

Background

I am a mother of a 6 year old with Cerebral Palsy amongst other co morbidities (less than 1% of children are born like my child). To name just a **few**- epilepsy, bronchiectasis, dysphagia, spastic quadriplegic, non verbal, incontinent, heart defects, sight issues, hearing loss.

But despite all of these medical terms, we have worked hard to find ways to communicate with our child, get her some sort of education, show her the world and life (albeit domestically and without leaving the state), help her to try and walk assisted with a walker and above all love her! We didn't know she was going to be born with any complexities, and we understand that life is not always fair, however to be treated like we are criminals every time we contact the agency that is supposed to understand and support us the most is disgusting.

My husband and I have been self managing our daughters plan since she was 5 years old. She has been involved with the NDIS since she was 6 months old.

We both work, my husband works full time and I work 4 days a week (almost full time hours), however require a day off each week to attend medical appointments at Queensland Children's Hospital (1 hour each way from our home), take our child to therapy that cannot be undertaken at home, school etc.

We are a sensible couple. Had a child in our 30's, own a home (mortgaged) and used to travel before the birth of our child. However in the past 6 years we have not had a proper holiday. Our child was granted a 'Make a wish' which was a domestic experience due to her immune sensitivity.

We have had to request a review of our plan no less that 6 times in her 6 years of life. We have proceeded to tribunal conferences on 6 occasions and attended 1 hearing for 3 days in person (2025). The outcome was in our favour [KDKJ and National Disability Insurance Agency \(NDIS\) \[2025\] ARTA 454 \(16 April 2025\)](#)

As a result of a request for review by the NDIA, we are returning back to tribunal (GAP) for 5 days to completely re-do what was undertaken in 2025 as the plan my severely disabled child holds, will put pressure on the sustainability of the scheme.

Key changes and focus areas

Whilst the inquiry is specifically aimed at the NDIS Amendment (Integrity and Safeguarding) Bill 2025, I would like to focus on some areas of discrepancy that I have experienced with the agency that may impact the proposed changes or the belief that the agency intends to act in the best interest of it's participants and their families providing necessary and ethical support and funding.

□ Integrity and safeguarding:

The NDIA ‘appears’ to be making some progress in the fraud sector, particularly with providers. However it is important that we expose internal integrity issues occurring with the misuse of public moneys by the agency.

A freedom of information request made by me showed that between May 2025 and August 2025, \$228,252.88 was spent on various legal fees (including a barrister and a Kings Council) to fight against our 6 year old child’s plan.

This case is still before the tribunal and a further freedom of information request has been made for costs to date for legal and independent medical reports, travel and all other associated fees.

Given this case is not before the tribunal until March 2026, one would assume that the amount of costs will be exorbitant. I know I am mortified to know that this amount of my tax payer dollars are spent on fighting what my child was unfortunately born with and cannot help.

FOI references are 24/25-2082 and 25/26-1301. I am very happy for the inquiry to have access to this information or to provide this information upon request.

□ New “Right Supports” Definition:

This area of change is ambiguous. In our case we continuously provide reports, evidence, medical history etc. to show reasoning for the requested support. No supports on our child’s plan are for things other than consumables for feeding or administering medication, allied health or nursing care. Our current medical reports have been disregarded by the agency, accused of showing bias towards our child, suggesting medical professionals at the top Children’s Hospital in the county and top 10 in the world would not only risk their license to unethically support our child for funding purposes but would lie about her severity.

However, it is suggested that strangers with no medical qualifications, just regular low level public servants, would know what our child needs better than we do.

This is very concerning. This is a violation of human rights to receive the best and appropriate care and a misuse of power at best.

□ Person-Centered Planning:

The understanding of this change that I have been able to locate is *to shift to a strengths-based approach, focusing on a participant’s needs rather than functional impairment, leading to fairer budgets.*

What is a strengths-based approach? The needs of a participant are based on their functional impairment. Our child needs nursing care. This has been ascertained by medical teams, us her parents and also the Tribunal, however to ensure that costs are kept low and her budget is reduced, the agency is suggesting a lower level of medical assistance (high support workers). This will impact on our respite, her trips to hospital (they will increase as any change in medical condition from baseline requires

intervention (ambulance) due to the lack of skills of a high support worker) and ultimately put my child's life in danger.

Budgets are meant to be assessed on a case-by-case basis. Some cases will require higher budgets than others. There is no evidence to suggest that the agency is looking to provide a better and more person-centered approach to plans but using their power to reduce funding, even at the cost of life.

Further to this, the planners we have experienced over the last 6 years are not of a standard or qualification to have any input or decision making of what is suitable or not suitable, reasonable or necessary for the plan of our child.

Funding and plans:

Changing funding periods are ridiculous. I am unsure what the explanation is for this but as a mother of a child who is highly complex with a baseline funding requirement, this is a waste of public money, resources and my time.

Not to mention added anxiety to a family life that is already trying to catch a break. No participant or their family would agree to more frequent plan changes let alone more frequent interaction with the agency. This does not streamline anything and does not have the participants' best interests in mind.

It would be interesting to know specifically who was consulted on these decisions, what their qualifications or experience with plans are and what participants/advocates agreed to this change. My feelings are this was a government decision not a participant request.

Provider Rules:

I am not a provider, but we have worked closely with our providers and cannot understand the methodology behind the capping of claims particularly with travel. Our child depends on providers travelling to us for her therapy. We as parents depend on this. The unfair and illogical penalties applied on providers, affecting the providers who legally do their job and make a difference to our kids lives are being affected. Financially this is a huge impact to their business and will eventually shut down some of the best providers who are changing lives.

Perhaps the agency can look at the misuse of spending elsewhere- perhaps reduce unnecessary costs for legal representation or less external representation?

Final Statement

We are tired. I'm 42 and have had to manage life by 4 hours sleep for 5 years. I have 1 child; I have had to restrict career progression to continue to advocate for my child and our needs. My husband and I continue to write to ministers with no reply, meet with lawyers, even

attend hearings while in Intensive Care with our child, all to fight a system that believes we are trying do wrong by the government, by our child.

We love our child; you have no idea how much we love her and do not ask for anything but respect and support and if possible, an easy way to live the short life we know she has.

We ask that this bill be reviewed, it will just add to further harassment and impost on participants and their families who just want to live.