



Joint Standing Committee on the National Disability Insurance Scheme

Provision of services under the NDIS
Early Childhood Early Intervention Approach

December 2017

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Abbreviations

AAC	Augmentative & Alternative Communication
AMSANT	Aboriginal Medical Services Alliance NT
ANAO	Australian National Audit Office
APD	Accredited Practising Dietitian
APS	Australian Psychological Society
ASD	Autism Spectrum Disorder
ASELCC	Victorian Autism Specific Early Learning and Care Centre
ASPECT	Autism Spectrum Australia
ATSI	Aboriginal and Torres Strait Islander
CALD	Culturally and Linguistically Diverse
COAG	Council of Australian Governments
CYDA	Children and Young People with Disability Australia
DSS	Department of Social Services
ECEI	Early Childhood Early Intervention
ECIS	Early Childhood Intervention Service
EI	Early Intervention
GPs	General Practitioners
HCWA	Helping Children with Autism
IAC	Independent Advisory Council
ICT	Information and Communication Technology
ILC	Information, Linkages and Capacity Building
LACs	Local Area Coordinators
MHYPDD	Mental Health of Young People with Developmental Disabilities
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Services
NGO	Non-Government Organisation
OT	Occupational Therapist
PEDI-CAT	Paediatric Evaluation of Disability Inventory–Computer Adaptive Test
PITC	Partners in the Community
POLR	Provider of Last Resort

RACGP	Royal Australian College of General Practitioners
RACP	Royal Australasian College of Physicians
RDI	Relationship Development Intervention
RIDBC	Royal Institute for Deaf and Blind Children
SWAN	Syndromes Without A Name
WES	Whole Exome Sequencing

Executive Summary

By 2019–2020, it is expected that 47 000 of the 460 000 total NDIS Participants with approved Plans will be children aged between 0–6. The NDIA estimates that a further 59 000 children aged between 0–6 may identify as having a developmental delay or disability but are not expected to need individualised funded supports.

The ECEI Approach is designed to individually determine and facilitate the most appropriate support pathway for each child aged 0–6 years with a disability or developmental delay (regardless of diagnosis), and their family.

The Approach is intended to uphold the eligibility criteria of the NDIS, while helping to ensure that less severe cases are supported outside of the Scheme.

The committee recognises that the ECEI Approach is in its infancy, however, it is concerned that the current access arrangements are potentially advantaging families who can afford to source expensive assessments and reports to expedite their child's access to the Scheme.

Improvements to the ECEI

The committee acknowledges the efforts being made by the NDIA to continually improve the operation and access to the ECEI pathway. However, the committee understands concerns regarding the ECEI eligibility criteria, and is of the view that unclear eligibility criteria increase risk of misinterpretation and conflicted understanding. The repeated confusion over whether one, or more than one area of developmental delay determines access to the ECEI pathway illustrates that more work is required to clearly announce which children will be eligible for support. Publication of clearer guidance around all aspects of entry to the pathway would assist all stakeholders.

The NDIA have recently made significant improvements to the Participant pathway, however the committee remains troubled by reports that Planners have poor understanding of the needs of the children they are developing Plans for. Planners should, at the least, have awareness of recommended intervention guidelines and therapies for the major disability cohorts, and demonstrate sensitivity in their communications with families.

Assessment tools

The committee is concerned by reports that the PEDI-CAT tool is unsuited to assessing the functional capacity of children with a developmental delay, including those with Autism Spectrum Disorder (ASD), yet it is being used by the NDIA and its Partners to inform access and funding decisions and track children's developmental progress. The potential inaccuracy of the PEDI-CAT in determining a child's functional needs leads to broader concerns about whether the number of children with developmental delay accessing the NDIS and the level of their delay is correct.

ECEI participant assessments and diagnosis

The committee is concerned that some families have had to fully or partially fund assessment and diagnosis reports to ensure their child could access ECEI services and have adequately funded plans. As discussed in chapter 2, there should be no need for families to provide these costly assessment and diagnosis reports at the time of lodging the access request for ECEI services with the NDIA or during the planning process.

Plans

The committee is concerned with the numerous reports of significantly underfunded plans for ECEI participants. The committee noted that the funding shortfalls and inconsistencies in plans appear to particularly affect children with ASD and those with hearing impairments.

Underfunded plans for children with ASD

The report also explores evidence in relation to recurring funding shortfalls in plans for children with ASD. It appears that the level of funding granted in many plans does not meet participants' needs and does not align with recommended evidence-based practice guidelines. This is resulting in those children not accessing the right level of support and therapies to achieve optimal outcomes.

Alarmingly, the committee heard that NDIS funding levels are often lower than previous national funding models such as Helping Children With Autism. It is concerning that some participants and their families are potentially worse off than under previous funding models.

With almost 40 per cent of NDIS participants age 0–6 years having ASD as their primary disability, it is of paramount importance that the NDIA urgently addresses the issues of scope and level of funding in plans for children with ASD.

Assistive technology

The committee believes that approval of funding for assistive technology should be systematically and consistently based on the participant's individual needs to achieve optimal outcomes. The funding decision should not be based on minimising costs. As a result, the committee is concerned that some submitters suggested that participants were given inappropriate assisted technology equipment to reduce costs.

Supports for families and carers

The committee believes access to supports for families and carers should be integral to the ECEI Approach. The committee agrees that, to date, the role of siblings of children with disability has been overlooked within the framework of the NDIS and its ECEI Approach. The committee believes that the NDIA should consider the development of sibling specific supports and how these could be integrated into the ECEI Approach. Development of tailored programs should be considered and delivered through the ILC.

Delays in accessing plans

The committee is concerned with widespread reports of delays in accessing and receiving services for ECEI participants with a plan. This can significantly impact on the success of therapies and the ability of participants to achieve optimal outcomes.

Where delays can be attributed to staffing pressures in the Agency the committee is of the view that the staffing cap currently in place should be removed to facilitate further resources being provided to address systemic blockages.

Delivery in rural and remote locations

The committee understands there can be significant additional costs to deliver services in rural and remote areas, including costs associated with travel. The committee noted that the new NDIA Price Guide introduced on 1 July 2017, incorporates a series of changes, including an increased price loading to apply for the delivery of supports to participants in remote and very remote parts of Australia. However, it appears that the issue of travel costs remain a significant cause of concern for services providers

NDIS website

The committee acknowledges that the NDIA has made efforts to publish a range of ECEI-related material on its website. However, it agrees with submitters' that the quality of information currently available for families and carers could be improved. The NDIA should ensure that information on the NDIS website is logically presented. All information should be clearly dated, indicate if it has been superseded, and identify related historical information. Information relevant to the ECEI Approach should consolidate information from multiple sources, and remove redundant and contradictory information.

Assertive outreach

The committee is of the view that ECEI Partners do not currently have the capacity or funding to conduct essential outreach and support services for vulnerable cohorts. The committee agrees with the Productivity Commission that adequately resourcing Information, Linkages and Capacity Building (ILC) is critical to ensure people with disability are connected with appropriate services.

Access for Aboriginal and Torres Strait Islander families

The committee is troubled by reports that there are Aboriginal and Torres Strait Islander families unable to use allocated funding because they are unsure how to access services. The committee considers that resources should be developed in co-design with people with disability, Aboriginal and Torres Strait Islander populations, and CALD communities to assist them to understand the Scheme, and how to use their funds to access services.

The work undertaken by the NDIA in developing an Aboriginal and Torres Strait Islander Engagement strategy is a positive step. However, it is imperative that the NDIA develop a specific strategy to ensure that culturally appropriate early intervention services are delivered for this community by specialised staff.

Conclusion

The committee received a wealth of information and evidence throughout the inquiry and thanks all those who participated. As a result, the committee has made 20 recommendations, which aim to strengthen the effectiveness of the Scheme to ensure that children can be appropriately supported to reach their full potential.

Recommendations

Access to the Scheme

Recommendation 1

2.30 The committee recommends that the NDIA clarify and publish current ECEI access points, and outline the future model for access arrangements.

Early Childhood Partners

Recommendation 2

2.37 The committee recommends that a nationally consistent process for the engagement of Partners be developed by the NDIA.

Eligibility

Recommendation 3

2.84 The committee recommends that the NDIA publish clear and comprehensive guidance around the eligibility criteria for children with developmental delay on its website.

Recommendation 4

2.95 The committee recommends that the NDIA publish information on its website about how List D is determined and how new conditions are incorporated.

Assessment tools

Recommendation 5

2.125 The committee recommends that the NDIA publish information on all of its functional assessment tools currently in use.

Recommendation 6

2.126 The committee recommends the NDIA clarify how it uses assessment tools, and specifically, how results are used to determine eligibility and level of funding of children with disability or developmental delay.

Recommendation 7

2.129 The committee recommends the NDIA liaise with the sector to co-design and develop a purpose-built assessment tool for children with ASD in Australia.

Adequacy of plans

Recommendation 8

3.40 The committee recommends that the NDIA provide ongoing and targeted training to Planners creating ECEI Plans for children to ensure they are equipped with the most up to date knowledge, expertise and resources in their decision making.

Assessment and diagnosis reports

Recommendation 9

4.18 The committee recommends the NDIA clearly communicate to families, Planners and ECEI Partners that assessment reports are not needed unless requested by the NDIA.

Recommendation 10

4.19 The committee recommends the NDIA ensures provision of funding for assessments in Plans is based on the Participant's needs and is not arbitrarily restricted to a yearly assessment.

Funding in plans

Recommendation 11

4.66 The committee recommends the NDIA urgently address the issues of scope and level of funding in Plans for children with autism with a view to ensuring that recommended evidence-based supports and therapies are fully funded.

Recommendation 12

4.69 The committee recommends the NDIA implement the Provision of Hearing Services under the National Disability Insurance Scheme recommendation 5 in relation to early intervention packages which says:

The committee recommends NDIA ensures that the early intervention packages take a holistic approach to the needs of Participants and include:

- scaled funding, depending on need;
- funding provision for additional services beyond core supports, depending on need; and
- retrospective payment of the costs borne by approved service providers for the provision of necessary and reasonable supports between time of diagnosis and Plan enactment.

Recommendation 13

4.73 The committee recommends the NDIA reviews and clarifies its Operational Guidelines on funding for assistive technology with the view of ensuring that Participants can access the most appropriate equipment to meet their needs.

Recommendation 14

4.76 The committee recommends funding be made available in Plans for interpreters, including funding an interpreter to communicate with the Participant's parents or carers.

Recommendation 15

4.78 The committee recommends the NDIA consider allocating specific funding for the development and provision of tailored support programs for parents, carers and siblings of children with disability through the ILC.

Provision of ECEI services in rural and remote areas

Recommendation 16

4.134 The committee recommends the NDIA develop a strategy to foster greater use of technology to deliver services in regional, rural and remote areas.

Adequacy of information

Recommendation 17

5.23 The committee recommends that the NDIA consult and engage with key stakeholders to continually improve ECEI information on its website.

Recommendation 18

5.38 The committee recommends that the NDIA allocate specific funding for information and support for vulnerable families to connect with ECEI Partners through the ILC.

Accessibility of Approach

Recommendation 19

5.53 The committee recommends that the NDIA collaborate with people with disability, Aboriginal and Torres Strait Islander, and CALD communities, to co-design and develop accessible information about the Scheme, the ECEI Approach, and how to use funds to access services.

Recommendation 20

5.55 The committee recommends that the NDIA develop a specific strategy to deliver culturally appropriate services for Aboriginal and Torres Strait Islander people under the ECEI Approach.

Chapter 1

Introduction

Referral of inquiry and terms of reference

1.1 The Joint Standing Committee on the National Disability Insurance Scheme (the committee) was established on 1 September 2016 following the passing of a resolution in the House of Representatives and the Senate. The committee is comprised of five members and five senators and is tasked with reviewing:

- (a) the implementation, performance and governance of the National Disability Insurance Scheme (NDIS or the Scheme);
- (b) the administration and expenditure of the NDIS; and
- (c) such other matters in relation to the NDIS as may be referred to it by either House of the Parliament.¹

1.2 The committee is required to present an annual report to the Parliament on the activities of the committee during the year, in addition to reporting on any other matters it considers relevant.

1.3 The committee is able to inquire into specific aspects of the Scheme. On 21 June 2017, the committee agreed to undertake an inquiry into the provision of services under the NDIS Early Childhood Early Intervention (ECEI) Approach.

1.4 The terms of reference for the inquiry are as follows:

1. That the committee will examine the provision of services under the NDIS ECEI Approach, with particular reference to:
 - (a) the eligibility criteria for determining access to the ECEI pathway;
 - (b) the service needs of NDIS participants receiving support under the ECEI pathway;
 - (c) the timeframe in receiving services under the ECEI pathway;
 - (d) the adequacy of funding for services under the ECEI pathway;
 - (e) the costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants;
 - (f) the evidence of the effectiveness of the ECEI Approach;
 - (g) the robustness of the data required to identify and deliver services to participants under the ECEI;
 - (h) the adequacy of information for potential ECEI participants and other stakeholders;

1 House of Representatives, *Votes and Proceedings*, No. 3, 1 September 2016, pp. 78–80.

- (i) the accessibility of the ECEI Approach, including in rural and remote areas;
- (j) the principle of choice of ECEI providers;
- (k) the application of current research and innovation in the identification of conditions covered by the ECEI Approach, and in the delivery of ECEI services; and
- (l) any other related matters.

The committee is to report by 7 December 2017.

Structure of report

1.5 This report is comprised of five chapters, as follows:

- Chapter 1 outlines the context and administration of the inquiry, and provides background information to the NDIS;
- Chapter 2 provides background information about the ECEI Approach, and considers the key issues relating to Early Childhood Partners, eligibility and access to the Scheme, and functional assessment tools;
- Chapter 3 explores key concerns raised by submitters, including delays accessing Early Childhood Partners and approvals from the NDIA, adequacy of Plans, and thin markets;
- Chapter 4 examines the funding and delivery of ECEI services, and reviews issues raised by families, carers and service providers; and
- Chapter 5 explores adequacy of information and accessibility of the Approach.

Conduct of the inquiry

1.6 The committee received 76 submissions to the inquiry from individuals and organisations. These submissions are available on the committee's website and are listed in Appendix 1.

1.7 The committee also held six public hearings:

- 19 September 2017 in Melbourne;
- 26 September 2017 in Brisbane;
- 27 September 2017 in Adelaide;
- 3 October 2017 in Sydney;
- 20 October 2017 in Canberra; and
- 8 November 2017 in Melbourne.

1.8 Transcripts from these hearings, additional information, and answers to questions on notice are available on the committee's website. Witnesses who appeared at the hearings are listed in Appendix 2.

Acknowledgements

1.9 The committee would like to thank the individuals and organisations that made written submissions to the inquiry, as well as those who gave evidence at the public hearings.

Note on terminology and references

1.10 References to submissions in this report are to individual submissions received by the committee. References to page numbers in *Hansard* transcripts may vary between proof and official versions.

Background information

1.11 Following the Productivity Commission's 2011 inquiry into Australia's disability system, all governments agreed to the introduction of the NDIS. In March 2013, the *National Disability Insurance Scheme Act 2013* (NDIS Act) was passed. The NDIS became operational on 1 July 2013 with the commencement of the trial sites. From 1 July 2016, the NDIS commenced transition to full Scheme. The transition from trial to full Scheme is guided by Bilateral Agreements between the Commonwealth and State and Territory Governments.

1.12 As an insurance scheme, the NDIS takes an investment approach in people with disability (under the age of 65), to build skills and improve their outcomes later in life. Eligible people, known as Participants, are given a Plan of reasonable and necessary supports, which is individually tailored to their needs and reviewed every 12 months. By July 2019, the Scheme is expected to support about 460 000 Australians nationwide.

Chapter 2

ECEI Approach

2.1 This chapter provides background information about the ECEI Approach, and considers the key issues relating to Early Childhood Partners, eligibility and access to the Scheme, and functional assessment tools.

What is the ECEI Approach?

2.2 The ECEI Approach is designed to individually determine and facilitate the most appropriate support pathway for each child aged 0–6 years with a disability or developmental delay (regardless of diagnosis), and their family.

2.3 Depending on their individual circumstances, families are provided with a combination of information, emotional support, referral to mainstream services, short-term intervention, or help to access the NDIS for longer-term intensive supports as part of a funded NDIS Plan.

2.4 The Approach is intended to uphold the eligibility criteria of the NDIS, while helping to ensure that less severe cases are supported outside of the Scheme.

2.5 The Approach was developed based on four research pieces,¹ the success of early childhood intervention in NSW and Victoria, and in consultation with early childhood practitioners and researchers.²

Introduction of the Approach

2.6 During the trial phase of the NDIS, higher than expected numbers of children aged between 0–6 years sought access to the Scheme.³ In response to this emerging pressure, the National Disability Insurance Agency (NDIA or the Agency) developed the NDIS Early Childhood Early Intervention (ECEI) Approach over 2015–16.⁴

2.7 From September 2015, the Agency piloted early intervention supports for children aged 0–6 years in the Nepean Blue Mountains.⁵ In February 2016, the Agency announced that it would implement a nationally consistent approach to supporting children with disability in the NDIS under the ECEI Approach.⁶

1 NDIA, *Submission 42*, pp. 1–2.

2 NDIA, *NDIS in NSW*, <https://www.ndis.gov.au/about-us/our-sites/NSW.html> (accessed 18 October 2017) and *NDIS Early Childhood Early Intervention Approach*, 29 February 2016, p. 3.

3 NDIA, *Submission 42*, p. 4.

4 NDIA, *Annual Report 2015–16*, 28 October 2016, p. 17.

5 NDIA, *Submission 42*, p. 4.

6 NDIA, *NDIS in NSW*, <https://www.ndis.gov.au/about-us/our-sites/NSW.html> and *NDIS Early Childhood Early Intervention Approach*, 29 February 2016, p. 3.

2.8 There are now two entry pathways for people to receive support under the Scheme; the ECEI pathway for children aged 0–6 years, and a general pathway for people aged 7–65 years. The ECEI pathway is designed to be a 'gateway' to the NDIS for children up to six years of age, ensuring that only children who meet the eligibility criteria of the NDIS become participants of the Scheme.⁷

Supports covered under the Scheme

2.9 As part of the transition to the NDIS, the interactions between the NDIS and mainstream services are guided by Bilateral Agreements between the Commonwealth and State and Territory Governments.

2.10 In April 2013, COAG agreed to a set of principles for determining the responsibilities of the NDIS and other service systems. These were updated in 2015.⁸ The principles outline specific roles and responsibilities for all governments and agencies:

- (a) The early childhood education and care sector has responsibility for meeting the education and care needs of children with a development delay or disability, including building the capacity of early childhood education and care services to provide inclusive education and care to all children.
- (b) The health system, including child and maternal health services, has responsibility for supports which are treatment-related, including acute, ambulatory, continuing care and new-born follow-up.
- (c) The NDIS has responsibility for personalised individualised supports, which are required due to the impact of the child's impairment on their functional capacity. This includes working with a child's family, carers and educators to implement supports or early interventions.
- (d) The NDIS has responsibility for early interventions specifically targeted at enhancing a child's functioning to undertake activities of daily living or specialised supports to transition a child with a disability into school.⁹

Role of Early Childhood Partners

2.11 To fulfil its responsibilities, the NDIA has engaged Early Childhood Partners to deliver the ECEI Approach.

2.12 The core role of Partners is to assess each individual child and provide a recommendation to the NDIA regarding the most appropriate pathway for that child.

7 Productivity Commission, *NDIS Costs Position Paper*, June 2017, p. 22.

8 NDIS, *Summary of key dates*, <https://www.ndis.gov.au/about-us/governance/council-australian-governments.html> (accessed 18 October 2017).

9 COAG, *Principles to Determine the Responsibilities of the NDIS and Other Service Systems*, 27 November 2015.

This can include information services, referral to mainstream services, short term intervention, or help to access a Plan.¹⁰

2.13 Partners also play a role in promoting the ECEI Approach at the local level. Partners work to build capacity in the community and expand opportunities for greater social participation for all children they work with.¹¹

Partners in the Community Program

2.14 The NDIA recruits Partners through an open competitive process called the NDIS Partners in the Community (PITC) Program. The Program establishes partnerships between the Agency and existing community organisations.

2.15 According to the NDIA, the assessment for PITC to deliver ECEI services is undertaken internally by NDIA assessors who have expertise across the field of early childhood intervention.¹²

2.16 In August 2016, PITC Program Round One commenced to engage Partners to deliver ECEI Services in Service Areas due to transition to the Scheme before 1 January 2018. It was determined that only one Partner would be appointed in each Service Area. In the case of South Australia, a single Partner was sought to provide ECEI services across the entire state (excluding Remote and Very Remote areas).¹³

2.17 In March 2017, PITC Program Round Two commenced engaging Partners to deliver ECEI Services in Service Areas due to transition to the Scheme before 1 July 2018. Funding was offered between the Activity Start Date and 30 June 2020. ECEI Services for South Australia were not included in PITC Program Round Two.¹⁴

2.18 In October 2017, PITC Program Round Three commenced to recruit Partners for Service Areas due to transition to the Scheme between July 2018 and January 2019.¹⁵ Grants are being offered for ECEI Services in 29 Service Areas across four jurisdictions (QLD, NSW, NT, VIC). There are 14 Service Areas due to phase into the Scheme, and 15 Service Areas due to commence where transition services are

10 NDIS PITC Program Round Three, *Statement of Requirements* October 2017, p. 7.

11 NDIS PITC Program Round Three, *Statement of Requirements* October 2017, p. 27.

12 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

13 NDIS, *PITC Program Round One Program Guidelines*, August 2016, pp. 9 and 15.

14 GrantConnect, *PITC Program Round Two*, <https://www.grants.gov.au/?event=public.GO.show&GOUUID=F428FA14-C1B3-09DA-018CDE70EF801811> (accessed 7 November).

15 GrantConnect, *PITC Program Round Two*, <https://www.grants.gov.au/?event=public.GO.show&GOUUID=6ED25D96-BC23-8CE7-A2BE951EF522FE56> (accessed 7 November).

already in place.¹⁶ Funding is being offered between the Activity Start Date and 30 June 2021.¹⁷

2.19 During the committee's hearing on 8 November 2017, Ms Stephanie Gunn, Acting Deputy Chief Executive Officer, NDIA, explained the basis upon which Partners are funded:

Partners are, in effect, another arm of the agency's delivery capability, so they would have otherwise been in the original funding of the agency—the agency staff would be doing the work that we are getting our LAC partners to do per the early childhood partners. They're funded on the basis of equivalence to the per cent of the population that fits within that age cohort and the amount of funding that the agency would have had. So it reflects the fact that we want them to do a whole range of activities, but it's within the funding envelope that the agency would have had available to do that function.¹⁸

2.20 In response to questions on notice, the Agency advised that funding is based on the phasing numbers set out in bilateral agreements which cover the service areas, together with estimates of participant volumes as well as the number of children unlikely to need funded supports. The overall value of the grant is proportionate to the volume of work expected to occur in each quarter.¹⁹

Rollout of the Approach

2.21 The ECEI Approach is being rolled out across Australia in line with Bilateral Agreements between the Commonwealth and State and Territory Governments.²⁰ The roll out to-date includes:

- four transitional pilot partners in the NSW Nepean Blue Mountains Service Area;
- two partners in Tasmania;
- one partner in the ACT;
- three partners working across five Service Areas fully operational in Queensland, including the Services Areas of Townsville, Mackay, Toowoomba, Ipswich and Bundaberg; and
- six partners in Victoria, with two additional Service Areas to commence in advance supports by October and November 2017.²¹

16 NDIS PITC Program Round Three, *Grant Round Summary*, October 2017, pp. 9 and 15.

17 GrantConnect, *PITC Program Round Three*, <https://www.grants.gov.au/?event=public.GO.show&GOUUID=6ED25D96-BC23-8CE7-A2BE951EF522FE56> (accessed 7 November).

18 Ms Stephanie Gunn, Acting Deputy Chief Executive Officer, NDIA, *Proof Committee Hansard*, 8 November 2017, p. 7.

19 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

20 NDIA, *Annual Report 2015–16*, 28 October 2016, p. 17.

2.22 Partners in the Nepean Blue Mountains and Townsville are the only areas that have been applying the ECEI Approach for over 12 months.

2.23 Transitional arrangements apply in NSW, where selected existing ECEI providers continue to provide limited gateway services and offer Planning and funded support provision to families; and in SA, where interim services for the ECEI Approach commenced in September 2016 through an in-house and outsourced clinical expertise model with the South Australian Government.²²

2.24 Until the SA Partner is operational, the NDIA in SA has established an internal Early Childhood Team. The team consists of NDIA staff who have experience in identifying and determining supports for young children. The NDIA has also contracted a clinical partner to assist the Early Childhood Team with providing information, early childhood intervention supports and strategies to children with developmental delays, and to work with families to build strengths to support early intervention.²³ All interim arrangements have an end date agreed with the jurisdictions and acknowledge that the future model will be to source ECEI services via the NDIS Partners in the Community Program.

2.25 As at 30 September 2017, 6716 children were in the ECEI gateway by the end of the quarter. Of these, 3611 had previously entered as at 30 June 2017, and an additional 3105 entered the gateway this quarter.²⁴

2.26 By 2019–2020, it is expected that 47 000 of the 460 000 total Participants with approved Plans will be children aged between 0–6. According to the Agency, estimates indicate that a further 59 000 children aged between 0–6 may identify as having a developmental delay or disability but are not expected to need individualised funded supports.²⁵

Access to the Scheme

2.27 Children can access supports as Participants of the NDIS if they require intensive intervention to help them meet their goals. In order to become a Participant, children must meet residence requirements and fulfil the early intervention criteria of the *National Disability Insurance Scheme Act 2013* (NDIS Act). Children are eligible for early intervention supports as a Participant of the Scheme if they meet the following:

1. Residence Requirements

Are an Australian citizen, or hold a Permanent Visa or a Protected Special Category Visa; and

21 NDIA, *Submission 42*, p. 7.

22 NDIA, *Submission 42*, p. 7.

23 NDIS, *NDIS in South Australia*, <https://www.ndis.gov.au/about-us/our-sites/SA.html>, (accessed 18 October 2017).

24 NDIS, *Quarterly Report*, 30 September 2017, p. 3.

25 NDIA, *Submission 42*, p. 1.

2. *Early Childhood Early Intervention Requirements*

Are a child aged less than six years of age with developmental delay, which results in:

- (a) substantially reduced functional capacity in one or more of the areas of self-care, receptive and expressive language, cognitive development or motor development; and
- (b) results in the need for a combination and sequence of special interdisciplinary or generic care, treatment or other services which are of extended duration, and are individually planned and coordinated; and
- (c) these supports are most appropriately funded through the NDIS, and not through another service system; and

There is evidence that getting supports now will help by:

- (a) reducing how much help they will need to do things because of their impairment in the future; and improving or reducing deterioration of their functional capacity; or
- (b) helping their family and carers to keep helping; and these supports are most appropriately funded through the NDIS, and not through another service system.²⁶

Multiple access points

2.28 The committee understands that families with concerns about their child's development can call the Agency and request an Access Form directly. These applications are processed by the NDIA National Access Team without the family having to meet with an Early Childhood Partner. Families that can afford to source reports privately are potentially able to enter the Scheme through this point quicker than those families awaiting assessment from an Early Childhood Partner. The potential flaws of having a variety of access arrangements were identified by National Disability Services:

This team assesses children on the basis of submitted reports and information, but the children are not seen by a specialist early intervention worker. Some families pay for numerous expensive assessments to support their bid for access and are referred to an ECEI Partner only after having been accepted as an NDIS participant, to have a plan developed. Advice from ECEI Partners suggests that the number of children accessing the NDIS through this channel is increasing and is taking precedence over their other ECEI work as they are required to prioritise the development of plans for these children.²⁷

26 *National Disability Insurance Scheme Act 2013*, s. 9.

27 National Disability Services, *Submission 14*, p. 3.

Committee view

2.29 The committee recognises that the ECEI Approach is in its infancy, however, it is concerned that the current access arrangements are potentially advantaging families who can afford to source expensive assessments and reports to expedite their child's access to the Scheme. The NDIA should clarify current ECEI access arrangements and publicise this information on its website. The Agency should also clarify whether multiple access points are expected to be permanent, and if so, how such access arrangements will embed equity, fairness and efficiency in its operation.

Recommendation 1

2.30 The committee recommends that the NDIA clarify and publish current ECEI access points, and outline the future model for access arrangements.

Early Childhood Partners

Engagement of Partners

2.31 Inconsistency in the engagement of ECEI Partners across jurisdictions was raised by several submitters.²⁸

2.32 Scope Australia highlighted that Victoria is securing Partners in each roll out area, while NSW is continuing to fund current Early Childhood Intervention Service providers to support new and existing participants on the ECEI pathway until full Scheme roll out in 2018, upon which tendering for Partners will commence. It argued that there should be a nationally consistent approach to the engagement of Partners.²⁹

2.33 KU Children's Services questioned the fairness of allowing the NSW Department of Family and Community Services to approach specific early intervention providers to engage them to provide ECEI supports as part of transitional arrangements to June 2018, rather than using an open, competitive process.³⁰

2.34 Submitters expressed criticism that, despite being a trial site, no ECEI Partner has yet been appointed in South Australia and that only one will be appointed for the whole state.³¹

2.35 The NDIA explained why it appointed one ECEI Partner for the state of South Australia:

We went to the market for one knowing that the vast majority of children zero to six were already in the scheme. The market response was not successful, so we have spoken to providers and the sector in South

28 For example: Scope Australia, *Submission 17*, p. 3; Can:Do Group, *Submission 34*, p. 3; JFA Purple Orange, *Submission 63*, pp. 6–7.

29 Scope Australia, *Submission 17*, p. 3.

30 KU Children's Services, *Submission 37*, p. 3.

31 For example: Can:Do Group, *Submission 34*, p. 3; JFA Purple Orange, *Submission 63*, pp. 6–7.

Australia. We are currently looking at our options to identify appropriate partners for South Australia.³²

Committee view

2.36 While the committee understands the complexities across the country due to bilateral agreements and local circumstances, its preference is that there is a nationally consistent process for engaging Early Childhood Partners, and consistent roles and responsibilities for those Partners.

Recommendation 2

2.37 The committee recommends that a nationally consistent process for the engagement of Partners be developed by the NDIA.

Expertise of Partners

Limited early childhood intervention experience

2.38 A key aspect of the ECEI Approach is the appointment of experienced and knowledgeable Early Childhood Partners. Partners must have strong knowledge about the local community and its services, and an understanding of the needs of children and their families in order to successfully deliver the ECEI Approach.

2.39 Partners are supposed to be selected based on their experience, clinical expertise, and best-practice approach to delivering ECEI services. However, according to submitters, some Partners have been appointed despite their limited experience in early childhood intervention.³³

2.40 Ms Trish Hanna, President, ECIA, highlighted that the NDIA has recruited Partners that do not specialise in early childhood intervention:

ECIA questions why the agency would recruit partners who have specialties in areas such as domestic violence, child protection and homelessness, as examples, to provide specialist advice and support for children with delays or disabilities. Other imperatives appear to have been prioritised by the NDIA, resulting in a drift away from the underpinning principles of the ECEI approach. A focus on applying a gateway and triage mentality has crept into the selection of partners.³⁴

Limited local knowledge

2.41 Appointment of ECEI Partners was intended to build on existing, local community knowledge and expertise. However, ECIA Victoria/Tasmania highlighted that a number of Early Childhood Partners have been appointed from out of area, and have limited knowledge of local supports and services.³⁵

32 Ms Stephanie Gunn, Acting Deputy Chief Executive Officer, NDIA, *Proof Committee Hansard*, 8 November 2017, p. 10.

33 For example: Scope Australia, *Submission 17*, p. 3; Victorian Government, *Submission 71*, p. 9.

34 Trish Hanna, President, ECIA, *Proof Committee Hansard*, 3 October 2017, p. 16.

35 ECIA Victoria/Tasmania, *Submission 7*, p. 4.

2.42 Mr Robbi Williams, Chief Executive Officer, JFA Purple Orange, drew the committee's attention to an aged-care provider based in Queensland which was commissioned for LAC services in South Australia:

It is very hard to understand how an aged-care provider based in Queensland can know anything about the northern suburbs of Adelaide and the Barossa and Light areas. It is the only area generally in South Australia where the LAC service has been commissioned. It is more involved than that. It would not be enough to have a South Australian agency covering those areas...communities have different histories, they have different traditions and they have different personalities operating. The only way that you can successfully navigate that is if you are embedded in those communities.³⁶

2.43 While the Victorian Government submission noted that some organisations have been appointed as Partners despite their lack of early childhood intervention experience; it argued that some have adapted quickly to the ECEI framework and achieved credibility in a short amount of time.³⁷

Conflict of interest

2.44 One function of the ECEI Partner role is to assist families and carers to develop Plans for children who are Participants of the Scheme. However, some Partners have also been approved to provide early intervention services to families.³⁸

2.45 The NDIA submission explained under what circumstances these arrangements have been necessary:

The intent of the transitional arrangements has been to assure timely access for families to ECEI supports...in some exceptional circumstances, transitional arrangements have allowed Partners to also deliver NDIS funded supports as a service provider. These arrangements have been approved when there is likely to be a market failure of qualified early childhood providers. Where these arrangements have been endorsed, there has been a requirement for a mitigation strategy and management of any actual or perceived conflict of interest in the provision of ECEI supports.³⁹

2.46 Some submitters were concerned that allowing Partners to provide services to families that they are developing Plans for raises serious potential for conflict of interest.⁴⁰

36 Mr Robbi Williams, Chief Executive Officer, JFA Purple Orange, *Proof Committee Hansard: Transitional arrangements for the NDIS*, 27 September 2017, p. 10.

37 Scope Australia, *Submission 17*, p. 9.

38 NDIA, *Submission 42*, p. 8.

39 NDIA, *Submission 42*, p. 8.

40 For example: National Disability Services, *Submission 14*, pp. 4–5; Vision Australia, *Submission 22*, p. 2. Speech Pathology Australia, *Submission 33*, p. 23; KU Children's Services, *Submission 37*, p. 3; Occupational Therapy Australia, *Submission 62*, p. 14.

2.47 Scope Australia argued that the NDIA's decision against appointing existing providers to avoid a conflict of interest may have resulted in Partners being appointed with no background or expertise in early intervention.⁴¹

2.48 Speech Pathology Australia and KU Children's Services argued that Partners can place families on their internal waiting lists rather than referring them to other organisations. Allegedly, some practices have already seen a decline in their referrals as a result.⁴²

2.49 There were also concerns that families might feel pressured to use the Partner for intervention services, or be deterred from requesting to continue services with their existing provider.⁴³

2.50 In October 2017, ECIA NSW/ACT published an open letter to the NDIA regarding its decision to preclude registered local service providers from applying for the NSW tender. It argued that the approach is contradicting effective best practice by preventing experienced organisations from applying.⁴⁴

2.51 Submitters argued that adequate safeguards and monitoring of conflicts of interest is required to ensure that families are being offered a choice of all available providers by ECEI Partners.⁴⁵

Regulatory compliance

2.52 Under the ECEI Approach, Partners are required to keep a record of all activity in the ECEI gateway on a monthly Actuary Reporting Tool. The tool is a reporting mechanism that allows Partners to provide detail to the actuaries to capture the numbers of children and level of supports being provided.⁴⁶

2.53 Partners are also required to develop a profile for each child they assess through the application of the Paediatric Evaluation of Disability Inventory–Computer Adaptive Test (PEDI-CAT) tool.⁴⁷

2.54 ECEI Partner, ASPECT, was critical of the administrative burden being placed on Partners. It argued that the Actuary Reporting Tool and the PEDI-CAT are labour-intensive and inefficient processes to complete.⁴⁸ ASPECT was concerned about the amount of therapist time being spent completing administrative processes

41 Scope Australia, *Submission 17*, p. 3 and 5.

42 Speech Pathology Australia, *Submission 33*, p. 23; KU Children's Services, *Submission 37*, p. 3.

43 Occupational Therapy Australia, *Submission 62*, p. 14.

44 ECIA NSW/ACT, *Open Letter to the NDIA*, <https://www.ecia-nsw.org.au/associationnews/statement-regarding-partners-in-communities-ecei-tender-nsw> (accessed 7 November 2017).

45 For example: Occupational Therapy Australia, *Submission 62*, pp. 2 and 3; Vision Australia, *Submission 22*, pp. 2 and 3.

46 NDIA, *Submission 42*, p. 13.

47 NDIA, *Submission 42*, p. 13.

48 ASPECT, *Submission 11*, p. 3.

'when there is already a scarcity of early childhood intervention therapists providing therapy'.⁴⁹

2.55 Early Childhood Partners are also required to meet a list of Performance Indicators, which have been developed by the NDIA to monitor and evaluate the Partners in the Community Program's performance through effective and efficient use of funds and resources. Failure to achieve Performance Indicators may be considered by the Agency in considering the Partner in future sourcing rounds.⁵⁰

2.56 The Performance Indicators relate to the Partner's ECEI functions (Information Gathering and Profile Development, Community Connections, Initial Supports, Access Recommendation, Plan Review), as well as Participants' safeguards and volumes.⁵¹

2.57 Of particular concern is the 'Access Recommendation' Performance Indicator. The performance target states that the Partner should ensure that 'no more than 50 per cent of children move from Initial Supports [short-term intervention] to obtaining an access decision for the NDIS for longer term planning'.⁵²

2.58 AMAZE was concerned that such a target would be set within an entitlement-based scheme and how it might influence the practices of Partners.⁵³

2.59 In its report on NDIS Costs, the Productivity Commission concluded that the target is inappropriate in an entitlement-based scheme. The Commission recommended that the NDIA remove the Performance Indicator target placed on ECEI Partners.⁵⁴

2.60 During the committee's hearing in Melbourne, NDIA officials advised that the target was not intended to be used as a constraint for entry to the Scheme:

We have acknowledged that that KPI is not framed in the way we wanted it to come out. It was based on the experience of our trial of the early-childhood approach in the Nepean-Blue Mountains where, in fact, the partners themselves said to us that it is about 50 per cent. Of the kids who come in, we can find alternate sources where they should be accessing mainstream supports, or we can provide them with those initial supports and set them on the right path which would mean that they did not need access to the scheme. Then about the 50 per cent do come in. That was what we were using as our guide. It has come out as if it is a hard parameter that we would want to see. We have changed that for round 3.⁵⁵

49 ASPECT, *Submission 11*, p. 1.

50 NDIS PITC Program Round Three, *Statement of Requirements*, October 2017, p. 45.

51 NDIS PITC Program Round Three, *Statement of Requirements*, October 2017, p. 45.

52 NDIS PITC Program Round Three, *Statement of Requirements*, October 2017, p. 77.

53 AMAZE, *Submission 23*, pp. 9–10.

54 Productivity Commission, *NDIS Costs*, Study Report, October 2017, p. 168.

55 Ms Stephanie Gunn, Acting Deputy Chief Executive Officer, NDIA, *Proof Committee Hansard*, 8 November 2017, p. 8.

2.61 In response to questions on notice arising from the committee's hearing on 20 October 2017, the NDIA provided the following clarification:

The Key Performance Indicators (KPIs) for National Disability Insurance Scheme Partners in the Community delivering Early Childhood Early Intervention (ECEI) services are included in the Grant Agreement Statement of Requirements. This level 2 KPI has already been removed from being assessed by the National Disability Insurance Agency based on the Productivity Commissions recommendation for its current Partners delivering ECEI services. The KPI will also be removed from the Round 3 Agreements and Statement of Requirements currently in draft before execution of the final documentation with new Partners.⁵⁶

Committee view

2.62 The issue of whether there is a potential of a conflict of interest is not limited to the delivery of ECEI services. Other roles in the Scheme, such as Local Area Coordinators, or advocacy organisations have also been subject to scrutiny over whether they can carry out their duties impartially. A balance has always been sought to mitigate any perceived or real conflict, while still being able to utilise the expertise of those delivering or recommending services. Given the relatively small number of Partners so far engaged in the ECEI Approach, the committee accepts that while those concerns are legitimate, in the circumstances it is content with the measures currently taken by the Agency to manage the situation.

2.63 With regard to the regulatory compliance obligations placed on service providers and Early Childhood Partners, the committee is supportive of a rigorous regime to manage performance. While it had objections, similar to those of the Productivity Commission, to the 50 per cent target of children who were recommended to become participants in the Scheme, it is content that that has been removed, and will not be included in any future contractual material.

Eligibility

Clarity of eligibility criteria

Interpretation of criteria

2.64 Submitters were concerned that a lack of clarity in the eligibility criteria has resulted in the criteria being applied inconsistently.⁵⁷

2.65 Speech Pathology Australia argued there have been cases where one child has been granted access under the ECEI criteria while the other has not, even though both children present with the same condition and similar functional impairment and needs.⁵⁸

56 NDIA, answers to questions on notice, 20 October 2017 (received 17 November 2017).

57 For example: Speech Pathology Australia, *Submission 33*, pp. 13–15; Making Connections Together, *Submission 46*, p. 1; Children and Young People with Disability Australia, *Submission 74*, p. 5; Queensland Government, *Submission 75*, p. 4.

58 Speech Pathology Australia, *Submission 33*, pp. 13 and 16.

2.66 The Queensland Government encouraged the Agency to ensure that eligibility information is transparent. It argued this would assist families to understand whether their child may be eligible for supports and on what basis, and help minimise the risk of conflicting interpretation of criteria.⁵⁹

2.67 Poor understanding is being compounded by perceived changes to the eligibility criteria. Autism Spectrum Australia (ASPECT) described how some children on early phasing lists were entitled to receive funded packages but now no longer meet the criteria.⁶⁰

2.68 The ACT Government contended that in late 2016, the NDIA changed its Operational Guidelines to require that children 'need a combination and sequence of special interdisciplinary or generic care, treatment or other services that are of extended duration and are individually planned and coordinated'. The ACT Government further argued that this change has resulted in some children—who were previously eligible for supports—being deemed ineligible under the new criteria and unable to have their packages renewed.⁶¹

2.69 ASPECT highlighted that changes to the criteria are placing Partners in the difficult situation of having to explain to families that their child no longer meets the NDIS eligibility criteria and helping them to access mainstream supports.⁶²

2.70 During the hearing in Melbourne on 8 November 2017, Mr Peter de Natris, Special Adviser, Early Childhood Early Intervention, NDIA, told the committee that a number of factors are taken into consideration when determining whether a child meets the ECEI criteria of the Scheme:

Where a child is presenting with something that might be deemed as 'on the cusp', we are asking our partners to make professional judgments as to the right pathway for them to be supported. It is difficult to sit in front of a committee such as this and say, 'We can determine that by saying this is the point that that happens,' because it is not only the delay or what the screen is throwing up; it is about the environment the child is in and it is about understanding the full impact of how you might best support those primary caregivers, parents, and that child going forward[...]Understanding what triggers access is quite grey. There are many leading paediatricians whom I talk to on a regular basis who have said to me, 'And that's the way it should be.' It shouldn't be that you just go: diagnosis; you're in. There needs to be a far richer exchange of information and decisions brought to bear around that.⁶³

59 Queensland Government, *Submission 75*, p. 4.

60 Autism Spectrum Australia, *Submission 11*, p. 2.

61 ACT Government, *Submission 66*, pp. 5–6.

62 Autism Spectrum Australia, *Submission 11*, p. 2.

63 Mr Peter de Natris, Special Adviser, Early Childhood Early Intervention, NDIA, *Proof Committee Hansard*, 8 November 2017, pp. 3–4.

Severity of developmental delay required

2.71 The committee received concerns regarding ambiguity around the severity of developmental delay required to gain entry to the Scheme.⁶⁴

2.72 The ACT Government was concerned that the NDIA's Operational Guidelines are being interpreted to mean that children with only one area of delay are not eligible for the Scheme.⁶⁵ The Queensland Government requested the Agency clarify eligibility arrangements for these children.⁶⁶

2.73 Speech Pathology Australia was concerned by reports that families have been told that children are required to need support from more than one allied health practitioner in order to be gain entry to the Scheme under the ECEI requirements.⁶⁷ Speech Pathology Australia argued that this could be inappropriate for some children, as support may best be delivered by one particular professional at particular points in the child's development.⁶⁸

2.74 In response to questions on notice, the NDIA clarified that the term 'developmental delay' is used in early childhood when a child's development is slower to develop in *one or more* areas compared to other children of the same age.⁶⁹ It clarified the situation for children with a single developmental delay:

If a child presents with a single developmental delay that has a functional impact on daily life, and this delay does not impact on the child's other developmental domains which are developing age appropriately, this single developmental delay is addressed by mainstream services. Children in this circumstance can be assisted by the Early Childhood Partner to connect to appropriate alternative support services. The National Disability Insurance Scheme does provide for access if the single development delay is of such a significance that that the supports required for this child evidence the need for coordinated, longer term, multidisciplinary service response that is extended in duration.⁷⁰

Emphasis on diagnosis

2.75 Although the NDIS ECEI Approach is not intended to be diagnosis-driven, lack of clarity around eligibility criteria appears to be compelling families to obtain a diagnosis as a way of demonstrating eligibility for the Scheme. For example, the

64 For example: ECIA National, *Submission 10*, p. 3; Autism Spectrum Australia, *Submission 11*, p. 2; Firstchance Inc, Early Links Inclusion Support, Hunter Prelude, RIDBC, *Submission 25*, p. 2; Speech Pathology Australia, *Submission 33*, p. 15; Children and Young People with Disability Australia, *Submission 74*, p. 9.

65 ACT Government, *Submission 66*, pp. 5–6.

66 Queensland Government, *Submission 75*, p. 4.

67 Speech Pathology Australia, *Submission 33*, p. 14.

68 Speech Pathology Australia, *Submission 33*, p. 14.

69 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

70 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

committee received feedback that 'decisions about eligibility for the NDIS focused solely on diagnosis and did not give consideration to their child's functional needs and capacity'.⁷¹

2.76 Submitters argued that, as diagnosis can be uncertain for some time, emphasis should be firmly placed on children's developmental vulnerability and functional limitation.⁷²

Changes to existing programs is creating confusion

2.77 Submitters highlighted that the eligibility criteria of previous Commonwealth and State programs are being confused with the criteria for the NDIS.⁷³ In NSW, for example, the State Government's Stronger Together Initiative supported children with a wide range of impairments in contrast to the NDIS which defines more narrowly who is able to be supported through a funded Plan. However, this difference 'is not well understood yet by early childhood intervention providers and other services referring children for supports'.⁷⁴

Changes to referral pathways

2.78 Providers in the Hunter Region argued that disruptions to referral pathways are also confusing families and providers involved in the ECEI Approach. The submission from Firstchance et al identified that, in the trial sites from 2013–2015, natural referral pathways were disrupted when families were required to go to the NDIA to test their child's eligibility for the Scheme, but the processes have now changed back again.⁷⁵

ANAO report on NDIS access controls

2.79 Specifically on the issue of access decisions, the ANAO tabled its audit report *Decision-making Controls for Sustainability—NDIS Access* in October 2017. The audit found that, between 1 July 2016 and 31 March 2017, the Agency implemented controls to ensure that access decisions are consistent with legislative requirements, but these have been inconsistently applied. The ANAO acknowledged that, at August 2017, the NDIA is developing an integrated assurance framework to enhance decision-making controls.⁷⁶

71 Children and Young People with Disability Australia, *Submission 74*, p. 9.

72 For example: Royal Children's Hospital, *Submission 20*, p. 2; Australian Association of Developmental Disability Medicine, *Submission 26*, p. 5; Royal Australasian College of Physicians, *Submission 68*, p. 7.

73 For example: National Disability Services, *Submission 14*, p. 2; and Lifestart Co-operative Ltd, *Submission 51*, p. 9.

74 Lifestart Co-operative Ltd, *Submission 51*, p. 9.

75 Firstchance Inc, Early Links Inclusion Support, Hunter Prelude, RIDBC, *Submission 25*, p. 2.

76 ANAO, *Decision-making Controls for Sustainability—NDIS Access*, Audit Report No. 13 of 2017–18, 19 October 2017, <https://www.anao.gov.au/work/performance-audit/decision-making-controls-sustainability-ndis> (accessed 21 November 2017).

2.80 The ANAO reported that it observed legislative and administrative non-compliance that potentially affected the transparency and accuracy of access decisions. The audit found limited evidence that the Agency monitored training completion by access decision-makers. It also found that the Agency had not established effective processes for internally reviewing access decisions, although it anticipated improvement as a result of new procedures introduced in May 2017.⁷⁷

2.81 The audit found that the access process was not well supported by the Agency's ICT system, but acknowledged that new ICT functionality was implemented from July 2017.⁷⁸

Committee view

2.82 The committee acknowledges the efforts being made by the NDIA to continually improve the operation and access to the ECEI pathway.

2.83 However, the committee understands concerns regarding the ECEI eligibility criteria, and is of the view that unclear eligibility criteria increase risk of misinterpretation and conflicted understanding. The repeated confusion over whether one, or more than one area of developmental delay determines access to the ECEI pathway illustrates that more work is required to clearly articulate which children will be eligible for support. Publication of clearer guidance around all aspects of entry to the pathway would assist all stakeholders.

Recommendation 3

2.84 The committee recommends that the NDIA publish clear and comprehensive guidance around the eligibility criteria for children with developmental delay on its website.

List D

2.85 The NDIA developed *List D—Permanent Impairment/Early intervention, under 7 years – no further assessment required* to streamline the access process for children under seven years of age. Where a child under seven years has been diagnosed with a condition on List D, the NDIA considers that the child meets the early intervention requirements without need for further evidence. If a child's condition is not on List D, families and carers must provide evidence of the impact of the condition on the child's life.

2.86 Submitters raised several concerns relating to List D. For example, it was argued that:

- it disadvantages families of children with rare or non-diagnosable conditions;

77 ANAO, *Decision-making Controls for Sustainability—NNDIS Access*, Audit Report No. 13 of 2017–18, 19 October 2017, <https://www.anao.gov.au/work/performance-audit/decision-making-controls-sustainability-ndis> (accessed 21 November 2017).

78 ANAO, *Decision-making Controls for Sustainability—NNDIS Access*, Audit Report No. 13 of 2017–18, 19 October 2017, <https://www.anao.gov.au/work/performance-audit/decision-making-controls-sustainability-ndis> (accessed 21 November 2017).

- there are an ever-expanding number of genetic conditions being identified with new technology that will need to be incorporated into the list;
- there are conditions known to have similar levels of impairment to conditions on the list which have been excluded; and
- the list disadvantages those without a specific aetiology for their developmental delay or disability.⁷⁹

2.87 The Productivity Commission's Position Paper on NDIS costs, released in June 2017, argued that List D can be useful, as it places less onus on families to demonstrate eligibility; reduces the administrative burden on the Agency; and provides some certainty to families. However, it can also represent an overly-generous gateway and stifle exits from the Scheme (as a child would remain eligible for the Scheme so long as their condition is present, even if early intervention benefits have been realised).⁸⁰ Furthermore, the presence of a diagnostic list can run counter to the insurance principle if it leads to the entry of children who are unlikely to benefit from individualised support.⁸¹

2.88 ECEI Partner, Noah's Ark, argued that, while diagnosis can predict risk factors, it cannot predict the extent of the impact of a disability on an individual.⁸²

2.89 The Productivity Commission's final report on NDIS costs suggested there needs to be an expedient process to change the list as new information becomes available, and that the process should be transparent. It argued that transparency would help the public understand the purpose of the list, and why some conditions are included and others not.⁸³

2.90 Several submitters agreed with the Productivity Commission and called on the NDIA to provide a public explanation as to how List D was determined.⁸⁴

NDIA response

2.91 In response to questions on notice, the NDIA advised that List D was 'originally created by the NDIA based on advice from a health professional'.⁸⁵ A description of the amendment process was also provided:

The inclusion of an additional condition to any of these lists is a policy decision made by the CEO from time to time, as the need arises. Changes to the policy are then reflected in updated NDIA Operational Guidelines.

79 For example: Australian Association of Developmental Disability Medicine, *Submission 26*, p. 7; and Royal Australasian College of Physicians, *Submission 68*, p. 3.

80 Productivity Commission, *NDIS Costs Position Paper*, June 2017, pp. 22–23.

81 Productivity Commission, *NDIS Costs*, Study Report, October 2017, p. 169.

82 Noah's Ark, *Submission 59*, p. 9.

83 Productivity Commission, *NDIS Costs*, Study Report, October 2017, pp. 168–169.

84 For example: Noah's Ark, *Submission 59*, p. 9; Children and Young People with Disability Australia, *Submission 74*, p. 5.

85 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

These lists are not exhaustive and in no way suggest that a person with a condition different to those listed would not have a permanent impairment that results in substantially reduced functional capacity. For people with a condition which is not on the aforementioned lists, they will be asked to provide further evidence of their substantially reduced functional capacity and how that is attributable to a permanent impairment to meet all the elements of the disability requirements in section 24 or section 25 of the NDIS Act.⁸⁶

2.92 The NDIA advised that a review of its Operational Guidelines (including List D) is scheduled to occur annually in consultation with relevant stakeholders. The Agency welcomed feedback from any person who wishes to provide input on its practices or processes, and directed them to the Feedback Manager of the Technical Advisory Team.⁸⁷

Committee view

2.93 While the committee accepts that the list is intended to streamline access decisions, by placing emphasis on diagnosis, List D runs the risk of introducing inequity by benefitting families of children with a diagnosed condition over those without a diagnosis. Moreover, families may attempt to obtain a costly diagnosis to expedite entry to the Scheme. The reported confusion has informed the committee's view that the NDIA should reiterate that entry is based primarily on the likely developmental trajectory of a child's condition.

2.94 The committee agrees there should be transparency around how List D is determined and how new conditions are incorporated.

Recommendation 4

2.95 The committee recommends that the NDIA publish information on its website about how List D is determined and how new conditions are incorporated.

Assessment tools

PEDI-CAT

2.96 The Paediatric Evaluation of Disability Inventory – Computer Adaptive Test (PEDI-CAT) is being used by Early Childhood Partners to determine, in combination with other information, the severity of functional impact in children with a disability or developmental delay, and their required level of funding.

2.97 Partners are required to make professional judgements about a child's abilities using the scores of the PEDI-CAT, in addition to their own observations and interviews. Partners then determine the most appropriate support pathway for that child.

86 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

87 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

2.98 It is unclear to the committee what other tools, assessments, or processes are currently being used by Partners to supplement PEDI-CAT assessments.

General criticisms

2.99 The Royal Institute for Deaf and Blind Children submission argued that PEDI-CAT questions are often inappropriate, and can be upsetting for families who have children that may not be able to complete tasks independently.⁸⁸

2.100 The Royal Children's Hospital argued that, whilst standardised questionnaires may be useful to quantify some developmental issues, they do not provide an indication of the family's needs.⁸⁹

2.101 Concerns were also raised that there is potential for PEDI-CAT results to be misinterpreted.⁹⁰ Noah's Ark questioned the reliability of using an algorithm to interpret scores and supports for children:

We understand that whilst the authors of the PEDI-CAT do not provide for a total score that sums across all four domains, the ECIA Partners are using an algorithm that has been developed to determine severity ratings. It has been reported that ECEI planners use the T-score (without referring to the standard area of measurement) on the algorithm to determine the level of severity, sometimes in isolation, and to determine subsequent funding. As this algorithm is not publicly available, we are unsure of its reliability and utility, if any.⁹¹

2.102 Submitters highlighted that inexperienced personnel that are unfamiliar with the tool's limitations could misinterpret its results.⁹² Many argued that assessment tools, such as the PEDI-CAT, should not be used in isolation to determine the eligibility or level of supports required for children under the NDIS.

Tracking short-term change

2.103 The NDIA requires Early Childhood Partners to capture changes in children's performance following the provision of short-term intervention by using the PEDI-CAT tool.⁹³ However, experienced stakeholders from within the sector argued that the tool is not sensitive enough to measure change over a short period of

88 Royal Institute for Deaf and Blind Children, *Submission 40*, p. 9.

89 Royal Children's Hospital, *Submission 20*, p. 8.

90 For example: Speech Pathology Australia, *Submission 33*, p. 13; Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 11; Noah's Ark, *Submission 59*, p. 10. Occupational Therapy Australia, *Submission 62*, p. 22; and Mr Scott Jacobs, National Disability Insurance Scheme Lead, Vision Australia, *Proof Committee Hansard*, 19 September 2017, p. 5.

91 Noah's Ark, *Submission 59*, p. 10.

92 For example: National Disability Services, *Submission 14*, p. 3; AMAZE, *Submission 23*, p. 12; Royal Institute for Deaf and Blind Children, *Submission 40*, p. 9; ECIA NSW/ACT, *Submission 58*, p. 4; Children and Young People with Disability Australia, *Submission 74*, p. 7.

93 NDIS PITC Program Round Three, *Statement of Requirements*, October 2017, p. 30.

intervention.⁹⁴ Noah's Ark argued that research into the sensitivity and responsiveness of the PEDI-CAT for young children needs to be conducted before the tool can be confidently used to track short term change in this manner.⁹⁵

Assessment of children with hearing loss

2.104 Dr Jim Hungerford, Chief Executive Officer, The Shepherd Centre, argued that the PEDI-CAT is also unsuitable for assessing children with hearing loss:

The PEDI-CAT for paediatric hearing loss is totally unsuitable because it is based on the observation of already present deficits. For a baby with hearing loss, there is nothing that you can observe in that instance. We're required in New South Wales to use PEDI-CAT on all of the children we're supporting, and with every single child the PEDI-CAT rating is well below their actual needs rating...⁹⁶

2.105 Dr Hungerford advised the committee that while the NDIA is developing an alternative assessment tool specific to hearing loss, it had not disclosed how ratings would be assigned; therefore, questions regarding its suitability as an assessment tool for children with hearing loss remain.⁹⁷

Assessment of children with autism

2.106 Several submitters argued that the results of the PEDI-CAT are often not a true indication of a child's functional capacity.⁹⁸ Partners reported that children presenting 'moderate-to-severe' autism are often classed as having 'mild' autism when assessed using the PEDI-CAT tool.⁹⁹

2.107 The Victorian Autism Specific Early Learning and Care Centre explained why the PEDI-CAT is ill-suited for assessing the functional capacity of children with autism:

Using the PEDI-CAT, despite having significant impairments, children with ASD may score as requiring little support due to being young and physically mobile. Families have expressed concerns that they were asked to answer questions based on the skills that their child could or could not physically perform rather than on the skills that their child functionally uses

94 For example: Scope Australia, *Submission 17*, p. 5; ECIA NSW/ACT, *Submission 58*, p. 9; Noah's Ark, *Submission 59*, p. 10.

95 Noah's Ark, *Submission 59*, p. 10.

96 Dr Jim Hungerford, Chief Executive Officer, The Shepherd Centre, *Proof Committee Hansard*, 27 September 2017, p. 12.

97 Dr Jim Hungerford, Chief Executive Officer, The Shepherd Centre, *Proof Committee Hansard*, 27 September 2017, p. 12.

98 For example: ASPECT, *Submission 11*, p. 2; SDN Children's Services, *Submission 35*, p. 5; Royal Institute for Deaf and Blind Children, *Submission 40*, p. 9; Lifestart Co-operative Ltd, *Submission 51*, p. 8.

99 For example: ASPECT, *Submission 11*, p. 2; SDN Children's Services, *Submission 35*, p. 5; Royal Institute for Deaf and Blind Children, *Submission 40*, p. 9; Lifestart Co-operative Ltd, *Submission 51*, p. 8.

in everyday life. For example, a child may be physically able to put their socks on, however may not perform this skill during daily routines. Given that children with ASD can often have challenges with using skills functionally, questions should be answered on the basis of what children consistently do rather than what they are physically able to do.¹⁰⁰

2.108 ECEI Partner, ASPECT, reported having to circumvent PEDI-CAT results in order to justify appropriate levels of support:

We are continuing to use a tool (PEDICAT) and we have concerns about the efficacy of this tool. It does not guide the development of planning in a meaningful and functional way. One of the flaws we have seen is that the tool does not identify the significant needs of many children with autism who score as having mild or moderate needs...The results of the PEDICAT are often not a true indication of a child's functional needs e.g. many of our children have scored in the mild range, however still present with functional difficulties, which means we need to provide much more detailed rationales regarding why they require the supports as outlined in their planning tool.¹⁰¹

2.109 The Commonwealth Ombudsman argued that the PEDI-CAT is unsuited to assessing children with autism, as it was developed primarily to assess children with cerebral palsy and is focused on physical impairment needs.¹⁰²

More appropriate assessment tool

2.110 Submitters raised concerns that children with autism are being assessed by the PEDI-CAT tool rather than the PEDI-CAT ASD tool, which has been modified for autism spectrum disorder (ASD).¹⁰³

2.111 The Victorian Autism Specific Early Learning and Care Centre explained that the PEDI-CAT ASD tool measures the skills children with autism *consistently* perform rather than what they are physically able to do in a more sensitive way than the PEDI-CAT.¹⁰⁴

2.112 The Victorian peak body for people with autism, AMAZE, argued that the PEDI-CAT ASD should be used as the NDIA's recommended assessment tool for children in this cohort. However, it cautioned that the tool is yet to be validated for the Australian population.¹⁰⁵

100 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 5.

101 ASPECT, *Submission 11*, p. 2.

102 Commonwealth Ombudsman, *Submission 21*, p. 5.

103 For example: AMAZE, *Submission 23*, p. 12; Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 5.

104 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 5.

105 AMAZE, *Submission 23*, p. 12.

2.113 AMAZE emphasised that 'there is currently no single functional measure which captures the range of difficulties young autistic children can present with'.¹⁰⁶

Standardising assessment and diagnostic processes for children with autism

2.114 Given the lack of consistent process across Australia, the Autism CRC has been researching the identification of 'behavioural markers' for ASD in the first two years of life, and has developed new methods for identifying infants with a high likelihood of being on the autism spectrum. These early identification methods will be trialled within GP practices around Australia.¹⁰⁷

2.115 Autism CRC highlighted that, if the approach is found to be successful, it will be Australia's first nationally consistent method for developmental surveillance and has significant promise in providing the NDIA with a clear process for determining ECEI eligibility and providing infants with intervention supports at the earliest possible age.¹⁰⁸

2.116 Autism CRC has also partnered with the NDIA to develop the first Australian guideline for ASD diagnosis, with the aim of describing an accurate, standardised, diagnostic process that is acceptable to autistic individuals and their families. The guideline was released for public feedback in September 2017, with a final version expected to be published and ready for implementation in January 2018.¹⁰⁹

2.117 While diagnosis is not necessary to commence intervention support under the ECEI Approach, Autism CRC argued that a consistent process would assist the NDIA to deliver targeted intervention supports.¹¹⁰

The way forward

2.118 Submitters called on the NDIA to review its use of the PEDI-CAT for children and seek more appropriate alternatives.¹¹¹ Some suggested using the Ages and Stages Questionnaires in place of the PEDI-CAT.¹¹² ECIA NSW/ACT argued for commissioning research into an alternative system and developing an appropriate assessment tool for children age 0–6 with developmental delay and disability.¹¹³

106 AMAZE, *Submission 23*, p. 12.

107 Autism CRC, *Submission 38*, p. 6.

108 Autism CRC, *Submission 38*, p. 6.

109 Autism CRC, *National guideline now open for community consultation*, <https://www.autismcrc.com.au/get-involved/participate-study/national-guideline-now-open-community-consultation> (accessed 18 October 2017).

110 Autism CRC, *Submission 38*, p. 4.

111 For example: Australian Association of Developmental Disability Medicine, *Submission 26*, p. 6; ECIA NSW/ACT, *Submission 58*, p. 10; JFA Purple Orange, *Submission 63*, p. 9; Royal Australasian College of Physicians, *Submission 68*, p. 3.

112 For example: ASPECT, *Submission 11*, p. 2; Firstchance Inc, Early Links Inclusion Support, Hunter Prelude, RIDBC, *Submission 25*, p. 6; SDN Children's Services, *Submission 35*, p. 6.

113 ECIA NSW/ACT, *Submission 58*, p. 10.

NDIA response

2.119 During the hearing in Melbourne on 8 November 2017, NDIA officials emphasised that the PEDI-CAT is not the only assessment used to determine the level of supports required for each child, but is used in conjunction with other information:

There have been concerns raised about the effectiveness and validity of the PEDI-CAT assessment tool and how the PEDI-CAT is applied to determine support needs of the child. We do want to put on record that the PEDI-CAT is not the sole determinant of the child's severity level. The PEDI-CAT provides information regarding strengths in a child's development in addition to areas of the development that are delayed. The PEDI-CAT result is used in combination with a wide range of other information, including parent reports and the use of other functional assessment tools that the expertise of our partner will bring to bear.¹¹⁴

2.120 The NDIA highlighted that Partners have been commissioned due to their skills in early childhood intervention, and are thus expected to conduct a thorough assessment of each child's and family's needs using their early-childhood expertise.¹¹⁵

2.121 The Agency confirmed that Early Childhood Partners are currently using the PEDI-CAT tool in their assessment of children with ASD, not the PEDI-CAT ASD. It noted that, while no qualifications are required to administer the tool, Partners have typically employed a mix of paediatric, allied health and early childhood professionals.¹¹⁶

Committee view

2.122 Under Part 7 of the *NDIS (Becoming a Participant) Rules 2016*, and Part 4 of the *NDIS (Supports for Participants Rules) 2013*, the NDIA is required to specify what assessment tools it uses in its Operational Guidelines. It is not possible to determine what assessment tools, other than the PEDI-CAT, are in use.

2.123 The Agency's submission to the Productivity Commission's study into NDIS Costs indicates that, in 2014, the NDIA identified 11 functional assessment tools (plus the World Health Organisation Disability Assessment Schedule version II for disability types where no specific tool could be identified) and validated these for the purpose of the NDIS. These tools informed the reference packages, which became the basis upon which reasonable and necessary supports were determined.¹¹⁷

2.124 The committee expects the Agency to comply with its legislative obligations and publish information about what functional assessments are in use.

114 Ms Stephanie Gunn, Acting Deputy Chief Executive Officer, NDIA, *Proof Committee Hansard*, 8 November 2017, p. 2.

115 Mrs Christine McClelland, Director, ECEI National Office Team, NDIA, *Proof Committee Hansard*, 8 November 2017, p. 9.

116 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

117 NDIA, *Submission 161* to the Productivity Commission Study into NDIS Costs, pp. 10–11.

Recommendation 5

2.125 The committee recommends that the NDIA publish information on all of its functional assessment tools currently in use.

Recommendation 6

2.126 The committee recommends the NDIA clarify how it uses assessment tools, and specifically, how results are used to determine eligibility and level of funding of children with disability or developmental delay.

2.127 The committee is concerned by reports that the PEDI-CAT tool is unsuited to assessing the functional capacity of children with a developmental delay, including those with ASD, yet it is being used by the NDIA and its Partners to inform access and funding decisions and track children's developmental progress. The potential inaccuracy of the PEDI-CAT in determining a child's functional needs leads to broader concerns about whether the number of children with developmental delay accessing the NDIS and the level of their delay is correct.

2.128 The committee acknowledges that the NDIA is continuing to refine its tools, but is of the view that the Agency should be driving innovation and research in this space. The committee considers there is a need for a fit-for-purpose assessment tool that can be used in Australia for children with ASD to be co-designed and developed with the sector.

Recommendation 7

2.129 The committee recommends the NDIA liaise with the sector to co-design and develop a purpose-built assessment tool for children with ASD in Australia.

Chapter 3

Provision of services

3.1 There are a number of steps a participant and their family have to take before they can access services. Evidence provided to the committee has illustrated the problems that can be encountered at each stage. This chapter explores key concerns raised by submitters, including delays accessing Early Childhood Partners and approvals from the NDIA, adequacy of Plans, and thin markets.

Access to services

Early Childhood Partners

3.2 Chapter 2 discusses the role and responsibilities of Early Childhood Partners, as one of the access points to the Scheme. However, evidence received pointed to issues in the early implementation of this approach. Submitters raised concerns that families of children with disability or developmental delay are facing extensive waiting lists for first contact with an ECEI Partner. Partners receive referrals from a range of sources, including early education settings, GPs or other health professionals, and self-referrals. On receipt of a referral, Partners must schedule an appointment with the referred family within two business days, and meet with the referred family within two weeks.¹ However, feedback to the committee indicates that time periods are often much longer.

3.3 According to Carers NSW, wait times for first contact with an ECEI Partner in the state have reached between six and 18 months, with some estimated at up to two years.² Early childhood intervention provider, Scope Australia, highlighted that some families in Victoria have waited 12 months between being identified to the commencement of planning.³

3.4 Extensive delays are placing families at risk of not receiving critical early intervention support:

The boy is due to start school in term 1 2018. The family had heard at the beginning of the year (from other parents) that there was an 8 month wait between registration with NDIS and receiving a plan. They felt that registration was futile due to this length of time (as he would be almost at school then), and did not act. At referral I suggested that the family urgently register for NDIS...the family have not been given an appointment with a planner and it is likely the boy will start school next year without the early intervention he requires.⁴

1 NDIS PITC Program Round Three, *Statement of Requirements*, p. 25.

2 Carers NSW, *Submission 12*, p. 2.

3 Scope Australia, *Submission 17*, p. 6.

4 Name Withheld, *Submission 6*, p. 1.

3.5 NSW disability advocacy organisation, Family Advocacy, was concerned that families are not being given an indication of when they might be able to see an ECEI Partner. It argued that even an approximate indication of time would help alleviate anxiety.⁵

3.6 Family Advocacy explained that, in an effort to spread distribution and minimise delays to families, selected NSW ECEI providers were provided with a list of transitioning clients who had been accessing funding through Better Start from the NDIA. It expressed concern that this prioritisation has ostensibly delayed services for families with newly eligible children, who are being forced to wait behind families on transitioning lists.⁶

Potential reasons for delays accessing Partners

Rushed implementation of the Approach

3.7 Early intervention provider, KU Children's Services, speculated whether delays accessing Partners may be a result of rushed implementation of the ECEI Approach.⁷

3.8 The NDIA's submission advises that an 'ECEI in advance' component of the Approach commences three to six months prior to the Service Areas phasing to allow time for the Partner to establish referral pathways, community awareness, and participant readiness activities across the early childhood sector.⁸

3.9 However, some areas had compressed timeframes in which to establish the ECEI Approach. KU Children's Services argued that in the NSW Year 1 roll out, some providers were only advised of their selection as ECEI providers a couple of weeks prior to the commencement of the Approach on 1 November 2016, and this created a backlog in assessments.⁹

Multiple roles and volume of workload

3.10 Submitters argued that Partners are struggling with the variety of roles they are required to fulfil, and the sheer volume of children they must support.¹⁰ RDI Consultants Australia highlighted that capacity issues may be resulting in Partners delaying less urgent cases, further lengthening some families' wait times.¹¹

5 Family Advocacy, *Submission 61*, p. 2.

6 Family Advocacy, *Submission 61*, pp. 1–2.

7 KU Children's Services, *Submission 37*, p. 4.

8 NDIA, *Submission 42*, p. 11.

9 KU Children's Services, *Submission 37*, p. 4.

10 For example: Carers Australia, *Submission 28*, p. 3; SDN Children's Services, *Submission 35*, p. 3; Royal Institute for Deaf and Blind Children, *Submission 40*, p. 6.

11 RDI Consultants Australia, *Submission 27*, p. 2.

Sector workforce shortage

3.11 Submitters highlighted that a wider workforce shortage is also impacting the sector's ability to meet demand. They argued there is a general absence of qualified workers, especially in the field of therapeutic supports.¹²

3.12 ECEI Partner, SDN Children's Services, argued that sector wide shortages have made recruiting early intervention staff 'a lengthy and difficult process'.¹³

Delays receiving Access decisions

3.13 Section 20 of the NDIS Act stipulates that the NDIA must, within 21 days of receiving an Access Request, decide whether or not the prospective participant meets the eligibility criteria, or make a request for more information, or for the individual to undergo further assessment. If the information is received within 28 days, the NDIA must make an access decision within 14 days or request further information.

3.14 Submitters were critical of the protracted nature of receiving access decisions from the Agency.¹⁴ For example, Occupational Therapy Australia reported that, in Queensland, the average wait for children to receive access approval from the Agency, even with clear developmental delay needs, is three to four months, while some are waiting up to six months for access approval.¹⁵

Delays receiving Plan approvals

3.15 Submitters were critical of turnaround times for the Agency to complete Plan approvals.¹⁶ According to ECEI Partner, ASPECT, some children can gain a Plan in one week, while others are waiting six months.¹⁷ AMAZE's 2017 survey of families and carers of ECEI participants found:

9% of respondents reported that the timeframe between lodging an application to access the NDIS ECEI pathway and eventually receiving a plan was 1 to 2 weeks, 27% of respondents reported this timeframe was 3 – 4 weeks, a further 27% reported 1 to 2 months followed by another 27% that reported 3 to 6 months, with the final 9% reporting that the timeframe was more than 6 months.¹⁸

12 For example: SDN Children's Services, *Submission 35*, p. 4; Deaf Services Queensland, *Submission 19*, p. 8.

13 SDN Children's Services, *Submission 35*, p. 4;

14 For example: Carers NSW, *Submission 12*, p. 2; AMAZE, *Submission 23*, p. 14; Occupational Therapy Australia, *Submission 62*, p. 8.

15 Occupational Therapy Australia, *Submission 62*, p. 8.

16 For example: ASPECT, *Submission 11*, p. 3; Scope Australia, *Submission 17*, p. 6; AMAZE, *Submission 23*, p. 14; Speech Pathology Australia, *Submission 33*, pp. 18–19.

17 ASPECT, *Submission 11*, p. 3.

18 AMAZE, *Submission 23*, p. 14.

3.16 Scope Australia reported that some families in Victoria have waited 12 months since being identified to the commencement of planning with the NDIA, with no access to state-funded ECIS services in the interim.¹⁹

3.17 Speech Pathology Australia argued that, in South Australia, Plan approvals are being deliberately delayed by the Agency:

...there are reports that there are significant delays in children who are in EI getting NDIS plans approved. These children meet the access requirements and may have had planning meetings but there are delays in having the plan 'approved' and/or put on to the Portal...members report that approval of children's plans is being delayed in SA until a 'place' opens up in the NDIS. Essentially, ECEI is acting as a 'capped' program. These families are in a 'holding pattern' until their Plans are approved and it is unclear if children are receiving any therapy or supports whilst they wait.²⁰

3.18 The Productivity Commission drew a link between issues in the planning process and the current cap on directly employed staff at the Agency:

The rationale for the cap on directly employed staff appears to be to encourage the NDIA to enter into community partnerships. While it is important that the NDIA works collaboratively with the community to deliver the scheme, it could also lead to poorer outcomes. For example, the NDIA outsourcing a lot of its work can present a particular risk when the agency is so new and needs to build institutional expertise and capability...This is especially the case in light of the problems with the planning process...The Commission recommends that the Australian Government remove the cap on directly employed staff. This is on the basis that the NDIA is best placed to determine the most effective and efficient staff mix to deliver the scheme, within the constraints of its capped operating budget.²¹

NDIA response

3.19 The NDIA submission advised that, where a child is found to meet the eligibility requirements of the Scheme, the average period of time from access determination to Plan approval is around 90 days.²²

3.20 When questioned on the subject of protracted wait times for Plan finalisation, the Agency emphasised that it is constrained by the bilateral agreements agreed between the Commonwealth and each State and Territory Government:

I think it's important that those wait times do reflect the bilateral agreements at any one point in time. In some jurisdictions the priority is given to existing families versus new families. We do have a limit on the number of new that we are allowed to bring into the scheme at any one point in time. It

19 Scope Australia, *Submission 17*, p. 6.

20 Speech Pathology Australia, *Submission 33*, pp. 18–19.

21 Productivity Commission, *NDIS Costs*, Study Report, October 2017, pp. 412–413.

22 NDIA, *Submission 42*, p. 11.

doesn't stop, however, a person seeking and being given access. You may be given access to the scheme, but we can't plan for you until such time as we've got to that point in our bilateral agreement during the transition period that we're allowed to have more new people.²³

Committee view

3.21 The committee is aware of the various pressures on all stakeholders within the system, including the Agency, but also on those stakeholders tasked with delivering key elements of the implementation of the Scheme. The pressure of Early Childhood Partners is a result of the scale and time imperatives inherent in the roll out schedule. That said, one of the key messages from the evidence heard by the committee is around the communication of the likely timing of key decision points, and the apparent disconnect between what the Agency reports on the time taken for decisions and the experience of people on the ground. The committee urges the NDIA to ensure that as much real-time local information is available to participants and providers to manage expectations wherever possible.

Adequacy of plans

3.22 In the context of the ECEI Approach, the committee understands that Plans are developed by either an Early Childhood Partner, if one has been appointed in the Service Area, or by a specialised internal NDIA ECEI team if no Partner has been appointed.²⁴

3.23 In NSW, a number of ECEI Providers, commissioned as part of provisional arrangements to assist with transitioning clients into the Scheme, are also responsible for developing Plans.²⁵

General concerns relating to Planners

Poor understanding of disability and developmental delay

3.24 The committee received concerns that many of the Plans created under the ECEI Approach are of poor quality, as Planners do not always have an adequate understanding of the needs of children for whom they are developing Plans.²⁶

3.25 Scope Australia argued that necessary supports are often missing from Plans, resulting in more reviews being sought.²⁷ Speech Pathology Australia argued that

23 Ms Stephanie Gunn, Acting Deputy Chief Executive Officer, NDIA, *Proof Committee Hansard*, 8 November 2017, p. 7.

24 NDIS, *Our locations*, <https://www.ndis.gov.au/about-us/locations.html> (accessed 18 October 2017).

25 NDIA, *Submission 42*, p. 8.

26 For example: Autism Aspergers Advocacy Australia, *Submission 18*, p. 14; Vision Australia, *Submission 22*, p. 3; Speech Pathology Australia, *Submission 33*, p. 17; Hear and Say, *Submission 44*, p. 3.

27 Scope Australia, *Submission 17*, p. 7.

Planners appear to be making decisions about how much therapy is required without advice from experts on best practice:

Speech pathologists repeatedly report that they see Plans for children with similar functional needs that do not include key supports (that are reasonable and would be considered necessary by anyone familiar with specific disabilities), over-fund certain supports or significantly under-fund certain supports.²⁸

3.26 Professor Andrew Whitehouse, Chief Research Officer, Autism CRC, raised the important question of whether any one individual Planner can have knowledge across every aspect of developmental disability or disability in general.²⁹

3.27 Mrs Amanda Mather, Director of Sustainability and Strategic Relations, Hear and Say, was concerned that interpretation of a child's early-intervention needs by the non-expert could result in inconsistencies.³⁰

Limited understanding of services

3.28 The Mental Health of Young People with Developmental Disabilities (MHYPDD) pointed out that Planners can only recommend services and supports of which they are aware. It encouraged the NDIA to actively incentivise the inclusion of evidence-based programs in Plans.³¹

Suggestions for improvement

3.29 Submitters suggested that the NDIA could improve the quality of Plans, and avoid the need for Planners to develop knowledge of every disability, by implementing the following processes:

- ensuring Planners consult all information provided by professionals;
- allowing families to review their draft Plan before finalisation; and
- introducing a process for incorporating minor amendments to Plans without the need to initiate a full Plan review.³²

Planning concerns for children with ASD

Poor understanding of ASD

3.30 Feedback from the ASD sector suggests there is limited understanding of the varying needs of children with ASD by those responsible for developing Plans.³³

28 Speech Pathology Australia, *Submission 33*, pp. 16–17.

29 Professor Andrew Whitehouse, Chief Research Officer, Autism CRC, *Proof Committee Hansard*, 26 September 2017, p. 13.

30 Mrs Amanda Mather, Director of Sustainability and Strategic Relations, Hear and Say, *Proof Committee Hansard*, 26 September 2017, p. 4.

31 Mental Health of Young People with Developmental Disabilities, *Submission 24*, pp. 3–5.

32 For example: Vision Australia, *Submission 22*, p. 2; Carers Australia, *Submission 28*, p. 11.

3.31 The Victorian Autism Specific Early Learning and Care Centre (ASELCC) highlighted that, at the time a child is diagnosed, families know the least about ASD, their child's strengths and difficulties, the quality and availability of services, and what their child's intervention needs are. It argued that families require knowledgeable Planners at this crucial time. Yet, many reported that their Planner had poor knowledge of ASD and lacked sympathetic communication when discussing sensitive issues.³⁴

3.32 From July to August 2017, AMAZE undertook a survey of parents and carers of ECEI Participants, to capture their experiences of the Approach. Despite its relatively small size, the survey delivered some concerning results:

- 46 per cent rated their Planner's understanding of autism as moderate to low; and
- (of those that had met with a Partner) 50 per cent identified their Early Childhood Partner's knowledge of autism as moderate to low.³⁵

Limited knowledge of recommended intervention guidelines

3.33 ASELCC argued that Planners have limited knowledge of the Roberts and Williams' recommendation that all children with ASD should receive 15–25 hours per week of comprehensive intervention for at least one year.³⁶

3.34 ASELCC reported that children who are severely impaired received the recommended amount of intervention in their Plans, but children with mild to moderate autism received limited funding which did not enable them to access the recommended intensity of intervention.³⁷

3.35 ASELCC was concerned that inconsistent knowledge of Planners, in relation to ASD guidelines and services, is resulting in unfair Plans:

One family reported that while their planner requested that they use a general term instead of 'ABA' during plan discussions, other families used the term 'ABA' and received greater amounts of funding to cover the costs of their therapy.³⁸

Planning concerns for children with vision loss

3.36 Vision Australia expressed concern that those responsible for approving Plans have limited understanding of the needs of children who are blind or have low

33 For example: Connect and Relate for Autism Inc, *Submission 13*, p. 3; AMAZE, *Submission 23*, pp. 7, 13–14; Mental Health of Young People with Developmental Disabilities, *Submission 24*, pp. 3–5. Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 1.

34 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 1.

35 AMAZE, *Submission 23*, pp. 7, 13–14.

36 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 1–3.

37 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 1–3.

38 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 1.

vision.³⁹ Vision Australia argued this may be compromising the quality of Plans being developed. It provided the following example as a case study:

The Vision Australia early intervention team recently submitted an Assistive Technology request for a 2 year old client with no vision. The application included a combination of 'Vision Impairment' and 'Physical impairment' related resources/equipment. The 'Physical impairment' related resources/equipment were all approved whereas all the 'Vision Impairment' specific ones were refused. This includes the most basic tool for a young child to access literacy – a Perkins braille. This is akin to denying the child access to a pen/crayon and paper to scribble...The Early Intervention team is concerned that the external parties who were tasked to assess the equipment application do not have sufficient knowledge and expertise about 'Vision impairment' to make the funding decision.⁴⁰

NDIA response

3.37 On 16 November 2017, the NDIA released details of a new NDIS 'pathway' designed to improve the experience of Participants.⁴¹ Central to the new pathway is the delivery of face-to-face engagement for all NDIS Plan development, unless the Participant prefers otherwise.⁴²

3.38 The pathway will be progressively piloted and tested over the coming months before being rolled out nationally. At the hearing on 8 November 2017, NDIA officials advised the committee that changes are expected to be implemented on a staggered basis to allow the Agency to test the cost and time frame implications of the changes. While the Agency could not provide a definitive timeline, it indicated changes should begin to be seen from April 2018.⁴³

Committee view

3.39 While the committee acknowledges the Agency's work to improve the Participant pathway, and its statements around the training and upskilling of its Planners, it remains troubled by reports that Planners have poor understanding of the needs of the children they are developing Plans for. Planners should, at the least, have awareness of recommended intervention guidelines and therapies for the major disability cohorts, and demonstrate sensitivity in their communications with families.

39 Vision Australia, *Submission 22*, pp. 5–6.

40 Vision Australia, *Submission 22*, pp. 5–6.

41 NDIS, *New NDIS pathway released to improve participant and provider experience*, <https://www.ndis.gov.au/news/pathway-experience.html> (accessed 17 October 2017).

42 NDIS, *New participant pathway experience*, 18 October 2017, p. 5.

43 Ms Stephanie Gunn, Acting Deputy Chief Executive Officer, NDIA, *Proof Committee Hansard*, 8 November 2017, p. 8.

Recommendation 8

3.40 The committee recommends that the NDIA provide ongoing and targeted training to Planners creating ECEI Plans for children to ensure they are equipped with the most up to date knowledge, expertise and resources in their decision making.

Thin markets

3.41 While the development of the service sector is in some cases keeping up with demand, the committee received evidence that the ECEI Approach is being affected by a shortage of providers in some areas.⁴⁴

3.42 In Queensland for example, thin markets currently exist in specialist therapy supports, such as complex seating, assistive technology complex paediatric feeding, and behaviour support.⁴⁵

3.43 Tasmania is also experiencing thin markets in regional areas, where there is limited access to supports such as allied health services.⁴⁶

3.44 The Commonwealth Ombudsman highlighted that inadequate supply can potentially increase the cost of the Scheme, by leaving children without supports for protracted periods of time.⁴⁷

3.45 State governments are working to address gaps in services. For example, the Victorian Government released a workforce development strategy to support implementation of the NDIS in the state over 2016–2019, which addresses skills shortages in rural and remote areas.⁴⁸

3.46 The Queensland Government has funded a peak body to investigate and identify specific issues in potentially thin market areas.⁴⁹ However, it noted that, even with significant efforts and investment, 'some markets will remain a challenge'.⁵⁰

3.47 The Productivity Commission's report on NDIS costs considered the issue of thin markets, concluding that, while the disability care workforce has grown considerably, 'it is unlikely to grow quickly enough to supply the increasing demand for services under the NDIS under current policy settings'.⁵¹ It recommended the Agency address thin markets by:

- considering a range of approaches, including block-funding;

44 For example: Queensland Government, *Submission 75*, p. 6; Tasmanian Government, *Submission 76*, p. 3.

45 Queensland Government, *Submission 75*, p. 6.

46 Tasmanian Government, *Submission 76*, p. 3.

47 Commonwealth Ombudsman, *Submission 21*, p. 5.

48 Victorian Government, *Submission 71*, p. 13.

49 Queensland Government, *Submission 75*, p. 6.

50 Queensland Government, *Submission 75*, p. 6.

51 Productivity Commission, *NDIS Costs*, Study Report, October 2017, p. 319.

- publicly releasing its Provider of Last Resort (POLR) policy and Market Intervention Framework discussed in the NDIS Market Approach: Statement of Opportunity and Intent as a matter of urgency; and
- collecting and publishing available disaggregated data, feedback, and reports on thin markets, including when POLR arrangements are used.⁵²

NDIA response

3.48 The NDIA acknowledged there is a challenging market structure for early childhood services and that it will need to provide interim strategies while the sector builds capacity and capability.⁵³

3.49 In March 2017, the NDIA released its *Rural and Remote Strategy 2016–19*, which indicated that the ECEI Approach will be tailored to each community in order to provide the most appropriate delivery in remote and very remote areas.⁵⁴

3.50 As part of the strategy, the NDIA is establishing regional hub and spoke models across Australia, to provide local area coordination and facilitate easier access to the NDIS for rural and remote Participants. Planning activities will be undertaken for remote and very remote areas by Regional Offices, whose role is to engage and research the current market and consider a tailored approach, as well as opportunities for co-design, in order to develop and support services to deliver the ECEI Approach.⁵⁵

3.51 Early in 2017, the NDIA funded peak body ECIA to complete service mapping in every jurisdiction across Australia to determine what services exist for young children with disability or developmental delay, such as mainstream and traditional disability services. The results are expected to be completed by June 2018.⁵⁶

52 Productivity Commission, *NDIS Costs*, Study Report, October 2017, p. 50.

53 NDIA, *Submission 42*, p. 15.

54 NDIA, *Submission 42*, p. 15.

55 NDIA, *Submission 42*, p. 15.

56 Ms Trish Hanna, President, ECIA, *Proof Committee Hansard*, 3 October 2017, p. 16.

Chapter 4

Funding and delivery of services

4.1 This chapter examines the funding and delivery of ECEI services, and reviews issues raised by families, carers and service providers. The chapter considers Participant views on the costs of assessment and diagnosis, the adequacy for support needs and reported delays in service delivery. The chapter also considers service providers' views on service costs; regulated pricing, gaps in funding and workforce issues.

Assessment and diagnosis reports

4.2 Submitters¹ reported that families have to partially, and sometimes fully, fund assessment and diagnosis reports to provide evidence of their child's need for support and access the funding they need. The costs of these reports can be significant and are, at best, only partially subsidised. As highlighted in the evidence below, the issue of sourcing assessment reports is particularly relevant to families with children on the autism spectrum.

4.3 In its submission, the Victorian Autism Specific Early Learning and Care Centre noted that 'families often report feeling pressured to source a private assessment team, at great cost, to get a diagnosis and access the funding they need'.²

4.4 In 2017, AMAZE, the peak body in Victoria for people with autism and their supporters, conducted a survey of parents and carers of NDIS ECEI Participants. The survey found 36 per cent of respondents incurred costs to access the NDIS ECEI pathway (that is, costs for initial diagnosis and providing evidence of reasonable and necessary supports).³

4.5 At a public hearing in Melbourne, Mr Braedan Hogan, Manager, Public Affairs and NDIS Transition at AMAZE, reported that some people with an existing diagnosis are asked to obtain an up-to-date diagnosis at a personal cost.⁴

Public health system

4.6 The committee heard that, due to long waiting lists in the public health system and limited Medicare rebates and services, families are self-funding assessment and diagnosis reports. For example, the grandmother of a boy with autism stated she 'borrowed money to pay for an assessment of [name of grandson withheld] as the public wait time was around 1 year'.⁵ Similarly a family 'self-funded occupational

1 See for example: Commonwealth Ombudsman, *Submission 21*, p. 6; Autism Spectrum Australia, *Submission 11*, p. 4; Scope, *Submission 17*, p. 6; CYDA, *Submission 74*, p. 4.

2 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 4.

3 AMAZE, *Submission 23*, p. 13.

4 Mr Braedan Hogan, Manager, Public Affairs and NDIS Transition, AMAZE, *Committee Hansard*, 19 September 2017, p. 35.

5 Name Withheld, *Submission 9*, p. 2.

therapist, psychologist and speech pathologist assessments as the NSW Health waiting list was too long—12 months plus'.⁶ The Australian Psychological Society Limited also reported that 'waiting lists for assessment in the public sector are lengthy (commonly 1–2 years, but often longer) and are not available in many parts of Australia'.⁷

4.7 There are only limited rebates under Medicare for these assessments. The Australian Psychological Society Limited explained:

Only some children will meet criteria for an assessment to be done under Medicare, and even then there is likely to be a substantial gap fee.⁸

[...] some children may be eligible for a Medicare rebate for an assessment for ASD. However, the rebate only supports a limited assessment and is significantly below the fees recommended by the APS. This means that many families pay full fees or a significant gap fee if the child is eligible for a Medicare rebate.⁹

4.8 Some diagnosis testings are not covered at all by Medicare. For example, the cost of genetic testing for SWAN Children (children with Syndromes Without A Name) is expensive and not covered by Medicare. SWAN Australia reported that the approximate cost for a singleton Whole Exome Sequencing (WES) is \$2500, and \$5000 for a trio WES Syndromes.¹⁰

Costs incurred

4.9 RDI Consultants Australia, an association representing and supporting RDI Certified Consultants and Trainees who provide the RDI (Relationship Development Intervention) Program, reported that assessments can cost \$450 to \$1500.¹¹

4.10 One of AMAZE's survey respondents reported spending a total of \$1200 on paediatrician reports.¹²

4.11 The costs of private diagnosis for Autism Spectrum Disorder (ASD) are high. According to the Australian Psychological Society, it is at least \$2000 to \$3000¹³ and is not covered by private insurance.¹⁴

4.12 Dr Jessica Paynter, a Member of the Australian Psychological Society described the situation and consequences for families:

6 CYDA, *Submission 74*, p. 10.

7 Australian Psychological Society Limited, *Submission 70*, p. 2.

8 Australian Psychological Society Limited, *Submission 70*, p. 1.

9 Australian Psychological Society Limited, *Submission 70*, p. 2.

10 Syndromes Without A Name, *Submission 53*, p. 4.

11 RDI Consultants Australia, *Submission 27*, p. 3.

12 AMAZE, *Submission 23*, p. 13.

13 Australian Psychological Society Limited, *Submission 70*, p. 2.

14 Autism Aspergers Advocacy Australia, *Submission 18*, p. 2;

We're also seeing then that there is a gap where there is no funding for things like an intellectual assessment to demonstrate cognitive impairment. And a private assessment for a cognitive assessment or for an ASD assessment can be upwards of \$2,000 to \$3,000 per child. That's a substantial cost that is either borne by families—or they're coming in to Planners without evidence of their child's level of need, which makes it challenging to advocate for the supports that they require.¹⁵

4.13 Occupational Therapy Australia argued that it is placing families who cannot afford assessments at a significant disadvantage.¹⁶

Annual assessment when on a plan

4.14 Current NDIS Plans cover the cost of an annual assessment. However, best practice in early intervention for children with hearing loss is to undertake biannual assessments, to allow clinicians to review a child's progress and adjust services as appropriate in order for a child to achieve optimal results.¹⁷ Hear and Say recommended that the assessment protocol be updated to allow Plans to include funded biannual assessments for children with hearing loss.¹⁸

Committee view

4.15 The committee is concerned that some families have had to fully or partially fund assessment and diagnosis reports to ensure their child could access ECEI services and have adequately funded Plans. The committee is also greatly concerned that some families feel pressured to pay for costly assessments to access funding and services.

4.16 As discussed in chapter 2, there should be no need for families to provide these costly assessment and diagnosis reports at the time of lodging the access request for ECEI services with the NDIA or during the Planning process. Furthermore, if the NDIS has made a request that a prospective Participant undergo an assessment or examination, the NDIS operational guidelines and the NDIS Act stipulate 'the NDIA will support the prospective Participant to comply with the request by providing assistance, including financial assistance where appropriate'.¹⁹ The NDIA needs to clearly communicate to families, Planners and ECEI Partners that assessment reports are not needed unless requested by the NDIA. The NDIA should pay for the costs of assessment and diagnosis it requests from prospective and existing Participants.

4.17 The committee believes that adequate provision of funding for assessments should be made available in Plans if considered necessary by clinicians, and not be

15 Dr Jessica Paynter, Member, Australian Psychological Society, *Committee Hansard*, 26 September 2017, p. 7.

16 Occupational Therapy Australia, *Submission 62*, p. 10.

17 Hear and Say, *Submission 44*, p. 5.

18 Hear and Say, *Submission 44*, p. 5.

19 <https://www.ndis.gov.au/operational-guideline/access/determining-access-criteria.html> (accessed 24 October 2017); National Disability Insurance Scheme Act 2013, Section 6.

limited to funding for an annual assessment if better results can be achieved with more frequent assessments.

Recommendation 9

4.18 The committee recommends the NDIA clearly communicate to families, Planners and ECEI Partners that assessment reports are not needed unless requested by the NDIA.

Recommendation 10

4.19 The committee recommends the NDIA ensures provision of funding for assessments in Plans is based on the Participant's needs and is not arbitrarily restricted to a yearly assessment.

Funding in plans

Overall funding

4.20 Some inquiry participants reported significant funding shortfalls in Plans under the ECEI Approach.²⁰

4.21 In response to AMAZE's ECEI survey, only 54 per cent of respondents felt satisfied that the amount of funding provided was adequate to meet their child's early intervention support needs.²¹ One of the survey respondents estimated 'that the funding is 40 per cent to 50 per cent below requirements'.²²

4.22 Children and Young People with Disability Australia (CYDA), provided examples of some family experiences that highlight issues of significant funding shortfalls in Plans:

Lack of funding has limited the access to supports in general and excluded some others. Our child's plan was cut from \$32000 to \$16000 in the second year and this has had a major impact.

We have just applied for the NDIS and received a first package which is half of what we applied for. We are currently launching an appeal.²³

4.23 The committee also heard from the grandmother of a three year old boy that his Plan is currently underfunded by \$50 000.²⁴

Underfunded plans for children with autism

4.24 Submitters expressed concerns about the inadequate level of funding ECEI Participants with autism are commonly receiving.

20 See for example: CYDA, *Submission 74*, p. 9; AMAZE, *Submission 23*, p. 16.

21 AMAZE, *Submission 23*, p. 16.

22 AMAZE, *Submission 23*, p. 16.

23 CYDA, *Submission 74*, p. 7.

24 Name Withheld, *Submission 9*, p. 3.

4.25 The Australian Psychological Society indicated that NDIS funding levels are lower than previous national funding models such as Helping Children with Autism (HCWA).²⁵

4.26 The Australian Psychological Society pointed out that current funding levels make it difficult to achieve good outcomes:

Current funding levels are not commensurate with recommended best/good practice guidelines in Autism Spectrum Disorder (ASD) of 15-25 hours per week making it difficult for consumers to obtain good outcomes.²⁶

4.27 Similarly, Victorian Autism Specific Early Learning and Care Centre submitted:

The funding ECEI Participants with autism have received does not align with evidence-based practice. The NDIS publication, Autism spectrum disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers (Roberts and Williams, 2016), recommends 15-25 hours per week of evidence based, early intervention for children with autism. However, thus far, NDIS Plans have only supported such intensity for children who are severely impaired. Children with mild-moderate autism have received limited funding and do not enable them to access the recommended intensity of intervention.²⁷

4.28 At a public hearing in Sydney, Mrs Tina Skapetis, a mother of a girl diagnosed with autism, reported:

In late November 2016 the NDIS advised that Emanuella's plan had been approved for \$22,000 for 12 months. This was \$38,000 short of what we needed. We were devastated. There was no way that we could afford to fund the shortfall. I expressed my disappointment, only to be told by the planner that I should be grateful for what I have gotten, as other families got only \$17,000.²⁸

4.29 In its submission, the Victorian Autism Specific Early Learning and Care Centre relayed stories from parents of children with autism who received inadequate funding in their child's Plan:

Parent 2: [...] Funding was not enough to cover everything we needed. [...] We had to cut therapies to make the funding we had last. We are still going to run out before review, and are having to obtain loans to bridge the gap.

Parent 4: [...] Her plan was approved in May, for 39 hours, or \$6900, which is woefully inadequate for what she needs.[...] Next year, I will have

25 Australian Psychological Society, *Submission 70*, p. 2.

26 Australian Psychological Society, *Submission 70*, p. 2.

27 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 3.

28 Mrs Tina Skapetis, *Committee Hansard*, 3 October 2017, p. 1.

to pay for private therapy (OT, speech and psych) to supplement funded therapy if we have the same amount.²⁹

Underfunded Plans for deaf and hard of hearing children

4.30 The committee recently reported on the issue of underfunded Plans for deaf and hard of hearing children in its interim report *Provision of Hearing Services under the National Disability Insurance Scheme*,³⁰ released in September 2017.

4.31 During the course of the inquiry, submitters from the hearing sector³¹ continued to report that Plans for deaf and hard of hearing children are generally underfunded and not meeting children's reasonable and necessary support needs.

4.32 First Voice and its members reported that families customarily receive NDIS funded Plans that are \$6000–\$10 000 per child per year less than the actual costs of services.³²

4.33 Mr Michael Forwood, Chair of First Voice noted:

So, most children who are entering into the specialist language development programs are now getting \$6,000, against a cost of between \$18,000 and \$22,000 for a comprehensive multidisciplinary program.³³

4.34 Mr Bart Cavaletto from the Royal Institute for Deaf and Blind Children told the committee that 'the plans that families are getting in no way reflect the cost of delivering services'.³⁴

Inconsistencies in funding

4.35 As with other cohorts in the Scheme, variations in types and amounts of funded support in NDIS Plans for children with similar needs remain a significant concern.³⁵

4.36 The Commonwealth Ombudsman reported that 'ECEI providers expressed frustration and concern that children in very similar situations could receive NDIS Plans with vastly different types and amounts of support'.³⁶

29 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, pp. 9–10.

30 Joint Standing Committee on the National Disability Insurance Scheme, *Provision of Hearing Services Under the National Disability Insurance Scheme*, September 2017.

31 See for example: Hear and Say, *Submission 44*, p. 4; First Voice, *Submission 64*, p. 6.

32 First Voice, *Submission 64*, p. 10.

33 Mr Michael Forwood, Chair, First Voice, *Committee Hansard*, 27 September 2017, p. 1.

34 Mr Bart Cavaletto, Director, Services, Royal Institute for Deaf and Blind Children, *Committee Hansard*, 3 October 2017, p. 28.

35 See for example: Mrs Amanda Mather, Director of Sustainability and Strategic relations, Hear and Say, *Committee Hansard*, 26 September 2017, p. 5, Commonwealth Ombudsman, *Submission 21*, p. 5; AMAZE, *Submission 23*, p. 16.

36 Commonwealth Ombudsman, *Submission 21*, p. 5.

4.37 The Royal Institute for Deaf and Blind Children found that 'the scope of supports provided to Participants in their Plans is highly variable despite similarities in needs'.³⁷

4.38 Early Childhood Intervention Australia Victoria/Tasmania and others³⁸ suggested that variations in funding can be attributed to parents' ability to advocate for their child's needs:

Inequities have been identified by service providers in many plans indicating parents who are better able to advocate for their child's needs or those who are supported through the process are receiving better supports and funding.³⁹

4.39 Variations and inconsistencies in funding have also been attributed to the lack of knowledge and expertise of NDIS Planners.⁴⁰

Assistive technology

4.40 The issue of funding for assistive technology in Plans was raised by many participants.⁴¹ Submitters noted inconsistencies in funding, approval and rejection of assistive technology, which can lead to suboptimal or inappropriate equipment being given to children.

4.41 Ms Gail Mulcair, CEO of Speech Pathology Australia, reported that some Participants are given inappropriate assisted technology equipment in their Plans to reduce costs:

We certainly see these decisions occurring around trying to limit the cost, in the situation of an AAC device or a communication aid, as an example, or other assisted technology equipment, that there is a cap on the expense. Decisions are being made around defaulting to something which may be more affordable but may not be appropriate, or certainly that has been recommended as not being appropriate for that child or in the case of adults.⁴²

37 Royal Institute for Deaf and Blind Children, *Submission 40*, p. 9.

38 See for example: Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 3; First Voice, *Submission 64*, p. 13; AMAZE, *Submission 23*, p. 14.

39 Early Childhood Intervention Australia Victoria/Tasmania, *Submission 7*, p. 9.

40 See for example: Occupational Therapy Australia, *Submission 62*, p. 8; Hear and Say, *Submission 44*, p. 4.

41 See for example: Vision Australia, *Submission 22*, pp. 5–6; Occupational Therapy Australia, *Submission 62*, pp. 21–22; CYDA, *Submission 74*, p. 9.

42 Ms Gail Mulcair, CEO, Speech Pathology Australia, *Committee Hansard*, 19 September 2017, p. 17.

4.42 Participants expressed concerns about funding for non-specialised technology, such as tablets being rejected in Plans despite being relatively low cost, to meet the needs of some NDIS Participants.⁴³

4.43 Deaf Services Queensland explained how tablets can reduce expenses to the NDIA over the short and long term by 'enabling children to participate in therapy or Teacher of the Deaf services via tele-practice, thereby increasing efficiencies and decreasing the impact of travel distances'.⁴⁴

4.44 Ms Michelle Crozier, NDIS Project Manager, Deaf Services Queensland, said:

We want to be able to deliver our services remotely through videoconferencing, and people need tablets for that—particularly for interpreting. We have arrangements with hospitals like Townsville Hospital, where they have an iPad and we do remote interpreting. But we can't do that under the NDIS for individual participants because a tablet or device that will support that can't be funded.⁴⁵

4.45 Mrs Rachel Tosh, General Manager at Therapy Alliance Group, reported the following case:

Just this week, we had a child where the therapist had recommended an iPad with a specific app for communication. The child's already familiar with the app from school, so it would provide a cost-effective alternative and augmentative communication method for this child. We were informed not to put in an AT request for the iPad, because it wouldn't be funded, because it's not a disability specific support.⁴⁶

4.46 Deaf Services Queensland noted that tablets were previously funded under Commonwealth schemes such as a Better Start and Helping Children with Autism (HCWA).⁴⁷

4.47 Similarly, Myhorizon noted that therapy resources such as Sensory Aids (weighted blankets, vests, and mini-trampolines) and Assistive Technology (iPads) are not being approved, but that 'these therapy resources are funded via Better Start and HCWA'.⁴⁸

43 See for example: Vision Australia, *Submission 22*, p. 6; Deaf Services Queensland, *Submission 19*, p. 7.

44 Deaf Services Queensland, *Submission 19*, p. 8.

45 Ms Michelle Crozier, NDIS Project Manager, Deaf Services Queensland, *Committee Hansard – Implementation and performance of the NDIS*, 26 September 2017, p. 17.

46 Mrs Rachel Tosh, General Manager, Therapy Alliance Group, *Committee Hansard – Implementation and performance of the NDIS*, 26 September 2017, p. 10.

47 Deaf Services Queensland, *Submission 19*, p. 8.

48 Myhorizon, additional information received 27 September 2017, p. 1.

4.48 A respondent to AMAZE's ECEI survey also reported that 'the NDIA refuses to fund sensory equipment that would make a big difference to my child's behaviour'.⁴⁹

Interpreters

4.49 Many submitters raised concern about the lack of funding in Plans for interpreters and translators.⁵⁰

4.50 Noah's Ark Inc explained:

The NDIS has a rule that it will not support the cost of translators. This means that non-English-speaking families cannot understand, gain information from services about their child's condition or the supports they need to provide. This rule undermines the purpose of early intervention.⁵¹

4.51 Occupational Therapy Australia reported that 'concerns have also been raised about the decision to no longer fund interpreters, and how this will affect service providers who are unable to afford the fees for an interpreter to communicate with parents from culturally and linguistically diverse (CALD) backgrounds'.⁵²

4.52 The Victorian Government is also concerned about the lack of funding for interpreter services and how this may affect the quality of services provided to Participants.⁵³ They submitted that the NDIS 'should fund interpreter services for culturally appropriate service provision'.⁵⁴

4.53 Similarly, Autism Spectrum Australia recommended 'funding for interpreters and translators as part of NDIS packages (not just for the Planning process) as this cost is not able to be met from NDIS funding'.⁵⁵

Support for families, carers and siblings

4.54 The lack of funding and support available for families, carers and siblings was raised by several inquiry participants.⁵⁶

4.55 Syndromes Without A Name (SWAN) Australia is of the view that 'funding needs to be directed into supporting families when they are first told there is an issue

49 See for example: AMAZE, *Submission 23*, p. 16.

50 See for example: Autism Spectrum Australia, *Submission 11*, p. 5; Scope, *Submission 17*, p. 7; Occupational Therapy Australia, *Submission 62*, p. 7.

51 Noah's Ark Inc, *Submission 59*, p. 13.

52 Occupational Therapy Australia, *Submission 62*, p. 7.

53 Department of Education and Training Victorian Government, *Submission 71*, p. 13.

54 Department of Education and Training Victorian Government, *Submission 71*, p. 5.

55 Autism Spectrum Australia, *Submission 11*, p. 5.

56 See for example: Carers Australia, *Submission 28*, p.5; Early Education (Early Ed) Inc, *Submission 60*, p. 2; Occupational Therapy Australia, *Submission 62*, pp. 3 and 9.

with their child's development'.⁵⁷ It recommended funding for counselling be made available for families and carers who care for a child newly diagnosed.

4.56 KU Children's services pointed out that because the NDIS focuses on individual supports, group support programs which supported families are no longer adequately funded to operate.⁵⁸

Sibling support

4.57 Submitters argued that the needs of siblings are being overlooked in the ECEI Approach and highlighted that siblings of children with a disability or developmental delay can experience a range of challenges, such as ongoing stress, which can affect their health, well-being, and contribution to society.⁵⁹

4.58 At a public hearing in Adelaide, Ms Kate Strohm, Founder and Director of Siblings Australia, explained the important role of siblings:

Siblings are also a key component of the sustainability of the NDIS. They are a major part of the informal support for a person with disability. But, again, there is no support for them. They are a key part succession planning as parents become older. Often, siblings will step in and take over that role.⁶⁰

4.59 Ms Strohm also pointed out the lack of dedicated policy or funding for sibling support under the NDIS:

Siblings are not in policy anywhere. There is a lot of rhetoric about families, but, unfortunately, here there is no mention of siblings. This is unlike in the UK, where the Children Act states that the needs of brothers and sisters should not be overlooked—they should be provided for as part of a package of services for the child with a disability.⁶¹

4.60 One submission provided a number of practical examples of how siblings could be supported, including through therapist facilitated sibling support groups or through individual therapy and counselling.⁶²

4.61 In response to the committee's question on supports available for siblings, the NDIA stated:

The National Disability Insurance Scheme funds supports that families need as a result of a family member's disability, such as:

57 Syndromes Without A Name (SWAN) Australia, *Submission 53*, p. 3.

58 KU Children's Services, *Submission 37*, p. 4.

59 For example: Siblings Australia, *Submission 3*, p. 2; Name Withheld, *Submission 5*, p. 5; Vision Australia, *Submission 22*, p. 5; Occupational Therapy Australia, *Submission 62*, pp. 3 and 9.

60 Ms Kate Strohm, Founder and Director, Siblings Australia, *Proof Committee Hansard*, 27 September 2017, p. 8.

61 Ms Kate Strohm, Founder and Director, Siblings Australia, *Proof Committee Hansard*, 27 September 2017, p. 8.

62 Name Withheld, *Submission 5*, p. 5.

- family support and counselling due to a family member's disability;
- building the skills and capacity of other family members to manage the impact of a Participant's disability on family life;

supports that increase the Participant's independence, as well as supports that enable the Participant to enjoy social and community activities independent of their informal carers; and

- supports aimed at increasing the sustainability of family caring arrangement, including personal care and domestic assistance related to the person's disability.⁶³

Committee view

Plans

4.62 The committee is concerned with the numerous reports of significantly underfunded Plans for ECEI Participants. The committee notes that the funding shortfalls and inconsistencies in Plans appear to particularly affect children with autism and those with hearing impairments.

Underfunded plans for children with autism

4.63 The committee received concerning evidence in relation to recurring funding shortfalls in Plans for children with autism. It appears that the level of funding granted in many Plans does not meet Participants' needs and does not align with recommended evidence-based practice guidelines. This is resulting in those children not accessing the right level of support and therapies to achieve optimal outcomes.

4.64 Alarmingly, the committee heard that NDIS funding levels are often lower than previous national funding models such as Helping Children with Autism. It is concerning that some Participants and their families are potentially worse off than under previous funding models.

4.65 With almost 40 per cent of NDIS Participants age 0–6 years having autism as their primary disability, it is of paramount importance that the NDIA urgently addresses the issues of scope and level of funding in Plans for children with autism.

Recommendation 11

4.66 The committee recommends the NDIA urgently address the issues of scope and level of funding in Plans for children with autism with a view to ensuring that recommended evidence-based supports and therapies are fully funded.

Underfunded plans for deaf and hard of hearing children

4.67 The committee has already made a number of recommendations in its interim report *Provision of Hearing services Under the National Disability Insurance Scheme*⁶⁴ to address funding shortfalls in Plans for deaf and hard of hearing children.

63 NDIA, answers to question on notice, 8 November 2017 (received 24 November 2017).

4.68 The committee reiterates its concerns regarding funding levels in Plans for deaf and hard of hearing children. The committee urges the NDIA to implement the *Provision of Hearing Services Under the National Disability Insurance Scheme* recommendation 5 in relation to early intervention packages.

Recommendation 12

4.69 The committee recommends the NDIA implement the Provision of Hearing Services under the National Disability Insurance Scheme recommendation 5 in relation to early intervention packages which says:

The committee recommends NDIA ensures that the early intervention packages take a holistic approach to the needs of Participants and include:

- **scaled funding, depending on need;**
- **funding provision for additional services beyond core supports, depending on need; and**
- **retrospective payment of the costs borne by approved service providers for the provision of necessary and reasonable supports between time of diagnosis and Plan enactment.**

Assistive technology

4.70 The committee believes that approval of funding for assistive technology should be systematically and consistently based on the Participant's individual needs to achieve optimal outcomes. The funding decision should not be based on minimising costs. As a result, the committee is concerned that some submitters suggested that Participants were given inappropriate assisted technology equipment to reduce costs. The committee acknowledges the existing NDIS operational guidelines on funding assistive technology available on the NDIS website.⁶⁵ The committee recommends the NDIA further clarifies in its guidelines its definition and interpretation of **minimum necessary** and **standard level** to determine funding for equipment in a Participant's Plan.⁶⁶

4.71 A major source of concern for families is the rejection of funding requests for certain items such as iPads, despite being recommended by therapists. According to the NDIS operational guidelines, the committee believes there is no reason for rejecting a request for a tablet or sensory equipment if it meets the following criteria:

64 Joint Standing Committee on the National Disability Insurance Scheme, *Provision of hearing services under the National Disability Insurance Scheme*, September 2017.

65 <https://www.ndis.gov.au/Operational-Guideline/including-4.html> (accessed 24 October 2017)

66 See following paragraph of operational guidelines: *Where assistive technologies are being considered, it is expected that the NDIA will generally only fund the **minimum necessary** or **standard level** of support required (i.e. a wheelchair with standard specifications and features, as opposed to funding additional items that are not related to the functional specifications required to meet the Participant's goal).*

[...]allows a Participant to perform tasks that they would otherwise be unable to do, or which increases the ease and safety with which tasks can be performed. [...] In addition to enabling Participants to be more independent or participate more fully in daily activities, assistive technology may:

- reduce the need for assistance;
- make assistance safe and sustainable; or
- prevent or slow the development of further impairment.⁶⁷

4.72 The committee believes the NDIA should clarify its guidelines in relation to funding non-specialised equipment.

Recommendation 13

4.73 The committee recommends the NDIA reviews and clarifies its Operational Guidelines on funding for assistive technology with the view of ensuring that Participants can access the most appropriate equipment to meet their needs.

Interpreters

4.74 The committee is concerned that costs for interpreters for families who need them appear not to be appropriately covered in Plans. The committee notes there is no specific information in the NDIS Operational Guidelines about supports in Plans for interpreters. However, there is a factsheet about Translation and Interpreting Services (TIS) available for Participants or their parents or carers which states that Participants with a Plan from a CALD background can access assistance from the National Translation and Interpreter Services when engaging with NDIA registered service providers.⁶⁸

4.75 The committee believes the NDIA needs to clarify its Operational Guidelines and ensures provision of funding for interpreters to enable efficient communication with Participants and their families.

Recommendation 14

4.76 The committee recommends funding be made available in Plans for interpreters, including funding an interpreter to communicate with the Participant's parents or carers.

Supports for families and carers

4.77 The committee believes access to supports for families and carers should be integral to the ECEI Approach. The committee agrees that, to date, the role of siblings of children with disability has been overlooked within the framework of the NDIS and its ECEI Approach. The committee believes that the NDIA should consider the

67 <https://www.ndis.gov.au/Operational-Guideline/including-4.html> (accessed 26 October 2017)

68 NDIA, *Translation and Interpreter Service Fact Sheet and FAQs* <https://www.ndis.gov.au/medias/documents/h9f/h3b/8803724886046/FAQs-TIS.pdf> (accessed 27 October 2017)

development of sibling specific supports and how these could be integrated into the ECEI Approach. Development of tailored programs should be considered and delivered through the Information, Linkages and Capacity Building (ILC).

Recommendation 15

4.78 The committee recommends the NDIA consider allocating specific funding for the development and provision of tailored support programs for parents, carers and siblings of children with disability through the ILC.

Delays in accessing and receiving services

4.79 As described by CYDA, 'early childhood is a well-established pivotal time for development and it is critical that children and families have timely access to expertise, services and supports during this time'.⁶⁹

4.80 Many submitters are thus concerned about the delays in receiving services under the ECEI Approach and the negative impacts these delays can have on the success of therapies and the future of their children and families.⁷⁰

4.81 Delays are not just occurring during the process to determine access to ECEI services and Planning phase to devise a first Plan but also once a child has a Plan.⁷¹

4.82 Ms Fleur Beaupert, Policy Officer at CYDA, reported that families experienced 'lengthy delays in accessing services' with some families 'waiting up to 18 months before accessing services'.⁷²

4.83 Similarly, Ms Teigan Leonard, Team Manager/Psychologist at Kalparrin Early Childhood Intervention Program Inc commented that they had 'families who have had to wait in excess of 90 days to be able to access any of their funds'.⁷³

4.84 The Royal Australasian College of Physicians expressed concern over long delays in South Australia for vulnerable children. This includes 'children in South Australia under the Guardianship of the Minister (GOM) waiting around 12 months between enrolment in the NDIS and therapy commencing'.⁷⁴

4.85 First Voice gave the following example from a service provider in South Australia:

69 CYDA, *Submission 74*, p. 8.

70 See for example: Early Childhood Intervention Australia, *Submission 10*, p. 4; Kids World Paediatric Therapy, *Submission 5*, p. 6; CYDA, *Submission 74*, p. 8;

71 See for example: Carers Australia, *Submission 28*, p. 3; Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 2; The Royal Australian College of General Practitioners, *Submission 57*, p. 1.

72 Ms Fleur Beaupert, Policy Officer, CYDA, *Committee Hansard*, 19 September 2017, p. 22.

73 Ms Teigan Leonard, Team Manager / Psychologist, Kalparrin Early Childhood Intervention Program Inc, *Committee Hansard*, 19 September 2017, p. 24.

74 Royal Australasian College of Physicians, *Submission 68*, p. 5.

Cora Barclay Centre statistics show there have been 48 new ECI referrals since the NDIS started of whom 11 (23%) commenced services with us 12 months or longer after confirmation of diagnosis. These include 3 who have taken longer than 2 years.⁷⁵

4.86 Other submitters⁷⁶ reported similar concerns, including Deaf Services Queensland, which attributes some of the delays in provision of services to provider availability, limited service options in some areas, and limited awareness from relevant Access Partner on possible pathways and services.⁷⁷

4.87 Long waiting lists to access relevant services are a common issue,⁷⁸ with one family reporting:

It took a whole year to access supports, but everything was booked out so my son's first plan was wasted. He used hardly any of his first plan because of waiting list times!⁷⁹

4.88 Disability sector staff shortages were identified as one of the contributing factors to delays in delivering services.⁸⁰

4.89 SDN Children's Services believes that 'the demand for ECEI support had been underestimated and this has increased waiting lists for new children'.⁸¹

4.90 As described by Deaf Services Queensland, issues of service delays are 'obviously exacerbated through the tyranny of distance and limited options of specialist providers within certain locations'.⁸²

Committee view

4.91 The committee is concerned with widespread reports of delays in accessing and receiving services for ECEI Participants with a Plan. This can significantly impact on the success of therapies and the ability of Participants to achieve optimal outcomes.

4.92 The committee noted that contributing factors to delays in accessing and receiving services for Participants are part of a broader range of issues across the Scheme, which include: overall disability staff shortages, underestimation of the demand for support, and the limited options of providers.

75 First Voice, answers to questions on notice, 27 September 2017.

76 See for example: RDI Consultants Australia, *Submission 27*, p. 1; Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 3; ACT Government, *Submission 66*, p. 9.

77 Deaf Services Queensland, *Submission 19*, p. 7.

78 See for example: AMAZE, *Submission 23*, p. 17.

79 CYDA, *Submission 74*, p. 8.

80 See for example: SDN Children's services, *Submission 35*, pp. 3–4; Commonwealth Ombudsman, *Submission 21*, p. 5; Muddy Puddles, *Submission 45*, p.3.

81 See for example: SDN Children's Services, *Submission 35*, p. 9.

82 Deaf Services Queensland, *Submission 19*, p. 7.

Costs of delivering services for service providers

4.93 Throughout the inquiry, ECEI service providers raised a number of issues regarding additional burdens and costs associated with operating as an ECEI service provider, the pricing of services and emerging gaps in funding.

Registration process and costs

4.94 Some service providers⁸³ expressed concerns about the registration process and the costs associated with becoming an NDIS service provider.

4.95 The Commonwealth Ombudsman stated:

Many smaller service providers, and even some larger ones, have also complained about the costs and administration associated with registering with the NDIS, claiming the arrangements are more onerous than the previous state requirements.⁸⁴

4.96 Speech Pathology Australia noted 'significant barriers to NDIS provider registration to deliver ECEI supports in some states and territories'.⁸⁵

4.97 Occupational Therapy Australia reported that 'The NDIA's apparent inability to engage meaningfully with service providers, and the difficulties involved in navigating the NDIA website, act as disincentives to registration as an NDIS provider'.⁸⁶

4.98 This has led to some services providers indicating they will not register as an NDIS provider and may mean that only larger service providers will remain in the market; reducing supply, decreasing competition and limiting choices for families.⁸⁷

4.99 For example, a small service provider explained:

To register for NDIS Early Childhood Supports as a new Provider is overly onerous; particularly for sole traders and small organisations [...] I need to make a business decision about whether I can absorb the costs associated with registration for NDIS. It is difficult to do this when I can't determine roughly what these costs will be. Many of my colleagues have decided not to register as the process is too onerous.⁸⁸

4.100 Speech Pathology Australia anticipates unmet need for speech pathology ECEI services unless issues with provider registration are addressed.⁸⁹

83 See for example: Occupational Therapy Australia, *Submission 62*, p. 11; Name Withheld, *Submission 4*, p. 1; Speech Pathology Australia, *Submission 33*, p. 24.

84 Commonwealth Ombudsman, *Submission 21*, p. 6.

85 Speech Pathology Australia, *Submission 33*, p. 24.

86 Occupational Therapy Australia, *Submission 62*, p. 4.

87 See for example: Commonwealth Ombudsman, *Submission 21*, p. 6; Name Withheld, *Submission 4*, p. 1.

88 Name Withheld, *Submission 4*, p. 1.

89 Speech Pathology Australia, *Submission 33*, p. 27.

4.101 The Dietitians Association of Australia drew the committee's attention to the issue of the exclusion of Accredited Practising Dietitians (APDs) from the Early Supports for Early Intervention Professional Registration Group.⁹⁰

4.102 Some submitters⁹¹ recommended streamlining the registration process for providers.

Administration costs

4.103 Submitters raised concerns about the pricing structure used by the NDIS. Significant new costs, including organisational overheads, are not reflected in the NDIS pricing structure.⁹²

4.104 The Victorian Autism Specific Early Learning and Care Centre noted that the NDIS Price Guide rates are often inadequate to cover the true costs of quality service provision as 'they do not allow for the necessary overheads of a well-coordinated (transdisciplinary) service'.⁹³

4.105 Similarly, Noah's Ark Inc argued:

The pricing structures being used by the NDIS are not realistic in a number of areas, including organisational overheads. There are significant new costs being introduced under the NDIS, including for marketing, administration (e.g. highly complex financial processes) and IT systems.⁹⁴

4.106 The Cora Barclay Centre reported absorbing significantly increased administration costs:

Under the NDIS, most of the very substantial burden of administration is borne by service providers and families/participants, not by the NDIA.⁹⁵

4.107 Ms Dee Hofman-Nicholls, Director at Enhanced Health Therapy Services, described the situation:

[...] for every one clinician we have on the ground we need a 0.6 FTE to support the administration costs of NDIA, which are exorbitant. Effectively, for \$175.57 we're paying two people's wages, not just one person's. When the new price guide came out with no increase to therapy cost because 'you are paid quite well,' it was quite insulting, because we aren't lining our

90 Dietitians Association of Australia, *Submission 36*, p. 3.

91 See for example: Early Childhood Intervention Australia Victoria/Tasmania, *Submission 7*, p. 7; Syndromes Without A Name (SWAN) Australia, *Submission 5*.

92 See for example: Refugee Council of Australia, *Submission 59*, p. 12; First Voice, *Submission 64*, p. 11; Early Childhood Intervention Australia NSW/ACT, *Submission 58*, p. 8.

93 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 4.

94 Noah's Ark Inc, *Submission 59*, p. 12.

95 First Voice, *Submission 64*, p. 19.

pockets. There are actual costs to administering the scheme. A lot of costs aren't being billed onto the client.⁹⁶

4.108 As a consequence, Mrs Hofman-Nicholls concluded that small businesses will stop operating:

Long term, small business will not be able to play in this field and it will return to what we had: several big service providers with long waiting lists and reduced or very little choice and control. There are some very, very, very fatal flaws that will affect small business continuing in this scheme.⁹⁷

Non-attendance at appointments

4.109 Occupational Therapy Australia and other submitters⁹⁸ reported that service providers are financially disadvantaged by clients who fail to keep appointments despite some recent adjustments to arrangements that partially compensate providers for non-attendance.

4.110 Until 30 June 2017, the NDIS price policy prohibited cancellation charges. The policy was amended, and from 1 July 2017, the NDIA advised that:

Providers may charge for up to 2 participant cancellations for therapeutic supports per annum. Each cancellation charge must be for no more than 2 hours of support, and may only be applied where the participant has failed to give 24 hours' notice.⁹⁹

4.111 Noah's Ark Inc noted that the NDIS rule on cancellation has been modified but considers that it is not enough for service providers supporting young children:

Young children, as is generally understood in the community, become ill more quickly and more frequently than older children and adults. As a result, the cancellations policy has a more adverse effect on service providers supporting young children.¹⁰⁰

4.112 According to Occupational Therapy Australia, the lack of compensation for cancellations is a contributing factor to providers not being able to have a reliable income and ultimately leaving the sector, especially in regional, rural and remote areas.¹⁰¹

96 Ms Dee Hofman-Nicholls, Director at Enhanced Health Therapy Services, *Committee Hansard – Implementation and performance of the NDIS*, 26 September 2017, p. 12.

97 Ms Dee Hofman-Nicholls, Director at Enhanced Health Therapy Services, *Committee Hansard – Implementation and performance of the NDIS*, 26 September 2017, p. 12.

98 Occupational Therapy Australia, *Submission 62*, p. 22; and see for example: Early Childhood Intervention Australia Victoria/Tasmania, *Submission 7*, p. 8; Early Childhood Intervention Australia (National), *Submission 10*, p. 5; Noah's Ark Inc, *Submission 59*, p. 12.

99 NDIA, *Letter to Registered NDIS Providers from CEO David Bowen*, 12 June 2017. <https://www.ndis.gov.au/news/letter-to-ndia-registered-providers.html> (accessed 25 October 2017).

100 Noah's Ark Inc, *Submission 59*, pp. 12–13.

101 Occupational Therapy Australia, *Submission 62*, p. 22.

Peer and group therapy

4.113 Pricing guidelines also impacted the provision of peer and group therapy services. Occupational Therapy Australia told the committee that:

The NDIS is currently not providing funding options for young children to attend small social group therapy. Currently, group therapy is funded at a rate that is not viable for clinics to implement, with rigid therapist to child ratios that do not take into account the needs of the child.¹⁰²

4.114 Some submitters argued that changes to the NDIS Price Guide are needed to reflect the costs of providing peer therapy to children with developmental disabilities who are transitioning from individual to group therapy.¹⁰³

Committee view

4.115 The evidence received to date about the registration process suggests that the current system is not operating as well and effectively as it should be. The committee also noted the issues around increased administration costs borne by providers and pricing issues. All these issues are threatening the sustainability of providers, especially sole traders and small organisations to operate in the NDIS environment. This has the potential to further limit choices for Participants and further extend delays in accessing and receiving services.

4.116 The committee acknowledges that, in response to the wide range of issues raised in the FY2017–18 Price Review, the NDIA has commissioned an Independent Pricing Review, which is currently being undertaken by McKinsey & Company. The committee understands that the Review will deliver its Final Report by the end of 2017.¹⁰⁴

4.117 The committee also notes finding 8.1 of the Productivity Commission in its recently released Study Report on NDIS Costs, which states that 'the benefits of the NDIS will not be fully realised if the Agency continues with its current pricing approach'.¹⁰⁵

4.118 Once released, the committee will consider the Independent Pricing Review report within the broader context of the NDIS market readiness.

Provision of ECEI services in rural and remote areas

4.119 Accessing and delivering services in rural and remote areas presents some challenging issues. Issues raised by service providers include lack of funding for travel and use of innovative technologies to deliver appropriate services.

102 Occupational Therapy Australia, *Submission 62*, p. 9.

103 See for example: Occupational Therapy Australia, *Submission 62*, p. 9; Name Withheld, *Submission 5*, p. 3.

104 <https://www.ndis.gov.au/news/letter-to-ndia-registered-providers.html> (accessed 25 October 2017).

105 Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, p. 55.

Transport

4.120 Transport costs for service providers to deliver services in rural and remote areas are high. Dr Jennifer Fitzgerald, CEO, Scope Australia described the situation:

Transport, particularly for us in rural and regional Victoria, is a major problem. We are unable to bill between services. We can bill for the first 40 minutes of the day. Our practitioners see approximately five or six children a day, if they're out on the road, particularly in rural and regional Victoria. All of that time and the actual cost of the vehicle—mileage cost, depreciation, maintenance and purchase—is unfunded.¹⁰⁶

4.121 Mrs Amanda Mather from Hear and Say reported that, due to lack of specialist services in rural and remote communities, Hear and Say has to travel to adequately support families and noted that 'the travel allowances that are currently provided for in the NDIS are inadequate and not satisfactory for the size and nature of Queensland'.¹⁰⁷

4.122 Deaf Services Queensland described travel as being the 'single most complex issue in terms of adequate funding to provide support, particularly in locations where the Participant does not live close to services'.¹⁰⁸ Their submission highlighted that 'the \$1000 a year limit on travel for therapists (across all therapy support delivered) does not provide fair and equitable access to supports and services for clients living in more regional areas or clients who are financially challenged and don't have access to transport to attend sessions'.¹⁰⁹

4.123 Similarly, Speech Pathology Australia highlighted that the limits for payment for provider travel can restrict access to specialised supports:

Rulings regarding NDIS payment for travel by providers further restricts access to these specialised speech pathology services to NDIS Participants who need them. Defining strict limits for payment for provider travel in all Participants plans and not allowing flexibility in travel expenses for individual Participants means that children who required the services of a speech pathologist with specialised expertise may not be viable to purchase within the parameters of the funded plan if that practitioner is located a significant distance away from the child.¹¹⁰

4.124 Vision Australia believes it is unfair for families and service providers to be put in a situation where they are required to draw down on Participants' support

106 Dr Jennifer Fitzgerald, CEO, Scope, *Committee Hansard*, 19 September 2017, p. 10.

107 Mrs Amanda Mather, Director of Sustainability and Strategic relations, Hear and Say, *Committee Hansard*, 26 September 2017, p. 5

108 Deaf Services Queensland, *Submission 19*, p. 9.

109 Deaf Services Queensland, *Submission 19*, p. 9.

110 Speech Pathology Australia, *Submission 33*, p. 22.

budgets for purposes of travel as this may impede them receiving adequate supports.¹¹¹

4.125 At a public hearing in Melbourne, Mr Scott Jacobs from Vision Australia further explained:

When you do bill for travel, it comes out of the support budget for the participants. In theory the participant is given an allocation within that budget that is intended for travel. It's not separated out, and the justification or rationale that leads to how much travel might be included in that support budget is not ever clear. If you have multiple providers billing travel, the limits are different for adults and children, but you are drawing down on what could potentially be your support budget for service delivery, which from a provider perspective is an ethical quandary and is not a particularly pleasant one. What would be ideal would be to have a specific limited budget for provider travel to be able to have the access that doesn't touch the support budget for families.¹¹²

4.126 Many submitters recommended allocation of additional funding, on top of the loading currently provided, for travel to address the significant challenges for families and service providers in rural and remote areas.¹¹³

Technology

4.127 AMAZE submitted that emerging research supports the efficacy of delivery of therapeutic services to remote locations via videoconferencing facilities.¹¹⁴

4.128 Speech Pathology Australia recommended greater use of videoconferencing to communicate with clients and families living in rural and remote areas.¹¹⁵ Similarly, Connect and Relate for Autism Inc argued that a telehealth service model can significantly reduce the demands and costs associated with families needing to travel long distances to access services.¹¹⁶

4.129 However, Early Childhood Intervention Australia reported 'inadequate resourcing of technology to enable collaboration and access to remote areas and consultations' and recommended 'funding for ICT infrastructure and technology solutions to enable case-conferencing, skype/online consultations and chat rooms and e-referral'.¹¹⁷

111 Vision Australia, *Submission 22*, p. 4.

112 Mr Scott Jacobs, National Disability Insurance Scheme Lead, Vision Australia, *Committee Hansard*, 19 September 2017, p. 10.

113 See for example: Syndromes Without A Name (SWAN) Australia, *Submission 53*, p. 5; ECIA NSW/ACT, *Submission 58*, p. 6; Firstchance Inc, Early Links Inclusion Support, Hunter Prelude, RIDBC, *Submission 25*, p. 7.

114 AMAZE, *Submission 23*, p. 18.

115 Speech Pathology Australia, *Submission 62*, p. 3.

116 Connect and Relate for Autism Inc, *Submission 13*, p. 4.

117 Early Childhood Intervention Australia, *Submission 10*, p. 5

4.130 Lifestart suggested that 'investment in the use of technology for some ECEI service provision is one way to resolve accessibility issues in some rural and remote areas'.¹¹⁸ Hear and Say also recommended 'improving funding for technology to assist with access to tele practice services'.¹¹⁹ Similarly, AMAZE called for the Australian Government and the NDIA to consider 'innovative service delivery methods such as telehealth models to mitigate potential market failure'.¹²⁰

4.131 Overall, Participants recommended a review of costs of service provision in regional, rural and remote areas.¹²¹

Committee view

4.132 The committee understands there can be significant additional costs to deliver services in rural and remote areas, including costs associated with travel. The committee noted that the new NDIA Price Guide, introduced on 1 July 2017, incorporates a series of changes, including an increased price loading to apply for the delivery of supports to Participants in remote and very remote parts of Australia.¹²² However, it appears that the issue of travel costs remains a significant cause of concern for services providers. The committee believes it is too early to evaluate the impact of the recently introduced increased price loading for delivery of supports in remote areas.

4.133 The committee notes with interest the call for a greater use of technology, especially videoconferencing for delivering services in rural and remote Australia. Submitters identified videoconferencing as an efficient and cost effective way to deliver some types of services. The committee believes technological solutions to deliver services should be encouraged as long as the quality of services is not compromised. The NDIA should, as part of progressing its rural and remote strategy, investigate how it can better support Participants and service providers to use technology.

Recommendation 16

4.134 The committee recommends the NDIA develop a strategy to foster greater use of technology to deliver services in regional, rural and remote areas.

Workforce availability, remuneration and training

4.135 ECEI service providers expressed concerns around the availability of a suitably qualified and experienced workforce.¹²³ Inadequate remuneration and lack of

118 Lifestart, *Submission 51*, p. 11.

119 Hear and Say, *Submission 44*, p. 8.

120 AMAZE, *Submission 23*, p. 18.

121 See for example: Early Childhood Intervention Australia Victoria/Tasmania, *Submission 7*, p. 12; Syndromes Without A Name (SWAN) Australia, *Submission 53*, p. 3.

122 NDIA, *2017/2018 Price Guide for NDIS service providers*, <https://www.ndis.gov.au/providers/pricing-and-payment.html> (accessed 26 October 2017)

123 See for example: Early Childhood Intervention Australia (National), *Submission 10*, p. 9; Scope, *Submission 17*, p. 4; Carers Australia, *Submission 28*, p. 4.

training and professional development opportunities were identified by submitters¹²⁴ as major contributors to current staff shortages.

Workforce remuneration

4.136 SDN Children's Services highlighted the inability for service providers to recruit and retain staff due to the limited funding available under the ECEI Approach.¹²⁵

4.137 Early Childhood Intervention Australia Victoria/Tasmania raised concern about funding constraints that 'will lead to the employment of graduates with lower qualifications and/or less experience'.¹²⁶

4.138 Carers Australia stated that specialists are 'often in short supply, especially when they may have more attractive employment conditions in the health sector'.¹²⁷

4.139 Occupational Therapy Australia argued that the ECEI Approach should ensure the viability of providers who work in a variety of capacities (as sole providers, in multi-disciplinary private practices, as part of NGOs) 'by recognising the costs of delivering services and ensuring these are offset by appropriate remuneration'.¹²⁸

Workforce training

4.140 National Disability Services and others¹²⁹ expressed concerns about the NDIS pricing model, which limits opportunities for training and professional development. This could contribute to workforce shortages in the future.

4.141 Noah's Ark Inc noted 'there is little indication that the NDIS costing has considered the recruitment and training of new staff or the need to provide careers for allied health professionals and teachers, who have other career opportunities in health and education'.¹³⁰

4.142 Early Childhood Intervention Australia NSW/ACT expressed the view that 'the ECEI Approach needs to assist with the mentoring of the future ECI workforce. This has cost implications and the funding should support the development of our future workforce'.¹³¹

124 See for example: Lifestart, *Submission 51*, p.7; Occupational Therapy Australia, *Submission 62*, p. 25; Early Childhood Intervention Australia NSW/ACT, *Submission 58*, p. 14.

125 SDN Children's Services, *Submission 35*, p. 5.

126 Early Childhood Intervention Australia Victoria/Tasmania, *Submission 7*, p. 11.

127 Carers Australia, *Submission 28*, p. 4.

128 Occupational Therapy Australia, *Submission 62*, p. 25.

129 National Disability Services, *Submission 14*, p. 4; and see for example: Lifestart, *Submission 51*, p.7; Noah's Ark Inc, *Submission 59*, p. 2.

130 Noah's Ark Inc, *Submission 59*, p. 2.

131 Early Childhood Intervention Australia NSW/ACT, *Submission 58*, p. 14.

4.143 National Disability Services and others¹³² recommended the development of a strategy for responding to skilled practitioner shortages.¹³³ Similarly AMAZE identified the need for 'a concentrated effort by Government to stimulate growth in the skilled disability workforce'.¹³⁴

Committee view

4.144 Workforce shortages are well documented. As described by the Productivity Commission in its recent Study Report on NDIS costs,¹³⁵ the disability sector workforce will need to double and in some regions triple or more over the transition period to meet demand. It is not surprising, therefore, that this issue was raised in the context of this inquiry.

4.145 The committee received evidence that workforce remuneration, training and professional development issues contribute to current challenges. The committee believes these important issues warrant further work and analysis, and be considered within the broader context of market and workforce readiness.

132 See for example: Noah's Ark Inc, *Submission 59*, p. 12; Early Childhood Intervention Australia (National), *Submission 10*, p. 3;

133 National Disability Services, *Submission 14*, p. 4.

134 AMAZE, *Submission 23*, p. 17.

135 Productivity Commission, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, October 2017, p. 36.

Chapter 5

Adequacy and accessibility of the Approach

5.1 This chapter explores adequacy of information and accessibility of the ECEI Approach.

Adequacy of information

5.2 Families and carers require accurate and accessible information to be able to make informed decisions about their child's early intervention.

5.3 Evidence received indicates widespread dissatisfaction with the quality of information currently available.¹ Submitters highlighted that information about the ECEI Approach is uncoordinated and can only be found through several sources, such as the NDIS Act, PITC Program Grant documentation, NDIS *Price Guide*, *Operational Guidelines*, and the NDIS website.²

5.4 The committee received feedback that even experienced staff working for specialist service providers are finding it difficult to locate relevant and definitive information.³ Ms Michelle Crozier, NDIS Project Manager, Deaf Services Queensland, argued that information could be presented in a more user-friendly way:

I consider myself quite well versed in the NDIS. I do a lot of research, I address all our internal questions and I have an academic background in it, but I still cannot find information doing a simple google search on the website. It is incredibly frustrating. It requires that I read the operational guides or it requires that I find the bilateral agreements. It requires that I know all of those things quite intimately if I'm going to give a factual and correct answer to a participant who just wants something very basic. I find that an incredibly frustrating part of it. Yes, the information is there—I won't say it's not—but to actually interpret it, translate it, find it and deliver

1 For example: ECIA National, *Submission 10*, p. 7; Deaf Services Queensland, *Submission 19*, p. 14; Firstchance Inc, Early Links Inclusion Support, Hunter Prelude, RIDBC, *Submission 25*, p. 6; Speech Pathology Australia, *Submission 33*, p. 2; Royal Institute for Deaf and Blind Children, *Submission 40*, p. 10; Occupational Therapy Australia, *Submission 62*, pp. 10–11; Australian Psychological Society, *Submission 70*, p. 3.

2 For example: ECIA Victoria/Tasmania, *Submission 7*, p. 4; ECIA National, *Submission 10*, p. 2; Vision Australia, *Submission 22*, p. 3.

3 For example: Vision Australia, *Submission 22*, p. 3; Ms Katrina Ives, NDIS Support Coordinator, AEIOU Foundation, *Proof Committee Hansard: General issues around the implementation and performance of the NDIS*, 26 September 2017, p. 8; Ms Dee Hofman-Nicholls, Director, Enhanced Health Therapy Services, *Proof Committee Hansard: General issues around the implementation and performance of the NDIS*, 26 September 2017, p. 12; Ms Michelle Crozier, NDIS Project Manager, Deaf Services Queensland, *Proof Committee Hansard: General issues around the implementation and performance of the NDIS*, 26 September 2017, p. 17.

it to a participant who has no service literacy is an incredibly frustrating experience.⁴

5.5 Ms Natalie Rose, Manager, Advocacy and Engagement, Li-Ve Tasmania, argued that, for individuals who do not understand the system and are just reading the Agency's documents, 'it's probably not going to be enough'.⁵

Lack of overarching policy information

5.6 Submitters pointed out that information about the ECEI Approach is currently available through a range of sources. However, the information is fragmented and fails to provide an overarching explanation of how the ECEI Approach will support children with disability or developmental delay and their families.⁶

5.7 Submitters expressed concern that there is no uniform understanding of what Early Childhood Partners should be delivering as part of short-term interventions.⁷

5.8 At the public hearing in Sydney, Ms Kay Turner, Chief Executive Officer, SDN Children's Services, argued there needs to be discussion around how Partners should best use their short-term funds to support families:

...there have been different approaches to early intervention across the country. But there have been issues, as there are in human services, in demonstrating efficacy—which things lead to the outcomes? For very young children, development is happening anyway and young children are involved in families, so it is very hard to draw correlations between what is working and what isn't. The literature around best practice early intervention is available, but when we look at ECEI with the broad requirements and the very short-term interventions, I would say the evidence is not clear for consistency nationally about what those short-term interventions should be. There could be a range of selected processes. For New South Wales, for example, our funding envelope would have been around \$6,000 per place. So to make a decision about what would work when you have, say, \$1,500 per child needs to be a discussion.⁸

5.9 Peak body, Early Childhood Intervention Australia (ECIA), argued that the development of a national policy and guidelines for the Approach would improve

4 Ms Michelle Crozier, NDIS Project Manager, Deaf Services Queensland, *Proof Committee Hansard: General issues around the implementation and performance of the NDIS*, 26 September 2017, p. 17.

5 Ms Natalie Rose, Manager, Advocacy and Engagement, Li-Ve Tasmania, *Proof Committee Hansard*, 4 October 2017, p. 13.

6 For example: ECIA Victoria/Tasmania, *Submission 7*, p. 4; and ECIA National, *Submission 10*, p. 2.

7 For example: ECIA Victoria/Tasmania, *Submission 7*, p. 4; and Ms Kay Turner, Chief Executive Officer, SDN Children's Services, *Proof Committee Hansard*, 3 October 2017, p. 9.

8 Ms Kay Turner, Chief Executive Officer, SDN Children's Services, *Proof Committee Hansard*, 3 October 2017, p. 9.

procedural consistency across jurisdictions, provide clarity, improve response times, and reduce confusion.⁹

NDIS website

5.10 Submitters were critical of the NDIS website, and expressed a myriad of concerns; including that it lacks clear information about the ECEI Approach, is fragmented, un navigable, has had documents changed or removed, and provides contradictory information.¹⁰ According to the Victorian Autism Specific Early Learning and Care Centre, families across the spectrum are experiencing difficulty finding relevant information online.¹¹ Ms Dee Hofman-Nicholls, Director, Enhanced Health Therapy Services, encapsulated the criticism when she likened the Agency's website to a 'rabbit warren'.¹²

Suggestions for improvement

5.11 The Commonwealth Ombudsman argued that the NDIA could better manage the expectations of families, providers, and professionals involved in the ECEI Approach by improving its online material. The Ombudsman suggested the Agency publish information about the focus of the ECEI Approach, what can and can't be covered under the Scheme, why Plans may vary, the likely timeframe for receiving a Plan, and review rights.¹³

5.12 The Royal Children's Hospital submission suggested that information should be relevant to the child's age and difficulties, and provide links to related services, such as Medicare rebates and community services.¹⁴

5.13 AMAZE argued that the website should provide cohort-specific information, for example, a dedicated autism section.¹⁵ Similarly, Mr Brett Casey, Chief Executive Officer, Deaf Services Queensland, argued that information for the deaf community should be made available in Auslan:

If we're talking about the website and access to the plan, all of it is English based...there is no information...in Auslan. The NDIA recently, early this year, provided some information in Auslan, but we had the rollout start in

9 ECIA National, *Submission 10*, p. 2.

10 For example: ECIA National, *Submission 10*, p. 7; Deaf Services Queensland, *Submission 19*, p. 14; Firstchance Inc, Early Links Inclusion Support, Hunter Prelude, RIDBC, *Submission 25*, p. 6; Speech Pathology Australia, *Submission 33*, p. 2; Royal Institute for Deaf and Blind Children, *Submission 40*, p. 10; Occupational Therapy Australia, *Submission 62*, pp. 10–11; Australian Psychological Society, *Submission 70*, p. 3.

11 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 6.

12 Ms Dee Hofman-Nicholls, Director, Enhanced Health Therapy Services, *Proof Committee Hansard: General issues around the implementation and performance of the NDIS*, 26 September 2017, p. 13.

13 Commonwealth Ombudsman, *Submission 21*, p. 8.

14 Royal Children's Hospital, *Submission 20*, p. 7.

15 AMAZE, *Submission 23*, p. 15.

July in Queensland last year and until recently there was no information available in Auslan. Even the information they do now have available is limited... 'What is the NDIS?' and 'Accessing the NDIS' are very, very short videos that have been made publicly available. In terms of fairness and accessibility, deaf community members are so far behind in getting access to information...¹⁶

5.14 Noah's Ark argued that information about ECEI Partners should clarify the multiple roles they are undertaking, and provide information about the Partner's relationship with the community.¹⁷

5.15 Service providers argued that the website should also include information:

- for prospective providers interested in learning about the Scheme;
- on the model of intervention being implemented;
- to alert stakeholders about changes to policy and procedure;
- that is consistent with the 1800 line;
- on conflict of interest;
- on how Planning priority is determined; and
- provide timeframes for determining Access and Plan approvals.¹⁸

General practice

5.16 The Royal Australian College of General Practitioners (RACGP) stressed the importance of the role of General Practitioners (GPs) in the ECEI Approach. It highlighted that GPs are often the first to meet with families who have concerns about their child's development, and play a significant role as sources of information and advocacy, in the diagnostic process, referral to services, and managing associated health issues.¹⁹

5.17 The RACGP argued that the NDIS is currently underutilising this network of professionals. A recent poll conducted by the RACGP found that 93 per cent of respondents 'had little information to help facilitate NDIS requests' from families.²⁰

5.18 Dr James Best, Member, Specific Interests Child and Young Person's Health Network, RACGP, told the committee that general practice was frustrated it had not

16 Mr Brett Casey, Chief Executive Officer, Deaf Services Queensland, through Ms Amy McCusker, Professional Interpreter, Auslan Connections, *Proof Committee Hansard: General issues around the implementation and performance of the NDIS*, 26 September 2017, p. 16.

17 Noah's Ark, *Submission 59*, p. 8.

18 For example: Firstchance Inc, Early Links Inclusion Support, Hunter Prelude, RIDBC, *Submission 25*, p. 6; Royal Institute for Deaf and Blind Children, *Submission 40*, p. 10; Occupational Therapy Australia, *Submission 62*, pp. 10–11.

19 Royal Australian College of General Practitioners, *Submission 57*, p. 3.

20 Royal Australian College of General Practitioners, *Submission 57*, p. 3.

had enough input during the development of the NDIS, which has made consistent communication with families difficult:

We really are a bit in the dark once we send people off to the NDIS to make an application, and we're frustrated that we don't have enough input into the process. It all seems a bit of a mystery once it goes over to the NDIS, and we certainly don't get any feedback, as well as not being integrated into the process.²¹

5.19 While Dr Best acknowledged that NDIS general practice fact sheets would assist in one respect, he argued that education programs targeting the role of GPs in the ECEI process would be of greater benefit to the sector.²²

NDIA response

5.20 The Agency drew the committee's attention to its general communication efforts targeting GPs and other health professionals. For example: publications; information booths and presentations at GP conferences; advertisement on the Australian Medical Association's 2017 GP Year Planner; and an article in the December 2017 *Good Practice* magazine.

Committee view

NDIS website

5.21 The committee acknowledges that the NDIA has made efforts to publish a range of ECEI-related material on its website. However, it agrees with submitters that the quality of information currently available for families and carers could be improved. The committee is concerned by reports that even experienced personnel working in the sector are having difficulties locating relevant information.

5.22 The NDIA should ensure that information on the NDIS website is logically presented. All information should be clearly dated, indicate if it has been superseded, and identify related historical information. Information relevant to the ECEI Approach should consolidate information from multiple sources, and remove redundant and contradictory information. Tailored information should be provided for disability cohorts, such as Auslan and ASD. The Agency should incorporate submitters' suggestions for improvement, such as: providing a substantive explanation of the ECEI Approach, its purpose and focus, the role of Early Childhood Partners, why Plans may vary, Participants' review rights, and link to websites with relevant information for families.

21 Dr James Best, Member, Specific Interests Child and Young Person's Health Network, Royal Australian College of General Practitioners, *Proof Committee Hansard*, 19 September 2017, p. 6.

22 Dr James Best, Member, Specific Interests Child and Young Person's Health Network, Royal Australian College of General Practitioners, *Proof Committee Hansard*, 19 September 2017, p. 3.

Recommendation 17

5.23 The committee recommends that the NDIA consult and engage with key stakeholders to continually improve ECEI information on its website.

Information for GPs

5.24 GPs are often the first point of contact for families with concerns about their child's development, therefore the committee is of the view that particular attention should be given to information and resources for general practice.

5.25 The Agency's *GP's Guide to the NDIS* factsheet provides brief information regarding the general pathway, such as: how GPs can provide supporting evidence for an Access Request, and the process once a person is granted access to the Scheme.²³ However, it does not provide GPs with substantive information about the ECEI Approach.

5.26 The NDIA should harness the opportunity general practice offers as a source of information to families with concerns about their child's development. GPs should be provided with information about the ECEI Approach, the role of Early Childhood Partners, how eligibility is determined for children under the early intervention requirements, what supports and services might consist of, and be provided with details of the ECEI Partner arrangements in their Service Area.

Independent information

5.27 Submitters raised concerns that families of children with a disability or developmental delay can be overwhelmed by new information at a time when they are unsure what to look for.²⁴

5.28 Professor Matthew Sanders, Professor of Clinical Psychology and Director, Parenting and Family Support Centre, University of Queensland, argued that more can be done to improve the ability of families and carers to exercise the principle of choice under the ECEI Approach. He drew the committee's attention to the current lack of independent information about evidence-based practices, and the evidence of their value to particular populations:

If we had a website where all evidence based practices that are pushed out there as having value to this population were accessible directly to parents as consumers, they could have a look at and get a feel for what the intervention involves, what their commitment is and what their requirement is. They could make judgements about whether they feel they have the capacity to engage in what's being required of them in the intervention...If you...inform the consumer better about the different products that are available and had some common lens through which to look at all of

23 NDIS, *A GP's Guide to the NDIS*, <https://www.ndis.gov.au/medias/documents/hb6/h13/8803902619678/GP-Factsheet-web.pdf> (accessed 7 November 2017).

24 Name Withheld, *Submission 4*, p. 1; AMAZE, *Submission 23*, p. 14. Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 6; Hear and Say, *Submission 44*, p. 6.

them...parents, with an adviser, could make a truly informed choice about whether it would be worthwhile to invest their time, effort, money and resources as an individual...²⁵

5.29 Peak body, ECIA, advised that it is currently developing online modules to help families and service providers understand what best practice might mean,²⁶ however, this does not address the absence of a consolidated, comprehensive hub of information from the NDIA about available practices and their substantiated benefit to certain cohorts.

Vulnerable cohorts

5.30 Submitters raised concerns that vulnerable families may be at risk of disadvantage under the ECEI Approach, as parental competence and advocacy skills can directly impact the level of funding allocated to a child. This in turn, can result in inconsistencies between the levels of funding allocated to families that can clearly communicate their child's needs and those that struggle to articulate the services required.²⁷

5.31 Ms Maureen Fordyce, Manager, AMPARO Advocacy Inc, described the difficulty some vulnerable families can face:

We have an example of a family in Toowoomba with very complex needs and from a refugee background needing access to interpreters. They provided evidence from their local GP about their disability, and that evidence was inadequate, so the NDIA wrote to them and asked for further evidence. They couldn't read the letter and they had no-one in their lives to explain what was required, so they never responded within the time frame. So when we contacted them, they had to restart their application to the NDIS again. That is not uncommon, from our previous experience, with people trying to access services.²⁸

5.32 During the committee's hearing in Melbourne, NDIA officials assured the committee that the role of the ECEI Partner, and individualisation of packages, is intended to mitigate potential inequity:

We are expecting our partners to be out in the community and to visit families and children in the home and natural settings...they can go into a home and get a really good understanding of what the informal supports are for the child, and if there is a need for some more supports, from a child and family support perspective. It's not actually around the family

25 Professor Matthew Sanders, Professor of Clinical Psychology and Director, Parenting and Family Support Centre, University of Queensland, *Proof Committee Hansard*, 26 September 2017, p. 14.

26 Ms Trish Hanna, President, ECIA, *Proof Committee Hansard*, 3 October 2017, p. 17.

27 For example: Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 3; Hear and Say, *Submission 44*, p. 4; Occupational Therapy Australia; *Submission 62*, p. 4; Australian Psychological Society, *Submission 70*, p. 3.

28 Ms Maureen Fordyce, Manager, AMPARO Advocacy Inc, *Proof Committee Hansard: General issues around the implementation and performance of the NDIS*, 26 September 2017, p. 5.

advocating...the package for the child in the first place, or how they target the supports for that family, should be geared to where the family is at, and in making sure that if there's additional supports required to address the needs of a child, that happens... the individualised package, or the planning and the support that will be targeted to what's required. So yes, a family that is more middle-class, and doesn't need more or other linkages to community or services—as, perhaps, a more vulnerable family would—that would look differently in that way.²⁹

5.33 The Victorian Autism Specific Early Learning and Care Centre argued that establishing and funding advocacy support services for vulnerable ECEI families is an essential safeguarding framework that must be built into the NDIS.³⁰

5.34 The Royal Australasian College of Physicians argued that programs specifically designed to identify and support vulnerable families should be developed, and charged with identifying developmental delay and providing advice and referrals.³¹

5.35 Ms Teigan Leonard, Team Manager/Psychologist, Kalparrin Early Childhood Intervention Program Inc, argued that there is currently a lack of support for families:

I think it's also using an advocacy model to support the families, and that's certainly what we find families are looking for. Your planning meeting is challenging. You're talking about your child on their worst possible day and all of the things that you need help with as a parent. Some families have described it as throwing your child under the bus. Having an advocate there who can help you say what you're trying to say in a way that is meaningful and who can support you afterwards as well—I think that's the model that's needed in this sector.³²

5.36 AMAZE recommended that a trusted, independent, and experienced organisation should be commissioned to develop resources about autism for a range of audiences in co-design with the NDIA, including autistic parents/carers, CALD communities, and Aboriginal and Torres Strait Islander populations to assist families in navigating the system.³³

Committee view

5.37 The committee is of the view that ECEI Partners do not currently have the capacity or funding to conduct essential outreach and support services for vulnerable cohorts. The committee agrees with the Productivity Commission that adequately resourcing Information, Linkages and Capacity Building (ILC) is critical to ensure

29 Mrs Christine McClelland, Director, ECEI National Office Team, NDIA, *Proof Committee Hansard*, 8 November 2017, p. 6.

30 Victorian Autism Specific Early Learning and Care Centre, *Submission 43*, p. 3.

31 Royal Australasian College of Physicians, *Submission 68*, p. 11.

32 Ms Teigan Leonard, Team Manager/Psychologist, Kalparrin Early Childhood Intervention Program Inc, *Proof Committee Hansard*, 19 September 2017, p. 29.

33 AMAZE, *Submission 23*, p. 15.

people with disability are connected with appropriate services.³⁴ Whether this is put in place through an advocacy model, or some other type of support model, the committee welcomes the Commission's recommendation that ILC funding should be increased throughout the NDIS transition phase. The committee considers that allocating specific funding for information and support for vulnerable families to connect with ECEI Partners through the ILC program is essential to the success of the ECEI Approach.

Recommendation 18

5.38 The committee recommends that the NDIA allocate specific funding for information and support for vulnerable families to connect with ECEI Partners through the ILC.

Accessibility of Approach

Aboriginal and Torres Strait Islander communities

Absence of culturally sensitive pathways

5.39 There are concerns that the unique cultural circumstances of Aboriginal and Torres Strait Islander people are not being taken into consideration under the ECEI Approach.³⁵ For example, the Planning process does not account for flexible family and kinship arrangements,³⁶ and the design and use of assessment tools are inappropriate for Aboriginal and Torres Strait Islander communities.³⁷

5.40 The committee heard evidence that the concept of 'disability' is not one that Aboriginal and Torres Strait Islander people readily identify with,³⁸ and there is often no equivalent term for 'disability' in many Aboriginal languages.³⁹

5.41 The Queensland Government raised concerns that engaging one ECEI Partner for each geographical location may have a negative impact for Aboriginal and Torres Strait Islander children who require culturally appropriate supports.⁴⁰

5.42 Submitters argued for improved cultural competency within the NDIA, and non-Indigenous providers, and for services to be tailored to meet the needs of Aboriginal and Torres Strait Islander people.⁴¹

34 Productivity Commission, *NDIS Costs*, Study Report, October 2017, p. 236.

35 For example: Commonwealth Ombudsman, *Submission 21*, p. 7; AMSANT, *Submission 56*, pp. 1–5.; Queensland Government, *Submission 75*, p. 10.

36 Commonwealth Ombudsman, *Submission 21*, p. 7.

37 AMSANT, *Submission 56*, pp. 1–5.

38 Commonwealth Ombudsman, *Submission 21*, p. 7.

39 Dr Nick Collyer, Systems Advocate, Queensland Advocacy Inc, *Proof Committee Hansard*, 26 September 2017, p. 9.

40 For example: Commonwealth Ombudsman, *Submission 21*, p. 7; AMSANT, *Submission 56*, pp. 1–5; Queensland Government, *Submission 75*, p. 10.

41 Queensland Government, *Submission 75*, p. 10.

5.43 ECIA highlighted that there are currently few incentives for service providers to actively show that they are able to respond to the needs of Aboriginal and Torres Strait Islander communities. It suggested that early intervention services should be required to incorporate cultural awareness training for staff.⁴²

General accessibility concerns

5.44 In addition to specific cultural needs of Aboriginal and Torres Strait Islander communities, the remoteness of some communities means there is limited phone and internet coverage for access to the portal or the NDIA, and an ongoing lack of specialist services.⁴³

5.45 The committee's attention was also drawn to the lack of sensitive, targeted material for Aboriginal and Torres Strait Islander populations. Following consultation with remote communities, the Commonwealth Ombudsman reported that many Aboriginal and Torres Strait Islander people are having difficulty understanding NDIA materials.⁴⁴ It found that many families who have received a Plan are often unsure how to use it to access supports and, as a result, many have not spent any funds during the 12-month period.⁴⁵

5.46 Mr Mark Baigent, Chief Executive Officer, Kalparrin Early Childhood Intervention Program Inc, expressed similar concerns:

We are dealing with nine ATSI families at the moment within our organisation—not a significant number, but it's very hard work even getting that nine well connected. It's crucial that those families have a culturally sensitive pathway from the beginning to the end in terms of their interaction with the NDIS, and we are certainly aware of two families that are funded in excess of \$25,000 per child with up to three children in each family involved under the NDIS. They've been holding their money for six months because they do not know how to enter the scheme, they do not know who is going to support them and they can't find culturally sensitive pathways, and their linkage from the scheme into the support regime hasn't been effectively handled. So there are gaps there that the ATSI families need support and help with to ensure that they're given the same opportunities as every other family.⁴⁶

5.47 Submitters argued that information should be developed in co-design with communities, and delivered in a variety of languages to ensure that particular cohorts are not disadvantaged.⁴⁷

42 ECIA National, *Submission 10*, p. 4.

43 For example: Commonwealth Ombudsman, *Submission 21*, p. 7; AMSANT, *Submission 56*, pp. 1–5.

44 Commonwealth Ombudsman, *Submission 21*, p. 7.

45 Commonwealth Ombudsman, *Submission 21*, p. 7.

46 Mr Mark Baigent, Chief Executive Officer, Kalparrin Early Childhood Intervention Program Inc, *Proof Committee Hansard*, 19 September 2017, p. 29.

47 For example: Royal Children's Hospital, *Submission 20*, p. 7; AMAZE, *Submission 23*, p. 15.

NDIA response

5.48 In March 2017, the NDIA released its Aboriginal and Torres Strait Islander Engagement Strategy. The strategy was based on the experience of the trial sites and the expertise of the Aboriginal and Torres Strait Islander Reference Group and associated working groups. It outlines the Agency's commitment to working with Aboriginal and Torres Strait Islander peoples, and identifies 10 priority areas for engagement.⁴⁸

5.49 The NDIA is currently working to develop tailored pathways for people from Aboriginal and Torres Strait Islander communities.⁴⁹ For example, it is developing culturally safe and responsive strategies to improve access to holistic allied health services for Aboriginal and Torres Strait Islander peoples with disability in collaboration with Indigenous Allied Health Australia.⁵⁰

5.50 The Agency—with the Department of Premier and Cabinet and the Department of Social Services—is partnering with local communities to develop place-based models for the delivery of the NDIS. Projects are underway in Anangu Pitjantjatjara Yankunytjatjara; East Arnhem; Ceduna; Mornington and Doomadgee; and Western Sydney.⁵¹

5.51 The NDIA is also proposing to launch a grant round of ILC specifically targeted to rural and remote communities in the second half of 2017.⁵²

Committee view

5.52 The committee is troubled by reports that there are Aboriginal and Torres Strait Islander families unable to use allocated funding because they are unsure how to access services. The committee agrees with submitters that investment in accessible information for a range of audiences is required. The committee considers that resources should be developed in co-design with people with disability, Aboriginal and Torres Strait Islander populations, and CALD communities to assist them to understand the Scheme, and how to use their funds to access services.

Recommendation 19

5.53 The committee recommends that the NDIA collaborate with people with disability, Aboriginal and Torres Strait Islander, and CALD communities, to co-design and develop accessible information about the Scheme, the ECEI Approach, and how to use funds to access services.

5.54 The work undertaken by the NDIA in developing an Aboriginal and Torres Strait Islander Engagement Strategy is a positive step. However, it is imperative that

48 NDIS, *Aboriginal and Torres Strait Islander Engagement Strategy*, 2017.

49 NDIS, *New participant pathway experience*, 18 October 2017, p. 7.

50 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

51 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

52 NDIA, answers to questions on notice, 8 November 2017 (received 24 November 2017).

the NDIA develop a specific strategy to ensure that culturally appropriate early intervention services are delivered for this community by specialised staff.

Recommendation 20

5.55 The committee recommends that the NDIA develop a specific strategy to deliver culturally appropriate services for Aboriginal and Torres Strait Islander people under the ECEI Approach.

Hon Kevin Andrews MP

Chair

Senator Alex Gallacher

Deputy Chair

Appendix 1

Submissions and additional information

Submissions

1. Bus Association Victoria
2. Child and Family Health Nurses Association NSW Inc
3. Siblings Australia
4. Name Withheld
5. Name Withheld
6. Name Withheld
7. Early Childhood Intervention Australia Victoria/Tasmania
8. Tasmanian Bus Association
9. Name Withheld
10. Early Childhood Intervention Australia (National)
11. Autism Spectrum Australia (ASPECT)
12. Carers NSW
13. Connect and Relate for Autism Inc
14. National Disability Services
15. The Royal Australian and New Zealand College of Psychiatrists
16. Association for Behaviour Analysis Australia
17. Scope Australia
18. Autism Aspergers Advocacy Australia
19. Deaf Services Queensland
20. Royal Children's Hospital
21. Commonwealth Ombudsman
22. Vision Australia
23. AMAZE
24. Mental Health of Young People with Developmental Disabilities
25. Firstchance Inc, Early Links Inclusion Support, Hunter Prelude, RIDBC
26. Australian Association Developmental Disability Medicine

27. RDI Consultants Australia
28. Carers Australia
29. Autism Association of Western Australia
30. NSW Government
31. Confidential
32. Confidential
33. Speech Pathology Australia
34. Can:Do Group
35. SDN Children's Services
36. Dietitians Association of Australia
37. KU Children's Services
38. Autism CRC
39. Lapstone Preschool Early Childhood Intervention Service
40. Royal Institute for Deaf & Blind Children
41. Blind Citizens Australia
42. National Disability Insurance Agency
43. Victorian Autism Specific Early Learning and Care Centre
44. Hear and Say
45. Muddy Puddles
46. Making Connections Together
47. KU Children's Services for NSW/ACT & Qld Inclusion Agencies & National Inclusion Development Fund
48. The Shepherd Centre
49. Autism Connections Inc
50. Confidential
51. Lifestart Co-operative Ltd
52. Kids Plus Foundation
53. Syndromes Without A Name (SWAN) Australia
54. Neurodevelopmental and Behavioural Paediatric Society of Australasia
55. Name Withheld
56. Aboriginal Medical Services Alliance of the NT (AMSANT)
57. Royal Australian College of General Practitioners

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58. Early Childhood Intervention Australia NSW/ACT
 - 58.1 Supplementary to Submission 58
 59. Noah's Ark Inc
 60. Early Education Inc
 61. Family Advocacy
 62. Occupational Therapy Australia
 63. JFA Purple Orange
 64. First Voice
 65. Australasian Newborn Hearing Screening Committee
 66. ACT Government
 67. Independent Advisory Council
 68. Royal Australasian College of Physicians
 69. Confidential
 70. Australian Psychological Society
 71. Department of Education and Training Victorian Government
 72. Central Australian Aboriginal Congress
 73. Kalparrin
 74. Children and Young People with Disability Australia
 75. Queensland Government
 76. Tasmanian Government

Additional information

1. Scope Australia, Engaging 'Hard to Reach' Cohorts, additional information received 28 September 2017.
2. Scope Australia, An exploration of different models of multi-agency partnerships in key worker services for disabled children: effectiveness and costs, additional information received 28 September 2017.
3. Scope Australia, Complex Disability (with complex support needs): engagement, reasonable and necessary supports, and cost drivers, additional information received 28 September 2017.
4. Scope Australia, Early Childhood Intervention analysis of situations in Europe key aspects and recommendations, additional information received 28 September 2017.

5. Scope Australia, Better systems, Better chances a review of research and practice for prevention and early intervention, additional information received 28 September 2017.
6. My Horizon, EI Recommendation, additional information received 27 September 2017.
7. Australian Psychological Society, related to Auditory Integration Training, additional information, received 27 September 2017.
8. Hear and Say, additional information, received 16 October 2017.
9. Hear and Say, First Voice report on education, employment and social outcomes of first voice member centre graduates (18-28 years), additional information, received 16 October 2017.
10. Hear and Say, cost-benefit analysis of First Voice's early intervention program, additional information, received 16 October 2017.

Answers to questions on notice

1. Occupational Therapy Australia, answers to questions on notice, arising from the public hearing on 19 September 2017.
2. Victorian Department of Education and Training, answers to questions on notice, arising from the public hearing on 19 September 2017.
3. First Voice, answers to questions on notice, arising from the public hearing on 27 September 2017.
4. Lifestart, answers to questions on notice, arising from the public hearing on 3 October 2017.
5. NDIA, answers to questions on notice, arising from the public hearing on 8 November 2017.

Appendix 2

Public hearings and witnesses

Tuesday 19 September 2017–Melbourne

AMAZE

Ms Fiona Sharkie, Chief Executive Officer

Mr Braedan Hogan, Manager, Public Affairs and National Disability Insurance Scheme Transition

Children and Young People with Disability Australia

Ms Stephanie Gotlib, Chief Executive Officer

Ms Fleur Beaupert, Policy Officer

Department of Education and Training Victoria

Ms Catherine Haire, Deputy Secretary, Early Childhood and School Education Group

Ms Kim Little, Assistant Deputy Secretary, Early Childhood Portfolio

Ms Simone Gardner, Senior Business Analyst, NDIS Reform Branch

Early Childhood Intervention Australia Victoria/Tasmania Ltd

Mrs Heidi De Paoli, Chief Executive Officer

Ms Sarah Riches, Manager

Kalparrin Early Childhood Intervention Program Inc.

Mr Mark Baigent, Chief Executive Officer

Ms Teigan Leonard, Team Manager/Psychologist

Noah's Ark Inc

Dr Kerry Bull, Senior Manager, Services

Occupational Therapy Australia

Ms Anne Sunners, Occupational Therapist, and Industry Adviser

Ms Lisa Vale, Occupational Therapist, and Industry Adviser

Royal Australian College of General Practitioners

Dr James Best, Member, Specific Interests Child and Young Person's Health Network

Royal Children's Hospital

Ms Rosemary Aisbett, Chief Nursing Officer, and Executive Director, Nursing and Allied Health

Ms Bernadette O'Connor, Director, Allied Health

Scope Australia

Dr Jennifer Fitzgerald, Chief Executive Officer

Mr Robert Moore, Government Relations Manager

Speech Pathology Australia

Ms Gail Mulcair, Chief Executive Officer

Ms Catherine Olsson, National Disability Adviser

Victorian Autism Specific Early Learning and Care Centre, La Trobe University

Ms Carlyne Jones, Psychologist

Ms Katherine Pye, Senior Coordinator

Ms Kristy Capes, Early Start Denver Model Trainer

Vision Australia

Mr Scott Jacobs, National Disability Insurance Scheme Lead

Occupational Therapy Australia

Ms Anne Sunners, Occupational Therapist, and Industry Adviser

Ms Lisa Vale, Occupational Therapist, and Industry Adviser

Tuesday 26 September 2017- Brisbane

Australian Psychological Society

Dr Jessica Paynter, Member

Autism CRC

Professor Andrew Whitehouse, Chief Research Officer

Connect and Relate for Autism Inc

Ms Prudence Watson, President

Deaf Services Queensland

Mr Brett Casey, Chief Executive Officer

Hear and Say

Mrs Amanda Mather, Director of Sustainability and Strategic Relations

Mrs Emma Rushbrooke, Clinical Director

University of Queensland

Professor Matthew Sanders, Professor of Clinical Psychology and Director, Parenting and Family Support Centre

Associate Professor Kate Sofronoff, Researcher, Parenting and Family Support Centre

Wednesday 27 September 2017–Adelaide**Can:Do Group**

Ms Heidi Limareff, Deputy Chief Executive

Ms Jena Mayne, General Manager, Group Service Development

First Voice

Mr Michael Forwood, Chair

Dr Jim Hungerford

JFA Purple Orange

Mr Robbi Williams, Chief Executive Officer

Ms Jackie Hayes, Leader, Social Policy and Initiatives

Ms Maria Vnuk, Project Officer

Siblings Australia

Ms Kate Strohm, Founder and Director

Ms Ruby Gates, Chair

Tuesday 3 October 2017–Sydney**ASPECT Therapy**

Ms Rachel Kerslake, National Manager

Mrs Maryanne Pease, Southern Regional Manager

Australian Association Developmental Disability Medicine

Dr Jaqueline Small, President

Early Childhood Intervention Australia Inc.

Ms Margie O'Tarpey, Chief Executive Officer

Ms Trish Hanna, President

Early Links Inclusion Support Service

Mrs Sue French, General Manager,

Lifestart

Ms Suzanne Becker, Chief Executive Officer

Ms Vanessa Robinson, Executive Project Manager

Ms Jennifer Kemp, General Manager, Client Services

Private Capacity

Mrs Tina Skapetis

Royal Australasian College of Physicians

Dr Jacqueline Small, Chair, Paediatric Policy and Advocacy Committee

Dr Robert Leitner, Member, NDIS Working Group

Royal Institute for Deaf and Blind Children

Professor Greg Leigh, Director, Renwick Centre

Mr Bart Cavalletto, Director, Services

SDN Children's Services

Ms Kay Turner, Chief Executive Officer

The Shepherd Centre

Dr Jim Hungerford, Chief Executive Officer

Friday 20 October 2017–Canberra

Carers Australia

Ms Ara Cresswell, Chief Executive Officer

Ms Sue Elderton, National Policy Officer

National Disability Services

Dr Ken Baker, Chief Executive

Ms Philippa Angley, Executive Officer to the Chief Executive

Wednesday 8 November 2017– Melbourne

Department of Social Services

Mr John Riley, Branch Manager, Market Oversight and Program Transition

National Disability Insurance Agency

Ms Stephanie Gunn, Acting Deputy Chief Executive Officer

Mrs Christine McClelland, Director, ECEI National Office Team

Mr Peter de Natris, Special Adviser, Early Childhood Early Intervention