

Australian Government

Australian Government response to the Joint Standing Committee on the National Disability Insurance Scheme report:

Provision of services under the NDIS Early Childhood Early Intervention Approach December 2017

Provision of Services under the NDIS Early Childhood Early Intervention Approach

Introduction

The Australian Government welcomes the Joint Standing Committee on the National Disability Insurance Scheme (the Committee) report on the *Provision of Services under the NDIS Early Childhood Early Intervention Approach*, December 2017.

As part of the Committee's inquiry into the National Disability Insurance Scheme (NDIS), the Committee agreed to undertake an inquiry into aspects of the NDIS Early Childhood Early Intervention (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;
- i) the accessibility of the ECEI Approach, including in rural and remote areas;
- i) 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
- 1) any other related matters.

The Committee received 76 submissions to the inquiry from individuals and organisations.

The Committee released the report on 7 December 2017.

In its report, the Committee acknowledges the efforts being made by the NDIA to continually improve the operation and access to the ECEI pathway, however, makes 20 recommendations in relation to concerns about aspects of the ECEI Approach.

The recommendations address issues relating to: access to the Scheme; Early Childhood Partners; eligibility; assessment tools; the adequacy of plans; assessment and diagnostic reports; funding in plans; provision of ECEI services in rural and remote areas; adequacy of information; and accessibility of approach for people with disability, Aboriginal and Torres Strait Islander, and Culturally and Linguistically Diverse (CALD) communities.

The Government agrees with all the recommendations. Of these, six are agreed in principle or noted, and one (Recommendation 12) is agreed in part.

Inquiry into the provision of services under the NDIS Early Childhood Early Intervention Approach

Recommendations made by the Committee:

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

Response: Agree and underway

Although the process to access an Early Childhood Early Intervention (ECEI) Partner is currently available on the National Disability Insurance Scheme website, it is clear from our recent pathway work that families are finding the transition from the state based systems to the national scheme confusing. This has been complicated by the complexity of the transitional arrangements that have had to be accommodated. In particular, families are unclear as to the extent of the responsibilities that remain in mainstream services and the linkages from those services to the NDIS early childhood partners. Material to further clarify the boundaries, roles and responsibilities of the National Disability Insurance Agency (NDIA) and mainstream services will be developed. The interpretation of access requirements for children will be undertaken as part of the ECEI tailored review of the pathway.

Details for contacting the ECEI Partners will be further clarified on the website.

Timetable - June 2018

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

Response: Agree

The NDIA is required to transition children from a range of disparate state and commonwealth programs across Australia into the NDIS. This process requires flexibility in the identification, development and recruitment of partners through the transition phase and early NDIS consistent with existing jurisdictional arrangements. The longer-term aim will be to have a consistent flexible response to ensure ECEI partners are recruited through a standardised process using contemporary best practice approaches for contracting the early childhood and allied health expertise required for the role.

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

Response: Agree in principle

The definition and interpretation of developmental delay eligibility criteria is available on the NDIS website in the Access Operational Guideline. This will be developed into a Frequently Asked Question (FAQ) on Developmental Delay on the NDIA ECEI specific page.

Material to further clarify the boundaries, roles and responsibilities, the type of supports that a person can expect from the ECEI partner and the interpretation of access requirements, specifically for those children with developmental delay, will be undertaken as part of the ECEI pathway review.

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

Response: Agree

List D are the conditions that were identified as permanent impairments following research by several disability experts in the early stages of the development of the NDIS. This list was designed to provide confidence to those families who have a child with disability which will always meet the disability definition of the Act.

Work to formalise consultation on these lists will be undertaken as part of wider analysis of the sustainability of the NDIS, patterns observed on access and those found not eligible in the second half of 2018.

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

Response: Agree

The NDIS use of Pedi-CAT as a standardised screening tool is publicly known. NDIA uses this screening tool under license. A broad range of information is publicly available on the Pedi-CAT website: www.pedicat.com. NDIA acknowledges that further clarification of the use of assessment and screening tools in ECEI is required and the ECEI national team will lead work in this area.

Early Childhood Partners are encouraged to utilise information from a range of individually appropriate functional assessment or screening tools to obtain an understanding of the nature and severity of functional impairment. This may be provided by the family or another professional, such as:

- Parents' Evaluation of Developmental Status
- Ages and Stages Questionnaires®
- Brigance Early Childhood
- The Child Development Inventory

Additionally, available reports from allied health and educational professionals involved with the child will be utilized to support the information attained by the partner in assessing the child's support needs. The Early Childhood Partner will apply other routine based assessments such as those listed above if additional information is required.

6. 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.

Response: Agree and underway

The NDIA has recently developed Pedi-CAT FAQs which are publically available and which explain how this is used as a standardised measure of functional impairment for all children.

The NDIA draws on a range of information to understand the support needs of participants.

Functional screening assessment tools serve as one information source to inform this understanding. This is not, however, the determinant of access to the NDIS, as there is no single measure or score that is used to determine access.

Rather, information is gathered by the Early Childhood Partner from a range of sources, including treating specialists, the family, the Pedi-CAT and other functional (and behavioural) screening assessments, which together provides critical information to understand the impact of any impairment on daily life.

Early Childhood Partners may also apply other routine based assessments, if required. The Pedi-CAT or other functional screening assessments are not the sole determinant of the child's level of function. As noted above, information gleaned from the Pedi-CAT is used in combination with a range of other sources of information, including parent report.

The funding within an individual's plan is not standardised and does not directly relate to the functional assessments undertaken but rather the family/carer's goals for their child. Funding will address the reasonable and necessary needs that are identified through this assessment taking into account evidence of the value of intervention and the role of families, informal supports and the responsibilities of mainstream services. Each plan is unique and not all goals require funded supports.

This is explained to families by the Partners and materials addressing feedback to be obtained from the current consultations on the ECEI pathway will be developed to explain this individualised approach further.

Timetable - June 2018

Over time as data is built by the NDIS and evidence of the effectiveness of the nature of interventions for particular functional impairments is built up, further information will be able to be developed as part of reference packages for children.

Timetable - June 2020

7. 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.

Response: Agree

Work is underway with the Autism Cooperative Research Centre to develop a national guideline for consistent diagnosis of Autism Spectrum Disorder (ASD) that focuses on the functional impairment and effective intervention for the types of impairment that may be associated with this diagnosis.

Overwhelming feedback from many stakeholders has indicated that while diagnosis has a role to play in understanding the impact of the condition, what should determine access is the functional impact of the ASD.

The NDIA will continue to work with experts and key stakeholders to develop a far more robust approach to the assessment of the functional impact of ASD.

Timetable – September 2018 for improved tool.

8. 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.

Response: Agree

The NDIA will continue to commission partners with strong clinical, early childhood intervention expertise. This includes strengths in family-based approaches and engagement with community. The ECEI national team specialised practice training is currently addressing this concern.

Timetable – ongoing

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

Response: Agree

No further comment.

10. 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.

Response: Agree in principle

Assessments to inform clinical recommendations for Assistive Technology and equipment are currently built into the funded supports as deemed reasonable and necessary and there is no expectation that assessments are performed only annually. Indeed, assessment to inform the direction of the intervention is funded through the capacity building hours in the plan. This can occur throughout the plan period as determined by the Early Intervention service provider.

11. 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.

Response: Noted

The NDIA acknowledges that this is an area in which further guidance to Partners and enhanced communication and expectation management for families is required.

The work underway with the Autism Cooperative Research Centre involves developing a consistent approach to diagnosis and to better understand and define functional impairment. This will enable the development of evidence-based guidance that ensures appropriate individualised support.

- 12. 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.

Response: Partly Agree

The NDIA established an Early Intervention Hearing Expert Reference Group in response to concerns raised regarding timely access and disruption to referral pathways for early intervention and outcomes for young children with significant or profound hearing loss under the NDIS.

As a result of that work, the NDIA is now implementing:

- Revised access guidance, which enables streamlined access to the NDIS for people
 with profound bilateral hearing impairment and for children and young Australians
 requiring early intervention for hearing impairment.
- A trial of the developed framework for considering 'Reasonable and Necessary' Supports for hearing impairment. Hearing Impairment Planning Questionnaire.
- The NDIS is responsible for providing or funding reasonable and necessary supports for participants from the date their first NDIS plan is approved. The NDIA will not consider providing or funding supports that have been purchased or funded by other parties prior to this date.

Retrospective payments for services prior to this date remain either the responsibility of previous Governments or programs. If exceptional circumstances in any jurisdiction warrant a response, the NDIA will explore options with the Department of Social Services.

13. 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.

Response: Agree and underway

This will be addressed in the ECEI tailored review of the pathway.

Equipment and assistive technology will be considered as per the therapist's clinical evidence recommendations, the practical implications, and what is reasonable and necessary. The NDIA acknowledges the need to ensure a more streamlined arrangement for these assessments is desirable. Work is underway to ensure improved practices can be implemented when transitional arrangements with state based equipment providers are no longer required.

In addition, the NDIA is scheduled to introduce changes by the end of March 2018 that will ensure those who require low value and low risk items in their plans can access them more directly.

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

Response: Noted

The NDIA has in place a funding arrangement that enables participants to access Translation and Interpreting Services from providers when required. This is not funded in a plan unless the support is related to a disability.

15. 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.

Response: Agree in principle

The ECEI approach recognises the fundamental importance of ensuring the sustainability of family and other informal supports. Appropriate supports such as those that enable a family to build an understanding of the child's individual disability or developmental support needs, assistance with self-care activities to minimise the impact on family life, group based community, social and recreational activities – disability specific programs or training either separate or as part of capacity building, can be funded in a child's plan.

Partners are skilled in ensuring appropriate connection to community and mainstream supports that, for example, assist siblings and parents to learn about and adjust to the child's disability and support needs.

The NDIA recognises the potential for Information, Linkages and Capacity Building (ILC) funding to contribute to strengthening this across the community and is working to ensure that the implementation of ILC is effective in supporting families and siblings of those with disability to build strong, supported, inclusive lives within their community.

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

Response: Agree

This is a key focus of the market stewardship and market intervention work. The potential for the use of technology in rural and remote areas to improve service quality and availability, as well as potentially reducing costs of supports and encouraging innovation is well recognised.

The NDIA welcomes engagement with key government and other service providers to develop a collaborative approach to build stronger and more robust access to technology in remote areas to, for example, provide training, supervision of staff and the direct provision of services.

Timetable - ongoing

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

Response: Agree and underway

This is currently being addressed in the ECEI tailored review of the pathway. Engagement workshops are currently underway.

The NDIA will continue to engage with a number of key stakeholders including Early Childhood Intervention Australia, Children and Young People with Disability Australia and the Early Childhood Partners to, in particular, make information on community based supports available for families more readily accessible through the NDIA and other websites.

Timetable - ongoing

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

Response: Agree in principle

The NDIA works closely with existing mainstream services for children in vulnerable home settings. The ECEI Partner and the NDIA staff receive and send referrals from and to these child and family services to ensure families of children with developmental delay of disability are linked to an Early Childhood Partner and/or other supports. Early Childhood Partners will ensure strong collaborative practice is established with the mainstream child and family services in their jurisdiction.

The recommendation will be considered as part of the ongoing refinement of the priority areas for investment for the ILC.

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

Response: Agree and underway

This will be addressed in the range of tailored pathway review work that is currently underway and we will ensure there is a specific focus on the 0-6 age group within each of these pathways.

ECEI consultations were held on:

- 10/10/2017 in Penrith
- 13/10/2017 in Geelong
- 12/12/2017 in Melbourne
- 19/01/2018 in Adelaide
- 23/01/2018 in Brisbane
- 16/02/2018 in Sydney.

Other related consultations with Aboriginal and Torres Strait Islander peoples and people who identify from a CALD background were held on:

- 18/10/2017 in Nhulunbuy
- 19/10/2017 in Groote Eylandt
- 25/01/2018 in Sydney (CALD)
- 7/02/2018 in Melbourne (CALD)
- 8/02/2018 in Melbourne
- 13/02/2018 in Melbourne
- 20/02/2018 in Bourke
- 27/02/2018 in Sydney
- 1/03/2018 in Alice Springs
- 7/03/2018 in Cairns
- 14/03/2018 in Kununurra
- 28/03/2018 in Ceduna

NDIA needs to ensure effective processes for those from an Aboriginal and Torres Strait Islander or CALD background fit well with our commitments regarding the tailored pathways.

20. 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.

Response: Agree and underway

This will be addressed in the ECEI tailored review of the pathway.

Early Childhood Partners bring a diverse range of experiences in outreach and support for children and families from Aboriginal and Torres Strait Islander communities and the NDIA will look to develop a community of practice to share effective operational response across all Partners.

The NDIA Rural and Remote Strategy 2016-2018 details the intention and goals of the NDIS working with people with a disability and their families and carers. In particular, it emphasises the importance of access to the NDIA, collaboration with local communities, creative approaches for individual communities and the complimentary use of technology in order to deliver services to people. The ECEI approach will be tailored to each area in order to provide the most relevant and effective delivery of ECEI to children and their families community by community.