



10 August 2017

Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

By email: ndis.sen@aph.gov.au

Dear Members of the Joint Standing Committee,

Re: Inquiry into the provision of services under the National Disability Insurance Scheme Early Childhood Early Intervention approach

Autism CRC is pleased to be providing comment to the Joint Standing Committee on the NDIA Early Childhood Early Intervention (ECEI) approach.

Established in 2013, Autism CRC is the world's first national, cooperative research venture focused on autism. Our vision is to see autistic people empowered to discover and use their diverse strengths and interests. Our program of work takes a whole-of-life view, from early identification, diagnosis and intervention; to improving educational settings and outcomes; through to enhancing employment, further education, and health and wellbeing in adult life.

Autism CRC has the unique, national capacity to develop and deliver evidence-based outcomes through its collaborative venture with the autism community, research organisations, industry and government. Currently, we have over 50 participant organisations and other partners based around Australia and internationally.

In its role, Autism CRC works with a number of national organisations and agencies, including the NDIA, to ensure both that policy and practice are underpinned and enhanced by a strong evidence-base, and that schools, workplaces and other communities build their inclusive capacity and value diversity.

While Autism CRC has a focus on autism, the effectiveness of the ECEI approach for the autism community is of significant relevance to an assessment of the approach more generally. Of the paediatric participants in the NDIS, 42% are on the autism spectrum. Further, there is strong evidence from autism-related research of the lifelong impact of appropriate early intervention in significantly reducing disability and enabling greater participation in society – benefiting individuals, families and the community, socially and economically – consistent with the insurance principles of the NDIS.



Autism CRC strongly supports the principles and objectives of the ECEI approach, aiming at a nationally consistent approach to providing early and efficient intervention supports to children with early developmental difficulties. We recognise that the intention of the ECEI approach, and the NDIA more broadly, is to provide access to intervention based on need, not on diagnosis – an approach which Autism CRC supports. In concentrating on the strengths and challenges of a given child, rather than on the diagnosis they have received, the intervention supports provided to each individual will be more effective in producing positive outcomes for the child and their family.

We have selected items from the Terms of Reference on which Autism CRC is qualified, and has expertise, to comment on. We have not commented where we do not feel we have a sufficient base of evidence to do so.

Our responses to these items follow. These responses cite a number of publications with comprehensive data and analysis that we would recommend the Committee review as part of its consideration of these matters.

a) the eligibility criteria for determining access to the ECEI pathway;

The scientific evidence is very clear that early identification of developmental difficulties and swift intervention is critical to promoting longer-term, positive functional outcomes in individuals on the autism spectrum (Chasson et al., 2007; Peters-Scheffer et al., 2012).

The diagnostic behaviours used to diagnose ASD typically only emerge between the ages of 2 and 5 years. However, delayed receipt of intervention until these ages does not capitalise on the highly ‘plastic’ elements of neurodevelopment within the first two years of life. There is now a wealth of scientific evidence for a range of ‘behavioural markers’ identifiable during the first two years of life that indicate a significant likelihood that an infant might subsequently be diagnosed as being on the autism spectrum (Zwaigenbaum et al., 2015a). Providing intervention to these young children once the ‘behavioural markers’ have been identified is highly likely to deliver better outcomes in reducing long-term disability compared to waiting until diagnostic behaviours emerge after 2 years of age (Zwaigenbaum et al., 2015b).

In order that early identification based on ‘behavioural markers’ delivers the optimal benefit for the ECEI approach, it is essential that a consistent, national approach be taken to its implementation. This would then avoid significant and unnecessary costs, both personal and economic, as have been evident from the substantial variation in ASD diagnostic processes across Australia (see response to (c)).

This approach is entirely consistent with the ‘insurance principles’ upon which the NDIS is based.

Given this clear scientific evidence, the Autism CRC urges the NDIA to:

1. *Maintain the current focus of ECEI eligibility on ‘developmental delay’ rather than diagnosis of a disorder.*



- 2. Incorporate these autism-related 'behavioural markers' into the eligibility criteria, within a nationally consistent approach to their identification, and ensure swift receipt of intervention once these markers have been identified in an infant. This approach is likely to lead to better long-term functional outcomes in a child on the autism spectrum, and is consistent with the insurance approach adopted by the NDIS.*

b) the service needs of NDIS participants receiving support under the ECEI pathway;

There is overwhelming scientific evidence that early and intense therapeutic intervention reduces long-term disability in children on the autism spectrum (Zwaigenbaum et al., 2015b), and that this can save substantial long-term health and societal costs (Chasson et al., 2007; Peters-Scheffer et al., 2012).

As highlighted in response to (a), the administration of intervention in the early years based the child's challenges and needs, and not requiring the *prior* receipt of an autism diagnosis, is likely to lead to even greater long-term gains for the individual and savings to Government and society more generally.

Research and evidence-based practice is advancing in both the better targeting and delivery of intervention to children at early ages, including infants under the age of 2 years. Autism CRC is an international leader in the development of therapeutic interventions (Whitehouse et al., 2016) for infants (< 2 years of age) showing early behavioural signs for autism.

In collaboration with the NDIA, Autism CRC is also undertaking a study of preschool children receiving intensive early intervention under different programs (led by Professor Valsamma Eapen). With the heterogeneous nature of autism, this study aims to identify autism subtypes, those groupings of individual children based on shared behavioural, clinical and neurocognitive characteristics. The objective is then that these subtypes will be predictive of differential intervention outcomes, including transition to school, that will provide an evidence-base to guide targeted intervention.

Based on the current state of the scientific evidence, in addition to the insurance emphasis of the NDIS, the Autism CRC encourages the NDIA to:

- 1. Provide adequate resources for children eligible for the ECEI approach to receive very early, efficient and intense intervention supports.*
- 2. Invest in the development and/or evaluation of very early interventions and their targeting, which has the great potential to reduce lifelong disability in children on the autism spectrum, and have a positive economic benefit to individuals, families, the NDIS and the broader society.*

c) the timeframe in receiving services under the ECEI pathway;

Early identification and intervention are key to the long-term reduction of disability in autistic children (Estes et al., 2015; Remington et al., 2007). Intrinsicly linked with this is the efficiency of timeframe in which an infant or child receives intervention once a developmental delay has been identified.



While early identification is the start of ECEI approach, without an efficient process through which funding support is received and early intervention commenced, the benefits of early identification efforts will largely be lost. To maximise the benefit, it is critical that those charged with facilitating access – that is, the critical step between identification and intervention - have an understanding of autism, its heterogeneous nature, the various types of evidence-based intervention available, and that in dealing with families, they may be dealing with parents who are on the spectrum as well as the child for whom support is sought.

On this last point, the NDIA would do well to collaborate with those with lived experience of autism to help form guidelines for facilitating access.

The Autism CRC encourages the NDIA to:

- 1. Develop and articulate a clear and efficient process that enables the provision of early intervention as soon as possible. This process must commence from the point of early identification of developmental delay, and conclude with the provision of early intervention.*
- 2. Address the design of the access process and resources, with the autism community, and ensure that those facilitating access are appropriately equipped and experienced to do so in an effective and respectful fashion.*

e) the costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants;

While not necessary in order to appropriately commence intervention support under an ECEI approach, diagnosis remains a critical step in the ASD clinical pathway, particularly given the heterogeneity of the condition, aiding the identification of targeted intervention and support. Previous research by the Autism CRC identified substantial variation in ASD diagnostic processes both between and within states / territories (Taylor et al., 2016). As a result of this research, the Autism CRC partnered with the NDIA to develop the first Australian guideline for ASD diagnosis (led by Professor Andrew Whitehouse), with the aim of describing a diagnostic process that is standardised, accurate, efficient, feasible to administer and acceptable to autistic individuals and families.

Critically, there is no international ‘gold standard’ diagnostic process, but rather an accurate and efficient process is dependent on local factors, such as the geographical spread, the availability of clinical expertise and training, and the interface with health and education systems. The guideline generated by the NDIA and Autism CRC has been developed through a rigorous research and a 12-month consultation period, with the Australian context specifically in mind. The guideline is scheduled to be released in a beta-version in September 2017 for public feedback, and the final guideline will be published ready for implementation in January 2018. International best practice on guideline development prescribes that once a guideline is finalised, there are systems in place to adequately disseminate, implement and evaluate a guideline within local settings. Whilst this guideline will be disseminated in late 2017, there are no current provisions to implement this guideline or evaluate if it has achieved the above aims.



Given the investment by the NDIA in the development of the guideline, and the prominence of autism within the NDIS, we strongly urge the NDIA to:

- 1. Evaluate whether the guideline achieves the aims of having a diagnostic process that is standardized, accurate, efficient, feasible to administer and acceptable to families.*
- 2. Facilitate implementation of the guideline within clinical practice and Government policy across Australia. Not doing so will highly likely see continued confusion within Australian community regarding ASD diagnostic practices, with significant, knock-on effects for the long-term operation and cost of the disability system and social services, generally.*

f) the evidence of the effectiveness of the ECEI Approach;

There is overwhelming evidence that early identification and intervention of developmental difficulties, including autism, leads to a greater reduction in long-term disability for children, with a concomitant reduction in costs to society (Chasson et al., 2007; Peters-Scheffer et al., 2012). Without the ECEI approach being a major element within the broader NDIS, it is clear that this major reform will be running counter to international best practice and the insurance principles under which the NDIS operates.

Given the huge potential for reductions in disability and costs, the Autism CRC urges:

- 1. That the ECEI approach remains a prominent and well-funded element of the broader NDIS.*

i) the accessibility of the ECEI Approach, including in rural and remote areas;

While not in position to comment specifically on current approaches, Autism CRC notes a number of approaches that may facilitate accessibility in rural and remote areas, some of which are being employed in Autism CRC's projects:

- A. approaches that may be delivered by wider networks of providers, for example, the delivery of early identification through primary healthcare providers, broadening diagnostic capacity through engaging other professionals and providing further education and training programs in this regard;
- B. providing telehealth and tele-consult platforms, content and services for remote support; and
- C. perhaps in conjunction with (B), use of parent-mediated interventions, such as the very early intervention program described in (k).

j) the principle of choice of ECEI providers;

Autism CRC strongly supports the principle of participants having an informed choice of ECEI providers of evidence-based support.



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

Autism CRC is the peak national body coordinating autism-related research in Australia. A core aim of the Autism CRC is to develop and translate new knowledge into clinical practice around early identification and intervention for children on the autism spectrum. Our researchers are international leaders in this area, with research outputs focusing on two major areas:

1. *Identification of 'behavioural markers' for ASD in the first two years of life:* The CRC has invested in translational research, led by Dr Josie Barbaro, that has developed and trialled new methods for identifying infants with a high likelihood of being on the autism spectrum within the first two years of life

Autism CRC has now defined a world-first research project that will trial these early identification methods within GP practices around Australia – that is, with primary healthcare providers – and is now seeking co-investors for this project.

If this approach is found to be successful in the identification of infants, it will be Australia's first nationally consistent method for developmental surveillance. This program has significant promise in providing the NDIA with a clear and efficient process for determining ECEI eligibility (please see answer to (c)), and providing these infants with intervention supports at the earliest possible age, thus promoting reductions in lifelong disability and costs.

2. *Developing new 'pre-diagnostic' interventions:* Autism CRC has played an important role in developing the evidence base around 'very early interventions' that may be provided to children in the first two years of life (often prior to receiving a formal autism diagnosis). Research led by Professor Andrew Whitehouse is trialling one of these interventions, which is based around coaching parents to provide a socially enriched home environment. This intervention has shown significant promise in reducing disability in children showing early 'behavioural markers' for autism (Green et al., 2015; in press), and is likely to lead to some children never transitioning from 'Early intervention requirements' (Section 25 of the NDIS Act 2013) to 'permanent disability' (Section 24 of the NDIS Act 2013).

Given the evidence of long-term benefits to the individual and the disability support system of appropriate early intervention in autism, and the prominence of autism for the NDIS's ECEI approach (42% of all paediatric participants), we recommend that the NDIA:

1. *Invest in the development and application of a consistent, early identification protocol, delivered by primary maternal healthcare providers; and in the development and/or evaluation of targeted, very early intervention programs, which together have the real potential to lead to clinical improvements that reduce long-term disability and costs for individuals and society.*



We thank you for the opportunity to make this submission.

Yours sincerely

Andrew Davis
Chief Executive Officer



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