

Introduction:

I am writing as I am deeply concerned for the future of our nation under the proposed changes to the NDIS for people who live with a disability, under the proposed budget and also the National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026. The NDIS was designed to support people living with a permanent disability to live a life with support and dignity, and the proposed changes are demonising disabled people and painting them as a strain on our nation, where they did not choose to have a disability and are still humans who deserve to live with support and dignity, and many of the things that are being painted as luxuries are actually basic needs or human rights.

I am deeply concerned about the proposed changes contained within the NDIS Future Generation Bill and the broader direction of reforms currently being implemented. While the stated intention is sustainability and consistency, I believe many of these changes risk reducing access to essential supports for disabled people with complex, fluctuating, developmental, or less visible disabilities.

I am particularly concerned about the impact on autistic people, women and girls, children with developmental disabilities, and participants whose needs do not fit neatly within rigid functional frameworks or are being labelled as “high functioning”.

Personal Context:

I express these concerns as a person who has lifelong lived experience in the disability community and has seen directly the impact that lack of supports can have.

My experiences began with growing up with my older brother Brendan. He is Autistic (Level 3), intellectually disabled, non-speaking, and has many other co-occurring conditions including epilepsy, bipolar, and OCD. When he was 8 or 9 years old (I was 2 at the time), he was put into an institution called Baringa in the Wollongong area because at the time this was what happened to people whose support needs were deemed too great to stay at home. My parents did this for his safety. Our home was not safe for him, and they could not give him the support he needed at the time. They did not make that decision easily; it was a very difficult decision shaped by the landscape and attitudes to disability at the time. He also attended the Autistic school in Corrimal from the age of 2 until he was 18 years old, one of the longest attendees at the time.

When the institutions were closed down in the late 90s, he was transitioned into a SIL, and my family has continued to have to fight as constant budget cuts and changes were implemented, threatening to reduce his supports. He lived in a house with two residents and two staff members full time with a pool to support his water obsession until this was deemed to expensive. He was then moved into a group home with five residents and two staff on rotation. He requires 1:1 support to access the community, but this is constantly challenged as the government would rather him be in a group setting with less staff to save money. He was transitioned over to the NDIS when it was first rolled out in NSW, and I am his plan nominee as he is unable to advocate for himself. My father thought tirelessly for my brother but unfortunately passed away in 2020 from injuries sustained in a suicide attempt in 2016. He also was an NDIS participant while he was alive due to his ABI and physical disability due to the injuries he sustained. Brendan is about to have his plan reviewed on May 26th, 2026, and I will be stepping in to ensure that he does not receive cuts to his funding and supports with the support of his dedicated support coordinator and SIL manager.

I also work as an inclusion teacher in a mainstream high school. Every day I work with young people with a disability who require support to access education and their communities. This is a basic human right but is seen by some as a financial strain and burden to society. These students also can be demonised and excluded by their peers for their differences. Their stims are seen as weird or disruptive, their dysregulation is

misinterpreted as bad behaviour or unsafe. They experience bullying or negative comments or social exclusion on a regular basis. Some of them have begun to deny supports they need as they believe this makes them more of a target with their peers and they desperately want to be “normal” and fit in. I have seen students try to access mainstream services like community mental health services and have their applications rejected due to an overwhelming number of people needing supports. I have seen people on extensive wait lists for services they desperately need, and parents stressed as they cannot financially handle the costs of self-funding services or diagnostic processes to gain access to supports. In every classroom we have students who are not diagnosed and are not receiving external supports due to barriers to accessibility and affordability. I have sat with parents as they broke down due to the stress of trying to keep their disabled child alive as they have significant mental health challenges and have wanted to end their own life because they feel broken and defective. This is partially because of how society frames disabled people, and the beliefs, attitudes, and ableism that form a large part of societal views. Difference is seen as bad, weird, or wrong. Many of our systems are broken and are not set up for people who deviate from the “norm”.

More personally, I have two daughters who both access the NDIS under the early childhood approach. My eldest daughter Eleanor, who is 7, is Autistic (level 2), ADHD, mildly intellectually disabled, has a moderate speech language disorder and mild speech sound articulation disorder. We are also currently exploring additional challenges such as possible Developmental Coordination Disorder, Dyslexia, Dysgraphia, and Dyscalculia. She has a chromosomal microduplication. She attends a mainstream state school, but I have to constantly fight for and advocate for supports. She has NDIS, but we have zero funding for a support worker or any assistive technology. Due to the current diagnostic process and biases within the autism assessors and treating professionals she had to complete two separate ADOS assessments due to bias towards externalised presentations of autism. She is seen by many as a “low support needs” person. She is a person who could have her supports cut under proposed changes.

My youngest daughter Clara, who is 4, currently only has a diagnosis of a chromosomal microduplication and global developmental delay. She has major delays in multiple areas and attends an ECDP program and kindy with limited inclusion support available. She likely shares many of the diagnoses of my other daughter but is younger, so we have not commenced formal assessment and diagnosis proceedings, although this will be required by the time she turns 6 years old. She is also very at risk under proposed changes.

I also live with a disability. I was diagnosed with Autism (level 2) and ADHD at the age of 33 after years of having my needs diminished and ignored. As I was not as obviously disabled as my brother, my parents were largely unaware of my difficulties, I was high masking, high achieving and intelligent but a bit sensitive. I also have multiple co-occurring chronic health conditions including severe obstructive sleep apnoea and suspected hEDS, POTS, and MCAS (official diagnosis of this is inaccessible and expensive). I just got my first NDIS plan, and I must say it was disappointing as it does not reflect my current level of need for support, but I was told to get more funding I need to provide more evidence of my support needs which means more of a burden on me, to prove I am disabled and need support. I am significantly burnt out, tired, and trying to remain a functioning member of society who contributes and be a carer and parent to my two children, but without the supports I am requesting I cannot do this. Does that not create a larger burden? If I can no longer work due to burnout, or take care of my children, does that not place more burden on society? I work, I pay taxes, I am asking for supports to live my life with safety, support, sustainability and dignity, but I am being told this is “not reasonable” and “hard to justify”.

When I was younger, I had significant mental health challenges. I was depressed, anxious and engaged in Non-Suicidal Self Injury because of the level of distress and brokenness I felt at just trying to exist. I did not know why I always felt so different, I felt like an alien from another planet or that there was something fundamentally wrong with me. I was told I was too sensitive, too much, that I needed to calm down, try harder and do better. I always have felt too much and not enough at the same time. Turns out I was AuDHD

and trying to live in a neurotypical world not designed for my needs. I am slowly working on trying to understand and accept myself and unlearn all of the lies I believed about who I am as a person, but to do that, I need supports. I need access to an OT and a psychologist. I also need access to other allied health and possibly a support worker to manage my other chronic health needs and responsibilities, but I don't have enough "evidence" so I either have to self-fund which is probably thousands of dollars a year that I do not have or "live with it" and "accept my new normal". That doesn't sound very fun does it?

Concerns About the Bill:

My biggest concerns about the proposed changes in this bill and all the talk of cutting up to 160,000 people off the NDIS is the impact this is going to have on those people. The disability community is the largest minority group that anyone can end up joining at any point in their life. We did not choose to be disabled. Many of us were born with disabilities, and last I checked I did not consent to being born. I had children before I knew I was disabled, and my children now also have disabilities.

It is also concerning to me that the NDIS is removing mental health services such as psychology as they are deemed a medical expense and should be under Medicare. I was told to go to my GP and get a mental health care plan. I have, for years; it does not cover my support needs at all, and over the years this has even had cuts. I have to pay over \$100 out of pocket for every psychology session I have, and my psychologist is not even one of the most expensive out there. My need for psychology is directly linked to my disability and medical issues, and so I will continue to need regular, ongoing psychological support, but apparently it is not reasonable to ask for support to pay for this.

I am also very aware that there is a chance that I will end up in the group of people being cut, or my children will. I cannot afford to pay for the supports we need from the money that I earn from my part time but above average paying job. Even with NDIS we still live pay check to pay check and have times our account is withdrawn for a day or two until more money comes in. If we do not have this funding, we will go unsupported to our detriment.

Impact on Autistic People / Children / Women:

It is very, very concerning hearing people like the Honourable Mark Butler MP, Minister for Disability and the National Disability Insurance Scheme, talking about people with disabilities using outdated functioning labels such as "high functioning" and "mildly autistic" to describe a very vulnerable population who his proposed changes are threatening to impact. Trust me, I do not feel my or my children's autism "mildly", and there are times I do not feel "high functioning". Using these antiquated terms is hurtful and harmful to our community, and you would hope that the government official elected to represent these people would know better than to use this kind of language, but it just shows how society as a whole views disabled people—particularly autistic people—as these views come from somewhere; they do not exist in a vacuum.

Cutting supports and funding to these people will also place a larger burden on other systems including education, medical, and mental health services. I also believe this could result in higher rates of suicide in some of the vulnerable disabled community, who are already three times more likely to die by suicide. For Autistic individuals, this is even higher with Autistic people 7 to 10 times more likely to take their own life.

There is also a lot to be said about the impact this is going to have on high-masking autistic people, particularly girls, women and gender diverse people who have a more internalised presentation of autism. A person who is able to mask still needs support, but these are the people that the government will cut. We mask to survive. We mask to make others feel comfortable, to our own detriment, because it is easier to do this than be judged, invalidated, and misunderstood. We learn to mask from an incredibly young age

because we learn that that is what society wants. We tolerate distress and discomfort because that is what we are taught is normal, expected, and wanted by society, and we gaslight ourselves into thinking we are the ones with the problem when it is actually the systems that we are in that need to make changes. We are the perfectionistic, people-pleasing, high-performing ones who are afraid to draw too much attention to ourselves. Just because we can do that, for your comfort, we do not get support until we have a mental breakdown or go into severe burnout.

Also disabled people who are also carers for children with disabilities, don't get me started. Australia relies on approximately 2.65 million unpaid carers, providing essential support that would otherwise cost tens of billions of dollars annually. We struggle to get any support, there is carers payment/allowance if you can do the mountain of paperwork for that, but that's not much. What do we do if we can't get support for ourselves or our kids? We are already struggling as it is.

Concerns About Functional Capacity Assessments and Administrative Burden and Evidence Requirements:

When I got my NDIS plan and expressed concerns about the lack of funding and supports that I had been given access to, I was told I needed to undergo a functional capacity assessment. In the current climate where the government is talking about cuts to "high-functioning" people, this can be frightening. You start to wonder if going to the significant effort of getting a functional capacity assessment to prove you need support is giving them the evidence they need to cut you off or reduce your funding further. There is also zero recognition for the amount of time, effort, and energy it takes to complete these assessments. As a disabled person, to get any help you have to sit with someone and say all of the negative things about yourself, identify every single deficit that you have and how much you struggle just to get a basic level of support. This can actually make you need more support, as focusing so much on the negatives has a detrimental effect on your personal wellbeing and mental health. For a person already struggling to stay afloat, in burnout, trying to take care of themselves and their family, asking me to do more to get the support I desperately need is a big ask.

It also takes a lot of effort to apply for the NDIS. There are so many hoops to jump through, piles of paperwork, hours of assessments and meetings, just to get access to things to make your life tolerable. Families often spend dozens, and in some cases hundreds, of hours preparing evidence for plan reviews and reassessments.

I understand there needs to be processes and evidence because they cannot just hand out money to anyone, but for a system designed to support disabled people, it has some serious accessibility issues in its application process for the people who have a disability. Many people do not have the knowledge or support to do this. I believe there are people who are not currently supported as they do not have the knowledge or capacity to apply. I also strongly believe there are people who will receive their plan, even if it is insufficient, and not have the capacity to appeal and will just accept what they are given even though they desperately need more because they feel they should be grateful for anything they get and could have gotten nothing at all.

I understand there is nuance. There are people taking advantage, but this is more providers or support coordinators or people taking advantage of people who have a disability for their own personal gain. Disabled people just want to be able to live their lives with as much normality as possible. We want dignity and to be able to do things other people can just do without a second thought. Most of us are not going into applying for the NDIS for financial gain; we are trying to get a little bit of support to live our lives safely, sustainably, and with dignity.

Foundational Supports Concerns:

Earlier this year Mark Butler announced a system of community supports to transition people to that do not exist. The supports for Thriving Kids do not exist yet. Community-based supports have been gutted and removed, and now within a short period of time it is expected these will be back in place. There has also been no consultation about this with local disability groups. The state governments are also not able to take on this burden, and so this means many people will be left with no supports as they simply do not exist or are not able to take on the load, they will be expected to take. When I went to my community access meeting with my LAC prior to my NDIS application being approved, she could not give me a single name of any additional supports I could access without out-of-pocket costs to get support for my disability. They simply do not exist currently, but the minister is proposing moving people off the NDIS and into these services... What services minister? Can you show me where to find them?

System Design and Broader Impacts:

I also want to highlight that many of the concerns I have raised are not the result of individual misuse of the system, but of how the system itself was designed. The NDIS was built on assumptions that did not fully account for the actual size, complexity, and lifelong nature of disability in our community. Because of this, what we are now seeing feels less like genuine reform and more like attempts to restrict access in response to pressures that were always going to exist in a system supporting people with permanent disability.

It is also important to say clearly that when supports are reduced or removed, the need does not disappear. It is pushed elsewhere. It lands on families who are already exhausted, on teachers trying to support complex needs in overcrowded classrooms, on already stretched health and mental health systems, and on carers who are quietly holding everything together. From my lived experience, I have seen how quickly things fall into crisis when support is even slightly reduced. Students with disability now make up approximately 1 in 5 school enrolments, placing increasing demand on already stretched inclusive education systems. What is framed as “savings” often just becomes invisible unpaid labour, stress, and breakdown in other parts of the system. For example, a significant proportion of Australians with mental health conditions still do not receive adequate or ongoing treatment, even with existing Medicare pathways. This is because the funding for these is not sufficient and even with a MHCP there are significant out of pocket costs and barriers to accessibility.

There is also a very real human impact in how decisions are made. As the system becomes more complex and the evidence burden increases, it is often the people who are already struggling the most who are least able to fight to stay in it. The people who are burnt out, overwhelmed, under-supported, or who do not have strong advocacy around them are the ones most at risk of falling through the cracks. That is not a fair system. It is a system that rewards capacity to navigate bureaucracy, not level of need.

I do not believe most disabled people are asking for anything unreasonable. Most of us are simply trying to hold our lives together, keep our families stable, and function in a world that is already difficult to navigate. A system that requires people to repeatedly prove their own disability, while already living with significant barriers, is not just administratively difficult — it is emotionally and physically draining in a way that actively worsens people’s health.

If sustainability is the goal, it cannot come at the cost of pushing people into crisis and then expecting other systems to absorb the consequences. True sustainability must include honesty about where the pressures are actually coming from, and recognition that removing support does not remove need — it only changes where that need shows up.

I can completely understand some of the government’s concerns about the cost of the NDIS. I know it is expensive, but this is not due to disabled people. They built a system and severely underestimated how large the disability population is. They also need to be doing more with providers to regulate their pricing and

police fraud. However, the solution is not to punish disabled people who genuinely need these supports by taking them away. There are no alternatives; do not leave these people in the lurch.

Recommendations:

The following recommendations are offered to ensure that NDIS reforms remain fair, evidence-based, and responsive to the lived realities of disabled people and their families. Future NDIS reforms, operational guidelines, and assessment processes should be genuinely co-designed with disabled people, including autistic adults, people with intellectual disability, women, carers, and those with complex or fluctuating support needs. The experiences of people most directly affected by these reforms must be meaningfully included in both policy development and implementation.

The government should ensure that autistic people and children are not excluded from necessary supports through overly narrow interpretations of functional impairment or developmental expectations. Autism and many other disabilities can involve fluctuating needs, masking, cumulative burnout, and significant invisible impacts that may not be immediately apparent in brief assessments or rigid functional frameworks. Reforms must acknowledge these realities, particularly for autistic women and girls, who often face delayed diagnosis, diagnostic inequities, higher rates of masking, and significant mental health impacts associated with unsupported disability and chronic burnout.

The NDIA should reduce the ongoing administrative and evidentiary burden placed on participants and families, particularly where disabilities are lifelong and well-established. Families are currently required to spend substantial time and financial resources sourcing updated reports, repeatedly proving permanence, navigating appeals, and coordinating fragmented systems. Existing evidence should be accepted for longer periods where appropriate, and unnecessary reassessments should be minimised to reduce preventable stress and instability for participants and carers.

Any functional assessment processes introduced through these reforms should be transparent, evidence-based, trauma-informed, and subject to strong independent oversight and appeal protections. Assessors should have disability-specific expertise, including autism-informed practice where relevant, and the evidence provided by treating professionals who understand the participant over time should carry significant weight within decision-making processes.

Foundational supports must be fully designed, adequately funded, and operational before any reduction in NDIS access or individualised supports occurs. These supports should complement, rather than replace, individualised disability funding for people with significant functional impairment. Without appropriate safeguards, there is a substantial risk that disabled people and families will fall through gaps in support and experience worsening outcomes.

Finally, efforts to improve the sustainability of the NDIS must not result in reduced quality of life, increased crisis presentations, family breakdown, educational exclusion, or unmet support needs. Sustainability should not be achieved through increasing barriers to support for disabled people, but through building a system that is accessible, preventative, responsive, and grounded in dignity and human rights.

Conclusion:

I know this submission is long. In the past I would have apologised for my lack of succinctness, but I will not apologise for trying to make my voice and the voice of others who may not have the capacity or ability to make such a long, eloquent submission for themselves heard. I hope that people, or at least someone, takes the time to read this and other submissions in their entirety and is moved to stand with us to try and

fight these harmful changes. I am a strong believer in the saying “Nothing about us, without us”. The government is trying to save money and make changes without consulting or listening to the people these changes are impacting. This is unacceptable as it goes against what Australians and, actually, all decent humans on Earth stand for. It is removing people’s rights to safety, both physically and psychologically, and will have a negative impact on a wide number of people who are already vulnerable members of society. It is removing people’s dignity and also operating on the assumption that having a disability means you should not be able to do things that non-disabled, neurotypical people can do because it costs society money to support you to be able to do these things. They would have us sitting at home, isolated and unsupported in the name of saving some taxpayer dollars to spend on other areas which I acknowledge are also important but there needs to be some balance. They could recoup some of these costs in other ways, but they won’t do that; instead, they are going after the country’s most vulnerable. So much work has gone into advocacy and changing the conversation within the disability and neurodivergent communities—look how far we have come; let’s not go backwards into darker times in the name of saving some money. Please do not place already vulnerable people at further risk of having their quality of life diminished. Many of us are very tired—tired of having to explain ourselves and justify our own existence and fight for basic rights or opportunities that other people have access to or don’t need due to lack of barriers. Tired of shrinking ourselves down to fit into peoples boxes to make them more comfortable and jumping through hoops to get basic support. I am not alone in my feelings; there are many people who feel the same way so please don’t make changes that are going to impact us without thinking about the cost to the people involved. Its more than just money, it’s our lives at stake.

Yours sincerely,

Janelle Richens