27th July 2025

Re: **NDIS Supports**

Content warning for preventable harm to, or deaths of, people with disabilities

To whom it may concern,

Here I am again, writing with a couple of hours to go. And of all the reasons I said I was angry in my August 2024 submission, DSS has addressed **one.**

Or so I thought, until I realised the Easy Read was grossly misleading about **what** was heard from the 7000 who responded last year.

To be honest, I'm even angrier this time around.

Why?

Because so many people warned DSS, the NDIA, and the Government that lists **would cause harm.**

Because we were criticised for fearmongering, when we were right.

Because we still are not being taken seriously when we talk about harms.

Harms like this recent ART comment:

"[Her] health and her life expectancy is highly likely to be compromised"

So, before I get to your questions, I've got some for those drafting the new rules, advising on them, or signing off on them: **What risk tolerance for harm are you basing these rules on?**

- What is the risk tolerance for **functional decline?**
- What is the risk tolerance for **hospital admissions?**
- What is the risk tolerance for **carer burnout** leading to **breakdown of informal supports?**
- What is the risk tolerance for **obstructing our economic participation?**

- What is the risk tolerance for **deaths** resulting directly from you deciding you know more about what we need to address our disability needs than we do, or our teams do, or forcing the **wrong** supports on us?
- What is the risk tolerance for **suicide** if you make our lives harder than they already are, rather than easier – or deny us the disability supports that allow us some **quality of life?**

Because if you cannot accept, own, and admit to the potential consequences of your policy decisions, **you have no business dictating those policies.** And you definitely do not get to gaslight us about the real impacts so many of us are feeling, as if it's all for our own good.

You don't get to rewrite history by proclaiming this is about returning the Scheme to its original intent, without revisiting that history.

Lists were rejected in 2013 because the 2012 consultation feedback was honoured:

"We do not want lists of things we can and cannot have.

People want flexible responses that best meet the needs of people with disabilities, families and carers.

However, a substantive connection between the plan and funded service needs to be made."

Last year, the community and legal experts were clear that disability-related supports should not be defined by where they are bought or who they are designed for.

Parliament and participants were promised an exceptional circumstances clause which was **not** delivered.

In Submission 183 to the second inquiry on the *Back on Track No. 1 Bill*, my co-authors and I questioned the real goal of Section 10:

> *"One must question whether this is the real motivation for restricting the definition of NDIS support. It would certainly be an attractive shortcut to more convenient compliance interventions, but that path is fraught and unlikely to achieve genuine savings if it denies participants access to many cost-effective and practical supports.*
>
> *What's the point of the Wedding Tax argument if we are forced into using those charging Wedding Tax just to have some confidence our claims will be paid out in a timely manner?"*

Unsurprisingly, that's exactly what an ANAO report just found: The Section 10 we were sold as reinforcing the constitutional basis by "implementing the CRPD" was really a bait and switch:

On 3 October 2024 the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Act 2024 *came into effect, which amended the NDIS Act* ***to strengthen the legislative basis for the NDIA's compliance activities*** *by:*

- *Defining NDIS supports (section 10 of the NDIS Act)*

Why? Because…

*In May 2023, the NDIA received advice that it was limited in its ability to recover payments as debt, due to difficulties in: **determining that spending was not in accordance with a participant's plan**; and setting a hard limit on plan budgets when supports were described generally in participant plans.*

What else did the ANAO report reveal?

*Lack of alignment with the NDIS Act (2013), resulting in the raising of **unlawful debts**…*

I find it quite infuriating to have that confirmed when our same submission that took aim at compliance activities had not only put forward an alternative in the same submission that took aim at compliance activities (as reproduced in the 2024 submission appended to this one), but demonstrated we were ready and willing to help build principles-based justifications into the claiming and audit processes.

What is the goal here?

To claw back funds and limit spending for poisonous political reasons? Or to uphold the original intent outlined in the Objects and Principles?

Because you're doing a fantastic job of making Australia a more hostile place to live if you need disability support, and the rhetoric of the last 14 months **and** the ANAO report strongly suggest it's the former. This rhetoric is making it ***unsafe*** for us.

These lists and the sick narratives they were sold with have placed targets on our backs by deliberately eroding social licence and encouraging the wider community to assume everybody is rorting the Scheme, whilst making it impossible for us to get the support we actually need to achieve the intended outcomes of full inclusion and participation.

I get that in some cases the 'right' support will cost more. But in many cases, the problem isn't how big a slice of the NDIS pie we get.

The problem is that the Government Approved Pie Recipe is inedible, overpriced rubbish we're expected to shut up and be grateful for, even if it makes us unwell – or causes a deadly anaphylactic reaction, and even if our own recipe would sustain us fabulously for half the price.

The current Section 10 Rules:

- Ban exceptional circumstances rather than allowing discretion for them
- Circumvent access to justice, by imposing a process the NDIA quarantined from reviewable planning decisions

- Place the burden on us to barter and beg the NDIA for things that make more sense
- Kill innovation under the flag of 'sustainability' while forcing us to pay Disability Shop™ wedding tax
- Disproportionately impact thin rural markets
- Create endless new barriers to achieving the objectives in Section 3, a.k.a. ***The (Actual) Original Intent™***
- Were made against all advice that "unintended consequences" could not be used as a shield for all the perfectly foreseeable harms
- Are keeping us shut in, and shut out

And let us not forget: **Lists failed the pub test you subjected our human rights to.**

Having now seen the version of the draft lists released under FOI which defaulted to using the existing 'day-to-day' tests: **What happened?**

I have no new solutions for you tonight, except to point you back to those in my appended 2024 submission, and to tell you that bureaucrats and politicians shouldn't be:

- Redefining internationally accepted definitions of assistive technology which explicitly include mainstream items put to disability purposes
- Telling us what isn't effective and beneficial if we have evidence of what is, and what has not and never will work for us
- Making the threshold of evidence for disability-related need higher than the threshold for work-related tax deductions (I don't recall ever needing an OT to sign off on mine), rather than basing what is 'in' around the golden thread between our disabilities and our goals

Politicians should be remembering what they told us all at the start, when Australia said:

"Aspire. Dream of a life where disability does not make your world smaller.

Those are the terms of the contract. That's how we'll decide what you need."

Forgive me for being so autistic I took that promise, that original intent, literally.

Forgive me for being so radical I aspired to a real life, when I was meant to aspire to getting un-disabled, not being the captain of my own ship and defining my own meaningful outcomes.

The rules you wrote last time told us tracking outcomes as meaningful as those defined for ourselves is too much work, without even considering letting us report that data for you.

The rules you wrote last time said we are worthless by making it impossible for Australia to ever discover the value we bring to our communities if we get to be who we are.

I have no personal examples I can share in a public submission except to say that if you do not restore genuine discretion for individual needs, **return that discretion to us and our treating professionals**, and remove the artificial barriers to merits review of discretion for higher cost items, you will kill my opportunities to be a contributing member of the Australian community.

And my life will be one of the lives you place at risk.

But what do I know? I'm just a participant, speaking up again because I know others can't.

Surrounded by endless new barriers to getting the meaningful value out her plan that a rights-based rule would, seeing harms she warned of in 2024 playing out.

Despairing over the toll of changes that say I was among those consulted, but which dismiss what I said about who they would hurt, how, and which of my peers might not survive them.

Virtually standing in front of her NDIS Ministers and the rule-makers who ignored us last year, asking them one more time to do the right thing: **To choose to love the idea of a rule truly grounded in the CRPD, and what it would mean for Australia to realise THOSE outcomes.**

Either way, we will mark your homework and interrogate your workings, because if there is one singular truth about disability maths, it is that **harm always costs more in the end.**

*"Because carers are required to stretch the bonds of obligation and kinship **past breaking point.** Because the nation **is being robbed of the human and economic potential of people living with disability and the contribution they can make** to our shared future.*

*Because while the promise of fairness and equality that lies at the core of our national ethos is denied to some Australians, **we are all diminished.**"*

Sincerely,

Cat Walker

25th August 2024

Re: DSS Engage consultation on draft NDIS supports lists for transitional rule

To whom it may concern,

I'm going to be direct with you. I'm pretty angry right now.

Angry that despite being someone who has engaged extensively with NDIS legislative reforms, I'm rushing to have my say with two hours to go and won't be able to address some of the specific banned or omitted items that most concern me.

Angry that it took uproar to hurry the Easy Reads along, and that the extension still only allowed 13 days from publication of the Easy Read versions which are, in fact, misleadingly incomplete.

Angry that answer NDIA IQ24-000035 to a question on notice from the final Senate inquiry hearing referenced the Participant Reference Group (among others), of which I am a member, as part of consultation referenced as "shaping the early thinking" during this hearing, without any indication whatsoever of what those consulted said about the brief outline we were given and the embargoed lists our group did not ultimately see until the public did.

Angry that the Government, DSS and NDIA think my life with my disabilities can be reduced to a list, rather than how I can tackle the barriers standing between my disability and my goals, without having lived my life with those disabilities.

Angry that they have no idea what the UNCRPD should – and could – look like in real life, if you throw out these lists and stick with principles and the trust-based approach that was the recommendation of the NDIS Review.

This is not like Medicare. In the medical system, doctors recognise that some of us respond differently to different medications and treatments, but medical treatment still ultimately does not need to take account of as many unique factors: Bodies are bodies, functions are functions, and preferences and needs can generally be accommodated without too much creative thinking.

Disability is not like that. Disability is the product of how our impairments interact with each other, our environments, our other medical conditions, but most importantly, our goals and aspirations. That is always going to be different for <u>everybody</u>.

I will need supports that may be unique to me among my 661,000 peers, because none of them have my multiple impairments AND live where I do AND want to participate in the activities I choose AND have exactly the same barriers I experience to doing those things.

Any lists will fail me and everybody else for that reason. This won't just compromise outcomes, but potentially our lives. The exception pathway is not fit for purpose to resolve this problem.

This is all I have had time for. Please see the alternative definition of NDIS support presented at the end of my commentary and endorsement of other submissions.

Summary of my position on the lists and recommendations:

1. **The notion of lists is dangerous, and the ridiculously short consultation timeframe makes them more so:** Even if the permanent rule ends up being list-based, it will need months of work to avoid very serious unintended consequences including risks to the safety and wellbeing of participants. We cannot take that risk with a poorly planned, under-consulted, absolutely-not-co-designed transitional list.

2. **The transitional rule should be principles-based, without requiring carve-outs to be approved by the agency:** It should continue reflecting the *Can I Buy It* checklist and require only a letter of support where advice is needed from our treating professionals.

3. **It <u>should not</u> be based on the *Would We Fund Its*:** They are unfair, have been overturned at AAT and FCA for very good reasons, and have always been a "generally" matter, not an "everybody" rule. They most certainly should not dictate how one can spend their approved flexible funding on disability-related needs, especially if one stays within their approved budgets and seeks advice from their treating allied health professionals for anything less clear.

4. **It is deeply unfair and ableist to impose the additional administrative burden of begging the agency for every exception we need on participants:** Our lives are hard enough. The NDIS Review said flexible budgets should be trust-based. Relying on the exception pathway and not our judgments of how to achieve outcomes in cost-effective and practical ways, or our treating professionals' opinions on whether an everyday/mainstream solution is the best one for us, should be considered indirect discrimination in the severity of the burden it imposes and the barriers it creates to accessing the supports so many of us need. ***My limited time and energy are valuable. Treat them as such.*** The lists and exception pathway steal even more of my limited capacity for economic participation and meaningful contributions to this world. That is in direct opposition to the "original intent" of the NDIS.

5. **Alternatively, I again put forward the Section 10 amendment proposed in Submission 183 to the second NDIS Amendment Bill 2024 inquiry** *(Cat Walker, Uli Cartwright & Kath Madgwick; first published as Supplementary Submission 80.1 to the first inquiry but not listed in that final report due to delayed publication)*:

    a. This alternative is drafted based on the current Reasonable and Necessary criteria and *Supports for Participants* Rules, with consideration of Sections 3, 17A and 31 of the NDIS Act, among others.

    b. This alternative preserves the lived experience evidence of the participant, which is an essential prerequisite to any claims of remaining true to the "original intent" of the NDIS.

    c. This could easily be operationalised as a checklist to be completed by participants/nominees and/or support coordinators and integrity officers alike. It could be incorporated into the claiming process in the app. ***This is not hard.*** Going with lists over principles is a choice, and one which will cause harm.

d. I was given the opportunity to present this informally to other members of the Participant Reference Group (PRG) after we were consulted on the slide outlining the basis of the lists (before seeing the lists when published). I cannot share the detail of that discussion, except to say that feedback from the group was overwhelmingly positive. Please compare that feedback to the feedback from our subsequent meeting on the lists once they were published.

e. I remain opposed to the definition of support being delegated permanently to Category A rules and believe the Act should be amended to include a co-designed, community-endorsed final definition of NDIS support, as attempted in our submission.

In lieu of a detailed submission, I endorse the following submissions and the alternatives they also suggest. Should others come to my attention after the deadline, I will send a follow-up email to endorse these.

***I also endorse those organisations opposing the use of lists to define NDIS supports*:**

- Joint DRO submission to DSS opposing the draft list
- Justice and Equity Centre
- Every Australian Counts
- Advocacy for Inclusion
- Disability Advocacy Network Australia
- People With Disability Australia
- South West Autism Network
- The Growing Space
- Amaze

I have been unable to access several submissions I was likely to endorse and will follow up to support these if they become available in coming days.

Yours sincerely,

Cat Walker

Proposed definition of NDIS support for transitional rule

10 Definition of NDIS support

Supports that are NDIS supports

A support is an ***NDIS support*** for a person who is a participant or prospective participant if:

1) the support will assist the participant to pursue the goals, objectives and aspirations defined by the participant in the participant's statement of goals and aspirations; and

2) the support is related to a need, barrier, or risk arising from the participant's disability, including the collective or compounding impacts of the participant's permanent impairments combined, or their interaction with other health conditions, the participant's environment, or other barriers; and

3) the support is likely to be effective and beneficial for the participant or prospective participant having regard to current good practice or other evidence of the likely benefit of the support, which may include:

    a) the lived experience of the participant, their informal supports, or peer support groups; or

    b) the evidence-informed advice of the participant's treating professionals with regard to the individual needs and lived experience evidence of the participant; or

    c) published and refereed literature and any consensus of opinion; or

    d) anything the Agency has learnt through the delivery of the NDIS, which must be transparently published and available for scrutiny by the public and other experts; and

4) the support is not more appropriately funded or provided through other general systems of service delivery or support services offered by a person, agency or body, or through systems of service delivery or support services offered:

    a) as part of foundational supports delivered by State governments, subject to:

        i. co-design of proposed foundational supports and associated NDIS Rules; and

        ii. delivery, successful implementation and practical availability of agreed foundational supports; or

    b) as part of a universal service obligation; or

c) in accordance with reasonable adjustments required under a law dealing with discrimination on the basis of disability; and

5) the support meets any of the following additional definitions of NDIS support:

a) the support will give effect to one or more of Australia's interdependent, interrelated obligations under the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12) for that participant or prospective participant without imposing limitations on those rights; or

b) the support is assistive technology, which will include any disability-specific or universal design technology or device that will help the participant or prospective participant:

i. do things the person cannot do because of their disability; or

ii. help the person do something more easily, safely, effectively, or independently, by eliminating or minimising a disability-related barrier or risk; or

c) the support is a participant innovation project as defined by the participant in their statement of goals and aspirations and with an agreed flexible budget defined in their statement of participant supports; or

d) the support is a tailored, flexible or innovative response to the individual goals and needs of the participant or prospective participant; or

e) the support will assist the participant or prospective participant to undertake activities, so as to facilitate the participant's social and economic participation, or is otherwise likely to support the independence or social or economic participation of the participant or prospective participant; or

f) the support enables the right of the participant or prospective participant to exercise control over their own life, including where they live and who they live with; or

g) the support is likely to advance the inclusion and participation in the community of the participant or prospective participant with the aim of achieving their individual aspirations; or

h) the support is likely to benefit the participant or prospective participant by:

i. mitigating or alleviating the impact of the person's impairment upon the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or self-management; or

ii. preventing the deterioration of such functional capacity; or

iii. improving such functional capacity; or

iv. strengthening the sustainability of informal supports available to the person, including through building the capacity of the person's carer; or

i) the support is otherwise declared by National Disability Insurance Scheme rules made for the purposes of this subsection to be an NDIS support for:

i. participants or prospective participants generally; or

ii. early intervention participants or prospective early intervention participants generally.

10A Protections for participants when spending flexible funding on NDIS supports

1) Before taking any action on the basis that a claim or NDIS amount received for a claim is, or would be, spent in contravention of Section 46, the Agency is to enable a participant the opportunity to defend the claim or NDIS amount received for the claim according to the criteria outlined in Section 10.

2) In assessing the participant's justifications under subsection (1), the Agency is required to take an individualised view of the unique circumstances and individual needs of the participant, the broader objectives of the NDIS Act, and the obligations of Section 31, which should be used as a guide when supports are not specifically defined in a plan.