



SCN2A Australia
Kris Pierce, Director

This submission is prepared to address the specific impacts of the proposed changes under the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 on individuals diagnosed with epilepsy, particularly those with developmental and epileptic encephalopathies. These conditions are characterised by frequent, treatment-resistant seizures and significant neurodevelopmental impairment, necessitating a multidimensional support approach.

Overview of the Bill

The Bill introduces significant modifications to the NDIS, including the implementation of a new framework for planning and budgeting, which relies on a standardised needs assessment tool to allocate resources to participants. These changes aim to streamline processes and ensure equitable distribution of funds but may also pose challenges in appropriately addressing the highly individualised needs of those with complex neurological conditions.

Specific Impact on Individuals with Epilepsy, specifically Developmental Epileptic Encephalopathies

- 1. Needs Assessment Tool Adequacy:** The proposed needs assessment tool may not adequately account for the fluctuating and complex nature of epilepsy and developmental encephalopathies. The tool's effectiveness in capturing the full spectrum of needs, including emergency medical interventions, ongoing therapy, support for episodic conditions and end of life support, is a critical concern.
- 2. Accessibility and Quality of Specialised Services:** With the shift towards generalised budget categories, there is a risk that specialised services for individuals with significant neurological impairments may become less accessible. The Bill's approach to budget allocation needs to ensure that those with severe and less common conditions are not disadvantaged.
- 3. Risk of Service Gaps:** The redefined scope of 'reasonable and necessary' supports under the new framework could lead to significant gaps in services for those with developmental and epileptic encephalopathies, particularly in areas such as specialised therapy and customised medical equipment.

Recommendations for Amendments

- 1. Enhanced Specificity in Needs Assessment:** It is recommended that the Bill incorporate provisions for the needs assessment process to be tailored specifically for individuals with



neurological conditions by involving neurologists and epileptologists in the development and execution of these assessments.

2. **Guaranteed Access to Specialised Care:** The Bill should specify mechanisms to guarantee access to specialised neurological and developmental support services, ensuring that these essential services are preserved under the new funding structure.

3. **Continuous Monitoring and Adaptation:** Establish continuous monitoring mechanisms to assess the real-time effectiveness of the implemented changes for those with complex neurological conditions, allowing for rapid adjustments to plans and budgets as clinical needs evolve.

Conclusion

While the proposed NDIS Bill 2024 aims to enhance the efficiency and sustainability of support distribution, it is crucial that these changes do not compromise the quality of care for individuals with epilepsy and developmental epileptic encephalopathies. This submission advocates for amendments that ensure these individuals receive tailored, continuous, and expert-informed support under the new NDIS framework.