



Foreword

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



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 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

- 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

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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.

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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

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.

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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.



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



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).



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.

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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



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.



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



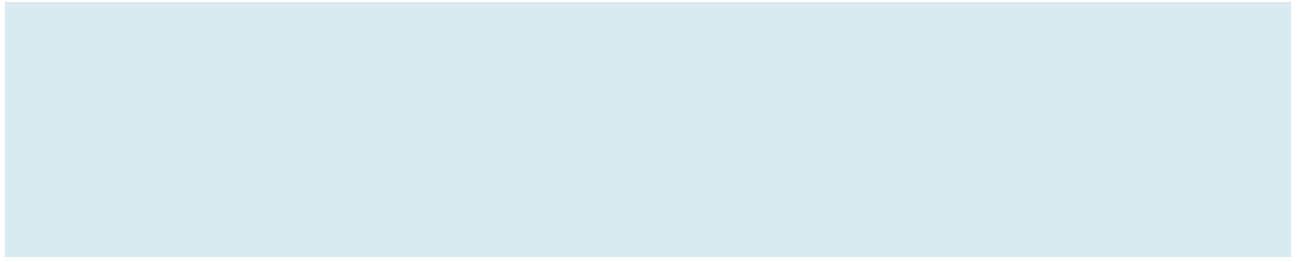
Service providers noted several changes in service provision; the size of the sector, the quality of services, gaps in services, over- or under-servicing, and inequities.

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 the increase in service provision, particularly the availability of case coordination and support. However, there were concerns about the quality of services and the impact on existing providers. Some providers reported a decrease in their caseloads, while others reported an increase in demand. There were also concerns about the sustainability of the sector and the potential for fragmentation of services. Participants also noted that the NDIS funding model was complex and difficult to navigate, and that there were significant gaps in services, particularly in rural and remote areas. There were also concerns about the impact of the NDIS on the wider health and social care system, and the potential for duplication of services. Overall, participants expressed a mix of optimism and concern about the future of the sector and the quality of services for children and young people.

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



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.

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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)

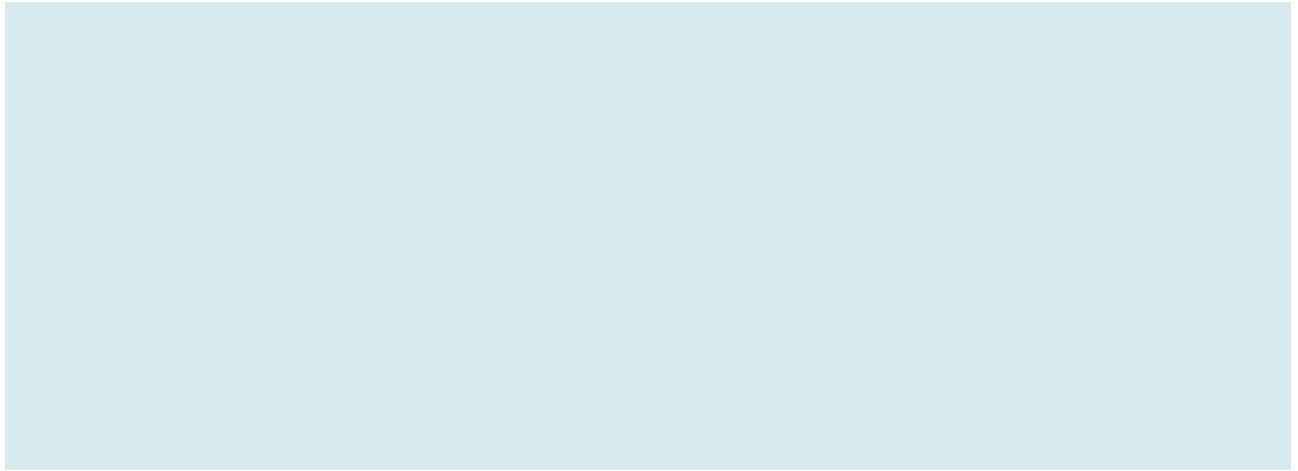
The NDIS legislation and ECIA Best Practice Guidelines both emphasise the child in the context of the family, but the service providers' experiences of the implementation of the NDIS were different. The perception of a narrower focus was generally negative. Most providers felt that previous block funding 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







recognised that collaborative and networking work was important to do, even if not billable.



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

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.



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

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 ipe w5kar whar

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.

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

the benefits of communicating via technology, but feeling that it was an equity problem if



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- 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.



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



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.



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 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.

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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

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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.



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 colleain2 (e4.7 (l)8.27)s thompo23 (y w)-3.5.7 (rc.18 (o)4., (b)-7(a)66(l)9.2 (a)9.4/T1_1 1i3 (i).



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.



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

Appendix A



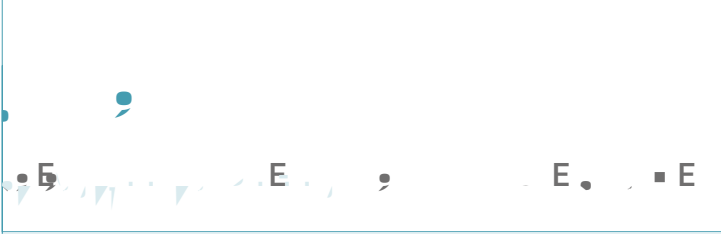
- Role and experience in early childhood intervention (ECI)
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Topics to cover Research Question 2: How should early childhood intervention be provided under the NDIS?

- 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



Appendix C



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.



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 g Iris sugoi9.1 (l)14.7 (S)J5 (. (r)14 ()7.4 (6t)18.5 (e)6.7 (r)-3.5 (a)13.5 (t)6 (u)11.4 (

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.

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 therefo

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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

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

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.



and specific information about their child. Similarly, Auert et al. (2012) found in their focus



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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).

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 the study (Fordham et al. 2011) 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 the study (Fordham et al. 2011) experienced 'respectful and supportive care' only to a moderate extent or less.



Appendix D



The ECIA Best Practice Guidelines are reproduced below and are available online at:

<http://www.ecia.org.au/161>



1. **Family-centred 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

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