpart, ECIA National:

Legislative and Regulatory Change

1. ECIA National should advocate for legislative and regulatory change to the definition of an insured party for the purposes of Early Childhood Early Intervention (ECEI) from a child to a family. As a result, services could flow to the parents and, through them, to their dependent child until the child reaches six years of age.

Bilateral Agreement between NSW and the Commonwealth

2. ECIA NSW/ACT should advocate to the State and Federal governments to transfer responsibility for supporting families through the diagnosis period and transition to school under its ECEI Approach from the State (i.e. the role and function of AbilityLinks NSW) to the NDIS.

3. ECIA National should work the federal and state governments to review the roles of early linkers (ADHC) and family support workers (FACS) and broaden the role of ECEI Approach under the NDIS to incorporate these roles.

ECEI Approach under the NDIS

4. ECIA National should closely monitor announcements regarding the Information, Linkages and Capacity-Building (ILC) component of the NDIS to ensure adequate 'interim supports' are provided for children who will not access an individualised funding package (IFP) and sufficient 'capacity-building' will be available for parents to sustain them in their caring roles.

5. ECIA National should lobby the NDIA to remove the current restrictions on support coordination and individual capacity building and ensure support for all parents without condition.

6. ECIA National should work with the NDIA to redefine disability and global developmental delay under the NDIS ECEI Approach in such a way as to ensure that needy families receive the supports they require. In particular, children who are born prematurely should be automatically eligible for services related to global developmental delay.

7. ECIA National should work with the NDIA to clarify what data will be required, for what purpose and how that data will be collected, used and shared for sector development.

Funding

8. ECIA should advocate for the funding of travel and key workers separately from the total funding allocated for services. These items should be budgeted as additional 'enabling costs'.

9. ECIA National should maintain a watching brief on the total allocations made under IFPs to ensure that the level and quality of intervention services provided to children and their families does not erode over time.

10. ECIA NSW/ACT should advocate for NSW government funding of a workforce adjustment program to ensure the smooth transition of workers from defunct local services to other services, including funding for additional training required by the NDIA, particularly for early childhood educators.

11. ECIA NSW/ACT should advocate for increased funding for Families NSW and other state-based programs in expectation of an increase in demand as a result of the discontinuation of the work of FACS (ADHC).

ECEI National Best Practice Principles

12. ECIA National should review and revise the *National Guidelines for Best Practice in Early Childhood Education* and add a new principle reinforcing the importance of timely early intervention and the need for 'soft entry' and 'interim supports'.

13. ECIA NSW/ACT should support ECIA national to undertake a comprehensive communication campaign to promote and explain ECI best practice directly to parents, medical, allied health, students, the NGO sector, ECI workers and government officials.

ECIA NSW/ACT

14. ECIA NSW/ACT should maintain a watching brief on local referral pathways and report to the NDIA regularly to ensure they are retained by ECEI Community Partners.

About this Study

THINK: Insight & Advice was commissioned by Early Childhood Intervention Australia NSW/ACT to undertake a process evaluation of the 2016/17 transitional arrangements negotiated and jointly implemented by the National Disability Insurance Agency (NDIA) and the Department of Family and Community Services NSW, Ageing, Disability and Home Care (ADHC). The study focuses on the program's operations, implementation and service delivery during the transition period (i.e. November 2016 to present).

The purpose of the study is to help ECIA NSW/ACT assess the effectiveness, appropriateness and sustainability of the ECEI transitional arrangements and to determine:

1. How this model might be utilised following the full transition to the NDIS in 2018;
2. What impact the arrangements may have had on:
    - ECI service providers;
    - ECEC sector and schools;
    - Health, Allied Health and community/mainstream referral partners; and,
    - Children and families, albeit indirectly, through service providers.

The objectives of the study include:

1. To examine the effectiveness, appropriateness and sustainability of various components of the transitional arrangements, including:
    - Assessment tools (e.g. PEDI-CAT tool);
    - Referrals to community and mainstream services;
    - Provision of interim support services
    - Planning process
    - Plan implementation and support coordination

2. To compare the efficacy of referral pathways pre-and-post-NDIS implementation and how the NDIS is likely to impact on or change current ECEI approaches

3. To identify gaps in universal services and the 'interim supports' required outside the scope of the ECEI Approach under the NDIS, including those experienced by children experiencing vulnerability and disadvantage and those with complex and/or child protection needs (especially when ADHC winds down from the funding of disability services in NSW)

4. To assess the efficacy of place-based solutions (i.e. community-based organisations delivering coordinated services in the local community for local children and families)

5. To describe models of collaborative partnerships with the broader health, community and education sectors

6. To assess the sustainability of the transitional arrangements in terms of financial sustainability, workforce pressures and community connections

This study was originally designed to compare the experiences of three cohorts of Transition Providers:

- **Nepean Blue Mountains** – Four ECEI services funded by the NDIA to trial the ECEI Approach between July 2015 and June 2017 in the Nepean Blue Mountains area of NSW
- **Year One Providers** – 8 of approximately 25 services who were selected by NSW FACS (ADHC) to gain experience with the NDIS gateway function utilising an amount equivalent to 45% of their residual ADHC funding for supporting families and children beginning in November 2016

- **Year Two Providers** – 7 of approximately 27 services selected and funded by NSW FACS (ADHC) to gain experience with the NDIS gateway function beginning in July 2017

However, this was found to be impractical, given the tight restrictions on the availability of quantitative data by the NDIA and the wide variation in the size and location of the providers. THINK subsequently found that there was as much or more variation among the members of each cohort than between the cohorts themselves.

This is a point-in-time study conducted within an unusually dynamic policy environment. New policies, interpretations and administrative arrangements were announced throughout the research period with one of the key research questions answered as recently as 6 September 2017. Given that the transitional period will continue through until June 2018, it is too early to determine outcomes from the arrangements.

Qualitative process evaluations of this sort have been commissioned by NSW government departments as major reform processes were underway as an early indicator of success and to flag issues that can be resolved through the roll-out period.[2] While qualitative findings can provide reliable information about the direction of a particular reform initiative, they should be corroborated by quantitative data at the end of the transition period.

Research Methodology

The primary research methodology used for this study was the semi-structured, one-on-one, interview. The interviews were conducted according to a detailed discussion guide that was developed in collaboration with the ECIA NSW/ACT Project Team.

A non-directive technique was used to moderate the interviews. Where possible, the asking of direct questions was avoided and participants were invited to engage in spontaneous discussion of the topic. To encourage full and frank disclosure of views, participants were assured that their comments would appear without attribution. To further protect their identity, stakeholders' names are not published in this report.

The data generated through interview discussion is essentially qualitative and anecdotal. Accordingly, no attempt has been made to quantify the findings, although emphasis is given to those opinions and attitudes which appeared to be consistent across the whole sample.

In addition to the 33 hour-long interviews, THINK observed a forum for ECI providers in the Nepean Blue Mountains area and invited follow-up submissions by email.

Research Sample

The research sample included 33 participants, spanning 7 stakeholder groups, as follows:

ECIA NSW/ACT – 3
Nepean Blue Mountains – 4
Year One Transition Providers – 8
Year Two Transition Providers – 7
Ancillary Providers (Local Area Coordinators/Early Linkers) – 4
Government – 4
Expert Observers – 3

[2] THINK: Insight & Advice Pty Ltd for Value Enhancement Management (2007). *Clinical Services Redesign Program: A good start and a happy ending make for a much better patient journey*. Second report in a three-year evaluation process. Sydney: NSW Health.

As this is a process evaluation, not an impact or outcome evaluation, interviewing or contacting families and children was specifically ruled out-of-scope.

The fieldwork for this study was conducted between 17 May and 18 September 2018 in-person, on-line and by telephone. The Nepean Blue Mountains Provider Forum was held on 8 June. Four of the seven Year Two Providers were interviewed twice since they had not received their lists of 'defined children' at the time of their initial interview.

How to read this report

This report is organised around six thematic chapters. The titles of the chapters and subtitles are written as research findings in and of themselves. They appear in **bold blue typeface**.

Extensive verbatim quotations are included so that readers can 'hear' the participants talk about the ECEI Approach under the NDIS. Verbatim quotations appear in *blue italics*.

Research Team

THINK: Insight & Advice is indebted to the ECIA NSW/ACT Project Team of CEO, Margie O'Tarpey, and Sector Development Manager, Enis Jusufsphahic, for their support and assistance. In particular, we would like to thank Enis for his careful technical review and for keeping the team abreast of the many rapidly changing developments in the sector throughout the study period. While we are aware that further changes have been made since the conclusion of the study. The findings and conclusions herein are based on the information in the possession of THINK on 18 September 2017.

Randall Pearce of THINK: Insight & Advice designed and facilitated this evaluation. The fieldwork process was managed by Grant O'Neill of Benson + Fox. Randall Pearce wrote this report.

Guide to terminology and acronyms

Ages and Stages Questionnaire – An assessment tool used to compare the function of a young child to that of his or her peers of the same age

'Defined Children' – Children who were previously receiving services from an ECEI provider under the former State Government program administered by FACS (ADHC)

ECEI – Early Childhood Early Intervention – Methodology for supporting with children with disability and/or global developmental delay and their families

ECEI Community Partners – The agencies selected by tender to administer the ECEI Approach under the NDIS in NSW. They will be appointed through a competitive sourcing process in late 2017

ECEI Transition Providers – 56 Service providers selected by NSW Family and Community Services to trial the ECEI Approach under the NDIS. There were two cohorts: Year One Transition Providers commenced their work in November 2016 and Year Two Transition Providers started in September 2017

ECI Providers – Providers of Early Childhood Intervention Services

ECIA National - Early Childhood Intervention Australia – The federal peak body for Early Childhood Educators and Early Childhood Intervention Services

ECIA NSW/ACT – NSW/ACT division of ECIA National

FACS (ADHC) –Ageing, Disability and Home Care division of NSW Department of Family and Community Services

Hunter Valley Trial Site – The area selected for the first trials of the NDIS in NSW 2013-15

Individualised Funding Packages (IFP) – Otherwise known as 'NDIS Plans' these are the approved plans for funded services selected by an insured party who meets the access requirements of the NDIS. There are three 'levels' of plans with associated tiers of funding available

Information, Linkages and Capacity Building (ILC) – Along with Individualised Funding Packages, ILC is the second component of the NDIS. While its structure and funding has yet to be announced, it is expected to include five streams of activity:

1. Information, Linkages and Referrals
2. Capacity building for mainstream services
3. Community awareness and capacity building
4. Individual capacity building
5. Local area co-ordination (LAC)

'Interim Supports' – Interim supports are any services provided to a child and his or her family when they first present at an Early Childhood Early Intervention Provider. These can take the form of supported playgroups and referrals to other services such as family support and early childhood education. A diagnosis of disability or global developmental delay is not required to access 'interim supports'.

Key Worker – A member of a transdisciplinary team who serves as the primary contact for a family of a child with disability or global developmental delay. A key worker can be a member of the family's early intervention team, a childhood educator, or a therapist could be selected to fill that role

National Guidelines: Best Practice in Early Childhood Intervention – A set of eight best practice guidelines developed by Early Childhood Intervention Australia in consultation with sector representatives and more than 60 experts from a diversity of fields related to ECI

NDIA – National Disability Insurance Agency – the Commonwealth Insurance Corporation that administers the National Disability Insurance Scheme

NDIS – National Disability Insurance Scheme – a social insurance scheme which provides funding for people with disability to choose what supports they use to maintain their health, well-being and mobility

NDIS ACT – *National Disability Insurance Scheme Act (2013)*

NDIS ECEI Approach – The best practice service framework adopted by the NDIA for providing supports to children 0-6 and their families to support them with disability and/or global developmental delay under the National Disability Insurance Scheme

Nepean Blue Mountains Trial – A NDIA-funded trial of the ECEI Approach under the NDIS by four services in the Nepean Blue Mountains area of NSW beginning in July 2015

'New Children' – Children who were referred to an ECEI Transition Provider after the commencement of the transition period

NSW FACS – Department of Family and Community Services NSW

PEDI-CAT – Paediatric Evaluation of Disability Inventory (PEDI) originally published in 1992 has been updated to operate on computer assisted terminals (CAT). Hence, PEDI-CAT. It is an American assessment tool used to measure discrete changes in function among children. It is also used to set benchmarks and measure progress so that other health and economic benefits of the NDIS can be measured and tracked over time

'Soft Entry' – 'Soft Entry' is a term used to refer to services of a non-therapeutic nature which can ease a child and their family into an Early Childhood Early Intervention Service. These may be specialised services or they may be mainstream services offered in the community.

Transition Advisors – Advisors appointed by the NDIA to support and advise Transition Providers and to pre-screen the initial plans written by a Transition Provider

Transition Providers – 52 Early Childhood Intervention services selected by Department of Family and Community Services NSW, Ageing, Disability and Home Care (ADHC) to trial the gateway function under the NDIS ECEI Approach

Transitional arrangements – The special arrangements negotiated between the NDIA and FACS (ADHC) to provide services to 'defined children' and 'new children' through the transition period

Key Findings

Introduction

What is ECEI and why is it needed?

> *I see ECEI as critical for the well-being of young children and families. It is a good thing that children don't have to be in the disability sector permanently. It plays a critical role in keeping children out of the child protection system as well. If families get holistic support early on, they will have the support to care for these children. There might be fewer relinquishments as a result. People should be able to choose the supports that they need. They need to be aware of the range of supports available. – LAC*

Early Childhood Early Intervention (ECEI) is an evidence-based approach to addressing disability and global developmental delay in children aged 0-6. It is grounded in academic research conducted in Australia and overseas. Early childhood educators in NSW have been national leaders in both the development and uptake of ECEI in Australia.[3] The sector in NSW is characterised by a large number of not-for-profit providers (i.e. more than 100 services) of various sizes. By comparison, early childhood intervention has been delivered in other states by a comparatively small number of NGO providers and state government agencies, using a variety of other approaches, some of which include elements of ECI best practice.

The underlying principles of the ECEI approach were embraced by Department of Family and Community Services NSW, Ageing, Disability and Home Care (ADHC) and operationalised through a disability support program entitled, *Stronger Together II: A new direction in disability services in NSW 2006-16. Stronger Together II* and its successor, *Ready Together*, adopted a 'person centred approach' to enable people with disability to determine what support resources they use.[4] The ECEI approach was formalised through the development of the *National Guidelines: Best Practice in Early Childhood Intervention* by ECIA in 2016. The approach was trialled by four services in the Nepean Blue Mountains region of NSW in 2016/17 with funding provided by the NDIA. An evaluation found it to be an effective way to support children with disability and their families and, as a result, the NDIA adopted the ECEI approach to early childhood intervention for the National Disability Insurance Scheme.

The arrival of the National Disability Insurance scheme has been widely anticipated by people with disability, their carers and families since it will almost certainly deliver more resources into the disability sector, enabling greater independence for many. Individualised funding is seen as superior to block-funded arrangements because the funding can be targeted to the functional needs of the person with disability rather than requiring them to 'fit' specific program criteria. However, it remains an open question if this approach designed for adults is appropriate for young children and their parents. A major issue is that not all children moving through the NDIS gateway will meet the access criteria by being diagnosed as having more than one permanent disability or global developmental delay.

The transitional arrangements were funded by the NSW government, utilising a specific funding program, equivalent to forty-five percent of residual funding previously paid to services directly by NSW FACS (ADHC). There were two cohorts of Transition Providers: 27 Year One providers who began 1 July 2016 and 25 Year Two providers who began 1 July 2017. Unfortunately, the transitional period was truncated because the Year

[3] (2014). *Early Intervention Best Practice Discussion Paper*. Authors Rani Dibley and Denise Luscombe. Revised. [online] Sydney: ECIA NSW/ACT. Available at: https://www.ecia.org.au/documents/item/114 [Accessed 30 Oct. 2017].

[4] NSW Family and Community Services – Ageing, Disability and Home Care website accessed 21 September 2017 at https://www.adhc.nsw.gov.au/about_us/strategies/stronger_together_2

One providers did not receive their lists of 'defined children' until November 2016 and Year Two providers waited until September 2017 to receive their lists.

Ongoing Community Partners are expected to be appointed to take over from the Transition Providers effective 1 July 2018 when the NDIS is scheduled to go 'full-scheme'. While the NSW ECEI sector would have preferred to learn more from the transition experience prior to placing competitive bids to fulfil that role, the NDIA has said that a new funding round and competitive sourcing process will go ahead in November 2017 as scheduled.

This qualitative evaluation has been designed to provide quick feedback on the transitional arrangements prior to the commencement of the competitive sourcing process and to flag any issues before the full-scheme is rolled out next year.

1 The transitional arrangements in NSW delivered on the stated and unstated goals of ECIA, FACS and the NDIA to varying degrees

1.1 ECIA, FACS and the NDIA each had goals, stated and unstated, for the transitional arrangements

ECIA NSW/ACT, Department of Family and Community Services NSW, Ageing, Disability and Home Care (ADHC) and the National Disability Insurance Agency each had goals, either explicitly enunciated in advance or articulated after the fact, for the transitional arrangements.

ECIA

The Transition Provider arrangements in NSW were proposed by ECIA-NSW as a way of ensuring ECI Best Practice would be continued under the NDIS. As a professional body, ECIA NSW/ACT openly acknowledges that it also wanted to serve its members by helping them make the transition to the NDIS. Given that its members are mission-driven, not-for-profit organisations, it was always about more than 'maintaining a business', according to ECIA and its members alike. Finally, there was a desire to ensure a large number of providers had a good understanding of the NDIS gateway function.

> *In NSW, the objective was to have a large number of providers with a good understanding of best practice and good community connections. – ECIA*
>
> *What was our strategic objective? To ensure smooth transition to NDIS and to follow ECI Best Practice Guidelines, not to maintain a business. It cannot be as narrow as supporting our members. We have to think long-term about what is best for our families and children. – ECIA*
>
> *There's probably some truth in that. Of course, we are going to support our members because we believe in what they do. NSW has led ECI in Australia for a long time. We have advocated a specialist, place-based model because we were able to do that in NSW under ADHC. There was no evidence that ECEI was being done well, or at all, elsewhere in the country. This is critical because NDIA had a view about their preferred early childhood partner. They supported the collaborative model but the roll-out has been tremendously problematic. In the absence of any service delivery model, NSW led the way. NDIA don't like it because there are 100 services. But that doesn't mean it is wrong. We wanted to test how it would work here. ECIA NSW/ACT never advocated that 50 services be funded. That was ADHC. - ECIA*

NSW Family and Community Services

For its part, the NSW Department of Family and Community Services (ADHC) embraced the transitional arrangements as a means of preserving local referral pathways in NSW. The government sought to ensure[5]:

- Established referral pathways for children and their families would be retained throughout the NSW transition
- The capacity of providers to provide information and short-term support to children and families would be maintained until the national model is in place

[5] National Disability Insurance Scheme - NDIS in New South Wales accessed 21 September 2017 at https://www.ndis.gov.au/about-us/our-sites/NSW.html#nswecei

- There would be minimal disruption for families currently being supported in the NSW system at the same as ensuring that new children had clear established pathways for their referral for support in their local communities
- The sector would have clarity on the changes required to engage with the NDIS at full scheme

NDIA

The NDIA accepted the arrangements as part of its commitment to implementing an ECEI approach for children with disability and their families under NDIS. To do that, services needed to be open to 'new children' while the State-based services were transferred to 'defined children'.

I said that it be would be tragic if services could not assist families that knocked on their door while in transition. We needed a 'No wrong door' approach for 100,000 children per year who have difficulties. – Expert Observer

1.2 ECIA and FACS largely achieved their goals for the transitional arrangements; NDIA was less satisfied

ECIA

Much work is yet to be done to ensure ECI Best Practice is secured under the NDIS (ee see Section 2 for a detailed discussion of how the best practice principals have been maintained entirely or partially under the transitional arrangements and the implications for the future(. However, ECIA NSW/ACT can claim to have achieved its two main goals.

First of all, 56 of the 100 providers in NSW are now acquainted with the approach as it will be operationalised under the NDIS. While only a few providers are likely to carry on work as ECEI providers in future, this familiarity with the system will no doubt be of benefit to the sector as a whole.

Secondly, ECIA was widely praised by its members for the support it gave to the 56 providers selected by FACS (ADHC) for their transitional roles. These activities were highly-valued and praised by providers.

We went to information sessions run by ECIA. I don't know what we would have done without them. – Year One

ECIA has been phenomenal in their support. We really appreciate that we have had the Year Ones who can tell us what to do. – Year Two.

They have done great work. They have provided every bit of support to sustain us and keep us viable. We cannot do without ECIA. I would like to thank ECIA for all that they are doing. – Year Two

The work that ECIA has done to support the sector has been absolutely vital. There is no way we would be so far advanced without them. – Year Two

NSW Family and Community Services

The State Government achieved two of its four stated goals: information and short-term supports were provided to children and families during the transition and the sector now has clarity on changes in the service system.

Fig 1.1 ECIA NSW/ACT Activities to support Transition Providers

- Regular Forums for ECI services in:
  - Nepean Blue Mountains
  - Hunter New England
  - Australian Capital Territory
- Research into the Implementation of the NDIS in the early childhood intervention sector in NSW - University of NSW, Social Policy Research Centre – November 2016
- Results Based Accountability (RBA) Case Study, Families NSW - February 2017
- A Partner in NDIS Readiness Forums Round 1 – February to May 2017
- ECIA NSW/ACT Manager's Forum - 2 March 2017
- Early Childhood Intervention Australia Regional Inclusion Forums March - May 2017
- Early Childhood Early Intervention (ECEI) 'Master Class': Transition Provider Practice Workshop - 24 May 2017
- ECIA NSW/ACT State Conference – 25 & 26 May 2017
- Evaluation of the ECEI Transition Provider Framework in NSW, THINK: Insight & Advice - May to October 2017
- Consortiums, Alliances and Partnerships Seminar for ECI Services - 11 August 2017
- ECIA NSW/ACT Member Forums - October to November 2017
- A Partner in NDIS Readiness Forums Round 2 – October to November 2017
- ECIA NSW/ACT Managers' Forum - 5 October 2017
- Inclusion Symposium - 30 November 2017

Source: ECIA NSW/ACT

However, the transitional arrangements did not fulfil the goal of causing 'Minimal disruption for 'defined children' while ensuring support for 'new children' through the transitional period. Although, it should be noted, the experience of 'new children' was highly variable from location to location.

It will not be possible to ascertain if local referral pathways will be maintained under the NDIS until the NSW competitive sourcing process is complete but one area where 'new children' reportedly suffered a lack of service was in the Hunter Trial Sites – Maitland, Newcastle and Lake Macquarie. Because these areas transitioned to full-scheme NDIS in 2015/16, local providers had no residual 2015/16 ADHC funding against which a 45% residual calculation could be made. As one provider observed, 'nothing of nothing is nothing'.[6] Since no funding for the Information, Linkages and Capacity Building (ILC) component of the NDIS has yet been announced or released, there was no federal funding to serve 'new children' during the transition period, resulting in long wait lists in those areas. Providers in the Hunter referred families onto NSW Families for support

[6] Note: The minimum allocation was $85,000 per service if no residual funding was left.

and LACs provided referrals to mainstream services for parents and children over the age of six years.

We saw some providers doing very well, developing tools, developing good quality plans and implementing the model effectively. Some others have found that challenging. Smaller and remoter providers have had more difficulty but not universally. Sometimes it's about how the model works, how funding works and sometimes about the quality of plans. – FACS

ECEI is a good model and it is working. The Transition arrangements have replicated the three kinds of funding available under ADHC: assessment, short-term or interim supports, referral to a long-term plan. - FACS

We get new referrals every day from our other business. We have also been receiving new children from traditional referral pathways. There has been some difficulty in juggling the two responsibilities. – Year One

There are a lot of providers that are upset because children are waiting because ECEI providers are so busy doing plans that they aren't doing the referrals. The whole point of ECEI providers doing this is to continue to provide early intervention while they are supporting transition. - LAC

NDIA

While the transition provider arrangements provided the NDIA a good opportunity to trial ECEI Approach in NSW before national roll-out of the full scheme, officials were not happy with the way the arrangements unfolded.

I would not describe the process as effective at all. We were contracting to too many third-party contractors to the NSW government. We had no ability to drive quality. There was a delay in getting the list. It was a tactical challenge. There were three in the contract but only two of them were party to the contract. There was a significant delay in getting providers to process the number of children through the system. We had no legal basis to provide the data but we faced complaints. It was the NSW government that caused the delay. The fault lies in the lack of clarity with this transitional model. – NDIA

It's been a very difficult transition to the NDIA. The NSW arrangement has been a little more challenging given the number of providers we are dealing with. The sheer scope of transition is the issue. There has been some confusion arising from the providers not understanding their role. – NDIA

1.3 There were no distinct differences in the experience of the three cohorts attributable to anything other than the slight differences in program design

This study was originally designed to compare the experiences of the three cohorts of Transition Providers. However, this was not possible due to the unavailability of quantitative data. The research team documented as much qualitative variation within cohorts as between them. Consequently, there were no overall trends observed.

Any slight differences in experience among the cohorts can be attributed almost entirely to the small difference in program design used by the different groups:

- **Nepean Blue Mountains Providers** were funded by the NDIA, not NSW FACS (ADHC). They were allocated a flat $1,700 per child but they were not required to acquit expenditure against individual children: they were free to pool the funds to serve all children coming through the gateway regardless if they would later meet the access criteria for an IFP under the NDIS or not.

- **Year One Transition Providers** were given block funding equivalent to 45% of their previous allocation from NSW FACS (ADHC).
- **Year Two Transition Providers** were funded in the same way as the Year One cohort but were assigned Transition Advisors for support.

2 ECEI Community Partners may be challenged to translate the theory behind the national guidelines into best practice under the NDIS

On the basis of the information currently available, it is difficult to determine if ECI Best Practice will be able to be maintained under the NDIS. Hopefully, the issues identified below will assist ECIA in addressing anticipated weaknesses in the system so that they can rectified prior to the launch of the full-scheme in June 2018. The main questions revolve around how a disability insurance scheme designed for adults with disability can serve the needs of children and families, how children exercise self-determination and how a family-centred approach can operate without supporting and building the capacity of parents.

The Act is clear that the investments you make in early intervention – they command the NDIA to follow evidence-based practice. There is tension between those making the decisions and those who understand best practice in early childhood intervention. – Expert Observer

2.1 Family-Centred and Strengths-Based Practice: There are concerns that ECEI could take a step backward under the NDIS and return Australia to a diagnosis-driven model

While adults with disability undoubtedly consult and rely upon their immediate family members for support throughout their lifetimes, the relationship between a parent and child is somewhat unique in that a dependent child is dependent and cannot exercise self-determination or 'choice' as an adult would. Some query whether a social insurance scheme designed for adults can ever meet the needs of both children and families. Hence, there are concerns that the notion of family-centred practice will not be upheld.

Individualised funding, while ideal for adults with disability, may be at odds with the best practice evidence-based approach to early childhood education. McDonald et al quoting Shogren and Turnbull (2006) note:

> Children spend the majority of their time, particularly in early childhood, in the home. The home environment mediates the opportunities children have to engage in behaviours that support the development of self-determination. Furthermore, opportunities to experience self-determination that occur outside the home…can be greatly influenced by the degree of family involvement and support for such initiatives.[7]

Some say that for very young children, child and parent should be considered as one and the same insured party under the NDIS.

It is a good idea for NDIS make an exception in the case of very young children – parent and child are one unit. - ECIA

A child is born into a family but the services are organised as therapy for the child. Is there a disconnect here? – NBM

Some others are concerned that early childhood intervention is going backward under the NDIS.

[7] McDonald, Davis, Mahar, 'When Funding Meets Practice: The Fate of Contemporary Therapeutic Approaches and Self-Determination in a Consumer-Centred Disability Funding Scheme' *Journal of Policy and Practice in Intellectual Disabilities*, Vol 13, No 4, p 280, December 2016

I am wondering if we can come back and recover after this. This service system works on a deficit model, a diagnosis-driven model. It is awful after we have had a good history of family-centred practice. – Year Two

Changes are needed to make the NDIS child and family friendly. Some specialist providers are already trialling process improvements to bring the gateway function into closer alignment with best practice.

We review the plan with the family and make changes before it is submitted. We received a lot of feedback that families did not have an opportunity to review the plan which resulted in the need for a change and a delay in accessing services. So, we bring in the parents to sign off before it goes in. We'd rather wear that 15 minutes than let kids go without support. – Year Two

Fig 2.1 Key Best Practices in Early Childhood Intervention

1. 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.

2. 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.

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.

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.

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.

Source: National Guidelines: Best Practice in Early Childhood Intervention, Early Childhood Education Australia accessed 21 September 2017 at https://www.ecia.org.au/documents/item/186

2.2 Culturally Responsive Practice: It is not possible to serve culturally and linguistically diverse communities in a single language

It is not possible to serve diverse communities in a multicultural country, like Australia, in English only. It is important that all families can access early childhood intervention services. Unfortunately, by refusing to initially fund language interpretation for non-English speakers, NDIA effectively denied service to tens of thousands of families in NSW. By failing to recognise the additional time needed to work through language interpreters, the NDIA shifted the cost of culturally-responsive practice onto not-for-profit providers.

The situation faced by Aboriginal and Torres Strait Islander families received no commentary from the participants in this study other than in the context of 'vulnerable families' (for a discuss of the situation faced by vulnerable families, please see Section 5.2).

2.3 Inclusive and participatory Practice: ILC funding remains a large question mark over the ECEI Approach under the NDIS

Children with disability and their families should have the same opportunity to access mainstream services as anyone else. However, in order for that to happen mainstream services need to develop the capacity to serve the particular needs of children with disability and their parents.

The NDIS is composed of two elements: Individualised Funding Packages (IFPs) and Information, Linkages and Capacity Building (ILC). ILC will provide grants to help mainstream services adapt and build capacity. This is intended to reduce the long-term costs of the NDIS by serving people with disability through mainstream services rather than plan-funded specialist services.

Given, the ILC funding arrangements are yet to be announced, it is too early to assess the adequacy of ILC funding structure or amounts.

2.4 Engaging the Child in Natural Environments: While familiar settings for therapy are ideal, it is more important to practise and reinforce therapy in the home

At the heart of this best practice principle is the belief that intervention is best delivered in an environment where the child and her family feel most comfortable. By delivering services in the community, ECI providers build a family's capacity to interact with the community and the community's capacity to support the child and their family.

Ideally, a therapist will travel to the family home to deliver the therapy. The idea is that if the therapy is delivered in the home setting of the child it can be replicated and practised by the parents in the absence of the therapist.

> *The best thing about ECEI is that the provider does not have to do anything directly with the child. It is about supporting the families to access the services. So, you might not need to travel each fortnight. You might have that discussion with those families and providers another way. Providers have to become smarter about how they engage. They might have to talk a family through the approach. It is what happens between the visits that counts. To get the family to clearly understand is very important. Yes, you do want to see the child in the early phase but counselling can be done through modern IT support. We are seeing a worrying trend of parents driving children to therapy appointments but not being involved. That is a big concern. – Expert Observer*

While, all families whose child qualifies for an IFP can allocate up to $1,000 for general travel and $3,000 if they elect to have a key worker as part of their plan, it is somewhat controversial for a couple of reasons. First, parents are reluctant to trade-off travel for therapy given their predilection to choose therapeutic interventions over other supports. People also say that travel suffers because it is included in the lump sum funding allocation. Under the previous system, 'enabling supports', like travel and key workers, were listed separately.

> *The packages for 0-8 are coming as a total figure. Families believe that they can use that money any way they want. The travel used to sit on top of whatever money they got. If it is part of the total figure, they don't value it. I think that is the reason families are not picking up family support. If it is not quarantined, they don't want it. They want therapeutic services. Not separating out family support and travel works against you all the time. – Year One*

Providers say that they are adopting innovative practices such as bundling sessions and servicing clusters of clients in rural and remote areas to stretch the travel dollar further. People in regional centres say that rural families like to organise centre-based therapy in conjunction with a 'trip to town' because it fits with the errands and doctor visits they usually schedule for those visits. While in-home therapy is ideal, it will be important for providers to be flexible and not make best practice the enemy of good practice.

> *Travel is capped at $3,000. It is a contradiction of best practice. People travel 100-150 kilometres to deliver therapy. We are reconsidering if it is still viable to provide support in more remote areas. There are no other people providing supports in those areas. It is not sustainable for us to do it. We do things to minimise travel costs (our therapists travel together and we group clients together). Someone has to pay for travel or people will have to travel to the clinic. People are asking if they can trade the $3,000 for more therapy. – ECIA*

> *Travel is a gigantic issue for us. $3,000 is sufficient. It does allow us to deliver our key worker model but it is not enough for our regional travel. We still have to work out what customers we see. We have to see some families on a fortnightly basis because they live an hour away and we can't afford to travel to them. – Early Links*

> *We have been trialling clusters. We have two staff members who go out to a small community once each fortnight. That is how we will conquer that tyranny of distance. Other families are prepared to travel the two hours into town because they can combine trips to the doctor and grocery store, etc… - Year Two*

2.5 Collaborative Teamwork Practice: Key workers are key

At the heart of the ECEI approach is a belief in 'transdisciplinary collaborative practice' whereby a team of professionals spanning speech pathology, physiotherapy, occupational therapy, psychology, early childhood education, service planning and coordination is engaged to deliver services to the child and his family. To coordinate this group of professionals and to provide a single contact point for children and parents, 'key workers' are appointed from amongst the team members. There is an overall preference to appoint educators to these roles because of their generalist training but the lead therapist can also perform this role.

The parents of 'defined children' were more likely to nominate funding for a key worker because their previous experience of key workers convinced them of their value. For parents of 'new children' a key worker's value proposition is not as clear and their perceptions of it come into

direct conflict with 'deeply held cultural assumptions' about what is 'real therapy'.[8] According to some, it is easier to convince families of the worth of a key worker if the individual assigned is also a therapist. One expert observer said that it is the job of the Community Partners to educate parents about the value of the various approaches which align with ECI best practice but others say that to do so would be to place pressure on families to purchase the services of the provider making the recommendation, violating the conflict of interest rules.

> *It's not that they don't value ECEs, it's just that they don't about know them. The fact that parents receive a diagnosis makes them favour a diagnosis-driven model over the collaborative approach. The key worker model is challenged by the fact that the families don't know what key worker means. In the future, it means there will be a team around the child and some collaboration but how that collaboration works will change. You can have team meetings but it won't be based on the best practice models that the key worker is based upon. Until there is a longer-term assessment of ECEI, we won't have the answer to these questions. It is just too early to tell. – ECIA*

> *We still have 60% of families utilising the collaborative model including a key worker. If the key worker is a therapist, it is easier to sell. – Hunter Trial Site*

> *Fundamentally, one of the issues that we're seeing with the rollout of IFPs is that parents don't know what supports to value. Families don't know what they don't know. Part of the ECEI approach is about helping families understand what they need as part of plans. However, if you are not a provider, it is easier to have that conversation with parents. If you are a provider, parents believe that you are looking to feather your own nest. – Expert Observer*

> *We do a lot of collaboration now but we're going to have to do more in future. I don't know if families will pay for that. We would need family approval to bill for that time. We like to break down the plan into smaller goals. We are wondering if families will pay for that after having gone through the NDIS planning process. – Year Two*

Certainly, the NDIA has done little thus far to advance parental understanding of best practice early childhood intervention beyond publishing a pamphlet. Providers and non-providers alike said that ECIA has a role to play in educating parents and children about the benefits of the ECEI approach. Some ECIA members already do. Others say it is the job of family advocacy groups but that they need more funding to undertake that work.

> *It is very difficult to communicate the value of something that families don't know anything about. This is not something supported by doctors or the NDIS. A doctor will say, 'You need speech therapy, you need OT, you need physio.' They don't mention support in transitioning to school. NDIA has done nothing to help families understand what best practice is beyond a couple of fact sheets. The best practice intervention is in jeopardy because of the processes and lack of promotional support of the NDIA to promote them. – Year One*

> *How to sell ECEI? We have developed a pamphlet on what is ECEI and we work with Family Advocacy NSW to distribute that. We don't work with families, service providers do. Service providers work with the families and they are doing what they can. There needs to be better resourcing and support to family advocacy groups. – ECIA*

> *We stand by our best practice but how do you convince families to believe in it? They listen to their friends, not us. They say, 'I will take my kid to individual therapy'. For the collaborative model to be accepted, we need champions advocating for it. – ECIA*

> *Our families have been choosing key workers because we have been talking to our families about transdisciplinary support and the importance of key workers. We have been very open with our families and saying that if speech is a main concern, we can work with the speechie as the coach. However, if they can't, then the educator or the OT is taking on that role. We have a great diagram that explains*

[8] Ibid, p 280

how the key worker role works. That diagram comes in handy. When we have new participants, we will use that diagram and we break down how many hours the workers spend with the children. – Year One

There needs to be a more independent campaign around educating families about ECI best practice. ECIA have put together a very good booklet and I encourage planners to leave that booklet with families. That information can't come from the NDIA because they have ulterior motives. It can't come from providers because of the conflict mentioned earlier. – Expert Observer

2.6 Capacity Building Practice: Supporting parents is essential to supporting children

Another key feature of the ECEI approach is to develop the capacity of parents to practise and reinforce the therapeutic interventions in the home. However, parents themselves are less confident that this approach is superior to traditional therapeutic approaches. According to Moore (2010), quoted in McDonald, Davis and Mahar, 'Families tend to assume that direct therapy from a trained professional is better than anything they can provide (or learn to provide) themselves'.[9]

However, this is contrary to the best practice advice of researchers. They argue parental involvement is needed to sustain the intervention for as long as it is needed.

> By developing the capacity of parents and family members to provide children with learning and developmental opportunities in everyday environments contemporary therapeutic approaches appear to be more effective at developing the foundational skills of self-determination (e.g., sustained engagement) than more traditional approaches which typically do not emphasise parent and family involvement.[10]

Providers and non-providers alike say that 'parent capacity building' could be difficult to access under the NDIS because, as a social insurance program, the sole focus is on the child with disability, not the parent. However, capacity building is needed by all families including those whose children will go on to IFPs and those who are referred back into the community. This is particularly true for vulnerable families who come from a low SES, CALD or Aboriginal and Torres Strait Islander background, have a disability themselves or who are affected by substance abuse.

The NDIS is not a social welfare scheme. It is an insurance scheme. It is about increasing children's functioning and opportunities to participate. When we look at vulnerable families, we look at supports that were never part of the NDIS. This is a difficult transition from Stronger Together where there was more of a wrap-around service. Who has responsibility for vulnerable families? How will the NSW government provide for that? – Expert Observer

I think we will see individualised funding packages and parents thinking they are doing the right thing. But if they don't know what they are supposed to be doing at home, we are not going to see the long-term outcomes for those children. It could be the biggest waste of money ever. – Expert Observer

The NDIA clearly places the responsibility for parent capacity-building and education with the ECEI partner. However, the agency is unclear if a partner can be compensated for that role. FACS seems to have the same understanding but seemed to point to other unspecified funding sources.

Our partners are responsible for ensuring a family has access to all the right supports, at the right time, in the right circumstances. It is their role to communicate about the supports and who can provide

[9] Ibid, p 219
[10] Ibid, p 280

them. Families should be educated to understand the types of supports that they will require. The responsibility is with the partner. Read the description of partner on the website. - NDIA

I don't know if it would come out in a line item but it is part of what we would expect the provider to do. The provider of the supports is not just delivering a therapy session in 30 minutes. So, that doesn't change. – NDIA

Once someone is in a plan, a support worker is not guaranteed. In the context of that, the planner would have to get a good appreciation of the family's vulnerabilities. If they are severe, they would recommend a case support worker. If there is just short-term support, there is nothing stopping ECEI providers providing that support. It is well within the provider's bailiwick to provide that key worker model as part of that delivery. If a family does not need a plan but requires support, they should be able to provide short-term support. I thought that there would be block funding for an agreed output. - FACS

For the NDIA, best practice parent capacity-building is a [national] work in progress.

We certainly would encourage families to embrace best practice. We want to ensure that workers speak to best practice and promote best practice, noting that in some jurisdictions there are no key workers. NDIA does acknowledge that parents have control over who they choose to support their children. We are working hard to progress that. In some States, it is not yet in existence. - NDIA

People with detailed experience of the emerging ECEI Approach under the NDIS say individualised parent capacity building is available within IFPs but that it is severely rationed. For example, some have said that parents will only qualify for 'support coordination' when a child is at 'significant risk of harm'.[11] And yet, it is precisely these parents who need support to prevent that from happening. Several people who participated in this study said that parent capacity building can have a protective effect if it is delivered before problems arise.

If you can link it to the child's disability, there is flexibility (i.e. parent needs to spend 80% of their time with a child and you can get respite or home care support but it needs to be reasonable). – ECIA

There is a program called 'Supported Coordination' from NDIS and that is for agencies to work with complex families (e.g. parents may also be disabled, or have low SES, mental health and alcohol and drug issues). In the past, under block funding, ECI services provided that support for complex families and children at risk. – ECIA

The clear message has been that ECEI families are highly unlikely to have family support approved. We have had intensive ADHC funding for many years. We have a history of supporting families. I would love to know the back door in because we think that that it is important. The only parent capacity funding available is for families with children who are at significant risk of harm. That is reactive, not proactive. The NDIS say if it is not about the child's disability, we are not funding it. However, we have seen that a child's disability affects the family. There needs to be funding for family support. Yes, there are programs like Early Links for families who don't get family support but they are bursting at the seams. – Early Links

Providers say that the NDIA doesn't understand the reality of working with children and families and that, as a result, most of the time they spend with parents is 'unbillable'.

It's hard to keep true to your philosophy when most of your service is unbillable. For example, we might spend twenty percent of our time with the child with disability but about eighty percent with the families. We try to hand them off to other services like Brighter Futures but not every child is in child protection. – NBM

[11] Section 34 contains rules around 'reasonable and necessary' supports. One of the rules is e) the funding or provision of the support takes account of what is reasonable to expect families, carers, informal networks and the community to provide. The other rule is about the responsibility of other systems (in this case, child protection). The NDIS will not duplicate any service even if that service is inaccessible.

If we are doing planning, we are talking to families about their needs while we are preparing plans for a child. Families could ask for support but they only ask for supports for their children. We're seriously worried about the support needs of families. When we deliver our ECEI services, we will develop their coaching abilities but we won't be looking after the extended family as we used to. – Year One

Providers also say that without more support, families are unlikely to take full advantage of the supports that have been planned for their children. This could result in large amounts of funding being allocated but not spent.

So, we're finding that parents are not using all of the money in their plans because there is no one there to tell them how to do it. - NBM

However, in August 2017, the NDIA issued a fact sheet, *'Support Coordination: Information for participants and providers'* which specifically rules out support beyond what the ECEI Provider or LAC can offer.

> For children aged 0-6 and their families, Early Childhood Early Intervention Partners provide assistance with plan implementation. Where either a Local Area Coordinator or Early Childhood Intervention Partner is assisting with plan implementation, support coordination is not funded in the participant's plan.[12]

Transition Advisors are currently helping connect with services but, in areas where there are not a lot of services, it takes too much time. We are saying that without support coordination, the plan won't deliver. But the NDIA says a flat no to support coordination. They are knee-capping us before we even begin. – Year Two

Some providers say that this directive makes it impossible to follow best practice. However, NDIA officials give contradictory advice, saying that parent capacity building is part and parcel of the work of an ECEI partner and that providers simply need to write that additional support into an individualised funding plan.

First and foremost, the expectation is that the ECEI Partner will work with the child and family at home to support the family. I would expect that the partners would identify supports needed for a more vulnerable family. The partner role is to know the community but also to work on the family's understanding of the child's development. Their plans should identify more hours needed because of the family context. For example, visits might have to be weekly at the beginning. – NDIA

Experts say that parents need support throughout a child's lifetime, not just at the time of early intervention and that ultimately, government will need to accept responsibility for supporting parents.

It's absolutely problematic for there not to be parent capacity-building. It drives a family to a medical approach. The parents are the experts in the child. ECI should commence as early as possible and should be continued for their school-aged life. If you don't back that up with service models that enhance the capacity of the parent, how do you think that parental support will happen? It becomes more about friendships and inclusion in mainstream activities. If parents don't focus on that the child will have difficulty making progress in other areas. They need to continue to receive support because the child evolves. For example, they need supports to tell them how to change when the child reaches puberty. There are very serious implications of not supporting capacity building of families. Families need ongoing support well beyond early intervention. – Year Two

[12] National Disability Insurance Agency (2017). *Support Coordination: Information for participants and providers*. Geelong: National Disability Insurance Agency, p. 2, accessed 22 September 2017 at https://www.google.com.au/search?source=hp&q=ndis+%22specialist+support+coordination%22&oq=NDIS+&gs_l=psy-ab.1.0.35i39k1l2j0i131k1l2.234.7183.0.9832.18.12.5.0.0.0.374.2406.0j2j5j2.9.0....0...1.1.64.psy-ab..4.14.2442.0..0j46j0i46k1j0i5i10i30k1.0.j2JTK6ymYsw

Yes, ADHC is getting out of the business but the NSW government still has a responsibility. – Expert Observer

2.7 Evidence Base, Standards and Accountability and Practice: Parents need help interpreting information to guide their choice-making

Regardless of educational background or individual circumstance, parenthood can be a daunting experience, particularly when parents suspect their child might have a disability or global developmental delay. Putting parents in a position to 'choose' in an area that is new and frightening can overwhelm them and force them to fall back on doctors' advice. For this reason, some experts question whether a consumer-directed service system, like the NDIS, is appropriate for young children and their families. They fear that by shoe-horning children into an adult system, early childhood intervention could be set back decades.

I agree that person-centred packages are best for adults with disabilities but, parents of young children under 6 are at a point where they are not aware of their needs. They are in the grief and adjustment phases. Therefore, they are not well placed to be educated purchasers of services. I am yet to be persuaded that packages for young children and families is the right way to go. It could lead to a very medical approach. It could lead us to a place where we were 25 years ago. – Expert Observer

Indeed, the Joint Standing Committee on the National Disability Insurance Scheme recently recommended 'an independent referral pathway for access to intervention services…to respond to paediatric hearing loss'[13] and identified a need for parents to be given guidance about the various options so that families can make an informed choice.

While hearing loss is no doubt a specialised field, other domains of disability are no less bewildering for parents. Even when information is available, it can be hard to interpret. While 'medical evidence' of standardised therapeutic treatments may seem unassailable, these research methodologies don't properly evaluate the kind of non-standard, individualised interventions recommended under the ECEI approach and could undermine best practice. According to McDonald et al., quoting Steultjens (2004), 'A research design that requires standardised treatment is not appropriate for a therapeutic approach that is flexible.'[14] The article concludes by saying, 'Clearly, parents need a framework for understanding the quality of different types of evidence and they need to know which types of treatment are effective.'[15]

ECIA can play an important role in helping families interpret information since it can offer impartial, evidence-based advice without the potential for conflict of interest.

2.8 Outcome-based practice: Functional needs, not a diagnosis must determine access to early childhood intervention services

[13] ECIA NSW/ACT (2017). *Provision of hearing services under the National Disability Insurance Scheme: Briefing note for the Board of ECIA NSW/ACT*. Sydney: Early Childhood Intervention Australia NSW/ACT.
[14] McDonald, Davis, Mahar, 'When Funding Meets Practice: The Fate of Contemporary Therapeutic Approaches and Self-Determination in a Consumer-Centred Disability Funding Scheme' *Journal of Policy and Practice in Intellectual Disabilities*, Vol 13, No 4, p 282, December 2016
[15] Ibid, p 282

According to the people who participated in this study, it will be difficult to maintain outcomes-based practice under the NDIS if the ECEI approach reverts to a diagnosis-driven model. Functional needs, not a diagnosis, must determine access to early childhood intervention services.

2.9 The missing 9th Principle: Early Intervention must be early

Perhaps it is self-evident but early intervention needs to be early in order to be effective. As expert observers explained the theory, you don't want to waste a precious day of a young mind's growth potential.

'Soft-entry' is important

Parents are in various states of awareness and/or acceptance and the system needs to treat them gently in the first few weeks and months after they notice an issue with their child. 'Soft-entry' points, like supported playgroups and parent support groups, need to be maintained to give parents a chance to discover how early childhood intervention works and to become comfortable with the approach and to get to know the service providers. Unfortunately, the Guidelines are not sufficiently explicit about the need for 'soft supports'.

'Interim Supports' are needed while children await an access determination

ECEI partners need to be sufficiently funded to ensure that children who will progress to NDIS plans *and* those who don't receive the support that they need when they need it. That will require flexible funding and open referral pathways into and out of ECEI interim supports. The NDIA says that they understand how important this is but there are real concerns the service system will not reflect the rhetoric.

> *You will understand that the reason we produced the ECEI approach was to reduce the risk of kids with delay not receiving support. There are two core functions. One, to support children as soon as they have been identified and connect them with services. Two, if they need the specialist support, they can spend more time with the ECEI provider. There will always be two streams of kids: ones that need specialist support and those who will benefit from supports with or without funding from NDIA. – NDIA*

The need for 'interim supports' receives scant mention in the Guidelines as well. If it is made explicit, it may help to hold the NDIA accountable for following best practice.

3 The ability to implement best practice ECEI under the NDIS will be impacted by the structure and adequacy of funding arrangements, workforce pressures and data

While the ECEI Approach under the NDIS is underpinned by a robust theoretical framework, the ability to implement best practice remains in doubt. How well the gateway performs will be dependent upon getting the structure and quantum of funding correct, managing workforce pressures and ensuring the right data is captured, analysed and shared.

3.1 ECEI Partners should be funded to provide ECEI services to support children and their families who will meet the access requirements for an NDIS plan and those who won't

Funding Structure

There are two kinds of funding that are needed to support the roll-out of the ECEI Approach under the NDIS: funding for individualised funding packages (IFPs) and funding for the ILC component. It is difficult to assess the adequacy of the funding under NDIS when it is divided into two components particularly it replaces a comprehensive 'wrap around' State service.

> *I agree it will be difficult to implement an ECEI service under the NDIS. However, we are totally committed to the principles of ECEI. ECEI services (most but not all) had a great commitment to that under the block funding. Under NDIS, it is much more problematic because the funding is focused on the child, not the family. The funding is premised around individualised therapeutic approaches. Unless the funding model changes, to de-incentivise a diagnosis-driven model and incentivise the collaborative approach, it will be difficult for services to take that up because they have to follow the funding. – ECIA*

ECEI partners will be funded to provide 'interim and short-term supports' but not all children require the same intervention. Some require more, some less. Under block funding arrangements, providers were able to balance the mix themselves. Under the insurance approach, there are more constraints. Some say that the early childhood education sector needs to work with the NDIA to define exactly what will be available for a range of children with variable needs.

> *We will continue to provide services to children if they don't have a plan. That is the ECEI approach. The critical issue is that we must define what are short, medium and long-term supports available under ECEI. If we don't define them and fund them, the ECEI approach will become a referral system. – Year Two*

> *To be an insurance model, you need to fund those supports until you determine the supports that are needed for those children. They need to ensure there is adequate funding while these families await a decision. For children under 1 years of age, it is easy. On the other hand, a diagnosis for older children can take a long time. It's this understanding that the NDIA don't have. Two and above are much more complex. If you only get $1,200 per family you are only getting between four and six sessions, that is a very short intervention. The provider has to have the flexibility to provide less to some so that they can provide more to others. – Year Two*

3.2 While IFPs have received generous initial funding, it is not yet known if ILC funding will be adequate

Children who go onto NDIS plans

Early indications are that funding will be adequate for individualised funding packages. The early actuarial data[16] that has been released by the NDIA indicates that the individualised funding packages awarded thus far are generous:

- 20% of children funded to date have received a package equivalent to $5,000
- 40% of children funded to date have received a package ranging from $10,000 to $15,000, and
- 20% of children funded to date have received a package equivalent to $15,000 or more

However, while first year plans have been generous, observers warn that the size of these packages could be substantially reduced upon review or renewal. People view this in one of two ways. Either, it is evidence that the intervention funded through the first plan had the desired effect, meaning that the child does not require the same level of support on an ongoing basis. Or, for others, it is proof that people with disability and their families will need to be ever-vigilant to ensure a proper level of funding is maintained.

> *It's good to see that our children are getting adequate funding. So, it seems to me that the ECEI approach is doing a good job. If children don't qualify for a second round of support that is a positive thing because it shows that the intervention is working. – ECIA*

ILC – Children who don't go onto NDIS plans

While early indications are that the NDIS is delivering in terms of offering more generous supports for those who qualify for individualised funding packages, there are concerns about the adequacy of funding for kids who do not yet, or may never, have a plan. It is estimated that 40% of children will access IFPs under the NDIS but one quarter of the remaining 60% (i.e. 15%) will not qualify for a package but will require support nonetheless.

> *We're not so concerned about all of the sixty percent of children who will not access the NDIS but the one quarter of that percentage who will need support from other agencies. The actuaries have done some projections and they say we are talking about fifteen percent of all children. – ECIA*

> *There needs to be an ILC to build a whole-of-family approach. The NDIS needs to go out to the child's life rather than the child coming into the NDIS. NDIA don't understand the early childhood environment. They lack imagination. – Expert Observer*

> *Kids who don't go onto plans probably need about 12 months to give them a kick-start. It is much more than 4 or 5 sessions. We are quite concerned that that is going to be insufficient for the provision of services for those who do not meet the access requirements of NDIA. – Year Two*

Expert Observers say that ILC supports such as peer-to-peer parent groups and supported play groups may be at risk under the individualised funding model as these services were previously funded from the provider's block grant. Unfortunately, the lack of information means that it is impossible to determine if the funding will be adequate. The Productivity Commission in its June 2017 position paper on NDIS costs, wrote that 'determining precisely what ILC should cover is unclear at an operational level'.[17] Others remain sceptical about what the future holds.

[16] Macgillycuddy, S. (2017). *Potential Income from NDIS based on actuary results*. [email].
[17] Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs, Position Paper, Canberra,* p. 32

In NSW, there were supports for those children who did not have a disability. Governments have put all their money on the table to pay for the NDIS but haven't thought about what the residual issues are. – Expert Observer

ILC, without some targeting, will not provide the kind of support that is needed. – Year Two

Mainstream services have a long way to go to develop services for children and families who are not going onto packages. – Expert Observer

The ILC program is intended to fund mainstream communities. That's great but we don't really know what that looks like yet or how it supports the referral pathways. If it does what it is supposed to do, it could be good. – ECIA

This situation will need to be monitored closely because it could impact the most vulnerable of families.

3.3 Providers are looking at supports funded by state and local governments to fill potential funding gaps

In the absence of any information about or funding of the ILC, providers are left to look to a variety of other avenues of support, including, Early Linkers, Community Health or Families NSW.

Community Health

Not surprisingly, providers are not keen on sending families back into the public health system, given the historically chronic wait lists. Those with the most experience with the new system say that Community Health is already accepting more children than previously but that the wait lists will almost certainly get longer and longer without significantly more funding.

We can refer them to community health. Other than that, there are no other places to refer them to. Now, if they don't have an IFP there is no way that we can provide that. Only Community Health is where they can get therapy support – there is no key worker, no one coordinating support. I think that Community Health is taking more children because the children they were looking after they have gone onto the NDIS. – Hunter Trial Site

Yes, we are working with the children but we are also working with the parents. Under the new system, there won't be that money. In a little community, it will be very hard to say no. There are cases we can refer on to community health. But we know if we give them a little extra support, they will do so much better in schools. We will need more funding. – Year Two

NSW Early Links

NSW Early Links is a program launched in 2013 to coincide with the launch of the NDIS Trial in the Hunter Valley. A subsequent evaluation found that it provides invaluable 'soft-entry' support and 80% of people surveyed or interviewed for the evaluation were satisfied or very satisfied.[18] Unfortunately, NSW Early Links is slated to be de-funded by June 2018.

The difference between the Linker and the ECI support, the Linker doesn't provide any therapy. The role of the Linker is to help the family overcome the grief of a diagnosis. It's about not letting people end up on a disability pathway only. The focus is on inclusion for the child and family – the focus is not the disability. Get them back enjoying the child. Sometimes you don't need a specialist to address the needs of the child. – Early Links

[18] Urbis (2016). *AbilityLinks NSW Final Evaluation Report*. [online] Sydney: NSW Family and Community Services - Ageing, Disability and Home Care. Available at: https://www.adhc.nsw.gov.au/__data/assets/pdf_file/0005/387698/AH16-205560-2016-Final-ALNSW-Evaluation-Report.pdf [Accessed 1 Oct. 2017].

Effectively, there are not services for kids without plans. Early Link is the only program we can send them to. We can send them to play groups and parent classes but there is not a lot out there, if you don't get onto a plan. – Early Links

Families NSW

Established in 1998, Families NSW is the NSW government's overarching strategy to enhance the health and well-being of children up to eight years of age and their families. It is the joint responsibility of three government departments: NSW Health, NSW Department of Education and Communities and the NSW Department of Family and Community Services. Families NSW does this by:

- Helping parents to build their skills and confidence in parenting
- Supporting parents and carers so they can respond to problems early
- Building communities that support children and families
- Improving the way agencies work together to make sure families get the services they need[19]

The research team did not gather any information about the future or funding of Families NSW or its ability to expand to meet the gap left once the ADHC division of NSW FACS closes in June 2018.

We have always had families with high support needs. We have referred them onto Family Support Services. We have a good relationship with them. If we think a family needs support ex-ECEI, we refer them on. We can do it a little bit under NDIS but not very much. Some of the services are only supporting families where there are children at risk of significant harm. – ECIA/Hunter Trial Site

Community-based mainstream services

Community-based mainstream services are many and varied and are funded and delivered by a combination of state and local government agencies and NGOs. However, the availability of these services differs greatly from place to place. Not surprisingly, these services are in short supply in small rural and remote communities.

There will be a greater pressure on mainstream providers to step up and provide the support traditionally provided by ECEI. Within NSW we have inclusion agencies that work with the long day care sector so there will be a greater pressure on them to act as a gateway of support. Mainstream educators will be requested to provide additional support to families but my concern is that children will be moved onto NDIS plans at older ages. They may not be eligible at '3' but by '8' they may need it. So, the whole premise of early intervention perhaps lost in the competing demands for ECEI providers. – Year One

3.4 Funding questions will only be answered through the competitive sourcing process

The sector is told that the NDIA will run a competitive sourcing process to select Ongoing ECEI Community Partners. Fortunately, providers have gained a much clearer sense of the costs of providing the service as a result of their experience as Transition Providers.

Without the experience gained through the transitional period, providers would have found it difficult to estimate what prices they should charge since this is their first foray into a 'market' for

[19] Families.nsw.gov.au. (2017). *About | Families NSW*. [online] Available at: http://www.families.nsw.gov.au/about.htm [Accessed 1 Oct. 2017].

ECEI services. We will only know how much funding is going to be provided to the successful Community Partner(s) when the financial data is released prior to the opening of the bidding process.

As ECIA noted in its most recent submission to the 'Parliamentary Inquiry into Provision of Services under the National Disability Insurance Scheme (NDIS) – Early Childhood Intervention Approach' the roll-out target for the program was reached in March 2017, almost a full year ahead of schedule.[20]

According to 2016 ABS Census data, a larger number of children can be expected. That number, on top of the number of children still waiting for service as a result of the delay in commencing the transition period, means that the program will struggle to deal with capacity issues.

ECIA and other advocates will need to monitor the service levels following the awarding of the contracts to ensure that children with disability and their parents are able to access the level of support they require to allow them to be full participants in family and community life.

3.5 Workforce pressures threaten the availability of therapeutic supports in some parts of the State

With the advent of the NDIS, the amount of funding that children with disability and their families have to spend on intervention services is expected to rise. As a result, the market for individual therapy services has expanded. Anecdotally, individual therapists have spotted an opportunity for self-employment. Reportedly, this has led to critical skill shortages in some areas.

According to seasoned early childhood intervention professionals, ECEI practice not only requires an advanced skill level but also several years of experience. These requirements place additional workforce pressures on providers who are committed to following best practice.

> *In the past, we had a robust team of people. However, since the arrival of the NDIS, we can't get therapists because they are setting up their own private practices. We are left to work with new grads. It is challenge from every angle. – Hunter Trial Site*

> *There are not enough therapists to serve the child population. All three are short – speechies, OTs and psychs. I only know of one behavioural specialist in our entire region. – Year One*

Some Transition Providers have reported that workforce shortages are already causing delays for both 'defined children' and 'new children'. The issue is two-fold. Therapists are needed and they are needed locally since many of the families accessing public ECEI services are unable to travel themselves.

> *We have some recruiting to do before we can get through that number of children. It will be some months. We have a workforce plan but we're looking at 3 to 4 months before we have people recruited, trained. That doesn't take into consideration other defined children the NDIA continue to send us. Nor, does it include new children. Our workforce is under the pump. They are dedicated to providing early intervention but they can't. – Year One*

> *If a key worker can provide the intervention, it can be done quickly. Or, if they have to be referred out to private practitioners they could wait up to six months. We will have jumped someone to the top of*

[20] Early Childhood Intervention Australia NSW/ACT (2017). *Submission to the Parliamentary Inquiry into the Provision of Services under the National Disability Insurance Scheme (NDIS) - Early Childhood Intervention Approach*. Sydney: ECIA NSW/ACT, p.p. 11.

the queue. Speech pathology is an example. In the Shoalhaven, there are none that can do swallowing diagnosis, other than us. Public Health doesn't have that service. Kids would have to travel 1.5 hours up the road to Wollongong but many of our families can't do that. – Year Two

Given the NDIA's stated preference to work with a small number of large-scale providers, a number of local community providers will cease to offer ECEI services or cease to exist at all. Workers in the sector are relatively confident that their skills will be in demand within other organisations but there is likely to be sufficient churn within the ECI employment market over the next few years as the NDIS goes 'full-scheme' in NSW.

The workforce is huge. Some will be employed by larger organisations. There will be more employment options. In my area, we are already having workforce issues. People need to think differently about how they are employed. – ECIA

Early childhood educators have been employed on the frontlines of intervention services for many, many years. Indeed, the vast majority of the professionals interviewed for this study began their careers as pre-school or kindergarten teachers. As generalists, early childhood educators have traditionally been seen as ideal key workers within a transdisciplinary team. As teachers, educators are well-equipped to transfer knowledge to parents. However, several participants in this study said that they fear that educators are under-valued by the NDIS and by parents because they are not therapists.

The funding model does not support educators. It supports therapeutic modalities. Educators have been devalued in the current system and I don't know how you change that. Educators are leaving because they can get better pay in primary and high schools than they can in ECI services. – ECIA

A lot of services are top heavy with therapy and the educators are being left behind. We need to support the education component of early childhood education. There is a lot we can do to promote the communication above the one-hour appointment. The educators are getting left out of the equation all of the time and yet we are the ones that keep the relationship with the family lubricated. It concerns me that private therapy services are coming in and educators are being pushed out. – Year Two

One provider flagged that the NDIA guidelines might be pushing out experienced educators by setting the qualification standards unreasonably high.

We employ four educators who have special education qualifications at the masters level. There is no issue with them working as part of a transdisciplinary team in the 0-6 age range. However, once the children hit seven years of age it seems the NDIS will only accept 'developmental educators'. This is a degree that many in NSW are unfamiliar with. We we need to have our highly-qualified and experienced educators able to work with this age group too. The strange thing is that in other teaching roles, such as with NSW Department of Education, these special education teachers would be sought after for working with children aged up to twelve years. So, why is the NDIS limiting their capacity? – Year One

3.6 Data is needed to demonstrate the effectiveness of the ECEI Approach under the NDIS but little-to-none was released during the study period

An evidence-based approach such as ECEI, needs to amass evidence of its effectiveness. Program data needs to be collected, analysed and made available to all players involved in ECEI so that adjustments can made immediately and over the longer term. Unfortunately, NDIA has not provided much information regarding the full range of data management activities from how to enter data, the reasons for collecting the data, how the NDIA will use the data or if the data will be made available for sector development. Nonetheless, some remain optimistic.

It's impact on service providers is more problematic. The pure model of ECEI is a question mark. We have argued that NDIA needs to put more money into research and forensic data investigation. – ECIA

We are concerned about the lack of transparency around the data. We wanted to support the process and to introduce some rigour into that rollout. Unfortunately, that is not possible. – ECIA

We don't have enough data yet. It would have been ideal if the NBM and other trial sites had another year so that we could get more data from their trials. – Year One

We did have one-day training and a follow up teleconference. We are prepared but not because of the training. We have had to chase up a lot of things with [the NDIA]. They are not prepared to talk about the actuarial data. They want consistency but they have not provided the training. – Year Two

The NDIA says that it is not able to release information on its own and requires the consent of other levels of government to do so.

3.7 There is some controversy about two data collection tools: the 'tablecloth' and the 'PEDI-CAT'

There are two tools Transition Providers have used to collect data about the program and the children who take part in it: 'The tablecloth' and the PEDI-CAT.

The 'Tablecloth'

The NDIA has employed a team of actuaries to collect and analyse data. They have asked transition providers to record their data in a spreadsheet known as 'the tablecloth' because of the checkerboard of cells that must be populated with data.

Providers report that they needed training in order to enter the correct data and that the NDIA and ECIA worked in partnership to meet the need. Unfortunately, the NDIA told services that for the time being they are not able to share the data or to use it for sector development. They have committed to making some of the information available but they have not committed to what data will be released or when.

The PEDI-CAT assessment tool

Transition providers have also been asked to use an American assessment tool known as the PEDI-CAT. However, some providers have not fully understood the role the PEDI-CAT results will play. Unlike other assessment tools like the 'Ages and Stages questionnaire', the PEDI-CAT results are not used to determine the level of support a child should receive through their packages. Rather, it will be used to measure the long-term economic impact of this major social sector reform. For example, it will capture how many caregivers are able to return to gainful employment after their children received intervention services. Such data will be used to justify the expenditure of public funds by offsetting demand for other public spending on income support for people who are unable to work outside of the home.

PEDI-CAT and the NDIA plan are not linked. They don't go and look at the score to determine eligibility. PEDI-CAT is in place as an accurate measure of the economic benefits. If you have a child who gets access to childcare and Mom can get a job as a result, they can demonstrate that the NDIS had a beneficial outcome. - Early Links

Providers also expressed dissatisfaction with the PEDI-CAT because of the perceived cultural inappropriateness of the American language and terminology used. Some said that they had to modify the questions to make them more suitable for Australian children and their families.

We changed some of the forms that we used. There were things that were missing, like date of birth. The forms were ambiguous if we were talking about from the child's perspective or the parent's perspective. For example, it is not practical to ask a six-year-old if they have ever been bankrupt. We were supposed to ask these questions verbatim for consistency purposes. – Year Two

There is also a widespread perception among providers that the PEDI-CAT Tool does not adequately pick up on global developmental delay and may understate the severity of autism spectrum disorder in young children.

The PEDI-CAT is supposed to measure discrete changes in function. We do it on first entry and when they exit. What PEDI-CAT doesn't do is measure the extent of the functional needs for kids on the autism spectrum. Many come out with mild behaviours. We then succinctly identify the functional need to justify a finding above the mild range. - NBM

4 Transitional issues are transitional in nature and are unlikely to impact on the ability to deliver best practice ECEI

Transitional issues arise when a service system undergoes a major period of reform. In NSW, there are two reform processes underway simultaneously: the ECEI Approach is being adopted by the NDIS and the State of NSW is closing the Ageing, Disability and Home Care Division of its Department of Family and Community Services. However, because transitional issues are transitional in nature, they are unlikely to impact on the ability to deliver best practice ECEI.

I just think that the challenge for all of us is that we are in transition. There is an absolute respect for the skills that ECEI providers offer in the marketplace. Our intention is to ensure those funded supports get provided and that we have a strong gateway function. - NDIA

4.1 NDIA funding of the Nepean Blue-Mountains Trial was assessed to be adequate for a short-term trial but was not sustainable on the long-term

The NDIA provided modest funding for the four providers who took part in the Nepean Blue Mountains Trial. It took the form of a $1,700 grant for each child processed through the NDIS gateway. The $1,700 was a rough calculation of the number of hours multiplied by the average prevailing therapist rate of $170 per hour. It was no more scientific than that. There were a range of views on the adequacy of the $1,700. In general, larger providers said that the $1,700 was sufficient while smaller providers said that it wasn't. Some providers said that it was sufficient because it wasn't necessary to acquit the amount against individual children: the monies were able to be pooled and apportioned based on the intensity of the intervention required. Others said that they were able to cope but that quality suffered.

Now that the Year One cohort has had nine months' experience, the sector is in a better position to assess the adequacy of the $1,700 per-child funding provided by the NDIA.

Essentially, the $1,700 is a notional amount. We work out the number of hours a child gets internally. If the child has minimal needs, we can shift the dollars around. However, there aren't many interventions like that. It's a big adjustment to families and staff because it reduces the amount of intervention a child will receive. – NBM

For us, the $1,700 was okay. We don't have cars or marketing budgets, so we can afford that. – NBM

The $1,7000 is not working brilliantly to be honest. When kids come to us we give them what they need, regardless of the funding. However, in the long-term, it will make it hard to meet the demands of all of the kids. - NBM

For some, $1,700 is reasonable. For others, it's not. Even large organisations are working off a low base – they might not have been providing interim supports previously, so 45% is quite low. It wasn't $1,700 per child. There are always swings and roundabouts with ECI. [Block funding] is a superior way of funding [from a provider perspective]. You have more economies of scale. You can work out how many children you can support with your front-end services. The minimum is $85K but that is not even equivalent to a FTE. – Expert Observer

$1,700 was not enough. What it created was a model that was too light on people to serve the number of families we should have been serving. We served the families we were sent but we were not happy with the service we were able to provide. It created very lean organisations. – ECIA

Anecdotal discussion has since centred on a range of between $2,500 and $3,000 per child, representing the actual cost of processing a child through the gateway.

4.2 ADHC funding was found to be insufficient to serve the needs of 'defined' and 'new' children passing through the NDIS gateway

In this final year of the transition period, providers have been given 45% of their residual ADHC funding to perform the gateway function. The adequacy of the funding coming from Department of Family and Community Services NSW, Ageing, Disability and Home Care (ADHC) will be a non-issue as of 30 June 2018 when the funding is scheduled to end. At the same time, the ADHC division of FACS will cease to operate in accordance with a decision by the NSW government to transfer disability services to the non-government sector.

> *The 45% was not the way to go. They don't know about the demand in services for children. When funding was plentiful, many children could receive service and not be counted. – Early Links*

Controversially, providers were not given 45% of their original ADHC funding. Had they been given the full 45% of their pervious funding, there would have been sufficient funds to serve both 'defined' and 'new' children. Providers in the Hunter Trial Sites were surprised since they no longer had residual funding other than the minimum $85,000. As one provider said, '45% of nothing is nothing.' However, FACS (ADHC) came to the aid of those who requested additional funding support on a case-by-case basis.

> *The Hunter Trial sites had already lost significant parts of our ADHC funding. So, 45% of nothing is nothing (e.g. we lost Maitland but 150 of 300 on the waiting list come from Maitland). We have no funding to provide that support in large areas. They took away that money before they came up with the concept of ECEI. We got notification of funding in May 2016. It was just rushed. It was only at the last moment that we found out that it was 45% of our residual funding; we thought it was 45% of previous ADHC funding. If you want us to provide support for Maitland, you have to provide 45% of what we used to have to provide for Maitland. We are within our rights to say we have 45% of mothing in Maitland, Newcastle, Lake Macquarie – the three Hunter Trail sites. – Hunter Trial Site*

> *Block funding has been stepping down but we have been in communication with ADHC about the funding being inadequate and so they have given us some of the money back. The number of children on plans didn't match the step down. Ours went to nothing. – Year One*

Providers who found themselves with a funding shortfall had to make a difficult decision –either withhold service, dip into reserves or rely on philanthropy to make up the shortfall. Many of the community-based services said that they had no option but to support their communities with their own funds, effectively subsidising the government to provide public services through the transition period.

> *$1,700 has some advantages. The amount NBM received was higher than what we got. We got a dreadful deal. We are trying to do a large amount of work with little money. I have put some of our money – drawing down on profit margins. I'm drawing down on our money to ensure that all of our defined children have plans that are done properly. We make sure the plans meet their needs, not that it fits a funding category. No, I can't do it forever. We only have the funding for another 12 months. – Early Links*

> *The goodwill of providers is such that we are providing services that are not funded. We are lucky because we fundraise.* - Year One

> *We still have the 45%. That is what we are managing on. We have huge philanthropic support in our community. We are subsidising the government. We have contributed well over one hundred thousand dollars in the last financial year. – Year One*

We are doing what is required, not what we can afford. If we have overspent, I will tell my board to draw down reserves. – Year Two

4.3 Innovation was required to handle wait lists and deliver short-term supports more effectively during the transition period

Under Block Funding, it was clear that when the money ran out, the service discontinued. In the transition from block funding to individualised funding, innovation will be needed to handle wait lists more effectively.

100% have gone to a plan because we are still in transition and we are working through defined children. We have kids on the waiting list and have referred them to Early Links funded by FACS. The waiting list for Western Sydney is long, we have had 170 enquiries for new children and they will be waiting. Once we get into full scheme, it will steady out. However, when you get 170 enquiries in three months, it is difficult to catch up. We are not funded to meet that need. No one has the capacity to meet that demand. Because they used existing ADHC contracts to calculate our funding, I can only fund 1.5 FTEs. We have to close our books. We will never be able to meet that before the funding runs out. – Early Links

We have allocated all of our team to this role for the 173. Over the school holiday period we will stop our normal ECI service. Hopefully, we will knock those over in two weeks. Then, we would have capacity to address the 40 or so children on our waiting list. It doesn't mean that the plans will get submitted but they will get written. – ECIA/Year Two

New families are being provided group supports at our Campbelltown venue while we work out how to support them. We are referring to ECEI but they are flat out trying to get the planning done. – Year One

Some services are overbooking because of the number of dropouts. While it might ensure a higher utilisation rate of some staff, it is also administratively labour-intensive, so the savings are minimal. – NBM

Historically, we deal with new children (30-50 new families per quarter). We have advised our existing families that we are going to drop their free service down to fortnightly so that we can continue to see new children. – Year Two

Plan Reviews will have a major impact on waiting lists

Year One Transition Providers say that they are uncertain how they will balance the competing priorities of writing new NDIS plans and reviewing and renewing existing ones. Plans do run out and, unless renewed, children and families could find that the intervention is interrupted at a crucial juncture.

We are extremely concerned about how we will cope with plan reviews. We have started our internal processes because that is going to impact on the number of plans we can facilitate. For us to do a plan review, it will hugely impact the number of initial plans we can facilitate. That is going to blow the waiting list right out of the water. We have 200 kids on our waiting list and we get through 5-6 a week. It will take the rest of the year to get through our list but it is never ending. We had nine referrals last week. How long is a piece of string? – Year One

4.4 Transition Advisors helped providers to navigate the gateway and provided much needed assistance to the NDIA to expedite access decisions

Each Transitiona Provider, either Year One or Year Two, were required to submit ten (10) draft plans to the NDIA to prove their competency in fulfilling the gateway function. Given that 52 separate providers were submitting plans, the NDIA soon fell behind in their reviews. As a result, Transition Advisors (i.e. Life Start and SDN) were appointed to assist Year Two providers.

The addition of the transition advisors is really about supporting both providers in writing their plans but also in expediting the access decisions. In NSW, they came from such a wide gateway and the NDIS is a narrower gateway. Not all will get an individualised plan. Getting providers to make appropriate assessments will assist them but it is more about building their capacity and understanding. They are struggling with transition issues and the legislative context they are working in under the NDIS. It's purely a transition issue. NDIA had no capacity to work with 56 providers across the State. Life Start and SDN were chosen because they were doing this for some time (i.e. planning and providing supports). – Expert Observer

There were mixed views regarding the support provided by the Transition Advisors. Some providers were effusive in their praise.

Life Start is our Transition Advisor. In the last month, they have put together an experienced team to work with us. They have given us a lot of time. They have been very responsive to emails and calls. They offer tips on how to explain things in a more friendly manner. They are working in partnership with us. – Year Two

Our Transition Advisor is SDN. The individual who has been working with us has been terrific. We have played around with the process, did some predatory work. She gave us good feedback and it was really good. – Year Two

The relationship with our regional coordinator has been positive. We have had some face-to-face meetings. They have agreed to meet with us twice a month. If we have a question, we can get an answer in a timely way. – Year Two

Other providers were more tentative in their assessment since the Transition Advisors were only appointed recently – some before the list of names arrived, some after. In reality, transition providers relied upon three sources for assistance:

- ECIA
- NDIA Regional Offices
- Transition Advisors

In at least one case, the transition advisor that was appointed was the main competitor of the provider. Not surprisingly, they have yet to make contact.

SDN is our Transition Advisor and our main competitor. We have had no contact from them. – Year Two

While the Transition Advisor function will conclude in June 2018, some have said there will still be a need for regional representatives of NDIA to assist providers with the interpretation of 'reasonable and necessary' and other issues going forward.

5 Outstanding issues require more work before ECI Best Practice can be secured

If the NDIA is 'building the plane while flying it' some turbulence can be expected. Much work remains to be done before best practice ECI can be secured and families assured they will have a smooth journey through early childhood intervention services.

5.1 Global developmental delay needs to be redefined with care so as not to exclude children and families experiencing disadvantage

According to the ECIA, a review of the definition of global developmental delay will soon be undertaken. While some of the people who participated in this study said that 'tight definitions' are necessary to ensure scheme viability, they were just as likely to say that 'too tight a definition' could mean that some children and families are denied needed early intervention services.

> *There is a review of the definition of disability and developmental delay. It is important to have strong definitions but the current tool is inadequate for assessing developmental delay. There needs to be a review of that. If they don't fit and do have developmental delay, they could access a mainstream service to prevent them from coming back into the NDIS. The definition is important but is there scope for other supports? Not sure there is because ADHC has given their money over to the NDIA. There is a role for national to advocate for funding for those additional supports. – ECIA*

> *Everything is seen through a trauma lens. Global delay doesn't fit their definition of disability. - NBM*

A case in point that was raised was the situation of children who were borne prematurely. One provider said that up to 70% of all children born prematurely experience global developmental delay. If these children go on to develop more significant disabilities they will be playing catch-up their entire lives. Advocates say it is best to intervene with these children early rather than wait for difficulties to emerge later on.

> *Seventy percent of premature children will have developmental delay. They are more likely to have disabilities and to have mental delay. Their brains weren't formed and they didn't get the attachment they need to grow. Premature children can access a program through the Department of Education but they needed a paediatrician's letter and a diagnosis of disability or developmental delay. They come into our services to have that protective factor and while they are with us, they show that developmental delay. These children need learning support when they go to school. – ECIA*

Global delay requires specialist attention. It is not something that a non-specialist providers can be expected to support, according to people experienced in the area. Limiting services to children with global delay can have serious repercussions, particularly for lower SES families.

> *This is really concerning to us. Parents are coming because they want help. The staff are not trained in this area and they need support even for mild delay. The community will need to lift their game and that is new because there have been specialised services. Other families can go and pay in town but these are the families that need to access the free service. This is where FACS come in. These children have to be referred back to Health for therapy. Up until now they have refused to see children with delay. – Year Two*

5.2 Engaging vulnerable families is a challenge that may be more difficult under the NDIS

While it is important for children from families of all backgrounds to engage with early childhood intervention services, it is particularly important for the children of vulnerable families to do so.

Research has shown that children from vulnerable backgrounds are at risk of falling behind in school and developing health issues later in life without early intervention services.

> *I believe that there is a missed opportunity for getting some of our more vulnerable families to engage. And, we are going to see some kids be worse off than what they could have been under Stronger Together II packaging. They don't need to be vulnerable at the time but when they have a child with a significant disability, one parent might have to quit work. They need other sorts of assistance to help them get through it.* – Year Two

However, providers say that vulnerable families are often the most difficult to engage in the service system.

> *We get them to engage with a huge amount of difficulty. We use it utilise the services of Uniting where they have a closer connection to the families. Other than that, we use any avenue we can get them to engage. We choose neutral locations. – Year Two*

Poor communication between FACS, NDIA and ECEI providers was a universal complaint among the people who participated in this study. The delay in providing the lists of defined children to Year One Transition Providers (by six months) and to Year Two Providers (by 6 weeks) was blamed on the dysfunctional communication between FACS and the NDIA.

> *Once a child is in full scheme, the NDIA should notify the LAC to say that this child is coming across. The NDIA has to be the conduit for that information. Everything is locked into the database. The only way that the LAC can get any participant information is from the NDIA national access team. I would think that the ECEI provider should assist in the transition. Maybe they should work with the families. They could start having those discussions in advance. - LAC*

While the communications difficulties are expected to disappear when one of the three parties involved (i.e. NSW FACS (ADHC)) vacates the field in June 2018, careful consideration will have to be given to the manner in which families, especially vulnerable families, are contacted to connect with early intervention services. Several providers said that families were getting missed because they failed to pick up when the NDIA called to let them know they had been referred to a service provider. The reason cited was that the NDIA number displays as 'Blocked Number.' This can be confronting for families who have experience with the child protection system. Unless this design flaw is addressed it could lead to a large number of the most vulnerable families in the State slipping through the cracks.

> *Children got lost off the spreadsheet. When NDIA rang the families to ask for access, many did not answer (especially where child protection was involved). Families won't pick up blocked numbers. Bugs have not been ironed out. Families answer our calls. – Early Links*

Providers also said that the available funding will not begin to compensate ECEI partners for the time it takes to get vulnerable families to engage with the service system.

> *What the NDIA does not seem to comprehend is that these families lead messy lives. They all need a friend but only thirty percent of families will go to a playgroup. You have to spend four to five hours trying to get them to come in but those hours are not billable. So, you have to make brutal decisions. - NBM*

'Soft-entry' is essential to encourage vulnerable families to engage

Soft-entry is critically important. A family's first contact with the service system can have a profound and lasting impact. ECI Providers know how to 'work their way into' a family. Current providers are less certain that a large State-wide agency will have the same nous or the funding to operate at a community level the way they have in the past.

The engagement of families who are vulnerable requires a greater amount of service provision. If literacy is a problem or they have transport issues or multiple children with disability, they require a greater amount of support to explain NDIS and to help them make the best decisions. We've got families with suspicion about what information government has on them. We have families who believe that they do not require disability services so ask why are you sending me there. Under the NDIS, we might be losing those families. If we don't have soft entry happening, educators or allied health professionals who have the first interaction with the child can't connect. If children don't access early childhood education because of finance or transport, the engagement is problematic. Or, if they don't engage with supervised play groups. The groups that ECI providers used to run, used to be a place where families would engage with the soft supports. We would have a speechie, OT or the psych at the groups to build the trust. – Year One

Who do you call when you've got a family who you know will go on to get a package but it won't happen unless you go out and meet with them? If you don't, they won't call and they won't follow up. Anglicare and some of the other big ones say, 'You come to us' but we're talking about the people who won't go. There must be money but where is it? – NBM

A number of private practitioners use a three-strikes rule. However, as government service providers, we have to operate differently. We have a responsibility to find out why a family is unable to engage. Services were fairly easy going in terms of working with families in the past. That will be different under billable hours. Some families will take longer. Children do get sick. So, we have to factor that in. – Year One

Family Workers are needed to help families connect with the service system

Under the previous block funding arrangements, providers were able to hire 'family workers' to assume some of the family support work of key workers. While key workers are able to be funded under IFPs, no provision to fund family workers has been announced. Family workers are needed because not all families entering the gateway will access an IFP and it is unknown at the time of intake which families will go on to receive packages.

Initially, providers, not families, benefit most from the help a family worker brings but the NDIS does not currently fund supports that are not directly linked to an individual child's disability.

Key workers and family workers have different roles. The family I was trying to engage has a child who needs occupational therapy. I eventually got him there but that time was not billable. However, if they had been referred to a Family Worker first, they might have made their own way to the OT. – NBM

We have a family support worker and her role will be defunct if we don't receive funding. That is a big gap that will open up as a result. – NBM

There is also the issue of getting families to accept support. People working directly with families say that families experiencing vulnerability are at different stages of understanding/accepted and that they are unlikely to approve funding for family support even if they need it and it were possible.

Families don't realise that they have mental health issues and so they won't agree to having hours billed against their plans. - NBM

Language interpretation services are necessary to engage with CALD families

Multi-lingual interpretation is absolutely critical for engaging with parents and children from a CALD background. During the study period, the only language for which NDIS will fund translation is Auslan (funding for multilingual interpretation has subsequently been provided). However, providers would also like the additional time it takes to work through an interpreter to be acknowledged and compensated.

We have spoken with Settlement Services International about a model where we would be in partnership with a bilingual support worker for our Liverpool family. Arabic is one language in demand as is Vietnamese. This is definitely an issue we want addressed. – Year One

One of the big issues with the first plan is that we need to work through interpreters so it takes longer. If I factor in translating, it would take six hours to complete a plan. We cannot get support for interpreters or for the extra time it takes. Support is just available for Auslan. – Year One

5.3 The perceived overlap between early linkers, Local Area Coordinators and ECEI professionals will be eliminated when the AbilityLinks NSW Program closes next year but their function is still needed to help families of all kinds engage with Early Childhood Intervention services

AbilityLinks NSW (ALNSW) was initiated in July of 2013 to coincide with the launch of the National Disability Insurance Scheme in the Hunter Valley Trial site and was subsequently expanded across the State in July of 2014. There are 347 Linker positions across the State, including 74 Aboriginal-specific Linkers and 79 Early Linkers. Linkers work with people with disability by making connections with the local community, including community organisations, clubs, businesses and mainstream services to help them become more welcoming and inclusive of people with disability. Whilst the NDIS has extensive access criteria, the Early Links Program has none. There is no formal assessment or referral process needed to access its services.

Throughout the gateway process, Linkers work alongside Local Area Coordinators to assist people who are ineligible for an NDIS Package but who would benefit from support to build their community connections. Alternatively, a Linker can refer users of mainstream services to the NDIS if they believe a package might better look after their needs.

An evaluation study of the EarlyLinks NSW program noted that there is a widely-held perception that there is significant overlap and duplication between the role of an Early Linker and an ECEI worker, 'Other services (particularly early intervention services) think that Early Linkers undertake early intervention work that overlaps with their role.'[21] However, whatever duplication there is will be eliminated in June 2018 when the Early Links Program will be discontinued. As the NDIA has stated, ECEI workers will be given the task of assisting parents through the grief process of a diagnosis and connecting them up to other services which may assist them but it is not clear to what extent.

EarlyLinks NSW has been described as 'brilliant' by those people who have used it and they say that it's function should be maintained because it provides the short-term and interim supports that are so important to putting the 'early' in early intervention:

> 'This provides a soft entry for individuals or families, particularly those that might not engage due to past experiences or a lack of confidence. ALNSW and ELNSW offer an effective pathway for individuals and families who may have fallen through the gap due to lack of disability, diagnosis or early intervention.'[22]

[21] URBIS (2016). *AbilityLinks NSW Final Evaluation Report 2016*. [online] Sydney: NSW Department of Family and Community Services (ADHC), p. 56. Available at: https://www.adhc.nsw.gov.au/__data/assets/pdf_file/0005/387698/AH16-205560-2016-Final-ALNSW-Evaluation-Report.pdf [Accessed 23 Sep. 2017]

[22] Ibid, p 71

Early Linkers' function should be added to the responsibilities of ECEI Community Partners so that the gateway serves families who go onto plans and those who don't. To eliminate duplication, the role of the early linker should be combined with that of family workers.

5.4 Key workers and LACs are needed to be consulted through the planning process to ensure a child has the right supports and that plans are handed over effectively

Key workers are the link between the child, her family and the ECEI service system. Providers say that planning proceeds more smoothly when a key worker is involved because the key worker knows the supports that the child had in place previously. While the NDIA has discouraged planners from planning 'on top of' pre-existing state plans, Transition Providers have found that when key workers are consulted on a plan's content, service gaps are less likely. Providers have also said LACs are needed to affect a plan handover. While parents are decision-makers, they are not professional and important services can be overlooked. However, if families choose not to fund a key worker, these links to the broader system can be lost.

> *One problem is that plans end and the service can't contact the family to get them to come in and create a new one. This results in unbillable hours being absorbed by the service but we can't really afford that. – NBM*

> *We made a really good link with the LAC this week. They are not experienced enough in the work that we do. They started with the PEDI-CAT but it is just a tool. They need a lot of support. Our families are articulate but it was difficult for them to explain their situation. So, they have given permission for the Key Worker to join the planning meeting with the families. It takes that linkage to make it work smoothly. – Year Two*

6 The future: The competitive sourcing process and moments of decision-making loom for aspiring ECEI providers

Even though 56 services have gained experience with the NDIS gateway function, it appears that very few providers will qualify to submit a bid to serve as a Community Partner. They have a limited number of potential options to consider.

NDIS is not ready yet to deal with market failure and a fracturing of service provision. There is going to be huge demand but it will be up to services to structure themselves to survive. There will be some services that go out of business. It is not about being big or small but operating smartly. – ECIA

6.1 Conflict of interest provisions have been controversial and will only be clarified through the upcoming competitive sourcing process

Separation of the planning function from the service delivery process has been a design feature of the NDIS since its inception. The conflict of interest provisions have been controversial, particularly among regional and remote services where there may only be one provider serving a defined geographical region. Services have tried to restructure their operations to separate the planning from the ECI service, with varying degrees of success. Some hold out hope that the NDIA might demonstrate some flexibility in regional areas but the experience of the recent funding rounds in Victoria and Queensland has shown that the agency is likely to be inflexible in its approach.

We absolutely endorse engaging with a partner locally to explain the diagnosis and assessment and connect with mainstream and disability services. That model is strongly endorsed by us but there is a difference when someone is referred to a service that refers to itself. We were surprised at the high numbers of referrals for an access decision. It was higher than we would have expected. - NDIA

The LAC approach is different to the ECEI approach as the current approach allows you to be both whereas the LAC will not allow you to have duality of those roles. They are being that strict. I had heard that there would be some leniency in remote areas but what I have heard is that the NDIA is doing plans for remote people. Life Start and other services are setting up telehealth services for kids and families in really remote areas. They are using technology to deliver those early intervention supports instead of appointing local ECI providers as partners. – ECIA

I'm not saying you can't do both in rural and regional areas. What I am saying is that in NSW you have almost all providers doing both. Because children are having their plans written by providers and providers will be providing the supports in the plans. Even the way the plans are written – 'these are the supports that we offer'. It should be 'these are the supports that these children need.' They don't want to do the wrong thing. They need to exert more independence. You almost need two parts of the organisation to manage that conflict of interest effectively. The marketplace is not big enough to meet the demand. In regional places, you wouldn't want to force a hard and fast rule. I think that orgs can manage Chinese Walls but the question is whether the agency will be prepared to do that. – Expert Observer

6.2 Prospective Community Partners face multiple, overlapping restrictions to becoming a Community Partner

Throughout the course of this study, more information has gradually come to light detailing the multiple and overlapping restrictions prospective Community Partners face as a result of conflict of interest provisions.

Not only will ECI providers not be selected as ECEI Partners but they can only be considered if they cover an entire service area (or grouping of service areas). Neither can the ECEI Community Partner or Local Area Coordinator subcontract to a local service if that service also provides ECI services to NDIS funded children. ECEI Partners may offer services to children not covered by funded plans but it is impossible to know at intake which children will meet access requirements. Neither can a Community Partner provide ECI services in any other state

6.3 NDIA has expressed a preference to work with a small number of large providers despite concerns about a single non-ECEI specialist agency taking control of the State

There are 100 ECI services in NSW, 56 of whom have gained experience as ECEI providers over the past two years. NDIA personnel have been quite vocal about the difficulty of communicating with 56 providers. Obviously, the government is looking to drive efficiencies and consistent quality by selecting a small number of sophisticated providers. However, there are grave fears that a single non-specialist partner will be appointed, as is the case in Victoria.

> *We were worried that the LAC model will be put in place. There are three orgs providing [LAC] service across the whole of the state. We are concerned that NDIA will not use the existing expertise and local community connections, acknowledging the existing relationships with specialist providers. – ECIA*

> *I agree with having local service providers but I question whether having so many of them is the right way to go. – Expert Observer*

> *The worst thing would be if it goes to large organisations where there is a risk that that money will be needed to support big structures or to cross-subsidise other services. They will never achieve consistency because it is about listening to a family's stories and interpreting what is 'reasonable and necessary'. When the NDIA had their own planners doing the work, they didn't have consistency either.* - Early Links

> *Our board doesn't think that the large charities can offer the same quality service that we do. They have significant other roles. There are benefits of scale but there are limitations too. – Year Two*

> *It would be detrimental to bring in a national provider. We would have grave concerns if some of the faith-based organisations come in because they don't have the community connections or the referrals from the Aboriginal community. – Year Two*

There has been no evidence uncovered through this evaluation that would suggest the NDIA is reconsidering its preference for a single large provider despite evidence to the contrary from the United Kingdom where a similar system of consumer choice was implemented. An evaluation of a consumer funded system in the UK found that there was a backlash against a single large provider and that a small number of mid-size providers is the preferred way to balance the need for quality and consistency while maintaining local referral pathways.

> *In the UK under individualised funding, there was a push to return to smaller providers after having experienced larger organisations. They will need to think through their options. They have had some time to do that. NDIS is not new. - Expert Observer*

6.4 NDIA has been particularly uncommunicative regarding the competitive sourcing process, placing providers under pressure to consider their limited options

One Expert Observer questioned the competitive sourcing process, saying that it is seriously outdated. He said a more collaborative approach to selecting Community Partners would deliver a better outcome.

A tender approach is very old fashioned. There would be a far more evolved partnering approach in the 21st century. For example, there should be high level collaboration before competition. I would be concerned if they take a one size fits all approach nationally. – Expert Observer

The NDIA has been particularly uncommunicative on the subject of future funding rounds. At the time of publication (September 2017), they had yet to confirm how many tenders there will be, when they will be issued or how long providers will have to respond to them. ECIA NSW/ACT tried to have the competitive sourcing process postponed but the NDIA was adamant that it would go ahead according to schedule, whatever that is. ECIA National defended the NDIA saying that to postpone the approach to market would not leave successful Community Partners the time they need to prepare for the commencement of the full-scheme in June 2018.

We have written a letter to NDIA to delay the letting of tenders to give Year Twos a chance to tender and to consider the research and to consider the importance of local community connections. National didn't send this request but we did in NSW for our members, families and children. – ECIA

I have some concerns about the communications from the NDIA. If Margie hadn't told me, we wouldn't know as an organisation that that is the plan. If the NDIA is not planning on telling organisations until they put the tender out, that is concerning. We absolutely need to be making decisions. We need to know what is involved. I would want to know a lot more detail. Are they doing it as a region? We need some information about what is involved. – Year Two

The lack of information has proved particularly stressful for services as they contemplate their futures. Some providers say that they would like to criticise the NDIA but that they are concerned about possible repercussions if they do.

We have had difficulties with communications and responsiveness. I would want to make sure the government agency is responsive and working in partnership with us before I put in a bid. Other government departments have worked very collaboratively – Prime Minister and Cabinet for Aboriginal Communities have changed their model and their tender process to be more collaborative. The most recent correspondence we had seemed to indicate that we got a slight increase in our ECEI funding but it is so unclear it is hard to work out what they mean. I have a whole list of NDIA staff who do not respond to calls or emails. I find that quite unprofessional. I have a dilemma. I'm trying to establish a relationship and communicate. I would normally make a complaint but I haven't because if I complain the NDIA will say that this is why we don't want 50 providers. A fine line between complaining and wanting to be positive. – Year Two

People are exhausted by the reform process. The transfer from ADHC to NDIA has been stressful for families and providers. They don't have the energy to do what they need to do to restructure themselves. - ECIA

Transition Providers have a limited number of potential options to consider:

i. Remain an ECI provider only

The people who participated in this study were near unanimous in their view that the safest option from a financial perspective is to remain an ECI provider only. According to them, ECEI is an uncertain prospect at best and not likely to be sufficiently well-funded to be without financial risk.

The best return for your buck is to remain a service provider under NDIS. The money for the ECEI approach is not big dollars so it shouldn't be something that is for everyone. It's not about the dollars, it's about the best practice. People have to be very tight to have a sustainable service. – ECIA

I think we will go for it but the discussions haven't been held yet. We would want to know if it would be financially viable for us and we would want to do it well. – Early Link

Most of the funding still sits at the back end (i.e. with ECI providers). Part of the issue is that there has been concern about being able to survive. Potentially, there is more funding than ever. Will they market well? Will they communicate their benefits in comparison to a diagnosis-driven model? - Expert Observer

ii. Tender to become an ECEI partner

Based on the recent Queensland experience, it would appear that providers will be forced to choose between being an ECI and an ECEI provider since they are not able to do both. It seems equally clear that the successful ECEI Community Partners will need to cover an entire region of the State – certainly more than one LGA. However, it was not been possible to confirm how many service areas, or groupings, will be opened up to competitive bids in NSW by the time of publication.

iii. Join with others to form a consortium of ECEI providers

People in the sector believe that it is critically important that local referral pathways remain open. For that to happen, the local services should remain in place. This was the preferred option among smaller, regional services, who participated in this study.

At the time of the fieldwork for this study it was believed that in order to satisfy the demands of the NDIA for quality and consistency, consortia might be an option. The idea, workshopped by ECIA, was for several providers to form a 'Company Limited by Guarantee' with the providers serving as the 'members' (or shareholders) of the not-for-profit company. However, since then, it has been confirmed that consortia, either informal or formal, will not be permitted by the NDIA:

> The NDIA wishes to enter into an agreement with a single lead entity and joint applications submitted on the basis of a consortium or that two or more persons or entities will be jointly and severally liable will not be considered. However, by excluding consortia there is no intention to exclude the use of subcontractors and listed as such in the relevant area of the application form and would need to comply with the Registered Providers Supports provisions.[23]

iv. Become a subcontractor to an ECEI partner

Another way for a provider to ensure local referral pathways are kept open is to become an ECEI subcontractor to a larger organisation. Again, on the basis of what providers were willing to disclose, there are few, if any, subcontracting arrangements being discussed at present among large or small providers. Subcontracting arrangements will either be negotiated during the competitive sourcing process period or following the awarding of contracts. Unfortunately, takeovers are considered unlikely to provide the desired outcomes for either party.

In the past, we have taken over smaller organisations. However, they might not be any more sustainable under their own umbrella than under ours. – Expert Observer

[23] Department of Social Services. (2017). *NDIS Partners in the Community Program*. [online] Available at: https://www.dss.gov.au/sites/default/files/ndia_qas_updated_15_08_2016.pdf [Accessed 26 Sep. 2017].

It would be good if Lifestart wanted to tender for the entire State and then subcontract to services like ours. Based on what they are doing now, I could work with them. However, they haven't shown that leadership up until now. – Year Two

v. Merge or be taken over by a larger organisation

There are some discussions taking place around mergers or takeovers of smaller organisations by larger ones. However, since smaller organisations are at a distinct disadvantage, there are few promising proposals at the moment. It is likely that there will be a bout of mergers and takeovers once the Community Partner(s) are appointed.

The board is very keen for us to merge. We have had meetings with the local hub, a therapist's organisation. We have talked to the CP Alliance but all they wanted was our building. – Year One

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