



Joint Standing Committee on the National Disability Insurance Scheme

Provision of services under the NDIS
Early Childhood Early Intervention Approach

December 2017

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.

Alarming, 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.