

NDIS Review: What we have heard report AEIOU response to consultation

Submitted by:

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Introduction

AEIOU Foundation welcomes the opportunity to provide a submission to the NDIS Review's ongoing consultation. We support an Independent Review into the NDIS to improve the wellbeing of Australians with disability and ensure the scheme's sustainability so that future generations receive the benefit of the NDIS.

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. Where possible, we look forward to further engaging with the review at future events and consultation.

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 work together to 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, an education curriculum that meets 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.

Executive Summary

The following points outline three key areas for improvement in the delivery of support to people with disabilities under the NDIS:

Defining "reasonable and necessary". While complex and challenging, this is an essential task to ensure people with disabilities have access to the support they need, and to safeguard the sustainability of the NDIS. The government must delineate the boundaries of "reasonable and necessary", emphasise evidence-based assessments, offer clear examples, tailor approaches for different disabilities, address quantification challenges, implement thorough training, and ensure unbiased decision-making processes.

Supporting children with disabilities and developmental concerns. Families of children with disabilities need access to unbiased resources, parent training and capacity building, and a coherent framework for collaboration among various services. The government should take steps to ensure these needs are met.

Setting SMART goals. Providers of support to people with disabilities should set SMART (Specific, Measurable, Achievable, Relevant, and Time-Bound) goals that are tailored to each individual's desired outcomes and learning rates. This will help to ensure support is effective and efficient.

How would you define reasonable and necessary?

One way to begin defining "reasonable and necessary" within the NDIS context is by first establishing clear boundaries for what falls outside of this scope, such as identifying aspects that do not meet the criteria or resemble what is considered "typical parent support".

Determining whether a support is reasonable and necessary should be contingent on individual need, clinical indication, and its potential to enhance the individual's quality of life directly linked to their disability. This determination should rely on evidence-based assessments and clinical reports (which include observation) rather than subjective opinion.

Given the complexity of defining a broad and universal approach to "reasonable and necessary", a potential solution to aide decision-making processes is to provide detailed examples, similar to the approach taken with the documentation for restrictive practices. Tailoring decision trees or flowcharts for various disability types, such as physical versus neurological disabilities, creates a structured framework accommodating individual differences.

A distinction should be made between what constitutes reasonable and necessary support, and subsequent guidelines developed for how to quantify that support. The challenge arises in determining who possesses the authority to gauge the optimal level of support – parents, clinicians, or the NDIS. If the NDIS assumes this role, a comprehensive training and credentialing program for decision-makers is necessary. Specialised training, potentially focusing on specific disability categories, could offer personalised guidance and assistance.

Additionally, it is imperative to ensure the decision-making processes remain unbiased and equitable. Flowcharts and guidelines should be designed to counter systemic biases. The role of the planner extends to verifying whether the chosen support is safe, reasonable and necessary, rather than dictating the individual's support choices.

It is essential to any discussion regarding "reasonable and necessary" supports that safety and cost effectiveness are key considerations. Safety considerations should encompass both physical and emotional well-being, ensuring the support does not pose any harm or risks to the individual, while cost effectiveness is important to ensure the long-term sustainability of the NDIS. Both factors should be reinforced within NDIS regulation.

Recommendation: defining "reasonable and necessary" within the NDIS context involves delineating its boundaries, emphasising evidence-based assessments, offering clear examples, tailoring approaches for different disabilities, addressing quantification challenges, implementing thorough training, and ensuring unbiased decision-making processes. Safety and cost effectiveness should also be key considerations that are reinforced through regulation.

What is the best way to support children with disability... and those with emerging developmental concerns?

AEIOU adopts a data-driven approach to determining whether our early intervention delivery model is effective. Our database, comprising longitudinal data from over 900 autistic preschoolers and their families, demonstrates strong and consistent gains in early learning skills (as measured by the Mullen Scales of Early Learning) and Adaptive Behaviour (as Measured by the Vineland Adaptive Behaviour Scales) of the autistic children receiving early intervention.

Further, 75 per cent of our cohort gained these skills at a rate over and above a neurotypical peer demonstrating that early intervention is critical in helping autistic children catch up on their developmental skills.

Not only is early intervention clinically effective, recent analysis of actual NDIS expenditure and clinical assessment data has found it offers excellent return on investment. An economic report by Synergies Economic Consulting, commissioned by AEIOU Foundation, quantified the cost benefit to the NDIS as a \$4.58 saving for every one dollar invested in early intervention.

Given the extraordinary cost to the NDIS of supporting adults with autism, especially those in Supported Independent Living, more investment in clinically effective early intervention will ensure the long-term sustainability of the NDIS.

To provide optimal support for children with disabilities and those displaying emerging developmental concerns, it is essential to offer comprehensive resources to families. Such resources should help families understand evidence-informed practices, enabling them to make unbiased choices based on their own judgment and that align with their values. To ensure a well-rounded representation of perspectives, it is important to maintain a balance of voices that deserve representation.

When devising a child's plan, it is crucial to allocate funding for parent training and capacity building. There is more to effective therapy and development of adult skills than a parent attending a therapy session. There needs to be a level of recognition that successful support and quality of life outcomes go beyond the child alone.

A pivotal aspect of this support entails establishing a pathway for collaboration with education and other relevant services. This could involve allocating funds to facilitate transdisciplinary planning meetings during pivotal junctures, such as transitions to or from services, or significant changes in the child's circumstances. While such an approach is widely acknowledged as the "gold standard" practice for successful transitions, the guidance and funding across differently funded services remain unclear.

Recommendation: in order to uphold a comprehensive and effective approach to assisting children with disabilities and developmental concerns, it is imperative to provide families with unbiased resources, prioritise parent training and capacity building, and establish a coherent framework for collaboration among various services.

How should outcomes and performance be measured and shared?

One approach is to establish clear definitions of targeted "outcomes" tailored to each individual. It's crucial for planners to understand learning rates among people with disabilities, as personal desired outcomes can greatly differ.

Providers should focus on these outcomes by setting SMART (Specific, Measurable, Achievable, Relevant, and Time-Bound) goals, with the emphasis on identifying measurable evidence that demonstrates the effectiveness of chosen supports in achieving those goals.

Recommendation: To effectively support people with disabilities, providers should set SMART goals that are tailored to each individual's desired outcomes and learning rates.