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**RACP Submission to the NDIS
consultation paper: Supporting young
children and their families early, to reach
their full potential**

February 2021

About The Royal Australasian College of Physicians (RACP)

The RACP trains, educates and advocates on behalf of over 18,863 physicians and 8,830 trainee physicians, across Australia and New Zealand. The RACP represents a broad range of medical specialties including general medicine, paediatrics and child health, cardiology, respiratory medicine, neurology, oncology, public health medicine, infectious diseases medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation medicine, geriatric medicine, and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

The RACP membership includes over 5,600 paediatric fellows and trainees, who routinely work with newborns, infants, young children and their families. Paediatricians play an important and often under-recognised role in caring for children and young people with mental health problems. The role of the paediatrician is particularly important in the face of limited specialised mental health services, especially in rural and remote Australia.

The RACP Paediatric and Child Health Division (PCHD) leads policy development in a number of relevant areas, including having developed position statements on [Health and the National Disability Insurance Scheme](#), [Inequities in Child Health](#), [Early Childhood](#) and [Indigenous Child Health](#).

Executive Summary

The RACP welcomes the opportunity to provide feedback on the proposed recommendations to reset the Early Childhood Early Intervention (ECEI) approach outlined in the [NDIS consultation paper: Supporting young children and their families early, to reach their full potential](#).

The RACP strongly supports the NDIS, its underlying values and principles, including individual autonomy, non-discrimination, and full and effective participation and inclusion in society. The RACP has contributed paediatrician perspectives and expertise at various stages of the NDIS roll-out and subsequent inquiries into specific aspects of the NDIS, including the ECEI approach.

We strongly support the concept of the ECEI, which acknowledges the early years as important in a child's development and supports children with developmental delay, disability and their families to achieve their best outcomes. Paediatricians are often the first to identify health issues in children and play an important role in referring the child to the NDIS and providing the family or carer with information about linkages and capacity building (ILC) and about the types of therapies, interventions and supports.

The RACP is concerned that inconsistent implementation of the ECEI approach has limited young children and their families accessing support. In particular this has negatively impacted culturally and linguistically diverse (CALD) children, Aboriginal and Torres Strait Islander children and children of parents with mental health issues. We welcome efforts to improve the ECEI approach and would like to see clearly articulated strategies on how equitable access to services and supports can be achieved for these children.

The RACP is overall supportive of the approach taken by the NDIS to improve the ECEI experience. This submission provides comment on a number of the proposed recommendations to reset the ECEI approach based on current RACP positions on the NDIS and disability and in consultation with paediatricians.

Feedback on Specific Recommendations

Overarching recommendations

Support for families and carers to better understand some of the terms the NDIA, and Early Childhood partners (Recommendations 1-4)

RACP Fellows reported that understanding the ECEI process can be cumbersome and confusing for families. Further changes are required to make it more easily accessible, and to increase its focus on optimising health outcomes. Information for parents and carers needs to be clearer, more extensive, and easier to find both on the NDIS website and through other NDIS access points (e.g. information provided to medical professionals, schools, childcare centres etc.). The webpage must state clearly:

- The role of Local Area Coordinators and other key roles.
- An explanation of the role and function of the ECEI in practice.
- What services ECEI organisations provide.
- Transition requirements from ECEI onto the NDIS.

The RACP agrees that regular provider reports written in a language understandable to family will help them keep track of their child's progress. Where parents speak a language other than English, interpreters should be provided to help ensure they understand what is being reported about their children. One way in which awareness of suitable services could be promoted would be through an electronic local service directory. The NDIS should also introduce initiatives which encourage parents to be actively involved in their child's therapy, as parents are often pivotal in the progress that children make.

Consider a range of mechanisms that will enhance compliance of providers with the NDIS Practice Standards on Early Childhood Supports and increase awareness by families of providers that adopt that best practice framework (Recommendation 6)

The RACP strongly agrees with this recommendation and the need to enhance providers' compliance with best practice standards and provide greater transparency on which providers are following Early Childhood Intervention best practice. All providers must have appropriate professional qualifications and references and newly qualified therapists should ideally first work in a supervised environment. When registering with the NDIS, all providers should be required to provide evidence of appropriate qualifications and membership of relevant professional body association.

Improve sector wide understanding of how to identify families and young children experiencing disadvantage and tailor culturally appropriate services and resources (Recommendation 7) and increase Early Childhood partner capacity to identify and help young children and families from hard-to-reach communities or those experiencing disadvantage or vulnerability (Recommendation 10)

The RACP strongly agrees with recommendations 7 and 10. The NDIS must be explicit about how this will be funded and achieved. The RACP would like to see the NDIS adopt the principle of proportionate universalism where there is sensitive identification of psychosocial vulnerability and enhanced funding /services/models of care that address access barriers for children from priority populations. For example, a child with same functional impairment from a disadvantaged family will get more supports than a child from advantaged family because their psychosocial risk is considered in their assessment and plan.

Enabling earlier identification of eligible children from families experiencing disadvantage would help maximise the benefits of early intervention and improve current inequities in the access process. The NDIS should consider innovative programs specifically designed to identify and support children and families within priority populations. Programs must be tailored, culturally appropriate, and community informed and led where possible, for example working with Aboriginal Community Controlled Health Organisations (ACCHOs) to strengthen engagement with Aboriginal and Torres Strait Islander children and families. Partnering with community organisations and listening to the experiences of diverse communities would assist the NDIS in better understanding the specific challenges and issues that children and their families and carers experience when accessing the ECEI.

The RACP is concerned that the national Telephone Interpreter System, which is free for health professionals and available on call, explicitly excludes Aboriginal languages, for which the provider is directed to a different service which costs at least \$100 per hour and requires advance booking. This lack of equitable interpreter services for Aboriginal and Torres Strait Islander people represents a significant barrier to accessing services. It is therefore essential that the NDIS introduce improved options for providing culturally appropriate interpreting services.

Families and carers often have difficulty navigating the NDIS, including case management and care coordination. The RACP supports the implementation of more streamlined and structured support for families within the NDIS, so they do not need to approach multiple services for different aspects of care. More effort needs to be made in supporting families to choose services during early stages as they may not be well informed or have a clear enough understanding of the needs of the child. To complement this, referral/coordination pathways between ECEI services, health, early childhood education and community services should be made clearer and strengthened so that there is no wrong door for families.

Tailored methods of delivering supports for young children and their families living in remote communities (Recommendation 8)

Rural and regional areas can experience a confluence of health and disability services workforce shortages that can impact upon the type, variety and, potentially, the quality of disability services available. Where services do exist in remote and rural areas, their workloads are often large and diverse, which limits time available for the provision of early intervention for young children. An opportunity exists to supplement these services in rural and remote areas of Australia with innovative use of telehealth, parent coaching and therapy assistance to supplement the service provided by existing allied health staff.

Tailored Independent Assessments (IAs) approach (Recommendation 9)

The RACP notes the recommendation of implementing a tailored Independent Assessments approach for young children to support consistent access and planning decisions. The RACP supports funding for assessments and their important role in supporting NDIS access, planning and review. However, we are concerned that the proposed model has the potential to disregard relationships with medical and allied health professionals who have developed a shared understanding of the child's individual needs. RACP Fellows noted that referrers often already have trust and a relationship with families, which is particularly important for priority populations. The NDIS must consider how the tailored independent assessments approach will complement, rather than replace, the input of health professionals. Further support should also be made available in any assessment of non-English speaking children and parents.

The NDIS must consider carefully who is best placed to conduct independent assessments. Rehabilitation medicine physicians routinely undertake functional assessments (either paediatric or adult) and are therefore specifically skilled in conducting them. They also play an important role in assisting children and families

access to the NDIS, including recommending the most appropriate allied health clinician(s), particularly for children with complex/multiple disabilities.

The RACP is supportive of building on the existing skills of early childhood partners who play an important role in assisting families understand the potential role of the NDIS and to guide them to appropriate supports and offer advice on providers most suited to their needs. Early Childhood partners may be able to provide an important supporting role in independent assessments, if they are provided with appropriate training.

Recommendations for early support

Increase Early Childhood partner capacity to provide Short Term Early Intervention (STEI) support (Recommendation 12) and increase the age limit for children supported under the ECEI approach from 'under 7' to 'under 9' years of age (Recommendation 14)

The RACP fully supports the STEI approach, however we would like the NDIS to provide further clarification about when it is judged that a child no longer needs STEI and does not need NDIS, and how the NDIS will better support children and families in this transition. The RACP is supportive of increasing the age limit for children accessing the ECEI approach to under 9. A key reason for this is that it would allow children who have only recently required medical attention and would benefit from further observation, investigation and treatment between seven and nine years of age to access the pathway.

Recommendations for transitions

Improve the existing annual progress review process for young children (Recommendation 21), ensure providers are using the recently introduced 'provider outcomes report' (Recommendation 22) and offer families of young children a 'transition out' plan for up to 3 months' duration (Recommendation 23)

The RACP supports the recommendation to offer families of young children a 'transition out' plan for up to 3 months' duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS. We would like to see a transparent public report on the impact of Recommendation 23, especially for children with ongoing support needs. The RACP would also like to see the NDIS commit to ensuring that there is no default transition out of the scheme if lack of contact, who may represent families experiencing disadvantage or vulnerability.

It is important that parents and carers are suitably prepared for their child's transition out of the NDIS. It would therefore be beneficial for providers to consider and comment on whether a child should be transitioned out of the system as part of the NDIS plan review process.