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.

NDIA, *NDIS in NSW*, <u>https://www.ndis.gov.au/about-us/our-sites/NSW.html</u> (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*, <u>https://www.ndis.gov.au/about-us/our-sites/NSW.html</u> 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.

6

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

⁸ NDIS, *Summary of key dates*, <u>https://www.ndis.gov.au/about-us/governance/council-australian-governments.html</u> (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*, <u>https://www.grants.gov.au/?event=public.GO.show&GOUUID=6ED25D96-BC23-8CE7-</u> <u>A2BE951EF522FE56</u> (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-<u>A2BE951EF522FE56</u> (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

25 NDIA, Submission 42, p. 1.

²¹ NDIA, Submission 42, p. 7.

²² NDIA, Submission 42, p. 7.

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

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

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 invention 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

- 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.

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*, <u>https://www.ecia-nsw.org.au/associationnews/statement-regarding-partners-in-communities-ecei-tender-nsw</u> (accessed 7 November 2017).

'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 entitlementbased 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 were 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

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

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).

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, <u>https://www.anao.gov.au/work/performance-audit/decision-making-controls-sustainability-ndis</u> (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, <u>https://www.anao.gov.au/work/performance-audit/decision-making-controls-sustainability-ndis</u> (accessed 21 November 2017).

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

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.

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

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.

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

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.

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

- 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.

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

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.

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

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

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.