NDIS Joint Standing Committee Submission 2025 Shirley Humphris

Thank you for your consideration of this submission. I am a grandparent of a child with multiple complex impairments who has been a participant since 2013. Her supports have needed 3 appeals at AAT. I am retired with a background of allied health and have become a lay disability advocate. I am not a lawyer but have had to delve into NDIS law.

This submission will draw attention to the Committee of the harms and financial costs resulting from the so called "reform" of the NDIS Act in Oct 2024 with a focus on:

- NDIS Act s10 Rules,
- NDIS Act s34 1 aa and s32 BA impairment notices,
- Needs Assessments NDIS Act s32L,
- Funding Periods

NDIS overhaul 'penny wise, pound foolish'

Bruce Bonehady June 10 2021 Canberra times

https://www.canberratimes.com.au/story/7292268/ndis-overhaul-penny-wise-pound-foolish/

S10 Rules Lists

Summary: The unintended consequences

- 1. Added costs both in the immediate and the future
- 2. Killed innovation "disability shop only" applies to 1&2
- 3. Added confusion to participants and staff
- 4. Flouted the Objects and Principles of the Act
- 5. Flouted the UNCRPD
- 6. Caused harm
- 7. Caused greater poverty
- 8. Caused exclusion and isolation
- 9. Has been a failed pilot with no risk analysis

A Story of Harm

Harm Costs More

About young adult Sam (not their real name)

Sam is fortunate to have a post AAT plan for now, so some of these supports have still been possible. But the plan will soon end.

Sam, a young adult, has level 3 ASD; Severe Intellectual Disability; CPTSD with flashbacks and nightmares; Behaviours of concern (BoC) and severe longstanding anxiety. Sam also has a mobility impairment.

Dysregulation can result in harm to self and others and random children have been targeted in public by Sam (even a kinder age child), as well as informal supports, support workers and therapists.

Supports for Sam

Sam cannot attend a day programme or group STA due to past traumatic experiences. Support workers have been difficult to find despite 2:1 funding. Their single mum on a pension is exhausted physically and emotionally from almost all the challenging care. Very effective low-cost supports may soon to be banned. All have been recommended by OTs and the Behaviour Support Practitioner and used and approved for years.

- Bubble Gum (biting is a BoC, including to random children)
- Weighted blanket
- Noise cancelling headphones
- Crafts and activities to distract as only home care is possible.
- Therapeutic massage, reducing mobility pain also mitigates BoC
- Mineral Bath Salts scented
- Activity books and scented textas in the car to keep the driver safe and avoid causing accidents.

To be honest it's not certain all these items are banned as there are grey areas of interpretation and confusion.

Looking at the list, the pub test may presume anyone should be able to self-fund these things, **but that is not so through the lens of poverty.** The bubble gum alone is costing \$2 - 3,000 a year due to intense use, two pieces at a time and replaced often.

It feels that the decision makers have <u>no idea of disability cost of living</u>. It is worse than general cost of living and usually lifetime long for those who cannot work. If the population are struggling the disabled are affected even more.

Disability has many extra costs that have never been claimable such as medical care, housing, medicines, transport etc. etc..

If the simple low-cost AT supports are not funded, Jane (Sam's Mum) doesn't know how she will manage Sam at home. She is worried that the tools will no longer be available for support workers to do their job and the workers will be even more difficult to find.

The alternative at far greater expense, it is SDA both financial and as a cause of predicted regression from harm. Because harm costs.

For the many Sams - New s10 Rules

principles-based approach to NDIS supports

From NDIS Supports (s10) consultation and engagement

- Stakeholders have advocated for a principles-based approach to the NDIS supports rule, like section 34 of the NDIS Act. YES
- The wording of the rule-making power in section 10 requires the rules to state what is, and is not, a NDIS support. it does not need to be a highly specific list to comply with s10. To claim a list is necessary is not lawful.
- The use of principles would require participants, providers and others to make complex decisions which are not supported by the changes to the NDIS Act. This is patronising. <u>However even "list" items still have to be decided</u> <u>disability needed otherwise anyone could buy anything on the list!</u>
- It is important the rules provide clarity about whether a person has a need for the support as a result of their disability, and whether the support is most appropriately funded by the NDIS. whether a person has a disability need is the antithesis of a restrictive list. It has not provided certainty or clarity.

I urge DSS/Health/NDIA to:

- Recognise the lawful use of disability principles in the finalisation of supports under section 10.
- Avoid imposing administrative limitations not found in the statute.
- Ensure that the implementation of section 10 mitigates harm and remains consistent with Australia's obligations under the CRPD.

The NO "LIST"

The following existing Rules are also clear on what are <u>not</u> NDIS supports. There is no reason that this couldn't be replicated in s10 Rules to satisfy what is not a NDIS Support

Part 5 General criteria for supports, and supports that will not be funded or provided

5.1 A support will not be provided or funded under the NDIS if:

- (a) it is likely to cause harm to the participant or pose a risk to others; or
- (b) it is not related to the participant's disability; or
- (c) it duplicates other supports delivered under alternative funding through the NDIS;
- (d) it relates to day-to-day living costs (for example, rent, groceries and utility fees) that are not attributable to a participant's disability support needs.

- 5.2 The day-to-day living costs referred to in paragraph 5.1(d) do not include the following (which may be funded under the NDIS if they relate to reasonable and necessary supports):
- (a) additional living costs that are incurred by a participant solely and directly as a result of their disability support needs;
- (b) costs that are ancillary to another support that is funded or provided under the participant's plan, and which the participant would not otherwise incur.
- 5.3 The following supports will not be provided or funded under the NDIS:
- (a) a support the provision of which would be contrary to:
- (i) a law of the Commonwealth; or
- (ii) a law of the State or Territory in which the support would be provided;
- (b) a support that consists of income replacement.

For the "IN" LIST

The new Rules, legislating similar to "APTOS" would allow compliance with s10 without anything else (albeit lawyers were concerned that APTOS was not written in a legislative format). The APTOS type inclusion needs more in-depth consideration from States and Territories. There cannot be "gaps".

This guidance (from the Explanatory Statement) MUST be included in the main Rules list (if such a list is a must). No list could include each and every support possible for the next 10 years.

"Column 2 of the table contains a description of the supports that fall within each category. Many of the descriptions include a list of included supports. These lists are not exhaustive so do not exclude an item that is not listed in the description. The purpose of the listed supports is to clarify the kinds of supports that fall within the overarching description." Explanatory Statement

The "allowed list" in the Rules should have no reference to "disability specific" or "standard" because this restriction could be more costly, as participants search for "what fits" rather than best value. Therapists are already recommending a disability specific item when a mainstream item would do the job at a fraction of the price.

Furthermore, it causes "othering" of disabled people, is not inclusive, as well as resulting in restrictions to pursuing goals.

Two examples of costs (and there are many):

- 1.A Speech Pathologist reported that she requested an iPad for communication. It was refused. But was told she could order a \$5000 communication device.
- 2. A severely disabled person with epilepsy and intellectual disability needed a simple \$500 Apple watch for falls. The person has no capacity to use any other function of the watch. It was refused but offered a falls detection device for \$1800

Failed supports not only cost more in the short term, but there are long-term implications of failed capacity building and/or regression and cost shifting to health, justice, police that must be considered.

The Replacement support rule has been a complete failure. Participants and NDIA staff have failed to understand and apply it. It should not have restrictions or limitations imposed and should be appealable. Participants frequently have nothing available for the swap.

Related, there is confusion between planners; plan managers; LACs; integrity staff; the call centre; and the participants. Does the plan need to specifically mention a support before it can be funded? The answer is NO because it would be an impossible predication for 2,3,or even 5 years. Itemisation fails flexibility, common sense, increases bureaucratic red-tape and costs. NDIA need to make clear statements to all concerned that supports can be *generally* described NDIS Act s33 (3).

S 34 1 aa and the impairment notice

Summary: The government have legislated an action that the NDIA find impossible to implement and participants are being harmed by illegal cuts.

Before s34 1aa can be implemented by the planner an impairment notice must be issued to the participant relevant at the time of planning (not the time of access). Policy is that only the access team can supply the impairment notice and they have this expertise. With over 700,000 participants how will they ever get around everyone?? We understand none have been issued for those with access prior to Oct 2024. The NDIS Act S32BA b) states that there must be circumstances specified in the Rules (which don't exist!) to give the participant an impairment notice. It follows that without an impairment notice planners must assess all impairments for supports despite s34 1aa.

The work around seems to be planners making ad hoc decisions, usually on the original access decision and other impairments have mysteriously disappeared from participants' files. The legislated Notes per s34 1 aa are seemingly not considered for an "arising from or affected by" impairment:

"Note: For the purposes of <u>paragraph</u> (aa):

- (a) the time at which the disability requirements or the early intervention requirements need to be met is the time the CEO decides to approve the <u>statement of participant supports</u>; and
- (b) a <u>participant</u>'s disability support needs arising from an impairment in relation to which the <u>participant meets the disability requirements</u> or the early intervention requirements may be affected by a

variety of factors, including environmental factors or the impact of another impairment in relation to which the participant does not meet either of those requirements."

s 32 L The Needs Assessment

The disability advocates are disturbed by the swift and opaque tenders for the forthcoming needs assessment tools. The real fear is that there will be an immediate and thoughtless implementation with no co design.

The construct of the needs assessment legislates under 32L:

- that the "tool" MUST be used
- that any assessment required by NDIA MUST be considered
- that the information about the person on file only MAY be considered

This format of s32L should be amended because of the seeming lack of appeal rights of the input of the needs assessment – namely:

- there are likely problems with a tool (tick box) being fit for purpose.
- an IME at the behest of NDIA with a possibly inappropriately qualified professional for the person. As we speak a participant at ART has had to ask the tribunal to intervene when old medical reports were sent to an IME but the NDIA refused to send a more recent update for assessment. At ART the weighting of a substandard IME can be challenged. This Needs Assessment IME will not be able to be corrected under 32L!
- the persons file could be incomplete either by mistake or gatekeeping design. It is also only of optional consideration.
- The ability of the participant to present their own information and reports is not considered even possible for consideration.
- Many participants cannot meaningfully interact with a stranger assessor.
- We do not know if an assessor will be appropriately qualified for the participant.

Remember Sam? They are triggered by assessments and suspicious of questions. They will ask if questioned by anyone "is this an assessment?" Even support workers are advised to avoid asking questions. A stranger with a questionnaire risks harm to self and Sam.

The INPUT to the Needs Assessment must be able to be appealed or better still abandon the Needs Assessment as a one off by a stranger. One replacement assessment (if approved) will not suffice for procedural fairness.

We are deeply concerned that the whole opaque action involves an algorithm to determine funding. A suspect algorithm driven by invalid input data can only result in harm to many or added supports that aren't even needed.

A false assessment from a quick shortcut may appear to satisfy cost cutting in the short-term but fails the participant outcomes. An invalid assessment also comes with costs of reduced capacity for the long term with resultant more reliance on welfare not employment, and cost shifting to health, justice and police.

Funding periods

The legislation allows for a maximum funding period of 12 months which makes sense for 3 to 5 year plans. However, much harm is being caused by the NDIA default to 3 months with no recognition that disability doesn't work like that. The default of 12 months would ensure the planner only sets shorter periods when that is needed.

Recommendations:

- Repeal s10 or introduce principles-based decisions within much shorter lists. An APTOS adaptation, carefully constructed with States and Territories to ensure no gaps could suffice to support s10. It must be made clear in the Rules that an IN list is not exhaustive.
- 2. S34 must include all impairments considered for Reasonable and Necessary funding until an official impairment notice is sent to the participant.
- 3. Funding periods shorter than 1 year only if there is evidence of need.
- 4. Amend 32L to provide flexibility within the Needs Assessment and the right to appeal the assessment and the documents included (amending s99)
- 5. Above all slow this rushed through change with adaptions and amendments to ensure participant safety. We are aghast that the brief to incoming Ministers from NDIA recommended Ministers push on with change to meet the 8% target despite harm to some. Not good enough.

Finally: Why did Labor lose its values?

"The NDIS will stand alongside the minimum wage, the age pension, Medicare and universal superannuation as one of the great Labor pillars of social justice and opportunity for all Australians.

It will change our society in profound and lasting ways, enabling those who live with disability to fulfil their potential as valued and valuable members of our society."

Bill reading 29/11/2012 Gillard Speech Transcript ID:18932

https://pmtranscripts.pmc.gov.au/release/transcript-18932

There is now a harm tracker being compiled and mentioned in the media here:

Aussies with complex disabilities are being left abandoned in their beds due to NDIS cuts https://www.heraldsun.com.au/subscribe/news/1/...