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Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100, Parliament House
Canberra ACT 2600
ndis.sen@aph.gov.au

Dear Sir/Madam,

Carers NSW wishes to thank the Joint Standing Committee on the National Disability Insurance Scheme (the Committee) for providing an opportunity to comment on the provision of services under the National Disability Insurance Scheme (NDIS) Early Childhood Early Intervention (ECEI) Approach.

Carers NSW is the peak non-government organisation for family and friend carers in New South Wales (NSW) and a member of the National Network of Carer Associations. Our vision is an Australia that values and supports all carers, and our goals are to work with carers to improve their health, wellbeing, resilience and financial security; and to have caring recognised as a shared responsibility of family, community and government.

Carers NSW has delivered the Registration and Information Service for the Department of Social Services funded program, Better Start for Children with Disabilities (Better Start) in NSW since the program's inception. Better Start is one of the Commonwealth funded programs identified for transition to the NDIS, with registrations having closed across NSW on 1 August 2017. As a result, Carers NSW has had the opportunity to engage with carers transitioning to the NDIS from all areas of NSW.

In recent months Carers NSW has become very concerned about the rollout of the ECEI approach in NSW. Increasing numbers of carers and service providers have reported to our staff indefinite and lengthening waiting times, administrative errors, incorrect and inconsistent information provided to them by the NDIA, and the inappropriate withdrawal of state funded early intervention services.

Some of these issues overlap with the experiences of carers in Queensland and other jurisdictions, as explained in the submission to this inquiry by Carers Australia. However Carers NSW is concerned that waiting times in NSW in particular have reached crisis point, which is why we are providing an additional submission.

Carers NSW has been informed by a number of carers and service providers that waiting times for first contact with an ECEI provider in several parts of NSW have reached between six and eighteen months, with some estimated at up to two years. While in some areas free state-funded services are available in the meantime, this availability varies between jurisdictions. We have been informed that in some areas waiting lists for these services have reached twelve months now, while in other areas services have simply been withdrawn or are non-existent.

This scenario places families that have not been able to register with Better Start, or have used up their Better Start funding and cannot afford private services, at risk of being without *any* early intervention support for up to two years. Carers NSW believes the Committee will agree that this is simply unacceptable, given that timely intervention for children with disability is critical to positive long-

term outcomes, and given the foundational 'no disadvantage' principle of the NDIS and bilateral commitment to continuity of support.

The NDIA have themselves highlighted the importance of acting quickly to set up early intervention supports in letters to families regarding the ECEI approach. If nothing changes, children, families and governments will face massive, unnecessary, long-term costs as a result.

Families and carers are understandably distressed and frustrated by the changing system and the uncertainty around services for their child. One carer has been waiting to be contacted by their local ECEI provider for over a year, and have recently had their state funded disability supports cease in line with the NSW rollout timetable. The loss of service has held serious implications for the safety and wellbeing of the family. They have been told they should get ECEI support 'before Christmas', but they don't know how long they can cope.

Another carer who just missed the cut-off date for Better Start registration was referred to their local ECEI provider, which has an eight month waiting list for support. In the meantime, there is nothing available for the child, and the family cannot afford private therapy. A third carer who also missed the Better Start cut-off had received approval for her child to become an NDIS participant, but then heard nothing for three months. When she followed up, she found nobody had transferred her child's details to an ECEI waiting list, resulting in a longer delay than necessary.

Carers NSW urges the Committee to hold the Department of Social Services and NSW Government to account in ensuring that this gap is addressed immediately. **Carers NSW strongly recommends that registration for Better Start packages be reinstated until adequate services are made available, and that state funded services receive additional funding to compensate for any gaps during the transition period.**

Thank for you for accepting our submission.

Yours sincerely,

Elena Katrakis
Chief Executive Officer
Carers NSW