# Submission to the Joint Standing Committee on the National Disability Insurance Scheme's inquiry into NDIS participant experience in rural, regional, and remote Australia

***Submitted by:***
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## Introduction

AEIOU Foundation welcomes the opportunity to provide a submission to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS). We support this inquiry's focus on the NDIS participant experience in rural, regional, and remote Australia and the experience of participants from Aboriginal and Torres Strait Islander, culturally and linguistically diverse, and low socio-economic backgrounds.

We acknowledge the recent NDIS Review and its wide-ranging recommendations for improving the scheme across all aspects. Additionally, we value the commitment of the Federal and state/territory governments to implementing reforms that aim to ensure fairer access to disability supports. While we commend the review's comprehensiveness and its potential to address some of the concerns raised in this response, our feedback to this inquiry's Terms of Reference reflects the current challenges faced by families within our service, offering a snapshot of their immediate experiences.

This submission draws on AEIOU Foundation's vast expertise and experience in the field of autism-specific early intervention for children with high support needs. We look forward to further engaging with the committee and reading the final report.

## About AEIOU Foundation

AEIOU Foundation is Australia's leading provider of autism-specific early intervention for children under six years of age. Operating 11 centres across regional and southeast Queensland, South Australia, and the ACT, AEIOU supports around 300 children each year. Over 18 years, AEIOU has supported and equipped thousands of children to develop the foundational life skills required to independently increase their social, educational, and economic participation in the community.

An expert transdisciplinary team of clinicians and educators support the children. Working with the family, they share the responsibility of assessing, planning, delivering, and evaluating each child's individual plan. Teams are comprised of speech pathologists, occupational therapists, behaviour analysts, teachers, early childhood educators, early intervention specialists and allied health assistants. The service integrates therapy, education (meeting the Early Years Learning Framework [EYLF]) and care in a holistic, naturalistic setting. Children who are typically unable to access mainstream settings in an inclusive and supportive manner are engaged to actively participate in both therapy and EYLF and are supported to achieve their individual goals at AEIOU.

Our mission is to enhance the lives of children with autism and their families, through evidence-based, successful early intervention programs and practical support.

We believe children:

- Have a right to early intervention
- Benefit from therapy based on individual needs
- Learn using different learning styles and at different rates
- Are individuals, with differing personalities, needs, wants, interests and levels of ability
- Require flexible routines in their daily program to cater for their individual needs
- Should receive evidence-based early intervention and access to appropriate assessment
- Are entitled to a balanced program that bridges the gap between the home, AEIOU Foundation and the community
- And can benefit from families and staff working together

Families also have a right to support other members of the family unit and to work and participate in the community.

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

Families attending AEIOU, especially in regional areas, face significant challenges prior to NDIS access, stemming from significant delays obtaining a formal diagnosis.

Extended waitlists for diagnosis delay therapeutic supports and impact the functioning and wellbeing of families. The public health system is most impacted, due to the costs associated with specialist referrals and assessments. However, many turn to private specialists, with typical waitlists of 12 months. The NDIS does not cover clinical diagnostic assessments under the current model and many families cannot afford the out-of-pocket expense, ranging from $1,500 to $3,000, to access these services. This can be a significant financial burden, especially for families with low incomes.

Data from 922 children who attended AEIOU for the 10 years up to 2023 shows children experience an average delay of 17 months from the age of first concern to the age of diagnosis, and a further 10-month delay from the age of diagnosis to the age of accessing early intervention. This results in an average delay of 27 months, or 2.3 years, from the age of first concern to accessing early intervention.

More widely, a recent Australian survey identified that on average, 12 months and eight professional consultations were required for parents to receive a confirmed autism diagnosis for their child (Bent et al., 2020), while another study from Sydney identified an average 3.3-year delay from age of first concern to receiving a developmental assessment (Boulton et al., 2023).

A new autism-specific Early Assessment Clinic service has been established by AEIOU Foundation to support referring practitioners with extensive waiting lists for a diagnosis. The clinic, for children five years and younger, aims to address the high volume of cases presenting to public and private health care systems, working with medical specialists to ensure timely diagnosis and access to tailored supports.

Based in Spring Hill, the Early Assessment Clinic will be rolled out to regional areas including Townsville, Bundaberg, and Toowoomba as a priority in the 2024/25 financial year. The clinic will facilitate standardised assessments and provide clinical reports to support specialists, such as paediatricians and psychiatrists, to enable faster and more informed diagnoses. As timely interventions are essential for autistic children, the clinic assessments can also be used for NDIS plan applications, allowing children to access tailored funding and intervention while waiting for their formal diagnosis.

When entering the NDIS, families frequently report that the application process is complex and overwhelming, especially for those unfamiliar with the disability sector. Many struggle to navigate the intricate procedures. The lack of readily available information and support further amplifies this difficulty.

Securing funding for intensive early intervention programs is challenging, leading to further delays in children receiving essential timely support. Often, clinically recommended early intervention support is inaccessible due to inadequate funding allocation. A focus group study conducted by AEIOU with families in service found parents reported high levels of stress regarding the limitations in NDIS funding, particularly when they are insufficient to cover the costs of clinically recommended supports.

The quality of NDIA's early childhood partners can vary significantly across regions, impacting families' experiences. Anecdotally, when staff at partners leave their positions or take leave in regional communities, there can be significant delays in the planning process due to difficulties in finding replacements in such areas.

For those seeking plan reviews, the process is often burdensome and time-consuming. Delays in processing reviews and plan renewals disrupt the continuity of essential therapy, impacting progress and stability. Parents shared in an AEIOU focus group that the NDIS process, especially plan reviews, could be very emotionally taxing and stressful, particularly if they are unsure whether they will receive enough funding to continue their child's supports. Additionally, reviewers may lack sufficient understanding of best practices for early intervention, particularly for autistic children.

To address some of these concerns, AEIOU has previously provided this committee and the NDIS Review with the following recommendations:

- The NDIA considers a scheme to assists to fund assessments for earlier diagnosis, removing a major financial barrier for the families of participants and addressing delays in accessing essential supports.
- The NDIA to streamline and expedite the process for approving plans for intensive supports.
- Process to ensure consistency and transparency around funding decisions within the NDIS. Ensure best practice planning and assessment with supporting evidence from a registered clinician that has ASD experience.
- Create an automatic, transparent, and direct pathway through the NDIS for children who receive a Level 2 or 3 autism diagnosis, ensuring they have immediate access to at least 20 hours of early childhood early intervention (ECEI) support each week for two years. AEIOU's research data demonstrates that intensive intervention is both safe and effective for this cohort of children.
- Extend measures for auto-extension of plans (or reduced time frames for reviews) for participants requiring intensive funding to ensure continuity of services and funding.
- Where possible, reduce the cost of access partners and administrative burden in determining reasonable and necessary supports by trusting the assessments and advice of clinical experts.

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

As outlined above, the lack of diagnostic specialists in regional, rural, and remote areas is an ongoing concern for families. AEIOU observations suggest NDIS plan amounts and designs vary significantly across regions, often leaving regional and rural families with inconsistent support.

Staffing challenges in rural and regional areas can also impact the effectiveness of the scheme in these communities. Instances like sudden staff losses in a particular early childhood partner can lead to significant delays in planning and accessing services for prospective NDIS participants in that region, hindering crucial early intervention for children.

Even with NDIS plans, participants can face limited options due to a lack of specialist service providers. This forces families to travel long distances for essential services, adding significant burden and cost.

For service providers in urban areas, the cost of travelling to remote and regional areas for short intervals proves expensive and unsustainable. The cost-prohibitive nature of fly-in, fly-out (FIFO) limits the frequency and duration of crucial interventions, along with opportunities to plan for adequate review preparations.

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

Inconsistent funding decisions create confusion and limits the choices families can make in choosing appropriate supports. Families often struggle to understand the justification for funding decisions and lack clear pathways for advocacy.

The shortage of qualified professionals, including autism specific therapists, hinders access to services, particularly in regional and rural areas. A lack of career progression opportunities and competitive salaries discourage professionals from relocating or working in areas outside of major cities. This is a concern for sustainability of service provision in these regions and its impact on participants' long-term access to quality support.

An action from the NDIS Review, tied to Recommendation 13 (strengthen market monitoring and responses to challenges in coordinating the NDIS market), is for the National Disability Insurance Agency to progressively roll-out provider panel arrangements for allied health supports in small and medium rural towns or where participants face persistent supply gaps. While we see potential for provider panels to improve services in regional and rural locations, the critical shortage of allied health professionals raises concerns about their effectiveness until workforce development and NDIA recruitment efforts lead to a significant increase in available practitioners. In the current environment, such an initiative poses significant risk to service providers that already operate with significant allied health shortages.

We note the NDIS Review's Recommendation 15 regarding attracting and retaining a workforce includes an action for the Australian Government to develop targeted and flexible migration pathways for care and support workers. To further address workforce shortages, particularly in rural and regional areas, we suggest the government collaborate with relevant professional associations to expedite the recognition of foreign qualifications held by skilled migrants in the allied health professional field. This would enable them to register with their respective professional bodies more quickly and contribute to improving access to quality disability support.

## 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

As previously highlighted, families frequently report that the NDIS application process is complex and overwhelming, especially for those unfamiliar with the disability sector. The process of navigating the red tape associated with the NDIS is often exacerbated for those in the CALD community.

AEIOU in 2023 concluded a study examining the demographic characteristics of 922 children who attended their service over the past 10 years. Data indicated a high proportion of CALD (35.7%) and First Nations (7.7%) families, both of which are higher than national population estimates (28% and

3.8%, respectively). However, the degree of linguistic diversity did not mirror these trends, with 17% of the sample speaking a language other than English at home, compared to the Australian population estimate of 23%. This suggests that while cultural barriers to accessing diagnostic and treatment services may have been reduced, there are ongoing linguistic barriers that continue to impede access to those with lower English proficiency.

As providers and sector experts, AEIOU made the following suggestions to the NDIS' CALD Strategy consultation in 2023:

1. Infrastructure: To improve access and engagement from the CALD community, specific systems, policies, procedures, and processes tailored to their needs should be in place, such as specific line items, questions during application processes, and processes for expediting high-risk participants from diverse linguistic backgrounds.

2. Staff capability: The NDIS should have CALD planner delegates, similar to the psychosocial coaches and complex needs pathway support coordinators already in the scheme. Staff should also have access to specific training modules, similar to the NDIS worker module, which acknowledges culture in individual support plans.

3. Accessible communications: Feedback surveys should be sent to participants and their families (via phone or email) after engaging with NDIS planners, and mandatory Welcome to County messaging should also be adopted for planning meetings. Additionally, incorporating more artistic imaging specific to First Nations cultures could be considered.

4. Data: Investing in further testing and research with suitable organisations, such as AEIOU, that have specific cohort and entry data available could help the NDIS understand CALD participants' needs.