Response to the Joint Standing Committee inquiry into the NDIS participant experience in rural, regional, and remote Australia

About Professionals and Researchers in Early Childhood Intervention (PRECI)

Professionals and Researchers in Early Childhood Intervention (PRECI) is the peak body for professionals and researchers working with young children with developmental delay or disability, and their families. It is an Australian research-to-practice network focussed on outcomes for young children with developmental disabilities. PRECI was established as a not-for-profit public company limited by guarantee in June 2022. preci.org.au

Our vision is excellence and equity in services for young children with developmental disabilities or at risk of developmental delay, and their families.

Our purpose is to lead Australian early childhood intervention[1] (ECI) research, knowledge translation, quality practice, and policy for young children with developmental disabilities.

PRECI has been formed to:

- provide a national network connecting ECI practitioners[2] and researchers with a focus on supporting collaborative research, knowledge sharing and peer support.
- provide ECI professionals, community organisations, researchers, higher education institutions and policymakers with an authoritative source of information about best practice in ECI.
- identify, develop, promote, and raise awareness of advances in effective models of service delivery to ensure consistent implementation of best practice for young children and families.
- promote a national approach to coordinated and comprehensive pre-service, in-service, and post-graduate training opportunities for professionals working with children with developmental delay and disability, and their families and related mainstream services, on contemporary and evidence-informed practices.
- develop a national research framework and conduct research projects to advance and inform ECI within Australia.
- promote interdisciplinary collaborations to ensure advances in research and translation of research into practice.
- provide nationally coordinated and timely responses to federal policy, funding, and service delivery guidelines to support consistent contemporary practice in ECI.

---

[1] Early Childhood Intervention (ECI) is described as "the process of providing specialised support and services for infants and young children with disability and/or developmental delay, and their families in order to promote development, well-being and community participation". (ECIA Vic/Tas, 2023)

[2] ECI practitioners are minimum bachelor qualified members of a collaborative team (e.g., speech pathologists, occupational therapists, psychologists, physiotherapists, specialist teachers, social workers...)

PRECI board members hold leadership positions across various professional and research organisations across Australia. Their views are based on Australian and international research and practice and have been continuously sought by Federal and State governments for the last 30 years.

Introduction

It is widely acknowledged that the general population in rural settings experience poor health, education, and social outcomes across levels of remoteness, from inner regional to very remote groups (National Rural Health Alliance, 2023). Children, in particular, are more likely to face concurrent social, economic, and environmental conditions that are known to unfavourably impact health and development when compared to their counterparts in metropolitan Australia (Department of Health, 2019). They are also significantly more likely to experience limited access to appropriate services in the community, known to mediate the impact of adversity in early childhood (Arefadib & Moore, 2017). This double set of challenges experienced by young children and their families has become more salient as a result of the introduction of the National Disability Insurance Scheme (NDIS).

The implementation of the NDIS with participants in rural, regional, and remote Australia has been a long-standing concern (Tune, 2019), which has been well documented in the recent NDIS review (NDIS, 2023a). In the first instance, numerous anecdotal reports indicate a failure to recognise the diversity in the characteristics of young children with developmental concerns, delays, or disabilities. They are often subjected to 'one size fits all', medicalised approaches, despite the presence of children's services (e.g., maternal and child health, early childhood education and care) that are immersed in the community. These services and supports are more likely to be accessible to children and their families locally, as they would be immediate and within reach. If these arrangements were maximised, well resourced, and responsive to the needs of these children, the delivery of timely identification of developmental delays or disability would be strengthened, and thus appropriate services implemented.

Since 2013, Early Childhood Partners (ECPs) have been contracted by the NDIA to provide early connections to children with developmental concerns, delays or disability (NDIS, 2023b). Unfortunately, this essential function of connecting families with appropriate services and supports through the ECPs is not available in all rural and remote areas for young children with disabilities (NDIS, 2023c). For example, in Western Australia, approximately 80 % of the state does not have access to NDIS early childhood partners (Kimberley, Pilbara, Mid-West, Goldfields, outer Wheatbelt). Importantly, the very limited availability of NDIS ECPs makes engagement of families with the NDIS difficult in these areas. This may mean that cultural nuances of service provision (e.g., shame associated with disability), can affect their understanding of NDIS processes. Other organisations such as health take on the role of the Early Childhood Partner without additional personnel or appropriate training.

Furthermore, the systemic barriers continue even when children and their families have an approved NDIS funding package. It has often been reported that these families have challenges in navigating primary services, experience delays, feelings of isolation and fears that their family member with disability may miss out on essential supports, and services (Cuskelly, 2022; Johnson et al, 2020; Loadsman & Donelly, 2021). Children who experience mental health issues who also exhibit complex behaviours, for example, are not able to access those supports. There are limited registered behaviour support practitioners in remote areas. Because of the lack of services, families are often faced with the difficult choice of moving to a larger regional town or capital city to access suitable services or remaining in their communities and accessing services (eg. via a hospital or other health service) that do not meet their children's early learning and developmental needs or facilitate inclusion and participation.

Despite efforts to address these issues (NDIS, 2021), research and anecdotal evidence indicate that policy and practice implementation for this population continue to present challenges fostering inequity and poor quality in service provision. It is in this context that PRECI provides responses to the committee inquiry into specific aspects of the NDIS participant experience in rural, regional, and remote Australia.

Responding to the Terms of Reference

This submission pertains to participants aged from birth to under 9 years; however, some of the literature used, while related to adults with disabilities, may concur with the experience of young children with disabilities.

PRECI’s submission focuses on the current NDIS service delivery model for this population; namely, the Early Childhood Approach and the extent to which this current policy and its implementation model is equitable and effective in terms of access to supports and services, timely early identification and diagnosis, planning, and monitoring of children’s learning and development.

a. The experience of applicants and participants at all stages of the NDIS, including application, plan design and implementation, and plan reviews.

Families of young children with developmental delay or disability in rural, remote and regional areas experience considerable challenges prior to entering the NDIS system in terms of accessing early support in the community. Once they commence their NDIS journey, from the time they first enter the NDIS system, to plan development, plan implementation and plan review, the barriers persist leading to families’ continued disengagement with services. Furthermore, the ‘People don’t know what good looks like’ report commissioned by the NDIS in 2021 found that people with disability in The Fitzroy Valley reported no improvement in services over the 24 months of implementation.

Application for NDIS funding: The application process to become an NDIS participant is complex, where parents have to do a considerable amount of research and become experts in their child's condition so they can navigate the system, to the extent that they have to play an educational and advocacy role with professionals. The application process to access NDIS supports is fraught with difficulties, including the terminology used, obtaining the right evidence, the bureaucratic and impersonal nature of the interactions with key staff, the long waitlists for services and supports, and the variable quality and availability of service providers (Kiind, 2023). An unintended consequence of families obtaining NDIS funding in rural and remote areas is that this then excludes them from accessing local and state government-funded child development services, even when there are no NDIS providers in the area. This leads to families choosing not to apply for the NDIS thereby adding to demand for locally funded services and increased waiting times for other eligible children.

Plan design: Service providers indicate that, often, the design of children's plans does not consider the availability of and accessibility to services in the community. For example, positive behaviour supports (PBS) are put in place where there are no providers. Even though plans may be significantly funded, the funding cannot be spent due to this lack of service availability. To engage these services may mean having to travel long distances (i.e., hours); however, travel items are often not adequately covered in the design of individual plans (Veli-Gold et al., 2023). Service providers and other supports have to rely on their resourcefulness and relationships to reduce travel time (e.g., flying out with the Royal Flying Doctor Service) which is sporadic and at times not suitable to families. The design of plans does not reflect the individual family circumstances and the consideration of other services in the community (e.g., early childhood education) that could be helpful, particularly when families are feeling overwhelmed and in need of respite. In short, having a plan does not lead to the care being provided. The system is ad-hoc, often relying on circumstances that are not conducive to the design of a robust plan that addresses the specific needs of children and their families.

Plan Implementation: This varies greatly in rural, regional and remote areas as there is a minimal number of service providers, at times poor quality service, and limited supervision of practitioners to enable best practice implementation. With the move from health to NDIS in some areas, the number of service providers has not increased. On the contrary, with the availability of NDIS funding for some children, service providers can pick and choose. Many set parameters for their services (eg., they will not travel out of town as travel costs are not covered). As a result, where services are travelling to remote areas, a considerable amount of pro bono work is occurring in those areas. Not only is there limited access to quality service providers, there is also scant or no support available through support coordinators or specialist support coordinators who understand the local context and cultural considerations, who have knowledge about disability or child development. Although there are often recommendations to access telepractice services, in many circumstances this is not viable. Families may not have access to the net (whether via computer or phone), their phone may be communal, phone plans may run out and phones lost/stolen.

Plan Review: The plan review process is often not understood by families, with changes made to the plan carried out with minimal support. Parents can spend a significant amount of time and energy requesting reports only to find out that their child's plan has been extended without communication. Carers often feel they are not listened to, respected, or cared for. Parents report that professionals do not value their expertise, with their concerns often being dismissed and at times pathologised (Kiind, 2023).

b. The availability, responsiveness, consistency, and effectiveness of the National Disability Insurance Agency in serving rural, regional, and remote participants.

Early Childhood partners are only available in metropolitan and some regional areas, and not in all areas classified as regional, remote or very remote. In areas where services do exist [e.g., remote community connectors (RCC) system] operating under the Kimberley Aboriginal Medical Service specifically set up for Aboriginal children), they vary in quality and timeliness with health system services often required to fill in the service gaps such as referral to NDIS. Anecdotal evidence from service providers in those areas also indicates limited responsiveness, inconsistent provision of services, and ineffective practices. A recent report (Kiind, 2023) reveals families experience systems of care as inflexible and impersonal, and being dictated to as to how they will access support across the service system. Similarly, obtaining a disability diagnosis is often a long and expensive journey that families have to undertake with their children, as they are not likely to gain supports for their child without one. This prolonged assessment process along with the associated long-wait lists for assessment, and broken referral pathways limits the options to provide early intervention at the right time. The wait times for children in the regional and remote areas are considerably longer than those in the metropolitan area, often requiring travel to the capital city to participate in the assessment and diagnostic process.

A significant challenge for families in the regional and remote areas relates to time spent travelling to access services, whether for early childhood intervention or associated health appointments. This translates into time away from school for children and siblings, distance to travel for care, time away from work and/or loss of income for the parent/s, and availability and expense of overnight accommodation. This is exacerbated or multiplied if appointments are not coordinated within the health system, leading to multiple trips.

c. Participants' choice and control over NDIS services and supports including the availability, accessibility, cost and durability of those services.

Challenges to NDIS participants' choice and control have been well documented (Wakely et al., 2023). In particular, families and carers experience reduced choice and control given poor access to and availability of supports. One of the major contributing factors expressed by service providers in these areas is the large turnover of staff in remote and very remote areas. Availability of accommodation or rental properties are often limited in country areas, with overnight accommodation not available when visiting children who live several hours away from the nearest available accommodation (e.g., hotel/donga). This is particularly challenging when there are a very small number of children (maybe only one child) who lives in that very remote area. Even in situations where services are available, they appear to be inconsistent and disconnected, particularly in situations where there are too many individual practitioners which creates a large workload for families. The gender divide is often evident in these families, whereby women have to stop working, with a deleterious effect on finances, careers, and overall sense of well-being.

d. The particular experience of Aboriginal and Torres Strait Islander participants, participants from culturally and linguistically diverse backgrounds, and participants from low socio-economic backgrounds, with the NDIS.

Due to the often experienced socio-economic disadvantage as well as community attitudes towards these populations, families experience social isolation, judgement and even abuse. The service system offers considerable challenges for families who experience vulnerability as there is an acute lack of specialised services (e.g., out-of-home-care) and availability of staff with the skill set to effectively address the needs of children and their carers. Families who have fewer social connections and financial resources will be most impacted by an ineffective service system, as they will tend to have diminished capacity to understand, organise, navigate and advocate for supports. Many parents report being emotionally drained and burnt out which can take a physical toll in the short and long term. Inequities as described above, and as experienced by these families given their socio-economic disadvantaged circumstances, are therefore amplified in rural and remote areas.

e. Any other related matters: Moving forward

There is an urgent need to address the considerable challenges experienced by young children and their families in regional, rural, and remote areas. In conjunction with other key stakeholders, PRECI can play a substantial role in addressing the above-mentioned concerns for this population and contribute to the creation of a vision of an equitable and high-quality service system. Specifically, we make the following recommendations.

- The Development of an NDIS model for regional, rural, and remote populations: well-resourced, coordinated, evidence-based, culturally appropriate, context-based, and funded flexibly to address the implementation issues known to have impacted NDIS participants in those areas.
- Implementation of early childhood intervention Best practice guidelines, with a subset of considerations (e.g., practical resources) that address the specific circumstances of these populations. This demands not only a focus on the child, but also on the family as a whole, including carers’ physical and mental health.

- Development of innovative models of service delivery that involve not only a holistic and integrated system of health, education and the NDIS, but also the inclusion of community-based organisations and services that can assist in addressing some of the reported concerns such as travelling, recruitment, retention, supervision and mentoring of staff.
- Development of formalised links with mainstream services to establish foundational supports. This includes increased upskilling of mainstream and foundational services in identifying, engaging with, and supporting families.
- Implementation of the NDIS review recommendations (NDIS, 2023, recommendations 13 and 14) in terms of setting up services that are place-based and community-driven and built on the strengths of rural and remote communities, where supports need to be coordinated and purchased across the whole community.

References

Arefadib, N., & Moore, T.G. (2017). *Reporting the Health and Development of Children in Rural and Remote Australia.* The Centre for Community Child Health at the Royal Children's Hospital and the Murdoch Children's Research Institute, Parkville, Victoria. Retrieved from https://www.rch.org.au/ccch/research-projects/Reporting_the_Health_and_Development_of_Children_in_Rural_and_Remote_Australia/

Cuskelly, M. (2022) Challenges for the National Disability Insurance Scheme in regional, rural, and remote areas. Reflections on "Connecting Tasmanian National Disability Insurance Scheme participants with allied health services: challenges and strategies of support coordinators" (Jessup & Bridgman, 2021), *Research and Practice in Intellectual and Developmental Disabilities*, 9:2, 124-133, DOI: 10.1080/23297018.2022.2051114

Department of Health (2019). National Action Plan for the Health of Children and Young People (2020–2030). Retrieved from https://www.health.gov.au/resources/publications/national-action-plan-for-the-health-of-children-and-young-people-2020-2030?language=en

Johnson, E., Lincoln, M., & Cumming, S. (2020). Principles of disability support in rural and remote Australia: Lessons from parents and carers. *Health and Social Care in the Community*, Vol.28 (6), p.2208-2217. https://doi.org/10.1111/hsc.13033

Kiind (2023). *Journey mapping*. Retrieved from https://s3.ap-southeast-2.amazonaws.com/kiind.org.au/app/uploads/2023/09/26134947/JM-Template-FINAL.pdf

National Rural Health Alliance (2023). *Rural health in Australia SNAPSHOT 2023.* Retrieved from https://www.ruralhealth.org.au/rural-health-australia-snapshot

NDIS (2021). *Rural and remote strategy: Statement on the Rural and Remote Strategy 2016-2019*. Retrieved from https://www.ndis.gov.au/about-us/strategies/rural-and-remote-strategy

NDIS (2023a). *NDIS review report*. Retrieved from https://www.ndisreview.gov.au/resources/reports/working-together-deliver-ndis

NDIS (2023b). The early childhood approach for children younger than 9. Retrieved from https://www.ndis.gov.au/understanding/families-and-carers/early-childhood-approach-children-younger-9

NDIS (2023c). Connecting with an early childhood partner. Retrieved from https://www.ndis.gov.au/understanding/families-and-carers/early-childhood-approach-children-younger-9/connecting-early-childhood-partner

Veli-Gold, S., Gilroy, J., Wright, W., Bulkeley, K., Jensen, H., Dew, A., & Lincoln, M. (2023). The experiences of people with disability and their families/carers navigating the NDIS planning process in regional, rural and remote regions of Australia: Scoping review. *Australian Journal of Rural Health*, *31*(4), 631-647. DOI: 10.1111/ajr.13011

Wakely, L., Green, E., Little, A., Fisher, K., Wakely, K., Currie, K., & Wolfgang, R. (2023). The lived experience of receiving services as a National Disability Insurance Scheme participant in a rural area: Challenges of choice and control. *Australian Journal of Rural Health*, *31*(4), 648-658.

PRECI board members would welcome the opportunity to meet and discuss our recommendations with the Joint Standing Committee.

We would also like to point out that we can see various ways in which PRECI could play a role in implementing some of the recommendations made in our submission, both in the short and long terms. PRECI board members would be happy to explore these with the Joint Standing Committee inquiry into the NDIS participant experience in rural, regional, and remote Australia.

Kind regards,

Denise Luscombe (Chair)
e. preci.australia@gmail.com
m. 0438350479
w. https://www.preci.org.au/

PRECI Board Members (in alphabetical order)

- Dr Anoo Bhopti: Senior Lecturer, Monash University, Dept of Occupational Therapy (Vic)
- Dr Kerry Bull: ECI consultant (Vic)
- Paula Buttigieg: Executive Director Wize Therapy (WA)
- Kerry Dominish: CEO EarlyEd (NSW)
- John Forster: CEO Noah’s Ark Inc. (Vic)
- Megan Fox: National Early Childhood Specialist (Tas)
- Dr Susana Gavidia-Payne: Adjunct Associate Professor, Educational and Developmental Psychology, RMIT University (Vic)
- Susan Gibson: Director Play, Move & Grow Assoc (SA)
- Prof Christine Johnston: School of Education Western Sydney University (NSW)
- Denise Luscombe: ECI Consultant, Director Postural Care Australia (WA)
- Dr Tim Moore: Senior Research Fellow, Centre for Community Child Health, The Royal Children’s Hospital (Vic)
- Trish Wachtel: Area Manager, Early Childhood Approach, Early Childhood Australia, Developmental Educator (NT)