Project Sponsor
Early Childhood Intervention Australia NSW/ACT

ECIA Reference Group
Margie O’Tarpey, ECIA NSW/ACT (Chair)
Lorraine Heywood, ECIA NSW/ACT
Rani Dibley, ECIA NSW/ACT President
Mary Hawkins, National Disability Insurance Agency
Ruby Wright, Connect Child & Family Services Inc (Service Provider representative from the NBM)
Linda Rolland, Firstchance Inc (Service Provider representative from the Hunter)
Sylvana Mahmic, Plumtree (Service Provider representative from outside an NDIS trial site)
Melinda Norton, Family & Community Services

SPRC Research Team
Prof Karen Fisher
Dr Ariella Meltzer
Dr Christiane Purcal
Ms Rosemary Kayess

For further information
Karen Fisher, karen.fisher@unsw.edu.au or Ariella Meltzer, a.meltzer@unsw.edu.au, ph + 61 (2) 9385 7800

Social Policy Research Centre
UNSW Arts & Social Sciences
UNSW Australia
UNSW Sydney NSW 2052 Australia
T  +61 (2) 9385 7800
F  +61 (2) 9385 7838
E  sprc@unsw.edu.au
W  www.sprc.unsw.edu.au

© UNSW Australia 2016

The Social Policy Research Centre is based in Arts & Social Sciences at UNSW Australia. This report is an output of the ‘Early childhood intervention review: Nepean Blue Mountains/Hunter Trial Sites’ research project, funded by the Department of Social Services.

Suggested citation

This project was funded through the NDIS Sector Development Fund.
Early Childhood Intervention Australia (ECIA) NSW/ACT commissioned the Social Policy Research Centre (SPRC) to conduct research into the delivery of Early Childhood Intervention (ECI) services in the context of the National Disability Insurance Scheme (NDIS) roll out in the Nepean Blue Mountains (NBM) and Hunter regions in New South Wales. Whilst there is some anecdotal evidence about the impact of the transition to the NDIS for ECI services and practitioners, there is little documented evidence, with respect to the relationship to ECI National Best Practice and how the NDIS transition is impacting on ECI service delivery and support for children with disabilities, developmental delays and their families.

The research was conducted with a small cohort over a limited timeframe and involved forums and interviews with service providers in the NBM and Hunter regions, including with direct workers and managers in ECI, NGOs, private ECI providers and a range of education, health and allied health employees who work closely with ECI providers. ECIA hopes this will be the beginning of more comprehensive research on ECI practice in the new NDIS environment, to identify the longer term impacts and outcomes for children with disabilities, developmental delays and their families.

The introduction of the NDIS as an insurance market model of support, requires a transformation for ECI services based on providing reasonable and necessary supports to children, their families and carers in early intervention. Social and economic participation, inclusion and functional participation in everyday environments is also encouraged.

In the past, most ECI services in NSW were funded from government (ADHC) to ECI organisations.

The report highlights a number of challenges and opportunities for ECI and ECIA. It highlights the importance of how the ECI sector could and should move forward over the next two years due to the NDIS transition. ECIA NSW/ACT will be monitoring the impact of NDIS, particularly in NSW where there has been a significant roll out across the state and a first trial of the Early Childhood Early Intervention (ECEI) Approach.

**ECIA response**

In response to the Research project and ECIA NSW/ACT’s complementary analysis and consultations with the ECI sector and our ECI members, we have identified a number of issues and concerns with respect to the ECI sector in the transition to the NDIS. These are currently being addressed in our representations to NDIA and to ADHC.
Background Research

In June 2016, ECIA NSW/ACT conducted a survey of providers that received funding from ADHC to deliver specialist ECI services in areas transitioning to the NDIS from 01 July 2016. The responses to this survey showed that a large majority of respondents have been actively planning for the implementation of the NDIS, introducing new systems, undertaking financial modelling and projecting cash flows. However there are some challenges ahead. There are many positives about the NDIS transition including an improvement of systems and additional services with more diverse and ongoing collaborative support.

The Way Forward

The ECIA National Best Practice Guidelines emphasise more inclusive collaborative practice between ECI providers, the community, social services and their families. Moving forward, this practice needs to be maintained.

ECI has a key role in supporting children from an early age in their natural environments - in their homes, schools, recreational and every-day settings.

ECI practitioners also provide coaching and training to mainstream staff in education and community settings, with the goal of including children with developmental disabilities in these environments.

ECI services often work with children that have undiagnosed issues. In these cases the child and family may only need short term support to ensure that the factors affecting the typical development of the child are addressed early so the longer term impact is minimised.

Community capacity building is currently a key role of ECI. This includes providing ECI support within community playgroups, working alongside Early Childhood Education and Care (ECEC) providers to identify/assess children that may need ECI or had no previous support, working with ECECs to encourage inclusion and offering support around inclusion for children not eligible for NDIS packages or parent peer support.

ECIA empowers families to take control and supports the principle of choice for families. However, there must be more information, referral and coordination offering informed choices about the role and importance of ECI and the role of ECI service providers.

ECIA endorses and supports the key areas required to develop national best practice in Early Childhood Intervention. In the context of the NDIS roll out this requires:

• Working alongside families in making informed choices about their child’s support
• Maintaining ECEI and/or other soft-entry pathways and funding to support the complex needs of disadvantaged families
• Improving equity of access to NDIS and ECI by supporting families through the NDIS planning process and by maintaining an approach, like ECEI, for children and families that do not need or will not receive an NDIS package
• Resourcing mainstream settings to support inclusion; ensuring culturally sensitive service provision and targeted services for indigenous and diverse cultural communities

• Supporting rural and remote service delivery, especially as this pertains to reasonable and necessary travel allowances in NDIS plans

• Providing funding and accountability measures to ensure enhanced community and inter sectorial collaboration with key external partners such as schools, pre-schools and medical/health services

• Facilitating ongoing discussions with practitioners, professionals and families about ECI good practice

• Requiring quality assurance standards and professional competencies for all providers of ECI

• Developing outcomes based approaches to inform good practice.

We would like to acknowledge the support of SPRC, ECIA staff for managing the project, the contribution and commitment of reference group members, research participants and DSS for their essential support in resourcing this project.

We commend the report and look forward to further research and discourse on ECI and good outcomes for children and families with developmental delay and disability.
# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glossary</td>
<td>ii</td>
</tr>
<tr>
<td>Brief Summary</td>
<td>1</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>3</td>
</tr>
<tr>
<td>1 Introduction</td>
<td>6</td>
</tr>
<tr>
<td>2 Methodology</td>
<td>7</td>
</tr>
<tr>
<td>Research questions and focus</td>
<td>7</td>
</tr>
<tr>
<td>Phase 1: Planning</td>
<td>8</td>
</tr>
<tr>
<td>Phase 2: Data collection</td>
<td>8</td>
</tr>
<tr>
<td>Phase 3: Analysis and reporting</td>
<td>10</td>
</tr>
<tr>
<td>3 Current changes in ECI</td>
<td>11</td>
</tr>
<tr>
<td>3.1 Changes in services</td>
<td>11</td>
</tr>
<tr>
<td>3.2 Changes in collaboration</td>
<td>18</td>
</tr>
<tr>
<td>3.3 Changes in funding and business models</td>
<td>23</td>
</tr>
<tr>
<td>3.4 Summary of current changes in early childhood intervention</td>
<td>29</td>
</tr>
<tr>
<td>4 Opportunities for Good Practice under the NDIS</td>
<td>32</td>
</tr>
<tr>
<td>Quality area 1: Family</td>
<td>32</td>
</tr>
<tr>
<td>Quality area 2: Inclusion</td>
<td>34</td>
</tr>
<tr>
<td>Quality area 3: Teamwork</td>
<td>36</td>
</tr>
<tr>
<td>Quality area 4: Universal principles</td>
<td>37</td>
</tr>
<tr>
<td>Appendix A: Forum and interview topic guide</td>
<td>39</td>
</tr>
<tr>
<td>Appendix B: Sample</td>
<td>41</td>
</tr>
<tr>
<td>Appendix C: Literature review about ECI service transition</td>
<td>42</td>
</tr>
<tr>
<td>Appendix D: Early Childhood Intervention Australia (ECIA) Best Practice Guidelines</td>
<td>52</td>
</tr>
<tr>
<td>References</td>
<td>54</td>
</tr>
</tbody>
</table>
## Glossary

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ECEC</td>
<td>Early childhood education and care</td>
</tr>
<tr>
<td>ECEI</td>
<td>Early childhood early intervention</td>
</tr>
<tr>
<td>ECI</td>
<td>Early childhood intervention</td>
</tr>
<tr>
<td>ECIA</td>
<td>Early Childhood Intervention Australia</td>
</tr>
<tr>
<td>IPSP</td>
<td>Inclusion and Professional Support Program</td>
</tr>
<tr>
<td>ISP</td>
<td>Inclusion Support Program</td>
</tr>
<tr>
<td>NBM</td>
<td>Nepean Blue Mountains</td>
</tr>
<tr>
<td>NDIA</td>
<td>National Disability Insurance Agency</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-government organisation</td>
</tr>
<tr>
<td>SPRC</td>
<td>Social Policy Research Centre</td>
</tr>
</tbody>
</table>
Early Childhood Intervention Australia (ECIA) NSW/ACT commissioned the Social Policy Research Centre to conduct research into the delivery of early childhood intervention (ECI) services in the context of the National Disability Insurance Scheme (NDIS) roll out in the Nepean Blue Mountains and Hunter regions in New South Wales. The research was conducted in March-June 2016. It aimed to develop an understanding of how ECI practice was currently changing in each site, what opportunities existed for implementing ECIA's Best Practice Guidelines under the NDIS, and how ECI good practice has developed under, and has been influenced by, the NDIS roll out. The research involved forums and interviews with service providers in the Nepean Blue Mountains and Hunter regions.

Key areas explored by the research were the changes in services, collaboration and funding and business models that occurred under the transition to the NDIS. The research found that in transitioning to the NDIS, the key issues to be worked through included managing the service level provided to children and families with different entry points to the NDIS; managing a renewed focus on interdisciplinary collaboration, often with new providers in the market; and learning how to fund different types of work under a billable hours system.

The following key areas were identified for further good practice development:

1. Support families to make informed choices about their child’s support
2. Maintain soft-entry pathways and funding to support the complex needs of disadvantaged families
3. Improve equity of access to the NDIS and ECI services by supporting families throughout the NDIS Access Request processes and by maintaining an approach like ECEI for families not receiving a NDIS package
4. Ensure culturally sensitive service provision
5. Resource mainstream settings to support inclusion
6. Include travel allowances in NDIS plans
7. Provide funding and accountability measures to ensure collaboration
8. Support collaboration with key external partners such as schools, pre-schools and medical/health services
9. Address concerns about how the key worker model and trans-disciplinary approach fit with other best practice standards from outside the ECI sector
10. Facilitate discussions with families about good practice
11. Require quality assurance standards for all providers of ECI
12. Guide how to apply outcomes based approaches, such as by releasing data about recipients and contents of plans, goals, reviews and packages to inform good practice
Executive Summary

Early Childhood Intervention Australia (ECIA) NSW/ACT commissioned the Social Policy Research Centre (SPRC) to conduct research into the delivery of early childhood intervention (ECI) services in the context of the National Disability Insurance Scheme (NDIS) roll out in the Nepean Blue Mountains (NBM) and Hunter regions in New South Wales. The research was conducted between March and June 2016. It aimed to develop an understanding of how ECI practice was currently changing in each site, what opportunities existed for implementing ECIA’s Best Practice Guidelines under the NDIS, and how ECI good practice has developed under, and has been influenced by, the NDIS roll out.

The research involved forums and interviews with service providers in the NBM and Hunter regions, including with direct workers and managers in ECI non-government organisations, private ECI service providers, and a range of education, health and allied health employees who work closely with ECI service providers. Family perspectives were included in the literature review about the transition experience of ECI services in a context similar to the NDIS.

Findings about ECI in the NDIS context

The introduction of the NDIS insurance and market model of support requires an extensive restructuring of Australia’s disability support system. Under the NDIS, ECI is to be based on providing reasonable and necessary supports to children and their families for early intervention and social and economic participation. In the past, most ECI services were funded by government through service provider organisations. In the NDIS context, access to services is through information and referral or an individual package provided to a family to make choices about which services best meet their needs. ECI service providers are now transitioning towards this new system. This includes changes in services, collaboration, and funding and business models.

Changes in services

The NDIS introduces new service and funding systems and an approach to ECI exemplified in the ECIA Best Practice Guidelines. The NDIS focuses on individualised planning processes to identify support and choice for children with disability and their family to achieve their goals. The Best Practice Guidelines emphasise support in the context of the family, teamwork, inclusion and universal principles. ECI service providers are embracing this new context by changing the way they provide services, as highlighted below:

• The ECI service sector has expanded under the NDIS. Established providers suggested that in this context, monitoring of service levels was needed for effective service distribution between children for whom it was and was not appropriate to
have an NDIS package. Monitoring good practice in package allocation could avoid children receiving inadequate or inefficient service allocation.

- ECI services have become more diverse under the NDIS, as providers aim to offer families more choice over their child’s support. Families in regional areas have narrower service choices as fewer providers and workers operate in these areas. ECI service providers expected the regional choices to broaden as the NDIS becomes established and the ECI sector adapts.

- As government block funding was withdrawn, some providers were struggling to continue to support families with complex needs. They had found solutions such as referring families to social services and supporting staff with mentoring and training.

- Children’s inclusion in mainstream settings and home-based support has become more frequent with the NDIS. School staff supported inclusion by integrating therapy into the classroom. Home-based support seemed suited to some children and families. Some providers have continued to offer families some centre activities and opportunities to connect with and support each other.

- Providers were concerned about inequities between families with NDIS packages, observing that some packages addressed the child’s needs better than others. They suggested that solutions could include more support and training for NDIA planners about early childhood disability and advocacy support from ECI services for families during the planning process.

**Changes in collaboration**

The NDIS approach relies on collaboration between disability and mainstream services. In particular, the ECIA Best Practice Guidelines emphasise collaboration between ECI service providers, other social services and families. While children and families may have always had many service providers involved in their lives, changes in the NDIS context mean that ECI service providers may now notice and feel a renewed need to work together with other service providers, as discussed below:

- Initially, the market-model of the NDIS prompted some ECI service providers to view each other as competitors. They said they were adapting to the change in context and were now learning to collaborate in new ways.

- ECI service providers often did not know how to bill for time spent on collaboration. They were learning when and how to charge families for collaborative time, as well as when to invest unfunded time in establishing and maintaining networks and professional relationships.

- Interdisciplinary collaboration has developed, as ECI service providers and the organisations they collaborate with have learned about, and developed confidence in, a trans-disciplinary model and have also built capacity and skills for collaborating. Some non-ECI service providers who worked closely with ECI services found it challenging to collaborate in a trans-disciplinary model. Trans-disciplinary work was not the standard in their own discipline or sector and, as such,
they were used to contributing their own expertise individually. They worried about whether children and families would receive that expertise in a trans-disciplinary model.

- With many of their old collaborative networks disbanded, some health and allied health workers said they were learning more about the new providers in the ECI field and re-establishing their professional networks and relationships over time.

### Changes in funding and business models

ECI service providers are adjusting from direct government funding to individualised funding, determined by the family’s choices about which services to purchase from which organisation. NDIS systems for information, referral and coordination are still developing, as highlighted below:

- Many ECI providers were concerned about how to fund work with children for whom it was not appropriate to have an individualised package and/or who did not have a diagnosis. In the NBM region, many providers valued the NDIS Early Childhood Early Intervention (ECEI) approach for allowing them to continue working with these children. In both sites, they had also found the solution of drawing on a range of other health system initiatives to fund this work.
- Navigating the move to billable hours required ECI service providers to learn how to discuss money with families, and to be transparent with families about how the billing system worked. Flexibility with families to adjust hours between providers at different times was also useful.
- Some ECI service providers were concerned about how to bill for travel, some particular job roles, and for the costs of running a business and restructuring to the NDIS. They were experimenting with solutions such as arranging services to avoid costs, or other ways to bill or fund this time, such as travel costs. They were less sure about how to proceed with some other costs.

### Implications for good practice

Based on ECI service providers’ experiences of current change, the following key areas for further good practice development in the context of the NDIS roll out were identified:

1. Support families to make informed choices about their child’s support
2. Maintain soft-entry pathways and funding to support the complex needs of disadvantaged families
3. Improve equity of access to the NDIS and ECI services by supporting families throughout the NDIS Access Request processes and by maintaining an approach like ECEI for families not receiving a NDIS package
4. Ensure culturally sensitive service provision
5. Resource mainstream settings to support inclusion
6. Include travel allowances in NDIS plans
7. Provide funding and accountability measures to ensure collaboration
8. Support collaboration with key external partners such as schools, pre-schools and medical/health services
9. Address concerns about how the key worker model and trans-disciplinary approach fit with other best practice standards from outside the ECI sector
10. Facilitate discussions with families about good practice
11. Require quality assurance standards for all providers of ECI
12. Guide how to apply outcomes based approaches, such as by releasing data about recipients and contents of plans, goals, reviews and packages to inform good practice.
1 Introduction

Early childhood intervention (ECI) is specialised support and services to infants and young children and their families, where the child has a developmental delay or disability. It has an important role in promoting children’s development and supporting the wellbeing and community participation of children and families (ECIA website, 2016). As such, it is an important component of services both for children and families, and for people with disability. In recent decades, ECI good practice has emphasised family centred support and trans-disciplinary approaches (Appendix C).

With the introduction of the National Disability Insurance Scheme (NDIS), the context for the provision of ECI services is currently changing in Australia. The NDIS requires ECI service provision to operate within the context of principles such as choice and control, reasonable and necessary supports such as individualised funding/packages, and to reflect the introduction of trans-disciplinary and personalised services. This will affect change and development in a nationally consistent approach to quality ECI practice over time.

These changes mean that new issues are emerging about how the practices of ECI service providers are changing as they integrate with the NDIS system; how children and families are referred to the NDIS through the ECI sector; and how they are supported, irrespective of whether or not it is appropriate for them to receive NDIS Individual Funding Packages.

The move towards the NDIS is also taking place at a time when the peak professional organisation for ECI services, Early Childhood Intervention Australia (ECIA), is rolling out its new National Best Practice Guidelines (Appendix D). The NDIS has also announced plans for a nationally consistent approach to early childhood intervention known as ECEI. It is therefore important to understand how ECI is changing in the NDIS context and what opportunities are available under the NDIS for the development of good practice. However, little research has been conducted about the provision of ECI under the NDIS or how it can best translate to good practice for children and families.

Based on these changes, ECIA commissioned the Social Policy Research Centre (SPRC) to conduct research into the delivery of ECI services in the context of the NDIS roll out in New South Wales (NSW). The research focuses on the recent NDIS roll out site in the Nepean Blue Mountains (NBM) region. It also includes examination of experiences in the Hunter region, where the NDIS has been operating for a longer time. The research aims to develop an understanding of how ECI practice is currently changing in each site, what ECI good practice could be under the NDIS, and how ECI good practice develops under, and is influenced by, the NDIS roll out.

It is the first research to examine the transition of a sector and its relations with government and the National Disability Insurance Agency (NDIA), with the goal of improving service quality in the context of the NDIS approach. Its findings have implications for how other sectors might adapt to the new opportunities.
2 Methodology

The research was conducted as an action research project. The research questions and focus are outlined in the sections below, followed by an account of methods used to conduct the research and details of the research participants.

Research questions and focus

The project addressed two research questions:

1. How is current ECI provision changing with the introduction of the NDIS?
2. How could ECI services be provided under the NDIS to develop best practice? What opportunities does the NDIS present to develop best practice?

In answering these research questions, the research examines experiences in the NBM and Hunter regions. The two sites facilitate an understanding of how ECI practice has developed and evolved as ECI service providers have more experience working within an NDIS service landscape and as the NDIS itself develops.

The research also focused on a number of areas identified by the ECIA as priorities. These include:

1. Current practices, services, partnerships and collaboration in ECI services
2. Referral pathways within ECI, with and without access to the NDIS
3. ECI inputs, activities, outputs and outcomes, including the experience of providing ECI services to children and families for whom it is not appropriate to have an NDIS package
4. Best practice in ECI services within the context of the NDIS roll out, referencing the ECIA National Best Practice Guidelines.

Overall, the purpose of this research was to enhance capacity building and sector development in ECI services, by providing more evidence and documented assessment of what is currently changing in these services and what could be happening to develop good practice in the context of the NDIS. This research aims to result in enhanced capability for ECIA members, the ECI sector, and community sectors more broadly, to assist in achieving good practice outcomes for children with developmental delay or disability, and their families, as the NDIS rolls out. It also contributes to understanding how the NDIS is likely to impact or change current ECI practice.
Phase 1: Planning

The research began with a planning phase, in consultation with ECIA to determine the details of the research focus. A reference group and literature review about the transition of ECI services also informed the planning phase. Ethics approval was obtained from UNSW Australia (reference HC 16160).

Reference group

A reference group was consulted three times throughout the research. The first consultation was early in the project to inform the research methodology, design, key contacts and an understanding of key concepts and capacity considerations. The second consultation was mid-way through the project to discuss preliminary findings, and the final consultation was to discuss the draft report.

Membership of the reference group was determined in consultation with ECIA. It included key ECIA staff and board members, ECI service providers who are ECIA members from each site, and representatives from the NSW Government (ADHC) and the National Disability Insurance Agency (NDIA).

Literature review

A brief literature review about ECI services in transition was conducted to inform the background for the research and the research design (Appendix C). It covered academic and grey national and international literature. The review focused on families’ and service providers’ perspectives of effective ECI services and ECI service transition and integration, including research on how ECI operates in other service contexts similar to the NDIS. Information from the literature review was used to inform the scope and focus of the research framework, design the fieldwork methods and instruments, and to help interpret the research findings.

Phase 2: Data collection

To inform a thorough understanding of the delivery of ECI services in the context of the NDIS roll out in NSW, data was collected through two forums and telephone interviews.

Forums

Two forums were held, one at the beginning of the data collection and one at its end. The first forum was an opportunity for ECI change leaders from the NBM and Hunter regions to come together to listen to each other and generate new ideas for sector development, and to inform the focus and content of the project. This included gaining an understanding of the profile of the current state of the ECI sector both internally and externally, and of future opportunities in the context of the NDIS. The forum participants were determined in consultation with ECIA and the reference group.

The second forum was by open invitation to service providers participating in a meeting of ECI managers from NSW and the Australian Capital Territory (ACT), held in metropolitan
Sydney. The purpose was to report back and to reflect on the preliminary findings of the project. It also provided an opportunity for managers to generate ideas from their own practice to address issues raised by the research and progress good practice in ECI services into the future. The discussion at the forum reinforced the findings and suggestions made by other research participants and helped to inform the structure and emphasis of this report. The forum had a capacity building focus so that participants could use the preliminary findings to stimulate discussion about how to best operate in the changing context.

**Interviews**

Interviews were conducted with ECI service providers and representatives of other wider community, mainstream and specialist support services who work closely with ECI services. The interviews focused on obtaining in-depth qualitative data. Their purpose was to understand how ECI practice is currently changing, how ECI good practice operates under the NDIS and how ECI good practice has developed under, and has been influenced by, the NDIS roll out. The interviews were also used to inform case examples for this report about good practice in ECI service provision, in the context of the NDIS. The interviews were semi-structured, conducted by telephone and took approximately 45 minutes. ECIA assisted in accessing and facilitating contact with interview participants. See Appendix A for the interview questions.

**Research participants**

Participants in the research included ECI service providers and representatives of other wider community, mainstream and specialist support services who work closely with ECI services. There was emphasis on including participants from different types and levels of ECI service provision, including direct workers with children and families and managers in NGOs, private providers, and a range of education, health and allied health employees who work closely with ECI providers, but are not necessarily working in ECI services themselves. A total of 19 people participated in the first forum and in the interviews; all were from the Hunter and NBM regions. The sample is further detailed in Appendix B. A different group of participants from wider NSW (Hunter, NBM and elsewhere in NSW) were included in the second forum, with 64 people registered to attend.

These research participants are referred to in this report in groups to preserve their anonymity. They are referenced in the following way: ‘Direct’ – direct workers and managers; ‘Private’ – private providers; and ‘Other’ – other education, health and allied health. The ‘Other’ sample is too small to identify any more specifically without breaching confidentiality. The location is also noted if it is relevant.

The sample size was small, but given the exploratory nature of the study and the in-depth qualitative data provided, it was sufficient to investigate diverse experiences of transition towards the NDIS. Families were not included in data collection because of project constraints, but literature about their perspective of change in ECI services is included in Appendix C.
Phase 3: Analysis and reporting

Data was analysed thematically against the research questions using NVivo 11 and a coding framework based on the research questions for the study, the structure of the interviews and mapped against the ECIA Best Practice Guidelines. Feedback on the interpretation of the preliminary findings from the second consultation with the reference group and second forum was used in the analysis and to prepare this report.

Case examples

Using data drawn from telephone interviews and other evidence provided by stakeholders for this research (e.g. documented evidence or otherwise – as available), the analysis was supplemented by a range of case examples highlighting good practice in ECI services in the context of the NDIS. These case examples are presented as break out boxes in this report and are intended to add depth to the qualitative data and further illustrate good practice in ECI services.
3 Current Changes in ECI

The first research focus was how ECI providers’ work is currently changing as the NDIS rolls out in the NBM and Hunter regions. The introduction of the NDIS requires an extensive restructuring of Australia’s disability support system. ECI is to be based on providing reasonable and necessary supports to children and their families for early intervention and social and economic participation. In the past, most ECI services were funded by government through organisations. Access to the NDIS is instead made through information and referral or an individual package to the family, to make choices about which services best meet their needs. ECI service providers are now transitioning towards this new system.

The focus on change was to understand how ECI practice is developing and evolving as ECI service providers gain more experience working within the NDIS. The following sections present the changes, challenges, responses and suggestions for managing the new context, based on the understandings and perceptions of ECI service providers and others who work closely with them. The sections detail the research participants’ experiences of three changes: services provided, collaboration, and funding and business models.

3.1 Changes in services

The first set of changes was about the services provided. The NDIS introduces new service and funding systems and an approach to ECI exemplified in the ECIA Best Practice Guidelines. The NDIS focuses on individualised planning processes to identify support and choice for children with disability and their family to achieve their goals. The Best Practice Guidelines emphasise support in the context of the family, teamwork, inclusion and universal principles. ECI service providers are embracing this new context by changing the way they provide services.

This section analyses service provider perceptions of how ECI services are changing in the transition to the NDIS, which challenges both providers’ experiences and the ways they try to manage them. The main areas of change that service providers referred to were:

- changes in service provision through increased funding and number of providers in the sector, including for school age children, which in many states is the first time this age group has been recognised in ECI
- changes in service content, including more and varied services, as well as an increase in choice for families;
- changes in service focus towards the child, towards inclusion and towards home-based support.

As expected, observed changes were more significant in the Hunter trial site than in the NBM, reflecting the longer time in transition to the NDIS.
Changes in service provision

Service providers noted several changes in service provision; the size of the sector, the quality of services, gaps in services, over- or under-servicing, and inequities.

The roll out of NDIS funding had a profound impact on the size of the sector in the Hunter trial site, with a considerable increase in the number of children receiving funded services and a corresponding emergence of new service provider organisations. These new providers offered traditional allied health services, as well as case coordination and support. Participants appreciated that many children were now able to receive professional early intervention support for the first time, or a level of support that adequately addressed their needs. However, some ECI and other service providers who had been operating since before the NDIS found the new service landscape confusing, especially when they needed to refer children, although they expected to learn about the new service providers over time.

Some established ECI and other service providers had concerns about the quality of new competitors as they felt that the NDIS had not yet put a comprehensive quality assurance mechanism in place. Others observed that the open market was starting to regulate quality, for example:

> We tend to find that parents themselves are now sharing information a lot more with each other, and parents are gravitating towards … service providers that have been here for a long time or that have a lot of former ADHC workers working for them [and therefore] have got more experience. (Other)

With the recent NDIS rollout in the NBM region, ECI service providers had also observed a sharp increase in children with funding packages in the area, but they felt the supply side had not met this demand, especially in the middle Blue Mountains. Existing services appeared to prioritise children with an NDIS package, and children without a package were either missing out or had to travel to Lithgow or Lapstone to access services. This issue will be temporary if the service sector and workforce expand over the coming years to fill gaps in coverage, as they did in the Hunter region. In the interim, service providers said they encouraged families to complete an NDIS Access Request.

Research participants voiced concerns that some of the expanded funding for early intervention services might be misdirected. One specialist provider felt that prices for interventions had increased, which represented a higher cost in the child’s funding package, and ultimately the NDIS. Others said they had observed that some children received excessive services compared to other children with similar needs. In addition to some providers advocating their own service types, the research participants also attributed the higher level of services to the way some NDIS access rules were translated into plans, such as by providing integrated trans-disciplinary support when a specific therapy or health service may have been more appropriate:

---

1 As noted in Section 2, the research participant groups are referred to in groups to preserve anonymity: ‘Direct’ – direct workers and managers; ‘Private’ – private providers; and ‘Other’ – other education, health and allied health. The ‘Other’ sample is too small to identify more specifically without breaching confidentiality.
I think that we’re over-servicing those children that would previously have been able to access health-based services. For example, for children with [milder developmental issues] we would know that providing intense speech pathology and parent-based intervention in the short term was going to be more effective than having a long-term intervention through the NDIS. (Other)

ECI service providers hoped these issues would resolve as the NDIS was refined during its country-wide rollout.

At the same time, service providers worried that some children might miss out on support altogether if it was not appropriate for them to receive an NDIS package and current block-funded ADHC programs were withdrawn. Providers were placing great hopes on the NDIS ECEI approach to fill these service gaps. State Government Early Linkers and NDIS Community Connectors had already been fulfilling the role of linking families with mainstream services, but service providers’ experience of their effectiveness was mixed.

Research participants had noticed inequities in access to the NDIS, due to differences in capacity among families. Access to a funding package relied on families initiating the planning process and advocating for their child during the process. A provider said:

It seems to me that the ones that get the best access to the NDIS and to early intervention services are still the ones that are the most motivated and where the parents are the best advocates for their children. (Private)

Some providers felt that once families had entered the NDIS Access Request process, planners were effective in leading them through and advocating for adequate support, while others had observed inequities in the size of funding packages in relation to the child’s support needs. They assumed these inequities were due to the knowledge of the individual planner and the presentation of the family. They expected inequities would reduce as experiences from the trial sites were incorporated into NDIS processes.

**Changes in service content**

Service providers noted two changes in service content; additional and more diverse services, and the consequence of more choices available to families. Increased funding amounts and flexibility in NDIS packages enabled ECI service providers to offer additional and more diverse services than before. Examples included music therapy and social skills building groups. Some providers had expanded their target group, for example from children with one type of disability to those with other support needs. Others pointed out that increased packages facilitated more comprehensive and varied support to individual children than had been possible with restricted funding before.
Case example: More diverse services under the NDIS

One service provider wanted to give families choices about the intensity and cost of services. They offered five different school holiday programs – including half-day and full-day programs, participation in the big group only or additional therapy sessions in small groups, and the option of daily, individual verbal feedback from the providers.

Service providers in both areas agreed that the NDIS offered children and families more control over their support and more choices than did previous funding. What families asked for in their plan was often outside the range of supports that had been provided in the past, for example for an occupational therapist to talk with a scouts group about how to include the child with disability. Some service providers also offered extended choice of services to other families without an NDIS package:

If it's good enough for NDIS parents then it must be good enough for non-NDIS parents. So all our processes and procedures we're applying across the board … and that means all of our parents have choice about different services and options which before they didn’t have quite so much choice. (Private)

Service providers said that families of children with an NDIS package also benefitted from more choice regarding service providers, ideally enabling them to secure good-quality support from a provider they trusted. Outside the regional centres, choices were still restricted by a shortage of providers and workers. This applied to the newest parts of the Hunter trial site as well as the NBM.

Service providers had observed that many families embraced choice and control:

The families themselves are becoming much more savvy at saying, what do I need, what’s best for me? You know, I want this person or I want that … (Private)

Other families seemed confused and overwhelmed by the choices as well as under-informed to assess the quality of providers, at least initially. Service providers also agreed that families needed skills and confidence to make decisions about their child’s plan. To those families who did not appear confident, service providers suggested solutions such as engaging a financial manager or support coordinator, or they hoped that families would learn the skills to manage their child’s plan over time. Most service providers felt that the NDIS planning process had been helpful for families engaged in it, and that the planners had been effective advocates and supporters of families. Others felt that planners could have more support to understand child disability, including specific training about the operational implications of the ECIA Best Practice Guidelines.

A mainstream service provider pointed out that increased family choice in the ECI marketplace put pressure on service providers to please families, potentially undermining professional judgement:

What we're finding is that certain parents who have got very strong opinions about what their children are able and not able to do are changing service providers regularly until they find a service provider that agrees with them. So we’re finding that
service providers are losing some of their objectivity because they need the parents to like them and be with them because these are the people that are paying their wages, whereas in the ADHC system, it didn’t matter if that parent didn’t like you, the government was paying your wage. (Other)

The service provider had no suggested solution for how to fix this problem, although it raises implications for effective ways to work with families to understand their needs and inform them about evidence based good practice.

One general disability service provider who also offered ECI support had not yet made any changes to services. The organisation covered a large geographical area and was waiting for the NDIS rollout to see what families asked for and respond accordingly.

**Changes in service focus**

Service providers referred to changes in service focus, including a stronger focus on the child, an emphasis on inclusion and increased home-based support. In the view of many providers, one of the major changes the NDIS had brought was the shift from support focussed on the family to a focus on the child:

> We tend to work more with the child than with the family. So we go in with the plans, with the goals that have been set through the NDIS and we work towards those because that’s what has been stated that the money’s for. (Other)

The NDIS legislation and ECIA Best Practice Guidelines both emphasise the child in the context of the family, but the service providers’ experiences of the implementation of the NDIS were different. The perception of a narrower focus was generally negative. Most providers felt that previous block funding had enabled them to provide family-centred support, where they could address urgent family issues so that support for the child could be effective. This was especially important for families with complex needs such as unstable accommodation, family breakdown, lack of transport, or lack of money to buy food. Under the NDIS, most service providers felt constrained by, as they saw it, the prescriptive nature of funding packages and inflexible NDIA administration. Some providers were trying to manage through testing a variety of possible solutions such as referring families to mainstream social services, debriefing with colleagues, and training staff in time management, child protection and working with complex families.

In the past, block funding had also enabled service providers to vary the intensity of support between families and over time, depending on their changing needs. Some felt they could not provide such flexibility under the NDIS. Other providers had developed solutions such as teamwork and management practices to continue working flexibly.
Case example: Flexible service provision

One service provider described how they continued working flexibly under the NDIS with a team of practitioners who supported numerous families. The practitioners were in frequent contact with each other and with the families so everyone knew how the children were progressing and what their current support needs were. If families asked to focus therapy on a particular aspect, the practitioner team arranged among themselves for one of them to provide more intensive support for a time while others pulled back. This gave families and service providers the flexibility to vary support over time, depending on changing needs and goals: “There was one child for example where the family said, ‘I really need the physio to work on this particular issue’, and it was decided to increase the hours [for the physio], and the OT said, ‘Well I’m okay right now’ and they backed way out for that period of a couple of months. Whereas if they had to see each person each couple of weeks because you have 90 hours and that’s how you’re going to use them for the year, then it would have been a problem.” (Private)

Service providers acknowledged that this approach might require larger teams of practitioners and effective collaboration.

Together with more choice and a focus on the child under the NDIS came an increased emphasis on inclusion; on supporting the child to participate in mainstream settings and activities in the community. At the request of families, NDIS plans often contained goals of taking part in sport teams or cultural programs such as art and dance. Service providers seemed to accommodate these requests readily; it was considered an extension of the established practice of providing support in preschools and primary schools. It also included supporting the families on outings and any other settings the families chose.

Case example: Supported family outing

One service provider said: “This family was quite secluded in their home, wouldn’t leave their home because it was difficult for their child to get out in the community because of their disability. The physio then supported the family to go to places like the beach. There’s a lovely photo of the physio and the child at the beach with the parents looking in rock pools, which is something they’ve never done. That was just wonderful to hear that physiotherapy could happen at the beach.” (Direct)

Some service providers cautioned against what they termed ‘pseudo-inclusion’ in mainstream group settings, where children received therapy individually or together with others with similar support needs, for example a language delay, rather than remaining in the larger, mainstream class where they had role models.

School principals in the Hunter region struggled with balancing the needs of the classrooms with those of numerous therapists wanting to provide support in the school. Requests
from therapists increased considerably with the NDIS because more children than before received funding and because many ECI service providers were now supporting children aged up to eight years, rather than the traditional cut-off at six years of age. In the absence of guidelines from the Department of Education, principals needed to create and implement their own rules. Different solutions were tested, for example asking therapists to work in the classroom – to enhance the child’s inclusion – rather than allowing them to pull the child out; allowing only speech pathology into the school; or allowing any therapy as long as it related to an educational goal. Some conflict and confusion ensued and there was recognition of the need for more consistency in the approaches used and more support and guidance for schools as they managed the issues. It was, however, anticipated that the issues would be resolved as the Department of Education develops guidelines while the NDIS rolls out. Guidelines and sharing good practice will hopefully contribute to greater consistency across education and other parts of the ECI sectors, including more guidance to schools.

**Case example: Including therapy in school education settings**

Due to increases in funding and therapy under the NDIS, a school principal needed to deal with a large increase in ECI service providers coming into the school to provide therapy. Having no departmental guidelines, the principal entered into a consultative process with service providers, developed a set of rules, empowered the teachers, and provided induction to any new service provider. This appeared to be a collaborative, respectful and effective approach to ensure service provision in the child’s natural environment, while balancing the interests of the child and family with those of the other children, teachers and the school.

Another change in service focus that occurred with the NDIS was a noticeable shift from clinic to home-based support. Service providers in the Hunter region said they now spent a lot more time working with children and families in their homes, as part of individualised service delivery. Some providers had restructured their organisations to accommodate this shift, while others had worked without a physical site before. Most welcomed the change because they saw clear benefits for the child and family. In the home, providers were able to coach families to incorporate supportive practices into their everyday routines, and consequently they had seen outcomes improve for both the child and the family as a whole, for example:

I worked with a family who’s been with us two years. She’s got four kids with learning needs … I can just see how her practices have changed within the family. Two years ago when I met them they were a family of all doing their own thing. Her engagement was just to feed them and clothe them. She is now playing games with them. She is now planning picnics, doing all these amazing things with the kids just by having, I truly believe, a team of people in the home just helping her think about other ways to, I guess, have a family life where there’s improved relationships, which was one of her goals. (Direct)
Several service providers saw a continued place for centre-based support. They said some families appreciated the opportunity to get out of the house, to a place where their child felt welcome and where families could make connections with others. Providers said families had formed lasting friendships around centre-based group activities that were threatened or had faltered, due to the withdrawal of block funding. An organisation was trying to solve this issue by continuing to facilitate peer support through newsletters, social media and support groups for specific diagnoses.

### 3.2 Changes in collaboration

The second set of changes in transition to the NDIS was about collaboration. The ECI service providers highlighted that they have always worked with a collaborative approach, but there were now perceived changes in how they were expected to collaborate under the NDIS, as other service providers in children and families’ lives became more visible with a renewed imperative to work together.

Early in the change process there was sometimes a drop in collaboration or a period in which ECI service providers needed to come to an understanding of how to work in a collaborative or trans-disciplinary model. During this time, some people were hopeful that increased collaboration, once properly established, would allow a simplified line of communication and a reduction in the need to repeat information to multiple service providers or colleagues. As change progressed, collaborative approaches became about coordinating information between a team of people working with a child and family, and about extending communication with families in private settings (as opposed to groups or centres), allowing in depth conversations about families’ needs and the adjustment of services and supports as needed over time.

Key challenges and potential solutions with regard to the new ways of collaborating were identified and are documented in the sections below.

**Collaboration in the market place**

ECI service providers highlighted that in the market place model of the NDIS, other service providers are not only colleagues to collaborate with, but also competitors for business and this sometimes created less incentive for collaboration:

> These days, there’s a little bit more competition, because they’re all clients and we all want to survive. (Direct)

However, others noted that, even though ECI service providers were in competition, there was still a willingness among those who were responsible to do what was best for children and families:

> As needs of children and family change maybe it’s better for someone else to be providing that service … Which totally goes against what people would think because you want to keep your business – but in actual fact I’m not sure that that’s always best for the child and family. (Private)

Others also noted that service providers were sometimes able to recognise their own skill
gaps and to seek collaboration with other providers to fill particular gaps, even in the market model:

I think we’ve had a few private services come back to us and say ‘Can you be part of the package, because this is not our skill fit?’ Not many. (Direct)

The final two quotes highlighted here show that even despite the market model and increased competition, ECI service providers are adapting and learning to collaborate within this new context.

**Cost of collaboration**

Several participants highlighted that collaboration costs money because of the time investment involved:

[Collaboration] takes a lot of to-ing and fro-ing and that’s tricky because if you’re working with a number of services in the package, then you need to communicate with them. That communication costs money. So working as that team around that child with a number of different service providers, then you’re going to cost more … time costs money. (Direct)

The cost of collaboration was experienced as a problem for several reasons. Firstly, it meant that families could not always afford to continue to have all service providers involved, and this meant that some ECI service providers needed to end their work with certain families:

So, say for example you have a family that’s got a trans-dis package and you’ve been part of that team supporting their inclusion … perhaps there’s no money left to have you involved. They’ve chosen to stick with seeing the therapist on a weekly basis in the rooms, in their offices. So therefore you can’t be part of that picture. (Direct)

Secondly, with individualised packages based on billable hours, ECI service providers understood that there was no money dedicated to collaboration, which meant that they had trouble billing for time spent on collaborative meetings and communication. Some people felt this made it difficult to collaborate, given the business model they had to work to. Other people were less worried about the cost and described how collaborative actions, such as circulating memos, could be charged within a plan:

But if you document and you send something that goes to everyone which is part of your collaboration … if it took you 20 minutes to do that you would go for that and you would put it on your service record. The next time you saw the family they would sign for that and you would bill for it. And families are fine with it because they know what makes the service better. (Private)

Thirdly, in relation to the increasing incidence of private providers, there was concern among NGO ECI service providers that those working privately have a comparatively low capacity to cover collaboration costs outside billable hours, as they do not have wider organisational support behind them, and that they might have a low level of understanding of other disability support models, outside their own therapy speciality. One person noted the challenge, also saying that some private providers tried to find a solution to the cost of collaboration by using technology to attend meetings remotely. Some private providers also
recognised that collaborative and networking work was important to do, even if not billable.

**Case example: Investing in collaboration**

One private provider noted that although she could not bill for collaborative time, her work benefitted from investing in networking and building relationships with colleagues. She said: “My feeling is that people, as professionals in providing this service, you have to understand that you’re going to need to provide that [networking] work”. She went on to say, “You can’t bill that to anyone – and that’s what makes it hard for people, like it’s your income – but again, once the relationships are developed it’s much easier”. As an example of her networking, the private provider noted being involved in the establishment of a quarterly meeting for private providers to network with service provider organisations to better aid collaboration.

Although challenging, it appears that many providers, including private providers, were finding solutions to fund the costs of collaborative time. They said they needed to be committed to actively working out how to manage these collaboration activities and costs to achieve the outcomes of collaborative practice.

**Interdisciplinary collaboration**

Some research participants commented on difficulties with collaborating with colleagues from other disciplines outside ECI, particularly disciplines that emphasise a specialist professional lead. Sometimes the difficulty was because people from other disciplines had different standards of good practice or different ways of collaborating:

- I guess we work in such a different way in terms of that collaborative teamwork approach that for some I don’t know that it’s the same for them. (Direct)
- … the different evidence based methods of intervention … everybody in the industry is aware of what’s best practice for them. I go by, as much as I can, the ECI best practice principles … I think it’s a work in progress about being aware of different ways of delivering a good quality service, but I don’t think that we’re on the same page about choosing different options. (Direct)

One person commented that people from some disciplines had more experience than others with the collaborative model encouraged under the NDIS, or with the preference of some families for multiple providers. This variation was challenging, but sharing experience was sometimes productive and useful when workers from other disciplines took up this model for the first time:

- We used to work as the educator as the key worker, no matter what. And then when the NDIA came along we had the other disciplines as key workers as well which, for all the other disciplines, it was quite tricky because they had to learn how to work as a key worker … So there’s been a big change there from key worker as educator to key worker as any discipline. Not necessarily a bad thing, it’s encouraged more team-work
approach, more of the trans-disciplinary approach to what it was. (Direct)

Some service providers and health workers who worked closely with ECI service providers, but were not in the ECI sector themselves, found it challenging to collaborate in a trans-disciplinary model, as this was not the best practice standard in their own discipline or sector. They perceived challenges with the model, including concerns that in the trans-disciplinary approach, children might not get the specialist support they had to offer (e.g. assessment for specialised equipment), that the approach could double up on the cost of workers, and that it could be confusing to families to have a suite of service providers involved when they had requested one specific therapy or support:

I think it confuses the families actually. I think the whole concept of working in a trans-disciplinary model has always confused families … They will go to an ECI provider and get allocated a key worker who doesn’t know the answers to the questions that they have and then they need to go and find a physiotherapist anyway. (Direct)

Others worried that the trans-disciplinary approach might ‘over-service’ some children who might not need such a thorough approach, but rather required a specific intervention. This issue may be addressed as planners learn more about when to allocate a trans-disciplinary package and when other specific supports may be more appropriate instead. It may also be addressed as families, ECI providers and others become more aware of, and experienced with, all of the available line-item options when allocating supports, and when the ECEI approach is available in all areas, enabling access to supports other than individualised packages.

Some participants also recognised that sometimes the variety between service providers’ ways of working could be of benefit to children and families. They said some children and families could benefit from different skillsets and approaches at different times.

Case example: Using different ways of working to benefit children and families

Two research participants noted that collaboration between service providers with different ways of working could be used to benefit children and families by drawing different people, with different skillsets and frameworks of working, into the key worker role at different times. They described switching between special educators and occupational, physiotherapy and speech therapists as the key worker, based on the child and family’s needs. One said, “It’s [about] talking to the family, working out with the family the best person for the key worker role” (Direct). Another noted, “Say along the way another problem turns up, when we can, and we’ve got the capacity, we’re more than happy to switch the key worker if that is what the family wanted” (Direct). Flexibility to change the key worker was an important way in which trans-disciplinary collaboration could benefit children and families.

Another issue with trans-disciplinary collaboration was that some players needed to be up-skilled in how to collaborate as equals. A school principal spoke about the process needed
to push back against too many service providers coming in to schools, as well as build the capacity of teachers to engage equally in collaboration:

… at one stage last year we had up to 65 service providers coming into the school … We’ve got that down to a bit more of a manageable level now through … linking the service provision under NDIA to a child’s individual learning plan. So what we’re saying now is that we are more than happy for service providers to come into the school during school time … but it must link the educational goals that we’ve all agreed upon, otherwise it doesn’t happen during school time and that’s reduced the number of visits from 65 down to about 36. (Other)

One of the other things we’ve had happen is that therapists do the service provision in the school and then want to talk to the teacher one-on-one at the end of it when the teacher is trying to run the class. So I try and empower my teachers to say, ‘Yes, I’m more than happy to have this service provision,’ when they talk to parents and therapists but, ‘We need to negotiate, we need to discuss, we need to collaborate, we need to consult,’ those sorts of words so it’s a combined thing, not some … therapist saying, ‘I’m coming …’ which we’ve had. (Other)

In this way, although collaborating with service providers from other disciplines could be challenging, particularly at the outset of new work together, ECI service providers and other colleagues were establishing solutions and ways of working together over time. The challenge of working across disciplines may therefore be largely a transitional issue.

Change in collaboration landscape

Some people from organisations not directly providing ECI services – for example, those in health and allied health – noted changes in the collaboration landscape. For example, in the NBM region, some organisations had received ECEI funding to serve children who do not have individualised plans, while others had not. This was challenging for external service providers referring to ECI organisations, who felt it was more worthwhile to refer to those organisations that had the funding than those who did not.

Another change in the collaboration landscape was that some of the old networks through which health and allied health workers had previously collaborated with ECI service providers (e.g. Early Childhood Intervention Coordination Program, Early Intervention Information and Service Coordination Agency) had been disbanded due to no longer receiving block funding to run the network. This meant the structure to support their established ways of collaborating were no longer available.

At the same time, many more new ECI service providers had entered the market and this made it challenging for health and allied health workers to know who they were and to collaborate with ECI service providers who they did not have previous working relationships with:

There’s so many more organisations and agencies than there used to be. So it’s made it more complicated … there’s many more of them and we don’t know them as well and there’s people that we haven’t heard of before that keep appearing. So I guess our knowledge of the other services is not as good, so that makes it harder to collaborate. (Other)
Just more generally of collaboration, there's a lot more players in that space now and I can't really keep up with it … I used to have a pretty good sense of what services were available, and I would know a lot of the people … in terms of how they work, what their area of skill or expertise was and could sort of help families to sort of direct them in a way or offer suggestions as to who might be the best person. But I now longer have that knowledge … everyone's putting their hand up and saying that they do therapy, or they do different types of supports but I don't know any of those people and I don't know what they do and I don't know what their background or their experience is. (Other)

In many ways, this issue may also be one limited to the NDIS transitional phase and may improve over time as new relationships are established. Those directly providing ECI services did not mention this issue as much as health and allied health workers, suggesting they may have already had some opportunity to get to know new service providers.

### 3.3 Changes in funding and business models

ECI service providers identified that transitioning to the NDIS had required changes to their funding and business models, which impacted on their work with children and families. These changes were set in the context of the insurance and market model of the NDIS, and in the introduction of individualised packages for some children with disability. ECI service providers are adjusting from direct government funding to individualised funding, determined by the family's choices about which services to purchase from which organisation. NDIS systems for information, referral and coordination are still developing. ECI service providers perceived challenges with regard to these changes and also suggested the potential solutions.

#### Serving children with and without individualised packages

Many ECI service providers had concerns about how they would fund services for children and families for whom it was not appropriate to have an individualised package, who did not have a diagnosis on which they could be assessed for a package, or who did not meet the residency requirements for a package. They felt that with the roll out of the NDIS, it was now easier to fund services for children with individualised packages than for children without. This was particularly an issue in the Hunter region, where the NDIA's ECEI approach had not been piloted:

> Whenever a child is referred to us, our first question is: What funding can we use to support this child? Whereas previously if a child came through without a diagnosis, we would just use our ADHC funding … whereas now, what we're saying is if this child doesn't have a diagnoses, we will have to fasten the pace a little bit … because we don't have funding … we don't have funding to support them unless they are NDIA funded. (Direct)

In the NBM region where the NDIA's ECEI approach was piloted, ECI providers were very aware of the role of this approach in funding and addressing the needs of children who did not have an individualised package and/or diagnosis. They were appreciative of the ECEI
approach and emphasised its importance for continuing to implement the best practice standards in ECI:

We’ve also got that other funding from the NDIS – the ECEI funding that we have that still allows us to see children and do assessments on kids that don’t have a diagnosis and that may end up not getting a plan, which we see is really important. (Direct)

The ECEI funding, that is … enabling us to sort of keep doing what we’ve been doing … which is just fantastic especially in early childhood in those nought to six years … because they’re such important years … it’s just so important to [be] getting there early. (Direct)

In both sites, ECI service providers spoke about finding other solutions to fund work with children and families who did not have an individualised package and/or diagnosis. Some spoke about funding this work by using remaining block funding that had not yet been phased out, while others mentioned the role of funding from Medicare plans, Enhance Primary Health Care plans, Mental Health Care plans and the Close the Gap initiative. In these respects, the NDIS appeared to be interfacing with other parts of the mainstream health system, consistent with its design. In other cases, providers spoke about building the cost of some work with children and families without individualised packages into their hourly rate for all clients, and/or using charitable donations to cover the cost of work with this group. These last two options were however framed as more problematic, given the equity implications.

Overall, capacity to serve children and families without individualised packages was an issue causing significant concern for many ECI service providers. Some providers recognised the importance of linking these children and families to other mainstream services and recognised the potential solution of using other types of mainstream health funding to meet their needs. As such, while it was a concern for many, some ECI service providers were also thinking broadly about how they could meet the needs of these children and families within the new service landscape and were finding ways to adapt. In addition, other parts of the NDIS implementation, including Local Area Coordinators and the Information, Linkages and Capacity Building initiatives are anticipated to address some of these needs.

**Working within billable hours**

ECI service providers also spoke a lot about the move with the NDIS from block funding to working under billable hours. For those who had not previously delivered packaged support, this was a significant change to their business model, which in turn affected the ways they worked and communicated with children and families.

ECI service providers described the change to billable hours, emphasising that it could affect how long they were able to spend with children and families:

In the old models under block funding, it didn’t really matter how long you stayed at somebody’s place or how often you went or didn’t go … there wasn’t this where you actually had to … bill for whatever time you use. (Private)
Accountability of time has been a big one ... before we had block funding – we worked with our families, we did what we had to do. Now because of the funds and the time, it’s all time-based ... Where[as] before a family may have wanted to talk to us for two hours, [now] we’re really needing to say, ‘Look, we can only do this in the hour, because we’ve got other clients we need to see.’ (Direct)

They said it was sometimes difficult to have the flexibility to deal with crises or heightened needs at transition points under the billable system, as extra hours could not always be allocated:

… you might be seeing a client, but then something comes up that might take more time, but you’ve got to be aware that you can only charge them for whatever they’ve agreed to be charged for … It’s just some things can take more time … how do you charge for that when … a crisis happened that day that requires more support or collaborating, liaising? (Direct)

For example, for a little child going to school transition, if the wheels are falling off, traditionally we could give some more intensive support in term one and spend at least three hours, because we know that that intensive support with a lot more time is beneficial in the long run, because we look at the long run. Now it’s like, okay, we’ll be there for an hour because it’s costing so much money. (Direct)

Some ECI service providers also noted that it was difficult under billable hours to account for time spent on collaboration and to cover the times when appointments were cancelled at the last minute, or when children, families or staff were unwell.

Importantly, ECI service providers also spoke about how they were adapting to the changed business model and learning of potential solutions to the issues raised by working under billable hours. One person recognised that she and her colleagues would need to improve the way they talk with families about money and the cost of services:

It’s also having these conversations about money … in these [kinds of helping] roles we don’t talk about money … it’s just something so different that we haven’t done before … I suppose we’ll … just have to work out having conversations with families about money and just have to do it – we’re going to have to do it, it’s just it feels weird. (Direct)

Some ECI service providers, still in transition, were using interim strategies to do extra work outside billable hours that were either unsustainable or inequitable, such as staff putting in unpaid work time.

Other people had however adapted their practice in more sustainable ways. For example, one person spoke about the importance of ensuring that even with the changed billing arrangements, funding did not dictate practice:

So what we had to adapt then was to figure out how can we do this in a way that the funding doesn’t dictate – this sounds funny, but we didn’t want the funding to be dictating what we do. We wanted to meet the family in order to decide what they need and then let the funding support what was needed. Because otherwise what happens is very quickly you start to think how many hours was the funding for, and it does limit
what you do. No matter how much you can say it doesn’t, it does. (Private)

Some service providers already had experience of adapting to new cost structures, such as differentiating centre-based and off-site costs, when they managed packages before the NDIS. This was the case across different types of providers. For example, one private provider spoke about the importance of being aware of the costs of servicing children in different settings and setting their billing rates accordingly:

Well we have one billable rate for children who are seen here in the clinic and another billable rate for children who are seen in schools and the reason for that of course is because we’re travelling to schools and there’s downtime with recess and lunch. So there’s a cost of my clinicians’ time in providing school-based services. (Private)

Adapting to the new billing arrangements could require transparency with families and flexibility in adjusting different workers’ hours with children and families at different times.

Case example: Transparency and flexibility in billable hours

One private provider highlighted that the two of the aspects of most importance in navigating billable hours with families were transparency and flexibility.

With regard to transparency, she said, “… we had to adapt because we had to have the systems in place in order to ensure that it was very transparent, that families knew what was being charged, how it was being charged, that they knew that there was indirect work that happens when you’re not with a child that is part of what has to happen in order for the child to receive the better service”.

She also spoke about how the collaboration involved in the trans-disciplinary model of the NDIS could be used to address restricted work under billable hours, by flexibly negotiating with other providers about how many hours they would each use at different points in time, and some providers stepping back to allow others to charge for more hours and then adjusting this arrangement later when different needs arose (Private).

In this way, the transition towards billable hours was challenging for many ECI service providers. Some, across different types of providers, had taken steps to adapt to it and tested some solutions. Many of the comments made about possible solutions were from private providers, suggesting that they are perhaps more experienced with experimenting with this kind of business model than some others. While already taken up by some other ECI service providers, adapting private providers’ practices (such as determining billing rates according to setting and ensuring transparency and flexibility with regard to billable hours) to a broader range of ECI providers might be a way of continuing to move towards good practice with billable hours under the NDIS. It is also important for organisations to fulfil obligations on good workforce management practices and other contractual commitments.

Billing travel and other activities under the NDIS

A further issue related to the change in funding and business model was how specific
components of ECI service providers’ work were billed and the identification of gaps where they were unsure how to bill for particular activities. They raised examples of travel and other activities, particularly in regional locations.

**Travel**

Most commonly, ECI service providers mentioned challenges in knowing how to arrange services to avoid travel or how to bill for the travel time required for their work. Where children and families lived locally, small amounts of travel were generally unproblematic, however where children lived further away, ECI service providers spoke of costs of travel as more of a problem:

So NDIA doesn’t fund travel separately. So for our staff who may be traveling … a two hour trip each way, NDIA won’t fund that. (Direct)

Although some ECI service providers knew that travel could be factored into individualised packages for rural and remote children and families, these families were not classified as residing in rural and remote locations, while still being far enough away that travel presented a financial problem for the service providers. The NDIS July 2016 price guide has greater clarity about travel costs, which will presumably continue to develop during the roll out.

ECI service providers were concerned about the difficulty of billing for travel because they saw it as an equity issue for children and families:

We have a family about an hour-and-a-half away from us who has a package. And if we were charging for two hours of travel for the one hour of actual face-to-face, it’d cost them a fortune … It’s not fair on the family. (Direct)

… a number of the families that we’re seeing [have] travel put into their plans … they probably get less variety and less options and they potentially could have less frequency of input, because of the fact that travel has to be taken out. (Private)

One person also felt that restrictions on billing for travel could impact on capacity to deliver some areas of ECIA Best Practice Guidelines, such as serving children in natural environments:

What I’m hearing from a lot of service providers is that the capacity to provide support in natural environments is limited significantly by travel, by how much funding people will receive for travel. (Other)

Despite their concerns about inequity for families, ECI service providers felt they did not have a choice in billing for travel, because to do otherwise would be a financial problem for their organisation under the NDIS business model.

As such, some ECI service providers had been creative in trying to find solutions to fund travel, or to arrange services that avoided travel costs. They described trialling options that included recruiting new staff in areas closer to children and families, partnering with other organisations who were local, drawing in staff who lived close to a particular child and family, joint visits by staff to minimise the auxiliary costs of travel, clustering visits to children and families in a similar geographic area together on one day, and using technology to communicate remotely. They were not always satisfied with the results, for example, citing
the benefits of communicating via technology, but feeling that it was an equity problem if children and families received no face-to-face time.

Sometimes ECI service providers could use NDIA-funded travel reimbursements and travel packages, where available. Some providers had also sought to revise some children’s packages to include more travel costs. One person suggested that the key worker model could be used to minimise travel costs by training up a local key worker:

Certainly there’s the key worker approach, where there’s a lot of training up of the key worker who’s already up there by the discipline specific staff [– that] will probably happen a whole lot more. (Direct)

As such, ECI service providers were testing a range of possible solutions to address the issue of how to avoid travel or cover travel costs. Their efforts to test alternatives highlight some adaption to the new business model and funding context.

Other activities

Aside from travel, ECI service providers also mentioned a range of other activities that they were unsure how to bill under the NDIS. Sometimes this was about the role of a specific worker, while in other cases it was about the costs of running a business or restructuring to adapt to the NDIS.

One person who worked as an Early Childhood Special Educator felt that the NDIS billing system did not adequately cover her role and therefore found it hard to justify her expertise with families. More broadly, this may relate to ECI concern about implementing the intention of the Best Practice Guidelines in the context of the NDIS by highlighting the critical role of early childhood educators to achieve the social inclusion of children, relative to health, allied health and other therapy interventions.

Another person, a private provider, commented on the difficulty of funding the costs of retaining long-term, good quality staff, and the problems this presented for working conditions in an increasingly casualised work environment.

The same provider also commented on the non-billable costs her business had incurred in restructuring to adapt to the NDIS, including the time spent gathering information about the new system and the administration, reporting and training involved in learning and adapting internal systems:

I suppose the word … is time consuming. I don’t know how a clinician who’s a sole clinician is going to cope with NDIS, because it has taken my clinical manager and myself hundreds of hours to do this and for every meeting that I go to I might learn one skerrick of information, but another skerrick of information that is an important piece in the jigsaw puzzle. We’re meticulous about reading everything, amending and updating every document that we have here for clinicians, for parents. But I think the word to describe it is that it has been incredibly time consuming and all of that for private practice has been non-billable … the landscape has changed and I think it’s a good landscape for parents, it’s giving them choice and control and access to services which they want … [but] it’s come at a huge, huge time cost to us. (Private)

ECI service providers did not mention many strategies that they had used to adapt to these
challenges, but the types of issues they describe indicate that many of these costs may be transitional. As service providers across the board gain greater experience in adapting to these transitions to the NDIS, future service providers may be able to learn and benefit from the lessons of those who have dealt with these issues before them.

3.4 Summary of current changes in early childhood intervention

The experience of service providers in the NBM and Hunter regions during the transition to the NDIS context are summarised below.

Changes in services

The NDIS introduces new service and funding systems and an approach to ECI exemplified in the ECIA Best Practice Guidelines. The NDIS focuses on individualised planning processes to identify support and choice for children with disability and their family to achieve their goals. The Best Practice Guidelines emphasise support in the context of the family, teamwork, inclusion and universal principles. ECI service providers are embracing this new context by changing the way they provide services, as highlighted below:

- The ECI service sector has expanded under the NDIS. Established providers suggested that in this context, monitoring of service levels was needed for effective service distribution between children for whom it was and was not appropriate to have an NDIS package. Monitoring good practice in package allocation could avoid children receiving inadequate or inefficient service allocation.

- ECI services have become more diverse under the NDIS, as providers aim to offer families more choice over their child’s support. Families in regional areas have narrower service choices as fewer providers and workers operate in these areas. ECI service providers expected the regional choices to broaden as the NDIS becomes established and the ECI sector adapts.

- As government block funding was withdrawn, some providers were struggling to continue to support families with complex needs. They had found solutions such as referring families to social services and supporting staff with mentoring and training.

- Children’s inclusion in mainstream settings and home-based support has become more frequent with the NDIS. School staff supported inclusion by integrating therapy into the classroom. Home-based support seemed suited to some children and families. Some providers have continued to offer families some centre activities and opportunities to connect with and support each other.

- Providers were concerned about inequities between families with NDIS packages, observing that some packages addressed the child’s needs better than others. They suggested that solutions could include more support and training for NDIA planners about early childhood disability and advocacy support from ECI services for families during the planning process.
Changes in collaboration

The NDIS approach relies on collaboration between disability and mainstream services. In particular, the ECIA Best Practice Guidelines emphasise collaboration between ECI service providers, other social services and families. While children and families may have always had many service providers involved in their lives, changes in the NDIS context mean that ECI service providers may now notice and feel a renewed need to work together with other service providers, as discussed below:

- Initially, the market-model of the NDIS prompted some ECI service providers to view each other as competitors. They said they were adapting to the change in context and were now learning to collaborate in new ways.
- ECI service providers often did not know how to bill for time spent on collaboration. They were learning when and how to charge families for collaborative time, as well as when to invest unfunded time in establishing and maintaining networks and professional relationships.
- Interdisciplinary collaboration has developed, as ECI service providers and the organisations they collaborate with have learned about, and developed confidence in, a trans-disciplinary model and have also built capacity and skills for collaborating. Some non-ECI service providers who worked closely with ECI services found it challenging to collaborate in a trans-disciplinary model. Trans-disciplinary work was not the standard in their own discipline or sector and, as such, they were used to contributing their own expertise individually. They worried about whether children and families would receive that expertise in a trans-disciplinary model.
- With many of their old collaborative networks disbanded, some health and allied health workers said they were learning more about the new providers in the ECI field and re-establishing their professional networks and relationships over time.

Changes in funding and business models

ECI service providers are adjusting from direct government funding to individualised funding, determined by the family’s choices about which services to purchase from which organisation. NDIS systems for information, referral and coordination are still developing, as highlighted below:

- Many ECI providers were concerned about how to fund work with children for whom it was not appropriate to have an individualised package and/or who did not have a diagnosis. In the NBM region, many providers valued the NDIS Early Childhood Early Intervention (ECEI) approach for allowing them to continue working with these children. In both sites, they had also found the solution of drawing on a range of other health system initiatives to fund this work.
- Navigating the move to billable hours required ECI service providers to learn how to discuss money with families, and to be transparent with families about how the billing system worked. Flexibility with families to adjust hours between providers at
different times was also useful.

- Some ECI service providers were concerned about how to bill for travel, some particular job roles, and for the costs of running a business and restructuring to the NDIS. They were experimenting with solutions such as arranging services to avoid costs, or other ways to bill or fund this time, such as travel costs. They were less sure about how to proceed with some other costs.
4 Opportunities for Good Practice under the NDIS

The second focus of the research was ECI service providers’ perceptions of how implementation of the ECIA Best Practice Guidelines (the Guidelines) has developed under, and has been influenced by, the NDIS roll out and what good practice in ECI looks like in a NDIS landscape. Many of ECI service providers’ comments on their experience of change under the NDIS in the previous section included implications for these topics as, although they often had different interpretations of the new service context, all were thinking about best practice implications. Further findings with implications for opportunities for implementing good practice are summarised in the sections below. The structure of the section is consistent with the Guidelines.

Quality area 1: Family

Quality area 1 of the Guidelines comprises the two key practice areas of family-centred and strengths-based practice and culturally responsive practice. This research indicates various good practice opportunities linked to these two key areas, organised below under five themes: supporting family choice; enhancing family-centred practice; working with disadvantaged families; improving access to the NDIS and ECI services; and engaging culturally diverse and Indigenous families.

Supporting family choice

This research indicates that the NDIS can facilitate increased choice for families, through encouraging an extended range of ECI services and a larger number and variety of service providers than before. Choice creates opportunities for families to better adjust support to the needs of the child and the family as a whole, but these opportunities can be realised only if families have confidence and capacity to make choices.

Service providers in this research accepted a role in supporting family choice. They said they worked with families to help them set their goals, taking their lead and supporting them to express their needs. Now that the Guidelines have been finalised, informing families about these principles would enable them to ask prospective providers relevant questions. Some suggested that the key worker role included supporting families by having a trusted person help them make choices.

More systemically, they anticipated that an NDIA quality assurance mechanism would ensure minimum practice standards among providers. In the meantime, the market mechanism was providing some quality control, where families exchanged information about their experiences with new providers or they remained with well-known, established services.
Enhancing family-centred practice

Providers in this research unanimously said that they had applied family-centred practice since before the NDIS. Some saw opportunities to further enhance their family-centred practice under the new scheme, for example by varying support over time, depending on the changing needs of the family. These providers were determined not to let funding dictate good practice, and they found that they could put sustainable, family-centred arrangements in place, underpinned by effective teamwork.

Providers were also attempting to strengthen responsiveness to family needs by intensifying their communication with families through a variety of strategies. Regular feedback discussions with families were mentioned, as well as emails, social media and information resources in plain language. Some providers acknowledged that business competition under the NDIS provided an incentive to communicate closely with families about their service satisfaction.

Working with disadvantaged families

Many providers in this research found it challenging to continue their family-centred practice, let alone enhance it, with disadvantaged families. They felt that the NDIS, with its focus on the child, sometimes poorly covered time and support for family crises or ongoing complex family needs. Other providers had found that effective advocacy during the NDIS planning process ensured that the packages covered support coordination for family health and wellbeing.

They agreed that the NDIA needed to maintain soft-entry pathways for disadvantaged families, who were often not engaged with the ECI system. This would involve, for example, funding of skills training for providers and of engagement visits to mainstream and community services that disadvantaged families used. The NDIA might also consider referral pathways for disadvantaged families who are unlikely to initiate an NDIS Access Request process. Such pathways could be, for example, through practitioners in the public health system. Where disadvantaged families received an NDIS package, it was suggested to keep plans flexible so that they could easily be re-negotiated if family circumstances deteriorated, or to give families and service providers access to emergency funds in times of crisis.

To support disadvantaged families from within the ECI sector, larger providers were able to draw on family support workers within their organisations and to organise internal mentoring and staff training. Improved professional networks and communities of practice might enable all providers, including smaller ones, to further develop processes and skills for supporting disadvantaged families under the NDIS.

Improving access to NDIS and ECI services

Equitable access to appropriate services is a prerequisite for good practice with families in need of ECI services. While disadvantaged families might require special referral and access pathways (above), this research indicates that children and families in general could also gain better and more equitable access if NDIS processes were adjusted.
Some providers saw service gaps emerging during the early diagnosis phase. Services that had helped families to enter and negotiate the system, for example special playgroups like the Early Childhood Information Team, had been unfunded in the transition to the NDIS. Providers suggested that Early Links be more prominent in the information and referral role or that future Access Partners fill the gap.

Services were clear that they needed bridging funding to work with a new family while they waited for a diagnosis or NDIS funding approval. These processes could take six months, and they considered that the current NDIA plan to give Access Partners a limited fund to support families during that time was insufficient. Bridging funding might also enable families to stay with a trusted provider throughout the process, thereby reducing the number of service transitions and associated stress.

Service providers also agreed that families needed effective support and advocacy during the NDIS planning process. At the same time, they considered that support and training to NDIS planners would help share good practice. Providers suggested training all planners so they had sufficient knowledge of childhood disability and ECI services. They expected that these measures would increase equity among families and improve the chances of each child receiving an adequate support plan or package.

They considered that families for whom it was not appropriate to have an NDIS package needed an approach like the ECEI. It would help families maintain access to ECI services.

**Engaging culturally diverse and Indigenous families**

Working with families of cultural and linguistic diversity or Indigenous background was not a particular discussion focus, yet service providers recognised the importance of providing culturally sensitive support.

They said that referral pathways needed to be further simplified to engage families more successfully. Good practice would also include culturally appropriate advocacy during the NDIS planning process. They said that to this end, some service provider and NDIA staff needed more cultural competency training. Some providers encouraged others and the NDIA to recruit staff from diverse backgrounds.

Providers felt that additional resources were often required when working with culturally diverse and Indigenous families. For example, workers needed time to include extended families when talking about the child’s needs, and they might have to engage interpreters. Research participants suggested that these resources could be factored into NDIS support plans as appropriate.

**Quality area 2: Inclusion**

Quality area 2 comprises the two key practice areas of inclusive and participatory practice, and engaging the child in natural environments. This research indicates good practice opportunities linked to these two key areas; supporting inclusion and providing services at home and in community settings.


Supporting inclusion

Service providers in this research embraced the concept of children’s inclusion in community and early childhood education settings. They spoke about how they readily provided support or therapy in various locations. In their experience, inclusion could be enhanced if mainstream settings had more resources to provide support to children with disability. At the time of the research, some areas had a shortage of supported local preschool spaces. Providers emphasised the importance of government-funded programs – for example the Inclusion and Professional Support Program (IPSP), or Inclusion Support Programme (ISP) from July 2016 – for building capacity among early childhood education and care (ECEC) professionals to include children with disability.

Some service providers reported that some therapists preferred giving one-on-one support to children at school or preschool, in part to reduce travel costs. Education providers generally rejected these requests because they considered them contrary to inclusive practice. Teachers were encouraged to incorporate therapy into activities for the entire class and to learn therapy techniques that they could continue with the child between therapy visits. Schools were anticipating guidelines from the Education Department to help them manage the increasing number of therapists’ requests with the NDIS.

Providing services at home and in community settings

Supporting children in their natural environments was a standard practice for most service providers, although it seemed to increase further with the NDIS and its individual funding focus. Some providers had even set up their business without a centre base and the associated overheads. Examples of good outcomes when support happened during established daily routines, or where it facilitated new activities that the child and family wanted to engage in, are described in the previous section.

At the same time, some providers maintained centre-based support where this was the families’ preference, or they created ongoing opportunities for families to keep connected and support each other outside the centre. Providers cautioned that sometimes home-based support was not appropriate, such as in the presence of violence or drug use.

Travel costs needed to be managed, especially outside high population centres. Although NDIS packages for rural and remote children would include travel allowances, the two research areas were not classified as rural or remote, yet providers experienced up to two hours travel each way. Interim strategies for managing travel costs within the billable-hours system included: recruiting local staff or partnering with providers close to family homes, varied hourly therapy rates depending on the location, training key workers to deliver various therapies, clustering appointment times, joint therapy visits, and using technology for remote communication. Families were generally understanding of the need to contribute to travel costs.

Many providers felt the system for funding travel was currently unsustainable for service providers and created inequities among families. They suggested a sustainable, systemic solution would involve inclusion of travel costs in all NDIS plans.
Quality area 3: Teamwork

Quality area 3 comprises the two key practice areas of collaborative teamwork practice and capacity building practice. The research indicates various good practice opportunities for collaboration between service providers; for the key worker and trans-disciplinary model; and for families and professionals working together.

Collaboration between service providers

Participants in the research highlighted a range of aspects that were important to facilitating the Guidelines’ approach to collaboration. Key aspects of importance were communication clarity with colleagues and an organisational and sector culture that supported ECI service providers’ adaption to the NDIS and to the collaborative way of working that the NDIS encouraged. This supportive culture was evidenced where ECI service providers had the opportunity to attend training and professional development on new NDIS practices, as well as networking to support new collaborative relationships for the trans-disciplinary model. Some people had found the administration, time and cost of restructuring to the NDIS to be challenging, whereas others had felt well-supported by their managers and by new tools, training and resources available in the sector.

ECI service providers acknowledged that collaboration took time and commitment. They emphasised that further developing good practice in collaboration between service providers would be aided by specific funding that enabled providers to bill for collaboration, and by an accountability system or mechanism implemented by the NDIA to ensure that all providers serving children and families were working collaboratively. Ensuring support was provided to key external collaboration partners such as schools, pre-schools and medical and health services was also seen as important.

Key worker and trans-disciplinary model

The research highlighted ECI service providers’ experiences of working within the good practice trans-disciplinary approach with a key worker and team of service providers. While some people had found it challenging to adapt to this new approach, others has been working in a similar collaborative way for some time already. Participants who were direct ECI service providers generally appreciated this model for the thorough service it could offer children and families, and its adaptability to draw on a range of skills to address different needs at different times, but still with a consistent team of support.

One issue that the research participants identified in delivering a trans-disciplinary approach is how to negotiate this approach with different best practice standards from outside the ECI sector. In particular, some service providers and health workers who collaborated with ECI providers, but were not directly in the ECI sector themselves, perceived challenges with the trans-disciplinary approach, worrying about it over-servicing some children or confusing some families who needed a specific intervention, but not necessarily thorough trans-disciplinary support. They had concerns about unnecessary doubling up of the costs of workers. In addition, other providers were concerned that children with very specialised needs (e.g. assessment for specialised equipment) might not receive this specialised
support in a trans-disciplinary model. Some also felt that while the trans-disciplinary approach met the best practice standards in ECI, it did not necessarily meet their own discipline’s standards of best practice. This was a conflict for them in collaborating in a trans-disciplinary team and meant that some organisations did not completely support the trans-disciplinary model.

Given that the trans-disciplinary model is premised on different disciplines working together, finding ways to address these concerns within the trans-disciplinary approach would be vital to continuing to implement good practice.

Family and professionals working together

Participants emphasised the benefits of the NDIS for the good practice of families and professionals working together. The increased choice and control experienced by families, as well as the capacity for professionals to visit children and families at home where they could have private discussions, both facilitated more communication between these two groups. This in turn allowed continual adaption of practice to suit children and families’ needs and also gave professionals more opportunity to communicate well and collaborate with families.

ECI service providers emphasised key aspects that facilitated families and professionals working together. This included coaching families in knowing how to assist their children and make service decisions for themselves. This was supported by providing clear, Plain English information to families about their service options and about the frameworks that guided ECI work. Some research participants also advocated including families in group communications, along with the group of service providers supporting them.

Key areas that ECI service providers felt would continue to build good practice in working together with families included ensuring that there was more discussion with families about what constitutes the best practice standards in ECI, as well as seeking further ways to manage situations where families were communicating with multiple service providers and there was a need to ensure that all parties were kept informed.

Quality area 4: Universal principles

Quality area 4 comprises a focus on evidence base, standards, accountability and practice and an outcomes based approach. Good practice opportunities related to these areas are outlined below.

Accountability to evidence and practice

Participants emphasised the importance of accountability to the ECI evidence-base and to best practice standards in the ECI sector. They acknowledged that enacting this accountability required knowledge not only of ECI, but also of NDIS policies and discipline- and disability-specific knowledge. They suggested that professional development, learning from each other through collaboration, and support from managers, were vital in ensuring that accountability occurred. In particular, several people felt that managers had a role in ensuring that ECI service providers were kept accountable from the time of their first
employment with a new organisation, in order to ensure that accountability was always an expectation.

ECI service providers acknowledged challenges for upholding accountability, including lack of timely information provided to all partners in collaboration, particularly schools, and the entry of a range of private providers and/or unregulated new service providers into the market, sometimes without a thorough background in disability services. Where the new providers were not undertaking key quality assurance mechanisms expected of more traditional service providers, such as clinical supervision in allied health, this was viewed as a problem for good practice. ECI service providers emphasised that all people involved in ECI provision should have quality assurance standards applied to them, which they anticipated would be developed by the NDIA.

**Outcome based approach**

Some ECI service providers noted that planning and measuring outcomes for children and families was an important component of good practice and accountability under the NDIS. Clear outcomes, benchmarking and tracking progress over time were all viewed as positive components of good practice. Further, some ECI service providers were keen to participate in an outcomes based approach as they felt this would allow them to understand more about whether, and how, their work was meeting the needs of children and families.

In general however, ECI service providers felt that there was little guidance from the NDIA on which outcomes to measure or on how measurement might be conducted or communicated to families. This is despite the NDIA whole of life Outcomes Framework released in December 2015, which covers early childhood. ECI service providers felt that more guidance from the NDIA in this area, such as releasing data about recipients and contents of plans, goals, reviews and packages would enhance their capacity to implement good practice for children and families.
Appendix A

Forum and interview topic guide

Background

- Role and experience in early childhood intervention (ECI)
- Experience of working with other service providers in the Hunter/Nepean Blue Mountains (NBM)
- Experience so far of providing services under the National Disability Insurance Scheme (NDIS)

Current change under the NDIS

Topics to cover Research Question 1: How is current ECI provision changing with the introduction of the NDIS?

- Background to and understanding of NDIS principles and its roll out in Hunter/NBM
- Past and present ECI provision and changes as the NDIS is rolling in
  • Changes to ECI practices and services provided
  • Changes to partnerships and collaboration with other related services
  • Factors specific to Hunter/NBM and which influence changes under NDIS roll out
- ECI provision inside and outside the NDIS
  • ECI inputs, activities, outputs and outcomes related to the NDIS
  • ECI inputs, activities, outputs and outcomes not related to the NDIS
- Key ECI issues in the context of the NDIS
  • Referral pathways into ECI through the NDIS and separate to NDIS
  • Provision of services to children and families not eligible for the NDIS
  • Key issues specific to Hunter/NBM sites
- Perceived influence of NDIS on ECI
- Perceptions of opportunities for ECI to help achieve NDIS outcomes
Developing best practice in ECI under the NDIS

Topics to cover Research Question 2: How should early childhood intervention be provided under the NDIS?

- Best practice in ECI under the NDIS
  - What best practice looks like – examples [develop into case studies]
  - Perceptions of how best practice is changing
  - Support needed to expand the incidence of best practice
## Appendix B

### Sample

Research participants from the National Disability Insurance Scheme (NDIS) sites

<table>
<thead>
<tr>
<th></th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total</td>
</tr>
<tr>
<td><strong>Forum 1</strong></td>
<td></td>
</tr>
<tr>
<td>Direct workers and managers in disability/early childhood intervention (ECI) non-government organisations (NGOs)</td>
<td>4</td>
</tr>
<tr>
<td>Other related roles in, education, health and allied health</td>
<td>2</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td>6</td>
</tr>
<tr>
<td><strong>Interviews</strong></td>
<td></td>
</tr>
<tr>
<td>Direct workers and managers in disability/ECI NGOs</td>
<td>6</td>
</tr>
<tr>
<td>Private providers</td>
<td>2</td>
</tr>
<tr>
<td>Paediatricians</td>
<td>2</td>
</tr>
<tr>
<td>Other related roles in, education, health and allied health</td>
<td>3</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td>13</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>19</td>
</tr>
</tbody>
</table>

Notes: *Early Childhood Early Intervention site

NB: The participants in the second forum are not included in the table above, because the second forum was for communication and capacity building with a wider group of service providers and was not focused on collecting data about what is happening in the NBM and Hunter regions specifically.
Appendix C

Literature review about ECI service transition

A brief literature review about the transition experience of early childhood intervention (ECI) services in a context like the National Disability Insurance Scheme (NDIS) was conducted to inform background information for this study. It covered academic and grey research. The review focused on Australian literature, but also included some international studies. The literature review examined ECI service transition and integration, including research on how ECI operates in other service contexts similar to the NDIS, as well as families’ and service providers’ perspectives on effective ECI services. Information from the literature review was used to inform the scope and focus of the research framework, design the fieldwork methods and instruments, and to help interpret the research findings. The literature review is provided in full in the sections below.

Part 1: ECI service transition and integration

This section of the literature review examines ECI service transition and integration. This includes looking at literature on how ECI has transitioned to, integrated with, and now operates in, other service contexts similar to the NDIS, as well as emerging literature on how the transition to and integration with the NDIS is currently occurring. Review of academic and grey literature in these areas highlights that very little work has been undertaken examining ECI service transition and integration. This suggests that the work in this project contributes to beginning to fill an important gap in the literature.

ECI service transition and integration pre-NDIS

Transition to and integration with child- and family-focused models

The literature highlights a long history of service transitions within ECI aimed at moving away from an impairment-focused and medicalised approach towards child-, family- and community-focused models.

In detailing the history of ECI services, Sukkar (2013) notes that over the past 40 years, ECI has moved from ‘professionally directed and impairment- and child-focused models of practice and service delivery to family-centred strengths-based, participant-focused models’ (p. 96). This has involved a move from a segregated model to ECI services being based in inclusion and servicing children with disability in the same environments as children without disability (Sukkar, 2013). It has also meant that ECI services have evolved from a focus mainly on medical intervention to an appreciation of an ecological model where there is a need to support children within their families and communities (Forster, 2013, KPMG, 2014, Bronfenbrenner, 1979, 1986). These changes have been coupled with a move from the ECI sector being small and family- or charity-funded, to a sector with federal government funding...
and government, non-government/not-for-profit or for-profit services being provided for the benefit of children and families. In this way, ECI is a sector which has already experienced and adapted to a large degree of service transitions and integrations. This has been aimed at targeting services more clearly to children and families’ lived experience and needs.

**Transition to and integration with individualisation**

Despite the previous history of ECI service transition and integration, the transition to and integration with service systems similar to the NDIS – such as individualised service approaches in general – is presented in the literature as a challenge for the ECI sector. Sukkar (2013) outlines three key concerns for the integration between individualisation and ECI services.

Firstly, there is concern that individualised budgets will mean a lack of equity among children, as children who are undiagnosed or not yet diagnosed will not be able to access individualised funding or services (Sukkar, 2013). This is a particular issue in early childhood intervention, as opposed to other disability services, as young children may not yet be diagnosed, but may still require support.

Secondly, there is concern about quality control, coordination and collaboration in the ECI sector in a market-based model (Sukkar, 2013). The concerns about quality control reflect the increasing focus on achieving outcomes in the social sector more broadly than only in the ECI sector (Muir and Bennett, 2014, Marjolin et al., 2015). Concerns about coordination and collaboration reflect the insight that families prefer a key worker model and that therefore, service providers need to be skilled in working in this way (Disabilities Pathways Project, 2005). Moving towards this type of collaborative practice remains an area that requires significant skill, time investment and resources (Forster, 2013), with many models available of different types of collaborative working (Bruder, 2010, KPMG, 2014).

Finally, there is concern about the increased demands of individualisation on families at a time – their child’s diagnosis – when they are already vulnerable, and concern that there may be inadequate information to help them make choices (Sukkar, 2013). While these concerns reflect issues that also apply to families of children and young people with disabilities more generally than only in the ECI sector (Meltzer et al., 2015), entry to ECI services may commonly be families’ first entry to the disability service system. Therefore, whereas families of older children or young people may already have had some experience of navigating the system, families in the ECI sector will likely not have had any experience yet of navigating disability services, and may therefore particularly lack information. In the context of the NDIS, this concern has been addressed, for example, by focusing on the importance of easily obtainable, accessible and internet-based information for families receiving ECI and other service options (Johnston et al., 2013).

In this respect, there are challenges in the service transition and integration between the ECI sector and individualised service approaches. Nevertheless, this transition is currently occurring as a part of the NDIS and, further, the transition began to occur prior to the NDIS implementation. One Australian organisation’s early experience (pre-NDIS) of this transition is summarised as a case example below.
**Australian experience of moving ECI services towards individualisation**

Despite potential tensions between the ECI sector and individualisation, some ECI services started to transition to, and integrate with, individualised service models prior to the introduction of the NDIS. Queensland's self-directed support for children in 2010 was an example of a case management model of ECI services, with a small individual package for families not already receiving disability services (Robinson et al., 2012).

Noah’s Ark – a large ECI and inclusion service in Victoria – was another service that moved to an individualised service model prior to the NDIS. The transition at Noah’s Ark to an individualised service model was based on a three-fold aim:

1. To better support children to be part of their family and community
2. To be more flexible in responding to families, and
3. To mobilise resources through families and communities to achieve more learning opportunities for children in a context of limited sector resources (Forster, 2013).

In practice, Noah’s Ark implemented their individualised service model through home visiting becoming part of their service for the first time, and through developing the role of a Transdisciplinary Key Worker (Forster, 2013). The Transdisciplinary Key Worker’s role was to offer information and advice, identify and address needs, provide advocacy, and manage service coordination for children and families (Forster, 2013). They were required to have skills in their own discipline (e.g. occupational therapy, physiotherapy etc.), transdisciplinary skills picked up from colleagues, family liaison skills, secondary consultation skills, and skills in consulting with other children’s services (Forster, 2013).

The experience of Noah’s Ark was that the Transdisciplinary Key Worker was a complex role, with an uneven split between the necessary skills required. They found that extensive work needed to be done in preparing staff to undertake the Transdisciplinary Key Worker role, and in defining its boundaries (Forster, 2013). Noah’s Ark also found that as the service moved into home visiting, they became more focused on meeting the family’s needs, making referrals to other services, and providing families with emotional support and information, as opposed to implementing specific child learning opportunities (Forster, 2013). They recognised however that both functions of their service were important.

The experience of implementing an individualised approach at Noah’s Ark is important for understanding some of the considerations and experience involved in ECI service transition and integration with respect to individualisation. Given that individualisation is a key tenant of the NDIS, the experience of Noah’s Ark is an important precursor to the ECI sector’s transition to, and integration with, the NDIS.

**International experience of moving ECI services towards individualisation**

Processes of individualisation are also occurring in countries around the world, other than Australia. For example, one report from the United Kingdom highlights that individual budgets have been available to children in the ECI age bracket through local councils (ibk initiatives, 2009). Based on the report, it appears that the individual budgets were not however built into a formal individualised-ECI service model (ibk initiatives, 2009). The experience of individualisation that resulted was therefore less about formal trans-
disciplinary work than the Australian experience and more about providing families with flexibility to use a defined budget in ways that they chose (ibk initiatives, 2009).

The families concerned reported greater flexibility in spending time together as a family as a result of the individualised budgets and doing more activities that the child with disability enjoyed (ibk initiatives, 2009). They also emphasised that the outcomes were for the whole family, not only the child with disability, as all family members enjoyed vacations, fun holiday activities and extra assistance with caring and domestic tasks (ibk initiatives, 2009). Challenges included knowing how to communicate with service providers (a single point of contact, as in the trans-disciplinary model, was preferred), and knowing the boundaries as to what the individualised budgets could be spent on (ibk initiatives, 2009). Service providers worked with families to address these issues.

The different inflection of this international experience to what has occurred in Australia highlights that individualisation for children in the ECI age bracket can look different in different international contexts. One commonality across contexts is the flexibility to have choice and control over using funding to address what an individual child and family needs. The combination of the Australian and international experience is important for informing the transition of ECI services to the NDIS. The emerging literature with respect to transitioning to the NDIS is reviewed below.

**ECI service transition and integration with the NDIS**

The roll out of the NDIS is an extensive restructuring of Australia’s disability support system, based on providing ‘reasonable and necessary supports’ to aid people with disability’s choice, control, interdependence, early intervention and social and economic participation (Productivity Commission, 2011). As it is part of the disability service system, the NDIS roll out affects the ECI sector and ECI services must transition to, and integrate with, the NDIS.

The literature highlights that the ECI sector’s transition to, and integration with, the NDIS holds many potential benefits. For example, Forster (2013:35) writes:

> There are also clear benefits for families and children from a national insurance model that eliminates waiting periods and attempts to better match resources to a child and family’s need. There are also benefits from parents of children with a disability having greater choice and control over services, as there are benefits for anyone using a service.

However, while acknowledging these benefits, the literature also highlights a number of concerns about the interface between ECI services and the NDIS. Given the early stage of the NDIS roll out, these concerns have been raised in the literature, but their potential solutions have not yet been addressed in the available evidence. This highlights the role of this current project in contributing new and important information to the evidence base. Two key concerns raised in the literature about the ECI sector’s transition to, and integration with, the NDIS are detailed below.

**Servicing children**

One concern highlighted by several authors, including Sukkar (2013), Forster (2013) and
Matthews (2014), is that the NDIS appears to have an adult-centric focus that may not be easily applied to children. This concern has several elements:

1. The NDIS is premised on covering a range of supports that may not always apply to very young children (e.g. transport, employment assistance, assistive technology etc.), while other areas, such as developmental supports, that do apply to young children, are not always covered (Forster, 2013).

2. Young children’s development may be changing more rapidly than that of adults, making it harder for individualised planning processes to adapt quickly enough (Forster, 2013).

3. Key concepts on which the NDIS is premised, such as individual decision-making, choice and control, are different for children than adults as, ‘it is the accepted community norm and legal right of parents/guardians to be making decisions for their child, whereas for adults it is important that the individual drive the decision making and others do not make decisions for them’ (Forster, 2013:29).

4. Fear that the NDIS will remove the responsibility for inclusion (a concept so important for children) from universal services (Matthews, 2014).

The concern to ensure that children with disability are specifically considered in the context of adult-centric disability services, supports and research is an issue seen more broadly than only in the ECI sector (see Curran and Runswick-Cole, 2013). In this sense, it is a general concern that has specific application to the NDIS. Furthermore, there has been concern about the capacity of the NDIS to service a range of particular groups of people with a disability, including marginalised groups (Soldatic et al., 2014) and people with complex support needs (Dowse et al., 2015). Therefore the concerns about the capacity of the NDIS to service children with disability are also part of a broader issue about how the NDIS will work for particular groups of people.

**Stressful transition for service providers**

Matthews (2014) also highlights concerns around the transition to, and integration with, the NDIS being a stressful time for ECI service providers. ECI service providers will need to re-evaluate the ways they provide services and will need to extend their practices and experience in collaboration, best practice development and strengthening of the universal platform (Matthews, 2014). Further, there are questions around who supports staff providing an individualised service, and acknowledgement that professional support for this has so far been far from comprehensive (Forster, 2013).

Again, these concerns for ECI service providers sit within a broader context in which a range of service provider groups have experienced challenges in adapting to the NDIS landscape, and in working across disability and mainstream service provision (Bigby, 2013). Workforce challenges for the NDIS include building a workforce that is stable and skilled in inter- and intra-agency collaboration, proactive support, case management and the provision of specialist support (Dowse et al., 2015). As such, the concerns in the ECI sector are part of and reflect a larger set of similar concerns.

The role of this project in exploring perspectives on issues such as collaboration, and in
mapping the impact of the Early Childhood Intervention Australia (ECIA) Best Practice Guidelines, is key to providing information that can assist service providers in transition and integration for the ECI sector. Given the prominence of the concern about stress to service providers in the literature, this therefore has the potential to be a key beneficial impact of this project.

**Part 2: Families’ and service providers’ perspectives on effective ECI services**

This second section of the literature review focuses on the perspectives of families and service providers; what is known about their experiences with receiving (families) or providing (service providers) ECI services respectively. It concentrates on studies from the last few years, just before the introduction of the NDIS and, as available, families’ and service providers’ early experiences with the NDIS and how the ECI sector is changing under the scheme.

These experiences have occurred in a service delivery context where the ECI sector in Australia has, over the last decade, as noted above, typically moved towards a family-centred approach. This approach encompasses collaboration with the entire family, often through a trans-disciplinary approach and key worker; strengthens family capacity; gives families choice about support priorities; and provides individualised, comprehensive and culturally appropriate services (Dew et al. 2014, Sukkar 2013). Family-centred principles have proved effective in promoting children’s learning, development and inclusion in mainstream settings, and are therefore considered best practice in the sector (Moore 2011). This is reflected in the recently published ECIA National Best Practice Guidelines.

Much of the literature in the field focuses on benefits, outcomes, facilitators and barriers to implementing family-centred practice, as the comprehensive reviews by Dew et al. (2014), Moore (2011) and Dempsey and Keen (2008) show. These reviews also point to the shortcomings of available research, such as the limited number of studies and their methodological weaknesses. Overall, research indicates that there is still a gap between the philosophy and reality of family-centred practice in some service provider organisations.

Few studies specifically include the perspectives of families of children with disabilities, and of ECI service providers. Regarding family experiences, five key themes are mentioned: information, coordination, access, quality and advocacy. Family experiences vary, but reported problems are consistent across the studies. Even less has been published about service providers’ experiences in providing best practice. Key themes are: information, workforce, cultural competence and business models. These key themes regarding families’ and service provider’ experiences are explored below.

**Families’ perspectives**

**Information**

Families often report having inadequate information about their child's support needs and support options. In a survey of 130 families attending ECI services in northern New South Wales (NSW) (Fordham et al. 2011), families rated information provision as the aspect of service provision that they experienced least frequently; this included general information
and specific information about their child. Similarly, Auert et al. (2012) found in their focus groups with families of children with autism that some had not received the information they needed from their speech pathology service provider to make informed decisions about therapies and support. On the other hand, both studies also found that adequate information provision was correlated with feelings of empowerment among the families.

Information gaps seem exacerbated for families living in rural and remote locations, due to the difficulty of travelling to either meet service providers or attend support groups (Hussain & Tait 2015). Families considered information they could get from existing telephone hotlines inadequate for making complex decisions about allocating individual funding packages (Dew et al. 2013). Indigenous families seem to experience even more pronounced information gaps because of culturally different understandings of disability, according to a recent study of an ECI program in regional and rural Indigenous communities (Purcal et al. 2014). These families felt empowered once they had received information about their child’s disability and about support options.

Accounts of early family experiences from the NDIS trial sites in South Australia (SA) (for children) and Hunter (NSW) indicate continuing information gaps, as well as confusion among families about the NDIS planning process. For example, at public hearings in SA, families voiced uncertainty about their rights when determining their child’s support plan with the NDIS planner (JSC 2014). In the early days of the Hunter NDIS trial, a study of families from two ECI services found that many had little information about the NDIS, and that much of the information they did receive lacked accessibility and clarity. In contrast, families said they had felt overwhelmed with information from various sources when their child was first diagnosed, confusing them and lowering their confidence to locate and understand information related to the NDIS (Howard et al. 2015).

**Coordination**

Previous research has shown that many families find it stressful to try and navigate a fragmented and complex service system (Moore 2011, Muir et al. 2008). Therefore, families who had an ECI professional coordinating their child’s services reported significantly better support than families where mothers performed the coordinating role (Fordham et al. 2011). Several studies relay that families value having a professional coordinator, or key worker, because it relieves stress and anxiety, provides emotional support, helps them navigate the system and improves their relationships with service providers (references in Maloney et al. 2013). Conversely, families in rural and remote areas cited lack of support with service coordination as an important barrier to effective use of individual funding for their child (Dew et al. 2013).

In the SA and Hunter NDIS trial sites, families who had experienced professional service coordination before the NDIS, considered it essential to dealing with the new scheme, which was still confusing to them (Howard et al. 2015, JSC 2014). The majority of families were reluctant to take on the coordination role themselves. This mirrors previous research about individual funding packages for children with disabilities, which many families found complex and preferred not to manage themselves (Dew et al. 2013).
Access

One of the crucial factors determining access to ECI services is the location where families live. Outside the major cities, the range and number of services decline, while distance and transport costs increase. These factors present enormous barriers to families trying to access ECI services, including Indigenous families (Auditor-General 2016). For example, long waiting lists and short duration of occupational and speech therapy services meant children missed critical windows for effective early intervention, families could not afford private practitioners, and driving long distances to access therapy was time-consuming, expensive and dangerous (Hussain & Tait 2015, Purcal et al. 2014). Even families who had individual funding packages found their access to services restricted, by limited choice of practitioners in their regional or rural area, and inadequate compensation of travel costs in their package (Dew et al. 2013). Indigenous families experience additional barriers due to cultural and social factors such as shame and lack of education (O’Kearney et al. 2015).

In the regional Hunter trial site for the NDIS, families often described transport and logistical barriers to accessing services, information sessions and support groups for the NDIS (Howard et al. 2015). Families in the SA trial site noted inconsistencies in NDIS planners’ decisions about including travel costs in their support plan (JSC 2014).

Quality

Some research discusses family experiences of how ECI professionals behave towards the families and their child. The majority of the 130 families surveyed in the Fordham et al. (2011) study experienced ‘respectful and supportive care’ only to a moderate extent or less. Some of the families in the Northern Rivers and New England regions of NSW who took part in surveys and interviews (Hussain & Tait 2015) observed lack of empathy and skill among medical professionals in dealing with their children’s multiple health and behavioural issues. Other families in the study, however, had had positive service experiences, especially with small, local non-government organisations (NGOs). In the same study, many families lamented the relative inexperience of doctors, specialists and allied health staff in the region, and the frequent turnover of staff; in the families’ view, both aspects reduced the quality of service provision.

Reviews and studies consistently highlight that Indigenous families and those from non-English speaking backgrounds need services provided in a culturally sensitive manner (Moore 2011, Purcal et al. 2014, Maloney et al. 2013).

Advocacy

The NDIS progress report (JSC 2014) represents the only account so far of the experiences of families of children aged 0-5 with the NDIS. The evidence in the report emphasises an aspect of family experiences that is not contained in the other, pre-NDIS studies reviewed above: the importance of advocacy. Families found that they needed some form of advocacy to support them when dealing with the National Disability Insurance Agency (NDIA), in order to understand the planning process, to achieve a package they felt was adequate for their child’s needs, or to support them if their package was reviewed and reduced without explanation. Some families were able to advocate for themselves, while others engaged a professional advocate or asked a service provider agency to support them in the planning process.
**Service providers’ perspectives**

**Information**

Similar to the families’ experiences reported above, ECI service providers report confusion and lack of information regarding individual funding policies in general (Dew et al. 2013) and the NDIS in particular (JSC 2014). According to these studies, NGO service providers and direct service workers said they could not keep up with changing policies, were overwhelmed by the amount of policy information provided to them, and found the nature of much of the information unhelpful. They felt this impacted negatively on service implementation. In SA, service workers reported receiving detailed information from the NDIA about the scheme rollout, but no context about how it fitted into the service landscape (JSC 2014).

**Workforce**

Workforce training is considered important to ensure services provide effective support (Moore 2011) and therefore bridge the gap between the theory of family-centred approaches and its patchy realisation in practice, as evidenced by families’ experiences above. However, it appears unclear which professional training approaches are most effective (Buysse et al. 2008, cited in Moore 2011).

Another workforce issue is staff shortages, especially in regional and rural areas, making it difficult for service providers to meet existing demand, even if a provider is willing and has the funding to expand services (Dew et al. 2013). Recruitment and retention difficulties are compounded for services working with Aboriginal families. Staff often spend extended time and effort building trust with children and families, which is lost when the staff member leaves, reducing the effectiveness of the service (Purcal et al. 2014).

ECI service providers have developed innovative approaches to provide services outside the major cities, for example, flying therapists into communities regularly, training local mainstream service providers such as early childhood educators to implement therapy strategies, and linking families with community health services that they had not accessed previously (Purcal et al. 2014, Dew et al. 2013).

**Cultural competence**

ECI service providers find they have to establish specific practices to support Indigenous and culturally and linguistically diverse (CALD) families effectively. Successful strategies include employing staff with compatible cultural and language backgrounds, providing cultural competency training for existing staff, and building relationships with relevant community organisations (Maloney et al. 2013, Purcal et al. 2014). In addition, providers might improve retention rates of Aboriginal and CALD staff by simplifying recruitment processes, being sensitive to different cultural work practices and mentoring (Purcal et al. 2014).

**Business models**

The NDIS and other individual funding approaches challenge traditional ECI service models based on block funding. In Dew et al.’s (2013) study, services in rural NSW reported concern
about the impact of individual funding on workforce planning and resulting viability of their businesses. Similarly, in the NDIS trial in SA, service providers said that capped individual packages, which often provided less per child than the previous block funding, were putting their programs and businesses at risk (JSC 2014). They also questioned the adequacy of NDIS funding for some children to achieve effective early intervention. Finally, ECI service providers in SA were left out of pocket when individual packages were backdated; the NDIS said providers were subsequently reimbursed and plan approval procedures clarified.
Appendix D

Early Childhood Intervention Australia (ECIA) Best Practice Guidelines

The ECIA Best Practice Guidelines are reproduced below and are available online at: http://www.ecia.org.au/documents/item/161

QUALITY AREA 1: FAMILY

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.

QUALITY AREA 2: INCLUSION

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

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

QUALITY AREA 3: TEAMWORK

5. Collaborative Teamwork Practice: is where the family and professionals work together as a collaborative and integrated team around the child, communicating and sharing information, knowledge and skills, with one team member nominated as a key worker and main person working with the family.
6. **Capacity-Building Practice**: encompasses building the capacity of the child, family, professionals and community through coaching and collaborative team work. The goal is to build the knowledge, skills and abilities of the individuals who will spend the most time with the child in order to have as great an impact as possible on the child’s learning and development.

**QUALITY AREA 4: UNIVERSAL PRINCIPLES**

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

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


References


