

## SUBMISSION

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

Submitted by: Annette Andersen

*Capacity: NDIS Participant | Primary carer | Founder, aXai Pty Ltd*

Date: May 2026

---

#### About Me

I am Annette Andersen. I am a 58-year-old autistic woman, primary carer to two adult children who are NDIS participants, and the founder and architect of aXai Pty Ltd, a software engineering and AI consultancy. I make this submission in my own name, as a person with disability, as a carer, and as someone who has spent the last several years living through exactly the kind of systemic failure this Bill claims to be fixing — while the Agency that caused it faces me as an adversary in both the Administrative Review Tribunal and the Federal Court.

My son is affectionately known on LinkedIn as 'Axel AI Assisted'. He is a young man with profound and complex disabilities: non-speaking autistic, severe intellectual disability, peripheral erythromelalgia — a rare and accepted pain condition that causes the sensation of fire in his hands and legs — dystonia, dysautonomia, complex regional pain syndrome, restless legs syndrome, and a novel genetic mutation of potential pharmacological significance. He is 6' 3" and 107kg. He has the emotional and communicative capacity of a toddler. He does not self-advocate in the conventional sense. He communicates through behaviour. He cannot organise his own supports. The idea that he could is, bluntly, absurd.

My daughter is also an NDIS participant. She lived in the same home, through much of the period described in this submission, exposed to the same violence. She is currently living in temporary accommodation.

This is not a submission about sustainability in the abstract. This is a submission about what happens to real people when a system fails — and about what this Bill will do to ensure that failure becomes the structural norm, with no avenue of recourse.

#### What 18 Months In Our Home Actually Looked Like

For approximately 18 months, I fought the NDIA over my son's support needs while simultaneously living in a situation that no system in this country is designed to address honestly. The NDIA's position, throughout, was that his needs were not as described, that

the evidence was insufficient, and that the requested supports were not reasonable and necessary.

The reality was this: his plan was approximately **\$800,000 short** of the support he required. During the period that shortfall existed, he deteriorated. The violence escalated. My daughter and I were subjected to what I can only describe as non-stop, high-intensity physical assault over an extended period — in our own home, with no ability to leave, requiring 6 police officers to remove him from the property, temporarily until the next round, and no funded support to ensure no paid worker was left alone in this situation.

I was assaulted on at least **six occasions so severely I believed I was going to die**. Each of those occasions occurred in the middle of the night or the early hours of the morning, when there was no funded awake overnight support. He overpowered me. I have lost count of lesser incidents. Research is clear that women, particularly mothers, bear a disproportionate risk of serious injury and death in these circumstances. The policy settings that produced this outcome — a plan that required a mother to fill an \$800,000 care gap — do not exist in a vacuum. They discriminate.

The image below shows one of the bite injuries I sustained during this period. I was unable to have it properly treated. I could not leave the house. I could not leave the workers alone. I could not leave my daughter.

*Bite injury sustained during the period of inadequate support funding. August 2025. Untreated.*

The system provided no mechanism that acknowledged the reality we were living. Producing this image again and again is not something I do without personal impact. I do it because decision-makers need to understand what 'inadequate support' looks like on a person's body.

My injuries during this period included serious physical harm. The process continued. The hearings were scheduled, rescheduled, prepared for at enormous effort. Then, **days before the hearing was due to proceed**, his plan was nearly tripled from the original plan under review.

I do not know what to make of that timing, other than to note that it is consistent with a system that imposes maximum attrition on the people who use it, and treats compliance as something to be achieved at the last possible moment when the evidence can no longer be avoided.

---

## What I Did During That Period

During the 18 months I have just described, I completed a **Graduate Certificate of Software Engineering at Torrens University Australia**, conferred June 2025. I completed it while providing near-continuous care, while managing active litigation, while recovering from serious injuries I could not get treated, while recovering from major surgery, and while running on whatever hours remained.

During the same period, I trained myself in AI-accelerated software development and built a methodology from scratch. I founded **aXai Pty Ltd**, a software engineering and access consultancy. I have since brought a number of innovative products to market, including tools for the disability sector: Savanax/Dialectica (a novel reasoning engine for complex decision making and autonomy support built on over 24,000 events from my son's own life), aXread (Easy Read AI Assistant), and Context Scanner (to support the AI Accelerated methodology).

I co-founded DSX ([dsx.org.au](http://dsx.org.au)), a member-owned cooperative of small-to-medium NDIS registered providers. I have been a pitch finalist. My son is credited publicly as a UX Consultant and Advocate. His lived experience has literally shaped the software. This is not metaphor — it is documented and public.

I have created pathways to meaningful employment for both of my children who are NDIS participants. I have done this as a person with autism, largely on a volunteer basis, because

it does not matter how innovative you are, how fast you deliver, how much you contribute — if you are autistic in the Australian employment market, you are already presumed to be lazy, unreliable, and unmarketable. That presumption is not accidental. It is the legacy of policy and public discourse that has never been honestly confronted.

I say this not to seek praise but to make a factual point: I did all of this while the Agency continues to fight me over things like UV-protective clothing for a man whose accepted medical condition causes burning pain in response to UV exposure.

---

### **The Home We Are Living In**

During the period of the \$800,000 support gap, my son caused significant damage to our home. He could not be removed without 6 police officers. His disabilities and the absence of adequate support meant he was in a state of chronic pain and dysregulation. The damage was extensive and ongoing.

The photos below show two aspects of that reality. The first is one of countless wall impacts throughout the house. The second is the makeshift kitchen we set up outside — so that cooking smells and sounds do not trigger his sensory system and escalate into an episode.



*One of many wall impact sites throughout the home. This damage remains unrepaired. August 2025.*



*Makeshift outdoor kitchen. Cooking indoors triggers sensory dysregulation. The TV was removed from inside for the same reason. August 2025.*

I made an insurance claim. The claim was paid in limited scope. The repairs have not been completed — because my son cannot be removed from the home, and construction activity itself is a risk. The bathroom remains unusable. The floor was replaced to address swelling that was preventing wardrobe access. Build costs have risen since the original payout. My insurance premium has nearly quadrupled.

I am, in other words, repaying money to an insurance company — in installments — for damage caused during the period when the NDIA refused to fund the supports that would have prevented the deterioration that caused the damage. And the NDIA continues to behave as if my son and I contribute nothing, produce nothing, and cost nothing beyond what it chooses to fund.

An OT report is pending recommending major bathroom modifications and like every other piece of evidence I have produced, thousands of pages, I expect it will be ignored. There is no mechanism in the current system, and nothing in this Bill, that addresses this kind of cascading harm.

---

## **What This Bill Will Do**

### **1. Eliminate or curtail the only appeal mechanisms that work**

The single tool that produced any outcome for my son was the Administrative Review Tribunal. An 18-month fight, at enormous cost to my health, my finances, my capacity to function, and the safety of my family — and ultimately, the plan was changed. That is the system working. Badly, slowly, at brutal cost — but working.

This Bill progressively removes the conditions under which that process is meaningful. Tighter unscheduled reassessment criteria, restricted request rights, budget resets proceeding under existing planning arrangements before new framework planning is even in place — these are structural barriers to the same process that, after 18 months, produced an adequate plan. They will ensure that families like mine hit every wall earlier, harder, with less ability to challenge. The only alternative in these situations is incarceration of the person because of their disabilities.

### **2. Reset budgets for supports that are critical, not peripheral**

The Government's messaging is that budget resets from 1 October 2026 will not affect 'critical care and daily living.' The supports that were disputed in our case — were all framed by the NDIA as non-critical, non-reasonable, non-necessary. The Agency's definition of 'critical' is not the same as a clinician's definition nor emergency services who also provided evidence during this period. Under this Bill, the mechanism by which those definitional disputes are resolved will be substantially narrowed.

### **3. Commission SIL in a way that removes individual arrangement flexibility**

The proposed commissioning of Supported Independent Living from July 2026 will affect my son directly. His support needs are complex, medically fragile, and require workers who know him, are trained in his specific condition, and can provide 2:1 awake overnight support. A commissioned SIL model that prioritises standardisation over individual complexity will, in practice, make it harder to maintain the support arrangements that have finally stabilised him.

### **4. Expand mandatory registration in ways that may harm, not help**

In practice, for a family like mine — where the pool of workers willing and able to support a high-complexity young man in a regional area is already vanishingly small — mandatory registration requirements for unregistered providers will shrink an already inadequate workforce further. I need to use unregistered providers as a last resort, not as a rule. That distinction matters and is not acknowledged in the Bill's framing.

### **5. Remove plan rollovers and create new financial cliffs**

Plans must be spent within the plan period. My son's condition is episodic. There are periods of relative stability — like now, following the plan tripling — where we can build reserves against the next acute episode. Under the proposed changes, that capacity disappears. Every plan renewal becomes a financial cliff.

---

## **A Question That Deserves an Honest Answer**

Has the Minister ever met anyone with profound autism and severe intellectual disability?

Not in a controlled setting. Not in a presentation. In a real moment — at 3am, in a home with a broken bathroom and a makeshift outdoor kitchen, with a young man in severe pain who does not understand what is happening to his body and thinks the nearest person caused this, with no funded support and no way out.

The idea that supports for someone like my son 'organise themselves,' that market forces will produce equitable and consistent plans, that tightening assessment criteria will improve outcomes for people at the extreme end of complexity — these ideas are not serious. They are the kinds of ideas produced by people who have never been in the room.

---

## **What I Am Asking For**

I am not asking for the NDIS to be unsustainable. I am asking for the following:

- A genuine carve-out for high-complexity participants that is defined clinically, not administratively, with independent verification — not NDIA self-assessment.
- Preservation of meaningful appeal rights at every stage of plan reassessment, including for budget resets commencing October 2026.
- Explicit acknowledgement in the Bill that primary carers, particularly women and carers with disability, bear a documented and disproportionate risk of harm and loss of social and economic participation when supports are inadequate — and that this risk is a form of structural discrimination.
- A mechanism that accounts for cascading harm caused by past support failures — including property damage, health impacts, lost income, and debt — before new eligibility criteria are applied.
- A commitment that the commissioned SIL model will not override existing individual arrangements for participants with complex medical needs without independent clinical review.

- Honest public acknowledgement that the framing of this reform as being about 'fraudsters and shonks' has caused direct harm to the reputations and livelihoods of disabled Australians who fight for legitimate supports — including people like me, who now face employment discrimination compounded by the public narrative this Government has chosen.

---

## Conclusion

I am 58 years old. I work around the clock to build a business that creates futures for my children and others like them. I am desperate to establish independence — for them and for myself. I am trying to leave a home that is difficult for me to function in, in a town that cannot support us, to relocate to Melbourne where my business is gaining traction.

Before I can do any of that, I now face the real and serious prospect that this Bill will drag me back into providing 24/7 care in a dangerous situation, with no adequate funded support and no meaningful avenue of appeal.

That is not a sustainable NDIS. That is the same system that almost destroyed us — repackaged as reform.

I urge the Committee to hear from families in situations like mine before this Bill proceeds. Not to hear that the system is hard. To hear what hard actually looks like.

---

### **Annette Andersen**

Founder & Architect, aXai Pty Ltd | [axai.com.au](http://axai.com.au)

May 2026