



AADDM

Australian Association of
Developmental Disability Medicine

Provision of services under the NDIS

Early Childhood Early Intervention Approach

Parliamentary Enquiry August 2017

The Australian Association of Developmental Disability Medicine (AADDM) is an organisation of medical and other health professionals who work with children, adolescents and adults with intellectual disability, and their families, to improve their health and wellbeing. Through professional development and advocacy, AADDM aims to improve the health and wellbeing of over 500 000 Australians with intellectual disability.

The NDIS Early Childhood Early Intervention Approach (ECEI) was introduced in order to adapt the NDIS to the special circumstances associated with the emergence of disability during the early childhood years. While the ECEI has in part addressed those, we hold significant concerns about aspects of the ECEI approach and how it responds to the needs of children living with disability and their families.

Aspects of the ECEI that are strengths and worthy of special note include:

- Acknowledgement that experiences for children and their families during the first 6 years of their life can be very different to those of later stages of life.
- The experiences during these early years can have life long impact
- Parents or carers are viewed as integral to the child's needs and accessing the right services
- Concerns held by parents or carers about their child's development are important to address
- Intervention provided during early childhood years for children with or at risk of developmental delay can lead to substantial savings and benefits in the longer term
- Children with disability ought to be included alongside their peers in the community.

However, we hold significant concerns about aspects of the ECEI approach and would like to address these in this submission. In any reform as complex as the NDIS, progressive changes are likely to be required as the system evolves and develops.

The early childhood years provide an unrivalled opportunity to address early determinants of lifelong health and wellbeing.

It is increasingly being recognised that the development of the brain progresses at a remarkable pace during the first years of life, including the period during pregnancy. There are critical periods in the early childhood years during which developmental skills are learnt more easily than at other times, with those skills providing the foundation for increasingly more complex skills. Although the early childhood years are particularly important, the process of development does continue beyond

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the early childhood years, and it continuous and ongoing. The Centre on the Developing Child, Harvard University, highlights that,

Early experiences determine whether a child's developing brain architecture provides a strong or weak foundation for all future learning, behavior, and health.

Furthermore, they highlight that limited benefit may ensue from programs that are poorly implemented in the community

Programs that cost less because they employ less skilled staff are a waste of money if they do not have the expertise needed to produce measurable impacts.

The interaction between the genes influencing development and the child's environment, especially the relationships with the primary carers, serves to remind of the importance of considering ecological factors that can lead to toxic stress for a child presenting with developmental delay. These include factors such as parents' mental health problems, family violence, insufficient finances and other resources to meet basic living needs and job insecurity. Failing to consider these important contexts for a young child can lead to missed opportunities for intervention.

Recommend:

1. ECEI approach should incorporate assessment of the family and social circumstances to identify if family and social factors exist that might compromise the child's developmental progress or lead to developmental delay.
2. Programs and policies designed to support young children and their families should specifically consider the implications for young children presenting with developmental delay or disability.
3. Intervention to support a child's development should be provided early and be sustained.
4. A focus on skill building is consistent with the importance of this period in life being a foundation for later learning.

NDIS ECEI should build on the wider services and systems in place especially those that serve to detect developmental delay

This addresses

- a. the eligibility criteria for determining access to the ECEI pathway;

A key function of universal child and family health services is to monitor child health, development and wellbeing, identify early disability and delay, support health issues (physical or socioemotional) and support the developing parent child relationship. A schedule of well child visits enables

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monitoring of child development with standardised assessment tools assisting in detecting developmental delay. Jurisdictions utilise different tools, but they tend to come from one of more of the following- PEDS, ASQ, Brigance Scales. See National Framework for Universal Child and Family Health Services 3.8.1 Developmental Surveillance and Health Monitoring (<http://www.health.gov.au/internet/publications/publishing.nsf/Content/nat-fram-ucfhs-html~framework~core-elements~development>). Additional tools such as the Australian Developmental Screening Test have found favour with some clinicians. Monitoring a child's socioemotional development as part of a developmental surveillance program, involves promoting the parent child relationship and the child's learning environment and onward referral to other services, such as parenting groups, where there is an identified need.

However, it is acknowledged that a minority of children attend an early childhood clinic, and even fewer attend on an ongoing basis or after the first birthday (NSW Child Health Survey: 2009-2010 Summary Report). Children may attend health practitioners such as general practitioners in the event of illness or when requiring immunisation, providing alternative opportunities for developmental surveillance using the recommended tools and approaches.

The case studies illustrating ECEI imply that a parent may approach an ECEI provider in the event that they have any concerns about their child's development, including undifferentiated concerns that may reflect behaviour typical for the child's age. This leads to the ECEI effectively being a developmental screening service, but without the context of the comprehensive developmental framework described above that is designed to promote child's wellbeing and relationships at each encounter over time and provide the professional with necessary tools, skills and supports.

Recommendations:

1. Developmental surveillance, that includes detection of developmental delay and provision of advice and referral, is best delivered by services established for that purpose, such as child and family health services, or alternative service providers such as primary health care. Inadequately resourced services may require enhancement to meet the community's needs for flexible, family centred models of care.
2. If the NDIS ECEI approach continues to provide a developmental screening service, in which parents may approach the ECEI prior to any professional confirming that there actually is a developmental delay, then it should do so within a comprehensive framework such as National Framework for Universal Child and Family Health Services.
3. Innovative programs specifically designed to identify and support vulnerable families should be developed and charged with identifying developmental delay, providing advice and referrals as part of their brief.
4. Onward referral from these services to ECEI ought to be accompanied by evidence of developmental delay such as completion of one of a range of recognised screening tools.

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5. All staff involved with developmental screening and provision of advice in relation to developmental be trained in working in partnership with parents, the importance of parent child relationship and attachment and typical child development across domains.

The ECEI should be funded to provide support for the children who can be expected to have developmental delay

This addresses

- b. the eligibility criteria for determining access to the ECEI pathway;

The NDIS was established to fund support for 460,000 Australians under the age of 65 with a permanent and significant disability with the reasonable and necessary supports they need to live an ordinary life (<https://www.ndis.gov.au/about-us/what-ndis.html>). This equates to approximately 2% of the population.

However, up to 1 in 5 young children are developmentally vulnerable in 1 or more domains and 11% will have vulnerabilities in 2 or more domains(AECD, 2015). Up to 8% of children will have delays in either language and cognitive skills or communication and general knowledge. Indigenous and those living in very remote locations are twice as likely to have developmental delay than other children.

The AEDC data emphasises the higher prevalence of developmental delay compared to rates of permanent and significant disability that need to be matched by funding and service provision. It is well recognised that providing intervention early gives these children the best start in life. Given that it isnt always possible to predict which children with delay might otherwise assume a typical developmental trajectory and who will progress to have a significant and permanent, early intervention programs must be broadly inclusive.

Recommendations:

1. Higher rates of conditions that present or are diagnosed during early childhood years must be expected and adequately funded.
2. Given the difficulty in diagnostic certainty and reliably predicting developmental trajectories in young children, emphasis must also be placed on developmental vulnerability as well as functional limitations in skills rather than specificity of diagnosis.

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Paediatricians can provide valuable assessments and contributions to management plans for young children presenting with developmental delays

This addresses

- c. the eligibility criteria for determining access to the ECEI pathway;

Paediatricians are called on to provide expert consultant opinion about children's development in the context of their physical health and family and social wellbeing. They are well connected to other important elements of the health system such as GPs and early childhood services, as well as with other family support services such as parenting programs and early childhood services. Throughout their medical specialty training, paediatricians are exposed to both normal and atypical child development across all the developmental domains and are intensively grounded in health conditions that can adversely affect normal development.

Paediatricians often form close and supportive relationships with parents and are seen as important advocates for the child and family. Some of the early questions parents may have such as *What caused the delay? Will my child get better? Is there any treatment?* can really only be answered by careful consideration and integration of factors including developmental skills and progress, physical health and family and social factors. Paediatricians are well placed to respond to parents questions.

Although paediatricians might not administer a developmental screening or assessment tool, their expert training often enables them to be able to identify whether a child has significant developmental delay and determine which domains are affected. This is extremely valuable for early detection and referral of children with developmental delay, especially those who might not be able to access formal assessment.

Recommendations:

1. ECEI services should ensure that they have close working relationships with paediatricians and provide, with parents' consent, intervention plans.
2. ECEI should accept referrals from paediatricians that provide evidence of developmental delay based on their expert clinical opinion.
3. All children determined to be eligible for ECEI should have a paediatric review to determine if treatable health conditions exist that are causing or contributing to the developmental delay.

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NDIA should review its use of PEDICAT

This addresses

- the eligibility criteria for determining access to the ECEI pathway;

As noted above, a range of developmental screening and assessment tools are in use in Australia, but these do not typically include PEDICAT. Given the limited familiarity with the PEDICAT and the caution in its use in young children with motor delays suggested by Dumas et al, 2015, the NDIS should review its use as the tool used to determine functional skills across a range of conditions presenting in early childhood. Some parents of young children suspected to have a developmental delay or ASD have been advised to have a PEDICAT done in order to determine eligibility, despite other more widely used and validated tools being available in community sectors.

Recommendations:

1. Validated screening and assessment tools approved for use by professional associations or government policy should take precedence over the PEDICAT, especially where these have already been completed for the child.
2. NDIA should consider an alternative tool/process for determining eligibility for ECEI.

Establishing a list (List D) of conditions associated with developmental disability introduces substantial complexity

This addresses

- the eligibility criteria for determining access to the ECEI pathway;

While it is laudable that the NDIA attempted to streamline access to ECEI and NDIS by maintaining a list of health conditions associated with significant disability, this has in fact introduced substantial complexity. Problems with this list include: an every expanding number of genetic conditions that will be identified with newer technology, many of conditions on the list are very rare and conditions associated with similar levels of impairment are likely to have been left off the list. It is also problematic that such a list risks a two tier entry system that may disadvantage those without a specific aetiology for their developmental delay or disability.

Furthermore, there is value for all children, especially those with an underlying health condition, to have at least one comprehensive developmental/cognitive assessment as all conditions are associated with a range of developmental or cognitive outcomes. Assessments at 5-6 years of age can be better predictors of longer term outcome. Where parents accurately understand their child's difficulties, they are in a stronger position to advocate for their child's needs.

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It is important that children who are known to be at risk of developmental delay on the basis on biological or other factors, such as extreme prematurity, Down Syndrome, severe abuse or neglect do receive early intervention to increase opportunity to reach developmental potential, educate and support parents to promote their child's development and inclusion. Most of these children are likely to be known to paediatricians. It can also reduce risk of secondary problems such as nutritional deficiencies due to limited food tolerance or challenging behaviour due to communication difficulties.

Recommendations:

1. Review of the value and limitations of maintaining list D in the face of ever increasing conditions being identified.
2. Aspects other than the underlying health condition are more likely to inform the types and extent of support needed and these should be understood during the eligibility process.
3. Consider an alternative system for entry to ECEI in which paediatricians indicate if there is a condition present that is very likely to be associated with developmental delay in a child too young to determine if delay is actually present.

There are weaknesses with the keyworker model that has been implemented under ECEI

This addresses

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

The NDIA introduced the ECEI keyworker model in an attempt to reduce the number of professionals and agencies involved in providing early intervention to children and their families. However, that seems not to have been achieved. Often parents who are accessing NGOs and the keyworker model are referred elsewhere, including for therapy which the keyworker might be professionally trained. In addition, often the keyworker's main role is provision of advice on where the family can go for intervention or support, rather than actual provision of intervention or therapy. Transdisciplinary model of care has led to a "dumbing down" of expertise that is sorely needed by children with developmental disabilities. For example, behaviour management advice may be provided by an OT who has little or no training in behaviour analysis and intervention and views challenging behaviour from a specific professional paradigm, eg sensory experience.

Significant challenges continue to be experienced by children and families in actually accessing services. Substantial delays have been experienced in funding approval and availability due to a range of issues with the design and early transition period. Particular concern is held for vulnerable families, such as those from disadvantaged, indigenous or refugee backgrounds or where parents may have limited English or education, with the shift towards payment for each encounter model.

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This will progressively advantage those children and families with less complex disability and socioeconomic needs, leaving the more vulnerable at greater risk of missing out.

It is important that children with disabilities are included alongside their peers. However, the emphasis on mainstream placements for intervention for children with disabilities risks loss of specialised placements that offer more intensive intervention. Some children require a much higher intensity of intervention in order to develop their skills and parents can justifiably expect this to be provided.

Recommendations:

1. The keyworker model may offer significant benefits for families who have little knowledge of services in their area, or where the child have less complex needs.
2. The ECEI must reintroduce professional specific services, especially where the needs are more complex or severe, eg psychologist for challenging behaviour, speech pathologist for severe communication limitations, particularly at key points in the child's intervention plan.
3. All current disability funding be maintained until all eligible children have approved NDIS plans.
4. Urgent policy and practice guideline development to support professionals providing early intervention, eg behaviour analysis approaches.

The needs of the whole family must be considered in the ECEI model

This addresses

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

The needs of all members of the family, including siblings, must be considered through the ECEI as the health and wellbeing of the family directly impacts the child with disability. The early childhood years present vulnerabilities not only for parents as they understand their child's emerging disability or delay, but also siblings. This may occur though diversion of parents' attention towards meeting the needs of the child with disability, additional developmental vulnerabilities in the sibling, challenging or violent behaviour directed towards the sibling and altered parent styles.

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Please don't hesitate to contact AADDM if we can provide further advice.

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MEMORANDUM



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