SUBMISSION

National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024

May 2024

Submitted by: Epilepsy ACT

About Epilepsy ACT

Epilepsy ACT is a dynamic not-for-profit organisation established in 1982 to serve the epilepsy community in the Australian Capital Territory (ACT) region. Over the years, we have evolved to become a leading voice for individuals with epilepsy, their families, and the broader community.

At Epilepsy ACT, our mission is simple yet profound: to empower and support every person affected by epilepsy to live a full and fulfilling life. Through our range of services and initiatives, we strive to foster understanding, provide practical assistance, and promote inclusivity for all.

Introduction

Epilepsy ACT is pleased to provide a submission to the NDIS Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 on behalf of individuals diagnosed with epilepsy, including those with developmental and epileptic encephalopathies. Developmental and epileptic encephalopathy conditions are characterised by frequent, treatment-resistant seizures and significant neurodevelopmental impairment, necessitating a multidimensional support approach. This submission is prepared to address the key areas that will impact people living with epilepsy, including those with developmental and epileptic encephalopathies.

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 such as epilepsy.

Epilepsy is the fourth most common neurological condition in the world that carries a lifelong burden, and the second most burdensome neurological condition after dementia. Diagnosis can occur at any time, with one Australian being diagnosed with epilepsy every 33 minutes.

At any one time 260,000 Australians have epilepsy. Over one million Australians will develop epilepsy during their lifetime with the prevalence of epilepsy predicted to increase over the coming years as people increasingly survive traumatic causes of the condition, such as stroke and injury[1] The broader impacts of epilepsy directly affect family and carers,

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[1] AIHW Report, 2019, primary ref. WHO 2019

frequently creating negative effects for approximately four times the number of those diagnosed with the condition.

Epilepsy causes recurring unprovoked seizures that are physically, psychologically and socially debilitating for the child, young person or adult with epilepsy. Causes include genetic factors, structural abnormalities of the brain, brain injury and infection or stroke. However, for half of all people with epilepsy, the cause remains unknown, there is no cure and treatment outcomes varying significantly with only 30% receiving seizure control with anti-seizure medications.

People with disability have a high degree of comorbidity with epilepsy, with epilepsy co-occurring at high rates with a range of disability diagnoses. For example, the percentage of people with disability with a co-occurring diagnosis of epilepsy include, Intellectual Disability – 25%, Cerebral Palsy – 30-50%, Autism – 12%, Down Syndrome – 5-45%, Acquired Brain Injury – 30%, Stroke- 7%.

Epilepsy is a complex neurological condition which often results in severe functional impairment, with a need for expert information, specialised care and equipment and personal assistance. Given the significant variations in epilepsy presentations, all support strategies and underlying legislation, must be responsive to individual needs and promote independence, capacity building, safety and quality of life.

Recommendations:

1. As the amended Bill relies heavily on new NDIS Rules, ensure the Draft Rules to be released for consideration as a matter of urgency. This will ensure that the new, and future, NDIS legislation be designed, developed and implemented with people directly impacted by epilepsy, including their family/carers/supporters, as well as the disability community.
2. Consideration of epilepsy, as a stand-alone condition against the Access requirements, rather than coupled with a 'primary disability' (as per existing Access requirements). This recognises the significant functional impact that can present with epilepsy, impacting independence, individual capacity building, achievement of employment & vocational goals, safety and quality of life.

3. Opportunities be facilitated to allow for feedback on the functional Needs Assessment Tool(s) being considered as part of revised NDIS Access Process. Consideration be given to the following recommendations for the tool/s in the context of epilepsy

    a) Improved data collection to ensure presence of seizures/epilepsy is recognised, recorded and responded to.
    b) Incorporate provisions for the needs assessment process to be tailored specifically for individuals with neurological conditions by involving neurologists and epileptologists, and other relevant allied health specialists, in the development and execution of these assessments.
    c) Describe the complex, episodic and unpredictable nature of epilepsy for each person, recognising limitations in current treatment options A recognised diagnosis of developmental and epileptic encephalopathy (DEE) at Access, will immediately highlight the complexity and high support needs of these individuals and families, including palliative care supports, and trigger the need for a comprehensive, coordinated and multi-disciplinary approach.
    d) Comprehensively describe 'impact' of epilepsy and relevance to 'disability support needs' i.e. social, emotional, financial, psychosocial, learning, education, employment, day to day functioning, safety/risk

   e) Ability to distinguish between participant having ’seizures’ (from other causes) and ‘epilepsy’ – which may impact outcome of assessment and corresponding budget allocation (this addresses issue when potential participants share their medical history as ‘seizures’ only)
   f) Appropriate skills and qualifications of all NDIA employees undertaking assessments

4. NDIS processes need to ensure potential risks are identified and supports put in place to minimise risk, without compromising the right to quality of life and decision making for the person with disability/epilepsy, including, but not limited to:

   a) Ensuring Service Providers have processes in place to ensure risks are identified and managed, and to provide mandatory training to staff to ensure best practice support for people with epilepsy
   b) NDIS processes mandate the requirement for an Epilepsy Management Plan and an Emergency Medication Management Plan (if relevant) wherever an NDIS participant identifies they have seizures/epilepsy
   c) Mandatory training program for NDIA staff involved in participant access or service/funding decisions and management;
   d) Identification of seizures/epilepsy in a new NDIS participant application should trigger contact with the National Epilepsy Support Service to access the most accurate information to support the planning process, as well as provide ongoing support and services.

5. Remove barriers to accessing the NDIS by ensuring the rules do not place a financial burden on consumers who require complex and multiple reports

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

7. 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 change and evolve.

Understanding Epilepsy under the NDIS.

These points underpin the reforms, and if not addressed, exacerbate access, services and safety issues for consumers.

The prevalence of epilepsy diagnosis is grossly-under-represented in NDIS data

- The prevalence of a co-occuring diagnosis of disability and epilepsy, or epilepsy as the condition granted Access, is under-represented in NDIS data. Exploration with key NDIA staff suggests that under-representation is due to the NDIS participant mentioning ‘seizures’ without sufficient recognition of the diagnosis of epilepsy. Ambiguity regarding definitions of Access criteria, has also created barriers for people living with epilepsy accessing the scheme and under-representation.

People with epilepsy face many preventable risks that could be better managed through NDIS planning and support

- Due to the unpredictable nature of seizures, people with epilepsy are at risk of serious physical injury, choking or drowning if left unsupervised.
- Sudden Unexpected Death in Epilepsy (SUDEP) causes more than 300 deaths in Australia per year, and people with complex conditions such as those with a co-occurring disability are at a higher risk.

Epilepsy Management Plans support achievement of participant goals

- People with disability and epilepsy need plans specific to their epilepsy needs. This may include:
  - Epilepsy Management Plan: describes seizures, how to respond, when to call an ambulance, post-seizure support and how to minimise risks
  - Emergency Medication Management Plan: medical prescription describing how to administer emergency ‘rescue’ medication
  - Mandatory training is required where a participant requires Emergency Medication.

Specialist information about epilepsy is available to NDIA staff and service providers

- There are more than 70 types of epilepsy and everyone’s experience is different.
- As is not feasible for NDIS Planners to understand all the complexities of epilepsy and how it impacts on people’s daily functioning and independence, , access to specialist information about epilepsy will help to ensure evidence-based and tailored services for people with epilepsy.
- The support services need to be holistic and flexible, ensuring participants can access their plan flexibly to address epilepsy-related needs, including, but not limited to falls management, mobility, cognitive impairment, household management, psychosocial needs, social engagement, participating in community safely, obtaining and keeping work/study options etc.

Conclusion

As many critical details about how the Bill will impact people with epilepsy and developmental epileptic encephalopathies is unknown, it is important that the Draft Rules be released for consideration as soon as possible. Development of the rules should be supported by a comprehensive and authentic consumer review and engagement process. The Explanatory Memorandum contains no indication as to the timing or process for how these Rules will be developed. It is therefore difficult to understand the full impact of the Bill and the changes it proposes.

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, including for those already under the NDIS or requires changes to their existing NDIS plan.