



Joint Standing Committee on the
National Disability Insurance Scheme

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

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Dear Committee members,

RE: Provision of services under the NDIS Early Childhood Early Intervention Approach

The Australian Psychological Society (APS) is the premier association for psychologists in Australia with over 22,000 members. We welcome the opportunity to make a submission to the Joint Standing Committee on the National Disability Insurance Scheme in relation to their inquiry into the *Provision of services under the NDIS Early Childhood Early Intervention Approach*. The feedback provided in this submission was developed in consultation with psychologists who are experts in the early childhood intervention sector, as well as consultation with members of the APS College of Educational and Developmental Psychologists.

In relation to the Terms of Reference (ToR), we state the following:

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

The eligibility criteria for determining access to the ECEI pathway are not clearly defined, nor informed by evidence-based tools and assessments. Although arguably the NDIS is not intended to be diagnosis-driven, this lack of clarity and standardised measurement tools means that there is a need to demonstrate a diagnosis as a means of demonstrating eligibility for the ECEI pathway. Moreover, there is currently a significant financial burden for parents in terms of obtaining a diagnosis. Only some children will meet criteria for an assessment to be done under Medicare, and even then there is likely to be a substantial gap fee (see also response to ToR e). This burden has been exacerbated by the move from block funding to the NDIS model of individualised funding. This means that service provider organisations cannot incorporate the costs of assessments into the services they deliver to consumers.

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

All support options should be evidence-based according to recognised guidelines. For example:

- NHMRC: <https://www.nhmrc.gov.au/>
- NICE: <https://www.nice.org.uk/>
- World Health Organisation:
http://apps.who.int/iris/bitstream/10665/75355/1/9789241504065_eng.pdf.

c) The timeframe in receiving services under the ECEI pathway

As the NDIS package application process is still difficult and unfamiliar for families to negotiate, this can delay access to interventions. There is limited or delayed access to timely language places for all children with language issues and in particular, children at higher risk of social/emotional and behavioural difficulties. The access to immediate funds, even just for an initial 6 months, would help to reduce this delay and risk.

d) The adequacy of funding for services under the ECEI pathway

It is noteworthy that NDIS funding levels (e.g., \$8000, \$10000, \$16,000 packages as suggested by NDIS guidelines) are lower than previous national funding models (e.g., Helping Children with Autism (HCWA)). Current funding levels are not commensurate with recommended best/good practice guidelines in Autism Spectrum Disorder (ASD) of 15-25 hours per week making it difficult for consumers to obtain good outcomes.

Families need appropriate support to allow them to recognise/understand/accept that their child has a disability or a developmental delay. The APS considers that providers must be funded to support families who are unable to recognise, understand and accept their child's needs. This education time can be extensive and will apply to some children who have professionally acknowledged disabilities as well as to those with disadvantaged backgrounds. Parents/guardians and children are often in incredibly vulnerable states, and transitioning through grief and acceptance can frequently require advanced competencies in counselling, understanding interpersonal relationships from a systemic perspective, as well as technical understanding of the conditions within a context of developmental stages.

Any discussion with parents requires a sensitive and empathetic approach and should be undertaken by an appropriately trained and qualified professional. Well-intentioned but under-skilled support can do more damage than good, and the consequent problems of family breakdown come not only at a considerable human but also economic cost. Best practice guidelines suggest that families benefit from including a second professional who can provide much needed family systems support to the family. The smoother and sooner the adjustment of the parents, the better the outcomes for the child. In summary, funding packages need to include ongoing parental and family support.

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

As indicated, there are significant challenges for families in obtaining an assessment and initial diagnosis. The waiting lists for assessments in the public sector are lengthy (commonly 1-2 years but often longer) and they are not available in many parts of Australia. There are only limited rebates under Medicare for these assessments. The cost of an assessment for ASD in the private sector is at least \$2000-\$3000, putting this out of the reach of many families. Some children may be eligible for a Medicare rebate for an assessment for ASD. However, the rebate only supports a limited assessment and is significantly below the fees recommended by the APS. This means that many families pay full fees or a significant gap fee if the child is eligible for a Medicare rebate.

Programs with evidence of cost effectiveness should be promoted.

f) The evidence of the effectiveness of the ECEI Approach

The ECEI approach encourages parents to become their child's therapist. Yet research suggests this places considerable burden on families who already show higher rates of depression, stress and lower quality of life than parents of children without ASD, and those with other disabilities or chronic conditions. APS member psychologists from the NDIS trial sites report that the philosophy to empower parents in the NDIS model can be flawed because parents do not necessarily "know what they don't know". It is not clear how the NDIS proposes to take parents on the learning journey of setting clear goals for their children, managing a budget for services and negotiating services for their children. Further, the research does not show sufficient evidence of effectiveness of this approach¹.

g) The robustness of the data required to identify and deliver services to participants under the ECEI

Data required to identify and deliver services to participants under the ECEI must be appropriate for developmental and also physical disabilities.

h) The adequacy of information for potential ECEI participants and other stakeholders

The information available for potential ECEI participants and other stakeholders is confusing, difficult to navigate, and places burden on parents to find the most appropriate treatment. However, research suggests that parents hold inaccurate beliefs about the evidence-base of interventions and tend to trust practitioners and "gut feelings" rather than research. This makes parents and carers vulnerable to choosing treatment options that have no evidence of their effectiveness and sham treatments².

A public communication strategy and a streamlined process involving Disability Local Area Coordinators is required to inform the community and families about what is best practice in ECEI. Informing the community and families about what is best practice in ECEI is critical so they can make informed decisions about their choice of ECEI providers and informed goals for their child. The APS contends that it is essential that families receive initial psycho-education from the professional who is the contact person. Families should be provided high quality, unbiased information about best practice in ECEI. Such information should be based on reputable sources such as Best Practice Guidelines from Early Childhood Intervention Australia and professional bodies rather than on the basis of financial issues or subjective opinion. Interventions and supports must be evidence-based and facilitate the best possible outcomes for children and families. Ongoing psycho-education for the family should be considered as part of the plan.

¹ Oono IP, Honey EJ, McConachie H. *Early intervention delivered by parents for young children with autism spectrum disorders*. 30 April 2013: <http://www.cochrane.org/CD009774/early-intervention-delivered-by-parents-for-young-children-with-autism-spectrum-disorders>

² Carlon S, Carter M, Stephenson J. *A review of declared factors identified by parents of children with autism spectrum disorders (ASD) in making intervention decisions*. Research in Autism Spectrum Disorders. Volume 7, Issue 2, February 2013, Pages 369-381: <http://www.sciencedirect.com/science/article/pii/S1750946712001407>

In addition, we provide the following relevant commentary on critical areas for consideration:

The role of Early Childhood Intervention (ECI) practitioners

Many children with complex needs will require a range of ECI practitioners who will need to work as a team to meet the needs of the child and their family. Plans need to include funding for communication among the team members to ensure all practitioners are working towards consumer goal-directed activity and not working at cross purposes. Without adequate information from planners, many families may struggle to prioritise team planning and collaboration. Ideally, planning/collaboration should be a standard funded component of all packages for children with complex needs.

The current popular approach in ECEI, particularly in Victoria, is the collaborative team approach led by a key worker. This may be new to families and to many service providers. It is important to note that there is no evidence to show it is effective to date. Support for the model is primarily through anecdotal evidence which suggests that it is most beneficial when agencies and families have access to a full range of professional disciplines. The reality is that this is not always possible, especially, but not only, in rural and remote areas. Research is needed to determine the clinical and cost-effectiveness of the collaborative team approach, to ensure it is the best model to meet the needs of the child under the NDIS.

Clear information about ECEI models, including the evidence-base, is crucial to ensure engagement and acceptance of the model by families and health providers. Families need to make informed decisions about how to best use their child's package of funding.

Rural and remote issues

It is well documented that there are challenges in developing a suitable provider market place in rural and remote Australia. Currently, there is limited or no choice of providers for many children and families living in rural and remote areas. The high cost of travel to rural and remote areas is a disincentive for service providers in a fee-for-service model where there are no or limited financial provisions for travel. Families can also lack capacity or the means to travel to services in regional or metropolitan areas. The burden of large distances can also make it difficult to deliver services in a child's natural learning environment.

Greater access to some services in rural and remote areas could be achieved by providing families with access to technology services. This has occurred with services for children with hearing impairments in Victoria (e.g., as part of specialised service programs at centres such as Aurora and Taralye). Government incentives to encourage more ECI professionals to work in rural and remote areas are also urgently needed.

Vulnerable families

Members inform the APS that the NDIS fee-for-service model is impacting upon support for vulnerable families. Firstly, the current fee-for-service model does not cover the cost of the time required by the provider to engage with a vulnerable family, build their trust and

develop a therapeutic alliance. The engagement process is critical to achieving positive outcomes and needs to take place before the practitioner can begin to provide ECEI support to the child. This needs to be addressed in the National Guidelines. Transience is also often observed in the most vulnerable and disadvantaged families. When families move, the therapeutic alliance is broken and re-engagement with new providers will again take time to establish but is essential for positive outcomes. Service providers have to be able to build the costs associated with engagement into the price.

Secondly, there are often a lot of 'no shows' and cancellations of appointments with children from vulnerable and disadvantaged families. Since providers are not able to charge for no shows, all agencies, but especially small ones and sole providers, are going to struggle to be sustainable in this market place. Innovative and highly respectful service models can increase the attendance rates of vulnerable families, but such models require workers with high level skills and regular high quality supervision. For these models to be viable under the NDIS, the costs associated quality supervision must be adequately funded.

In summary, thank you for the opportunity to provide feedback on the provision of services under the NDIS Early Childhood Early Intervention Approach. Many APS members are currently providing supports to consumers under this approach and appreciate the opportunity to voice their concerns about this important service. [REDACTED]

Kind regards

[REDACTED]

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