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Provision of services under the NDIS Early Childhood Early Intervention Approach

Royal Australasian College of Physicians (RACP) –
written submission

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Joint Standing Committee on the National Disability Insurance Scheme: Provision of services under the NDIS Early Childhood Early Intervention Approach

Introduction

The Royal Australasian College of Physicians (RACP) is supportive of the NDIS and its Early Childhood Early Intervention approach. We welcome the *Federal Parliamentary inquiry into the Provision of services under the NDIS Early Childhood Early Intervention approach* (the ECEI approach) as an important step in reviewing and improving the implementation of the ECEI approach across Australia.

The RACP understands that the ECEI approach was introduced in order to adapt the NDIS to the special circumstances associated with the emergence of disability during the early childhood years. While some elements of the ECEI approach are successfully addressing early intervention needs of young children, paediatricians are concerned about other aspects of the ECEI approach including how it responds to more complex health and support needs of children living with disability and their families.

The RACP has consulted with members of our Paediatrics and Child Health Division, the Neurodevelopmental and Behavioural Paediatrics Society of Australia, the Australian Faculty of Rehabilitation Medicine, our NDIS working group, State and Territory offices as well as members of our Aboriginal and Torres Strait Islander Health Committee to provide the following comments:

Terms of reference

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

Eligibility criteria and young children with high or complex needs

There is a risk that those with high or complex support needs will not be adequately supported by the NDIS under its current models of service. This is especially the case for young children with physical or intellectual disabilities, who also display challenging behaviours. Often referred to as “hidden disabilities”, NDIS ECEI planners may not understand the type of supports that are suitable to address these challenges and include insufficient funds to properly meet a child’s needs. Some non-government organisations as well as private companies providing ECEI services do not have sufficient experience to address physical disability, aggressive or violent behaviours, complex behaviour presentations and coexisting issues. NDIS ECEI must ensure that families do not relinquish care, see their services suspended or be inappropriately referred to mainstream services such as health to provide their early intervention needs.

The issue of permanent disability versus high risk designation

Different screening/developmental surveillance pathways exist for children with different developmental problems. However, there are now advanced mechanisms being applied by health professionals for identifying children “at risk” of developmental disabilities such as cerebral palsy as early as four months of age for example. This compares with the average age of diagnosis at 19 months of age. The investigations and tools for identification include the Prechtl’s “General Movements Assessment” which is done by video and can therefore be assessed at a regional and remote location. Neonatal brain imaging can be carried out via ultrasound and/or MRI and there are other assessment tools such as the Hammersmith Infant Neurological Examination (HINE).¹ The critical period for early intervention to mitigate or ameliorate the potential consequences of early

¹ Novak, I et al (2017): Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy Advances in Diagnosis and Treatment. *JAMA Pediatr.* doi:10.1001/jamapediatrics.2017.1689

neonatal insult occurs frequently prior to the confirmation of a final diagnosis and the terminology ‘at risk’ is used in the interim.

The provision of services should therefore commence at the time a baby is identified as being “at risk.” It is important that children who are known to be at risk of developmental delay on the basis of biological or other factors receive early intervention to increase opportunity to reach developmental potential, educate and support parents to promote their child’s development and inclusion. Other factors include extreme prematurity, Down Syndrome, severe abuse or neglect. Most of these children are likely to be known to paediatricians.

The RACP recommends that the NDIA establishes an “at risk pathway” recognising the latest emerging evidence in early intervention provision. This “at risk pathway” would be particularly beneficial for children in rural and remote areas. There is a reasonable expectation that either diagnosis could be confirmed or future functional capacity can be projected accurately by 2 years of age. Telehealth could be used to deliver some assistance during this critical period of development. There is an expanding evidence base emerging to outline which interventions are effective.

In cases where it is likely that children are going to be long-term NDIS participants, identifying these children and dealing with them separately would help families to set up appropriate services for their child living with a disability. Having an NDIS package instead of an NDIS ECEI plan will help families where routines are not adhered to easily and will lead to better longer term health outcomes. Placing children who will have a long relationship with the NDIS straight on to an NDIS package avoids the need for a transition from ECEI to the NDIS down the track.

Use of PEDICAT

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 PEDICAT and evidence cautioning against its use in young children with motor delays², the NDIS should not use PEDICAT as a tool to determine functional skills across a range of conditions presenting in early childhood. There are reports that parents have been advised to have a PEDICAT assessment done in order to determine NDIS (ECEI) eligibility, despite other more widely used and validated tools being available in community sectors.

The NDIA should use validated screening and assessment tools already approved for use by professional associations and/or government policy frameworks. Assessments undertaken with those validated screening and assessment tools should take precedence over using PEDICAT.

Concerns regarding List D³ of conditions associated with developmental disability

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. Below are examples of potential problems with List D:

- an ever- expanding number of genetic conditions that will be identified with newer technology, and
- some conditions on the list are very rare and conditions associated with similar levels of impairment are likely to have been left off the list.

The list risks a two tier entry system that may disadvantage those without a specific aetiology for their developmental delay or disability. There is value for all children, especially those with an underlying health condition, in having at least one comprehensive developmental/cognitive assessment as all conditions are associated with a range of developmental or cognitive outcomes.

² Dumas, HM et al (2015): Pediatric Evaluation of Disability Inventory Computer Adaptive Test (PEDI-CAT) and Alberta Infant Motor Scale (AIMS): Validity and Responsiveness, *Physical Therapy*, Volume 95, Issue 11, 1 November 2015, Pages 1559–1568, <https://doi.org/10.2522/ptj.20140339>

³ NDIA. 2017. Access to the NDIS, Permanent Impairment/Early intervention, under 7 years – no further assessment required. Accessed 18.08.2017: <https://www.ndis.gov.au/operational-guideline/access/list-d>

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.

The NDIA should consider the limitations of maintaining list D as more eligible conditions are identified. Elements beyond the underlying health condition are more likely to inform the types and extent of support needed and these should be understood completely during the NDIS ECEI eligibility process.

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

All NDIS-funded services, including ECEI supports delivered privately by service providers should be evidence-based. It is important all treatments funded by taxpayers have a compelling, peer-reviewed evidence base supporting them. It should be ensured that practices and therapies delivered through NDIS ECEI pathways are explicitly goal-directed and accountable to meaningful, measurable outcomes over set time frames. Families of children with developmental delay requiring early intervention should be free to select those early intervention services that most suit their child's and family's needs, however both they and the NDIS' limited funding pool should be protected from therapies that can:

- negatively impact outcomes;
- take the place of evidence-based treatments; and
- lead to cost blowouts.

Therefore, appropriate education and training of NDIS planners/advisors including NDIS ECEI service providers is necessary to avoid unnecessary or inadequate early intervention services and therapies being offered to a child living with disability or developmental delay.

ECEI providers' expertise and experience

It is critical that all ECEI providers have sufficient experience, skills and equipment to provide the range of early intervention therapy services required by the child. For example a child with cerebral palsy might, as part of their therapy, require a splint to be made, and/or serial casting to be performed for contracture management. Some families choose providers who are unable to supply these services for multiple reasons and in some cases do not seek solutions (e.g. another provider) to provide these services if and when needed. Families may lack the knowledge to notice this gap in service. This can increase NDIS-eligible work requested of health services, but more importantly it is not family-focused or best-practice care.

The RACP recommends that young children with developmental delay who are likely to require long-term NDIS funding should be required to see a paediatrician or specialist trained to assess their physical and cognitive development as well as their health.

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

Some young children will benefit from accessing appropriate early interventions services before being definitively clinically diagnosed. Early intervention services should be accessible for children being "at risk". ECEI services are also time critical and should be made available to children living with disability and developmental delay as soon as possible after diagnosis to ensure optimal outcomes. The RACP is concerned about reports that public waiting lists for NDIS medical assessments by a paediatrician or health professional are already too long in most roll-out areas. Affordable public medical assessments for children identified as "at risk" need to be made available to avoid families paying for required NDIS medical assessments provided by private health services.

Vulnerable children in need of timely early intervention who were previously prioritised under the Federal Rapid Response Framework may now be facing longer delays in accessing care under the

NDIS. This is not in step with the principles of the National Clinical Assessment Framework for Children and Young People in Out-of-Home Care and Closing the Gap initiatives.

There would be benefit in establishing mechanisms to expedite access to the NDIS and NDIS ECEI for more vulnerable children such as “immediate response” policies and procedures in health and hospital settings for example. This would ensure support for children diagnosed with significant changes or deterioration in skills or behavior and preventing loss of placements. Such “immediate response” mechanisms would again require better communication between the NDIA and the health sector.

This is also true for young people and adults already living with disability. It is important that children living with disability and their families have a clear understanding of their eligibility for the NDIS, and their pathway to participation.

Below are some reported experiences in accessing early intervention services, after being diagnosed and deemed eligible for services under the ECEI pathway, in a timely and effective manner in different Australian states and territories.

Delays in accessing NDIS ECEI in South Australia

There is a concern over long delays in South Australia for vulnerable children in need of early intervention in accessing appropriate therapies under the National Disability Insurance Scheme (NDIS).

It has been reported that children in South Australia under the Guardianship of the Minister (GOM) are waiting around 12 months between enrolment in the NDIS and therapy commencing. As a result, these children are not receiving any therapy during a crucial period in their development.

Factors that may be contributing to the delays and possible solutions include:

- When a child first enters out of home care arrangements via an Intervention Assessment Order (prior to a youth court granting guardianship), it can take months for them to be enrolled in the NDIS. Factors such as the NDIA’s processes not allowing contact with Department of Child Protection (DCP) case managers without consent of a parent or until guardianship is approved contribute to the delays.
- Some parents from difficult circumstances or disadvantaged backgrounds are ill-equipped to navigate NDIS processes. This can also be the case for families from culturally and linguistically diverse (CALD) backgrounds. In some instances, it may be beneficial to the future health and wellbeing of the child to offer parents the option to delegate responsibility for their child’s case management to an appropriate guardian at the beginning of the process.
- The NDIA should review the methods it uses to engage with DCP case managers, who may have little training in disability and the importance of well-timed early intervention. In some instances, case managers did not proceed with NDIS enrolment for children in need of therapy. One solution may be to accept direct referrals from clinical staff and hospital based assessment teams working with vulnerable children.

Transition of ‘Helping children with autism’ (HCWA) in NSW

There is concern about the Department of Social Services (DSS) management of transitioning the funding of the Helping Children with Autism (HCWA) program in NSW to the NDIS. The relative short notice from DSS about HCWA funding ceasing took many paediatricians and their patients by surprise. Newly diagnosed children are at risk of missing out on vital, early intervention services originally provided by HCWA and its autism advisors.

HCWA service providers and paediatricians were asked to refer any children newly diagnosed with autism spectrum disorder and their families directly to the NDIS.

It is important to give health professionals appropriate time to transition patients to the NDIS without newly diagnosed children having to face unreasonable delays in trying to access the NDIS ECEI.

NDIS roll-out in Tasmania

There are reports that the NDIA is not fully prepared to provide information to stakeholders around accessing the ECEI. For example, there are reports that no referral form has been developed yet. There are also concerns about insufficient engagement with stakeholders in health, similar to other States.

Tasmanian RACP fellows also expressed their concerns around the approach's keyworker model often referring to inadequate 'mainstream services' rather than specialised early childhood intervention services.

Accessing NDIS ECEI services in Victoria

There are reports from Victoria that NDIS ECEI plans have been created and approved rapidly but are not appropriate or adequate to the child's needs. Thereafter, the process of review of the NDIS ECEI package or NDIS plan delays the child's access to vital early intervention services.

Some families, including two recent refugee families with approved NDIS plans whose child is enrolled in an NDIS ECEI package, don't know how to access the services to receive the early intervention or therapy in the standard NDIS plan.

d. the adequacy of funding for services under the ECEI pathway;

The NDIS was established to fund 'reasonable and necessary supports' for about 460,000 Australians under the age of 65 with a permanent and significant disability enabling them to live an ordinary life. This equates to approximately 2 per cent of the population. However, Australian Early Development Census (AEDC) data shows that up to 1 in 5 young children are developmentally vulnerable in 1 or more domains and 11 per cent will have vulnerabilities in 2 or more domains.⁴ Up to 8 per cent of children will have delays in either language and cognitive skills or communication and general knowledge. Aboriginal and Torres Strait Islander children and those living in very remote locations are twice as likely to have developmental delay as non-Indigenous children and children living in regional and metropolitan areas.

The AEDC data emphasises the higher prevalence of developmental delay compared to the rates of permanent and significant disability which therefore need to be matched by appropriate ECEI funding and service provision. Given that it isn't always possible to predict which children with delay might otherwise assume a typical developmental trajectory and which will progress to have a significant and permanent disability, the NDIS ECEI must be broadly inclusive and NDIS ECEI plans adequately funded.

A lack of individualised NDIS ECEI packages/plans can result in current funding levels being insufficient to pay for early intervention services for children with higher level needs, compromising the benefits of receiving appropriate, high quality early intervention services.

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

The transparency of costs associated with care means that some families choose to spend NDIS ECEI funding on direct therapy rather than on administrative tasks such as writing reports or

⁴ Australian Early Development Census National Report 2015: A Snapshot of Early Childhood Development in Australia, page 31

communicating between providers. As families often deal with multiple ECEI service providers involved in their child's care, this means that communication between the providers is sometimes not occurring effectively. Families want better coordination and information exchange between the agencies and professionals involved in their child's care⁵, and feel the NDIA is not achieving this effectively. The NDIA has identified lower than expected exit rates from the Scheme as an early cost pressure. Improved collaboration between providers, professionals and families may impact the rates of successful early intervention and exit from the Scheme and thereby cost pressures.

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

Limitations of the keyworker model established under the ECEI approach

ECEI has led to a more accessible first point of contact for families and young children showing signs of developmental delay and in need of disability supports. However, the key worker model presents significant limitations when a child requires health professional-specific assessment, advice and therapy. Anecdotally, there have been instances where families are directed by NDIS ECEI service providers to external, private therapists.

NDIS planners require training and skills that are adequate for building NDIS packages for children that meet their needs. Some NDIA staff have been reported to have very limited experience in disability, learning or behavioural issues, and seek little or no input from the health, allied health and education professionals who are involved in the care of the child. For example, behaviour management advice provided by an OT who has little or no training in behaviour analysis and intervention may view challenging behaviour from their specific professional paradigm.

It is important that NDIS ECEI providers offering the key worker service also be in a position to provide specific therapeutic services as part of the ECEI package. Evidence is emerging which suggests more direct, targeted therapy (using approaches such as GAME for example) is more effective than a key worker model. It is often the case that a series of therapy sessions working intensely on a goal produces greater improvement in function than low intensity key worker models. The NDIA should consider introducing professional-specific services to their NDIS ECEI approach, especially where the child's needs are more complex or severe and particularly at key points in the child's intervention plan.

The RACP recommends that the NDIA considers systems for entry to ECEI in which paediatricians can 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 certainly present.

Challenges in finding ECEI service providers

Paediatricians report significant challenges are being experienced by children and families in accessing services. Lengthy delays to funding approval and service availability issues due to a range of problems with the design and early transition period are occurring. Once funding is approved, families often need to piece together input from various services and providers to meet their child's needs. This is becoming burdensome for families who need to engage multiple service providers in order to meet their child's needs.

Particular concern is held for vulnerable families, such as those living in regional and rural areas, from refugee backgrounds or where parents may have limited English or education, with the shift towards a pay for each encounter model. This will progressively favour those children and families with less complex disability and socioeconomic needs, leaving the more vulnerable at greater risk of missing out.

⁵ Burton K et al (2017): Using family and staff experiences of a botulinum toxin-A service to improve service quality. Child Care Health Development. 2017;1-7. <https://doi.org/10.1111/cch.12500>

The RACP recommends that the NDIA consider investing in a portal for information exchange between stakeholders including health professionals to integrate the access to ECEI services for the child and family.

g. the robustness of the data required to identify and deliver services to participants under the ECEI;

NDIS ECEI ability to accredit therapists

It is important the NDIA only accredit therapists with appropriate experience and who use evidence-based therapeutic approaches as NDIS ECEI service providers. Many families do not have the means to make educated choices regarding which therapists and therapeutic approaches are best suited for their child's support needs. At present, there is widespread use of early intervention therapies without any evidence base. Therefore the RACP recommends that the NDIA include a review of the evidence base when undertaking the NDIS ECEI provider accreditation process.

There is an opportunity for the NDIA to investigate best practice using research methodology and produce evidence to support ongoing models when accrediting therapists.

h. the adequacy of information for potential ECEI participants and other stakeholders;

Case management service

A case manager service should be considered for all NDIS ECEI families for their broader support needs, ideally provided by highly trained professionals. Some families might have the capacity to manage the organisation and planning of their NDIS ECEI package themselves, but lack the local knowledge and understanding of specific acute and chronic conditions. Case management can also help families to guide distribution of funds for a child whose condition or level of support may fluctuate throughout the year. Families in crisis may choose to divert funds to support agencies such as respite services at the expense of vital early intervention therapy. Episodes of crisis can sometimes affect longer term planning and foresight leaving children with a paucity of vital services until their NDIS plan is reviewed.

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

There appears to be some duplication of services under the NDIS, sometimes without regard to ensuring high standards of care or targeting services appropriately. For example, in Tennant Creek in the Northern Territory, one of the remote trial sites, there are 22 agencies involved in service provision for the NDIS – in a population of 3,000 people, complex social issues, and known difficulty attracting and retaining skilled staff to implement services in a remote area.

It would be more beneficial to NDIS participants to identify different agencies to cover grouped areas of services such as allied health services, housing support services, respite and social participation and education issues to concentrate skilled staff within less agencies. In regional and remote areas this could improve professional support and continuing education of NDIS service providers ultimately improving the standard of service provided, as well as avoiding duplication of services and inefficient expenditure.

The NDIS in WA remains behind given its late adoption of the NDIS, and this should be addressed as soon as possible. A universal approach across Australia is the best approach for people and young families who may be moving around the country according to the availability of work.

There is concern about reports from RACP Members that NDIS ECEI access has been difficult in some regional centres in Western NSW and Victoria, because of a lack of ECEI services being made available.

j. the principle of choice of ECEI providers;

The principle of choice of ECEI providers is difficult for some families to understand where required services are not locally available. The choice of providers is often limited so families are not necessarily choosing from high quality providers for their child. For example, some areas lack paediatric-specific providers such as continence services that could provide an individualised intervention to learn to self-CIC (Clean Intermittent Catheterisation). For those goals communication between clinicians is even more important and should be facilitated without costs that might act as a disincentive to families.

RACP Members report that ensuring consistency of the expertise of service providers and helping families or other health professionals choose an appropriate provider could be better supported. Improved support would strengthen the principle of choice.

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;

Even in the best case scenario, early intervention supports and services that are not evidence-based will result in ECEI participants failing to reach the full potential offered by the NDIS ECEI approach. It is important evidence based early interventions and therapies are commenced at the right time for the right child.

Some RACP Members report that young children are not being offered targeted services which would better meet their needs, and that some fundamental services are not provided. For example, core therapies and any necessary home/transport modifications should be accessed and in place, before additional therapies or services are started.

l. any other related matters.

The role of universal child and family health services under the NDIS ECEI approach

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 the monitoring of child development with standardised assessment tools assisting in detecting developmental delay. While different jurisdictions utilise different tools, they tend to come from one of more of the following: Parents' Evaluation of Developmental Status (PEDS), Ages & Stages Questionnaires (ASQ), ASQ-TRAK⁶ and Brigance Scales⁷. Additional tools such as the Australian Developmental Screening Test have found favour with some clinicians.

Universal child health services also monitor a child's socioemotional development as part of a developmental surveillance program, which involves promoting the parent-child relationship, the child's learning environment and onward referral to other services, such as parenting groups if necessary.

It is well established that a minority of children and their families attend an early childhood clinic, and even fewer attend on an ongoing basis or after the first birthday⁸. Children also attend other 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.

⁶ ASQ-TRAK is a developmental screening tool for observing and monitoring the developmental progress of Australian Aboriginal children at 2 months, 6 months, 12 months, 18 months, 24 months, 36 months and 48 months of age

⁷ 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>)

⁸ NSW Child Health Survey: 2009-2010 Summary Report

The NDIA case studies illustrating the NDIS ECEI imply that a parent may approach an ECEI service 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 service provider effectively being a developmental screening service, but without the context of the comprehensive developmental framework described above. That framework promotes the child's wellbeing and relationships at each encounter over time as well as providing the health professional with necessary tools, skills and supports.

Therefore, developmental surveillance, including the detection of developmental delay and provision of advice and referral, is best delivered by services already established for that purpose, such as child and family health services, or alternative service providers such as primary health care. Inadequately resourced or trained NDIS ECEI services may require enhancement to meet the community's needs for flexible, family-centered models of care.

If the NDIS ECEI approach continues to provide a developmental screening service, in which parents may approach the ECEI service provider prior to any health professional confirming that there actually is a developmental delay, then it should do so within a comprehensive framework such as National Framework for Universal for Universal Child and Family Health Services.

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.

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

Moving interstate

The non-transferability of NDIS ECEI packages and NDIS plans when families need to move interstate should be addressed. It's being reported that these families have to negotiate new NDIS support plans and find new local NDIS ECEI service providers under that new plan.

Parent/carer satisfaction and support needs

The NDIA should measure and collect data on the outcomes of intervention as well as the satisfaction of parents and carers. Many parents will require professional health support in line with their concerns and anxieties about their child's developmental delay.