NDIS Senate Submission 2026

Submission regarding the National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026

To the Senate Committee,

My name is and I am the mother and primary carer of two children with disability in Victoria.

I am writing to express my deep concern regarding the proposed changes to the NDIS, particularly the move toward standardised functional assessments and tighter eligibility and reassessment processes.

My eldest son has profound and permanent disability with extremely complex support needs. He is non-verbal and communicates using partner-assisted AAC. He is a wheelchair user, PEG fed, requires high-intensity daily supports, and depends on coordinated care across health, education and disability systems every single day.

His disability is lifelong. There is no pathway where he will suddenly “recover” or no longer require intensive supports. Yet under the proposed reforms, families like ours are being told that a standardised assessment tool may become one of the primary ways support needs are measured.

I cannot adequately explain how dangerous and distressing this feels for families caring for children with profound disability.

Children like my son do not fit neatly into tick-box assessments.

His functioning varies depending on fatigue, illness, pain, environment, sensory regulation, communication partner familiarity and physical health. Some days he may appear settled and engaged. Other days he may require full assistance for every aspect of care and regulation. A short assessment or observation by someone unfamiliar with him cannot capture the complexity, risk and intensity of his daily life.

I am deeply concerned about a future system where: treating clinicians and therapists carry less weight than standardised assessments; assessors may never build meaningful understanding of the child; participants must repeatedly prove permanent disability; families are pushed into crisis before reassessment thresholds are met; and supports are reduced under broad funding categories rather than individual need. I am also the parent of a younger child with autism and developmental support needs. Early intervention and consistent supports are critical. Families should not have to wait until children fail, regress or reach crisis point before receiving help.

The NDIS has allowed our family to keep our son safe at home, access school safely, attend medical appointments, participate in the community and maintain dignity and quality of life.

Without appropriate supports: family burnout increases; hospital admissions increase; school participation decreases; workforce participation for carers drops; and children with disability become further isolated. I understand the Government’s responsibility to ensure the NDIS is sustainable and properly regulated. Fraud and exploitation should absolutely be addressed. However, reforms aimed at sustainability must not unintentionally harm people with genuine and lifelong disability.

I ask the Senate Committee to carefully consider the real-world impact these reforms may have on children and adults with complex disability and their families.

Specifically, I urge the Committee to recommend: strong protections for participants with lifelong and profound disability; meaningful weighting of treating clinician evidence; transparent assessment tools that are co-designed with disabled people and families; robust review and appeal rights; safeguards for children requiring early intervention and developmental support; and guarantees that standardised assessments will not override functional reality. Families like mine already navigate enormous complexity every day. We should not also have to live in fear that essential supports may disappear because a future assessment tool fails to capture our child accurately.

Thank you for considering my submission.