



**Submission to the Joint Standing Committee on
the National Disability Insurance Scheme:**

**Provision of services under the NDIS Early
Childhood Early Intervention Approach**

9 August 2017

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Provision of services under the NDIS Early Childhood Early Intervention (ECEI) Approach

Introduction

Carers Australia broadly supports the concept of an integrated approach to early intervention services for children with developmental needs, whether or not those children will have ongoing challenges even with early intervention which will require continuing support through the NDIS.

The overall effectiveness of this approach as it has been implemented through the two key pilots sites – the Townsville and Northern Queensland region and the Nepean region in NSW - is not as yet tested widely enough to draw hard and fast conclusions about its effectiveness.

As the ECEI approach rolls out across Australia, the impact, outcomes and experiences of families will need to be comprehensively evaluated to ensure the ECEI/NDIS approach is meeting their needs.

Carers Australia and the Network of Carer Associations around Australia have direct experience in tracking implementation at the grass roots level through our management of the Better Start for Children with Disability Program which is being replaced by the NDIS funded ECEI approach in line with the NDIS roll out.

In addition, we have had direct engagement with carers in the ECEI pilot sites with the parents of children with developmental challenges.

While most of our information is of an anecdotal nature, it does point to a range of problems with implementation which need to be addressed. In particular our experience to date indicates that there has not been a smooth or easy transition either for children who will be eligible for NDIS packages of support but are assessed to potentially benefit from early intervention, or for children who will not qualify for an NDIS package but are deemed to benefit from short-term intervention services. Confusion around how to access ECEI, long delays in accessing planning meetings and more delays in actually implementing plans have featured prominently in our consultations. As a result, children residing in areas where the NDIS ECIE approach has rolled out are falling through the gaps between existing early intervention services (such as Better Start for Children with Disability Program and Helping Children with Autism Program) and timely intervention under ECEI.

We believe that, to a large extent, these problems can be traced back to a rush to implementation without adequate consideration of the processes and resources which need to be in place for transition to proceed smoothly. Workforce is of particular concern, since

Early Childhood Early Intervention Coordinators, who are the gateway to intervention supports, are drawn from the local, specialist allied health workforce in areas such as speech pathology and occupational therapy. Such specialists are often in short supply, especially when they may have more attractive employment conditions in the health sector.

Most of our comments can be encapsulated under two Terms of Reference for the inquiry:

- c) the timeframe for receiving services under the ECEI pathway
- h) the adequacy of information for potential ECEI participants and other stakeholders

Probably the two biggest problems with the transition to the ECEI approach is that there is great confusion and misinformation among families, mainstream referrers, providers of existing early intervention services and NDIA staff, combined with very extensive delays between moving from existing early intervention funded supports to the new gateway.

How it is meant to work

Pathways through to NDIS ECEI support is based on a single gateway approach to providing services to children aged between 0 and 6 years of age. Where parents don't yet know but suspect their child is facing developmental delays or challenges, they can be referred to an Early Childhood Early Intervention (ECEI) Coordinator in their locality by maternal health nurses, pediatricians, and GPs or self-refer to have their child screened for intervention. These ECEI service providers are contracted through the NDIA to provide an assessment as to which pathway for supports is required for individual children screened. The ECEI Coordinators have relevant therapy backgrounds, strong local service referral knowledge and an understanding of strategies for families to implement in conjunction with the needs of children with developmental delay.

The screening process will determine whether the child at this stage only requires short-term three to six months support, in which case the ECEI Coordinators will provide that support. While such support is funded by the NDIS, these children are not on NDIS plans. In cases where it is determined that the child will have ongoing needs for support, including early intervention, the ECEI provider will support the family to fill out eligibility documentation for access to NDIS supports. In normal circumstances, it is expected to take about 21 days to establish eligibility, after which the family will be referred back to an ECEI Coordinator who will conduct an NDIS planning meeting with the family to establish an NDIS plan for the child.

Where a child has been in receipt of funding under the Department of Social Services funded Better Start for Children with Disability Program or Helping Children with Autism (HCWA) Program, both of which are early intervention service programs which preceded the NDIS, their access to these programs ceases in areas where the NDIS becomes available in their

locality. The expectation with respect to children already registered in both these programs is that the Department will inform the National Disability Insurance Agency of the child's details, and the NDIA will notify parents that they are on a list to be contacted by local ECEI organisations when the NDIS is due to roll out in their region. However, parents of these children can also apply directly to the NDIA to have their child referred for screening and the development of a plan with a local ECEI Coordinator.

For those children who are assessed as being best supported through community health services, ECEI Coordinators will seek to refer these children back out of the gateway and to community health settings for support

While it is comparatively early days for this transitional approach, it is clear that these processes are not always operating smoothly. In each region, state, and territory ECEI service providers are experiencing their own issues in bringing such a large cohort of children into the scheme.

Delays in accessing support

Access to initial screening and planning processes

Carers NSW and Carers Victoria have advised that many of the problems are centred around confusion and timely access to the first part of the process – initial screening and getting access to planning meetings.

Carers in NSW have reported long, indefinite waiting periods with no contact from an ECEI provider or the NDIA to confirm that they are still on the waiting list. Some carers have become concerned and have followed up, only to find that their contact details have been misplaced or their referral completed incorrectly, further lengthening their waiting time. Others have contacted their local ECEI provider only to be informed that the waiting period is even longer than first anticipated.

“Mum applied to the NDIA and was registered in December. She was told to wait and an ECEI would be in contact with her. After 3 months of no contact, she contacted them and found out that her daughter is not on any current list of any ECEI and they will not be able to see her until after July for a planning meeting. She has now missed the cut-off for applying for Better Start and cannot afford early intervention.”

CASE STUDY SUBMITTED BY CARERS NSW

It is also concerning that some carers in NSW are having existing state funded services withdrawn in the meantime, or are being referred to services that do not have the funding or capacity to meet their needs.

*Janelle**'s grandson James* is three years old. Before the ECEI approach was implemented in his area, James had a planning meeting with a NDIS a Local Area Coordinator scheduled for August last year. This meeting was changed in favour of referring James to his local ECEI provider. In the past twelve months, Janelle has been 'bounced around' time and again, constantly getting different stories about how long the wait will be. More than once it has appeared they have 'fallen off the wait list' for their intended ECEI provider and have had to be reinstated.*

Recently Janelle was informed that the support James has been receiving from the NSW Government – including social skills groups, occupational therapy and weekly speech therapy – would cease, even though they are yet to be contacted by their ECEI provider regarding support for James. The most recent estimate they were given for getting support from the ECEI provider was 'before Christmas'.

At the time Janelle spoke to us, James' supports had been withdrawn for only one week, and she had already noticed the difference. James' routine had gone out the door, he had been violent towards his parents, and he had demonstrated some absconding behaviour. This outcome is particularly frustrating for Janelle because the original letter they got from the NDIS stated that there would be no gap, and that the timing of early intervention is critical for good outcomes. Janelle submitted a complaint in February by email to the NDIA, who said that if providers were having trouble meeting demand there was not much they could do.

** Name changed*

**CASE STUDY SUBMITTED BY
CARERS NSW**

The timeframe for receiving NDIS plans

As commented above, the process of determining access to supports for children screened as having significant needs, regardless of whether they have a diagnosis, will often indicate that their benefit from short-term intervention will be limited and they will require support to access an NDIS plan.

This pathway means that the child is not provided with any short-term early intervention and is placed on hold while waiting to receive an access decision, which should be about 21 days. However, this time period is often reported to be much longer. Once access has been provided, families are then referred back to the ECEI Coordinators to have an NDIS plan put in place. Carers Associations have received numerous calls from families where the wait to have a planning meeting is reported to be about 1-2 years, leaving families in limbo and with no early intervention support provided to their child.

Carers Australia and state and territory Carers Associations are of the view that that the policy of ceasing Better Start and Helping Children with Autism services as soon as the NDIS becomes available in new sites is ill-conceived in circumstances where serious gaps in early intervention support arise because of lengthy processing delays under the new system.

RECOMMENDATION:

Access to the Better Start and Helping Children with Autism (HACWA) programs should continue in NDIS sites until such time as children serviced by these programs have in place plans for accessing services under the NDIS.

The timeframe in receiving services under the ECEI pathway

In line with Early Childhood partner KPIs, the ECEI Coordinators are required to support children who have received an NDIS plan through helping the families to connect with services and implement the plan. The ECEI Coordinators are supposed to help the families access service providers and set up service agreements.

However, families in regional areas of Queensland are contacting Carers Australia and Carers Queensland with concerns about their plans not being able to be implemented because required services continue to be lacking in those areas.

We don't know who is responsible for addressing workforce shortage, especially in a context where state governments are withdrawing from some of the disability services they supported before the NDIS. However we note particular problems in relation to ECEI, especially in regional and remote areas. If NDIS price guidelines for services are part of the problem, they will need to be revised.

Poor and confusing information

Potential referrers are not adequately informed

The ECEI outreach role in relation to health and medical providers, who in many cases will be the first to alert families to their options, often seems to be failing. These may include maternal childhood health nurses, child and family networks in the region, general practitioners, paediatricians, Aboriginal health services, and community health services.

These 'first point of contact' referrers are often ill-informed about ECEI and the pathways to access it. Carers Australia staff receive phone calls from paediatricians and general practitioners across Australia requesting information about the transition from Better Start funding to NDIS, along with information about the ECEI gateway process. This indicates a clear lack of understanding about the referral pathway and leads to delays in children accessing timely early intervention supports.

RECOMMENDATION:

ECEI Coordinators must be properly funded to deliver easily understood information to first referrers to smooth the transition to the new gateway.

Some NDIS staff seem to be inadequately informed about application procedures

There is a clear need for NDIS staff to be better informed about the relationship between Better Start and Helping Children with Autism and the NDIA.

Carer was told in the assessment of her now 3 ½ year old son not to apply for Helping Children With Autism early intervention support, because if she did, he would be ineligible for the NDIS...Carer received a letter to state that they had been approved for an NDIS package worth \$17,000 but there had been no planning meeting and she had not been consulted. When she called up the NDIA to state that she thought there had been a mistake, because she never received a phone call or a visit from an NDIS planner, she received different responses from the staff...She hopes that clear information to the NDIA staff will result in less communication breakdown as well as preventing carers and people with disability being misinformed by the NDIA staff themselves....she, like many other carers, was very unaware of what to expect and what to do for her son...she felt it necessary that practitioners conducting assessments, especially for funded supports, be well informed so as to not lead carers and people with a disability in the wrong direction.

**CASE STUDY SUBMITTED
BY CARERS NSW**

Both Carers NSW and the Department of Social Services have advised that the NDIA is telling many families that they cannot apply for the NDIS directly as Better Start will be transferring their details over, even though this is not always the case.

A number of families appear to have been advised to spend their Better Start money in advance of the NDIS, but are now facing a long delay with no remaining funding and therefore no access to much needed services.

Overall, a number of families have cited frustration at being told contradictory information from multiple sources, including different NDIA representatives. Information provided through the 1800 number appears to be particularly inconsistent and uninformed.

RECOMMENDATION:

NDIA staff, especially those providing advice through the 1800 number, need to be better trained to provide informed, consistent advice about ECEI/NDIS guidelines and processes generally, and the interface and transition processes between programs such as the Better Start for Children with Disability Program and Helping Children with Autism (HCWA) Program in particular.

Family confusion about planning processes

A family's experience in Townsville

A family with a 4 year old daughter with albinism was contacted by the ECEI partner about a plan for their child. The child is legally blind as a result of the albinism.

The family were unaware that the initial call with the ECEI partner was in fact a planning meeting and therefore all the child's needs were not included in the initial plan. This was in June 2016.

The mother has since been trying to have the plan reviewed to include the equipment that her daughter needs, particularly to start school in 2017. This revision of the plan involved a CCTV system so the little girl can participate in the classroom and have the class whiteboard projected onto her work space. A walking cane was also part of the request to help her get to school.

The family have been waiting since June 2016 to rectify these things and are frustrated with the process and the fact that their daughter has struggled to start school without the equipment she needs to help her.

**CARERS AUSTRALIA
CASE STUDY**

Cases such as the one above illustrate that planning processes in the ECEI space are demonstrating the same poor communications processes as beset the current broader NDIS processes. As the Productivity Commission has remarked in its recent *Position Paper on the National Disability Insurance Scheme (NDIS) Costs*, a focus on the speed of roll-out at the expense of clear and considered planning processes involving effective communication with both participants and providers is putting the Scheme's success and financial viability at risk. This is resulting in poor outcomes for participants and costly and time-consuming plan reviews. With respect to early childhood intervention, where plans are inadequate or cannot be operationalised and need to be reviewed, the risk is that services will come too late to redress developmental problems, increasing the likelihood that participants will not be able to exit the NDIS.¹

¹Productivity Commission, *Position Paper: National Disability Insurance Scheme Costs*, June 2017, pages 2, 14, 25-29

RECOMMENDATION:

ECEI planning processes should incorporate the following requirements:

- It should be made clear to participants when they are involved in a planning meeting.
- They should be able to review the plan before it is finalised
- There should be processes to allow for minor adjustments or amendments to plans without triggering a full plan review.