Submission for the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No 1) Bill 2024

11 July 2024

To whom it may concern,

I am a disabled person, NDIS participant, and a Disability Consultant and Writer. I have the following concerns about the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No 1) Bill 2024 – "the Bill".

Lack of Co-design of the Bill

If passed, this Bill will fundamentally change how the NDIS operates – who's eligible, how participants will be given funding, what supports participants will be able to use their funding for, and how participants will be treated by the NDIS.

There has been no co-design nor consultation with the disability community about this Bill. Giving feedback about the Bill has been inaccessible for most of the disability community due to:

1. A lack of accessible information about the Bill.
2. A lack of information about the consequences of the Bill or plans for how the NDIS will operate if the Bill is passed.
3. The Bill being tabled in Parliament without any prior warning or consultation with the disability community and being quickly passed through the Houses. The community has not had adequate time to analyse the Bill and its implications.
4. Numerous amendments being made to the Bill without accessible information about these. It has been difficult to keep up with the latest version.
5. Tight timeframes for public submissions.

I have heard many disabled people and disability service providers comment that they would like to know more about the Bill or make a submission but they do not understand it enough or due to their disability, they do not have the time, energy or skill to prepare a submission.

For example, I have not seen an Easy Read explanation of the Bill for people with cognitive impairments. I have only seen one offer from a disability organisation to assist disability people to prepare for this round of submissions and it came 2 days before the submission due date. There was a callout in the ME/CFS community to prepare a joint submission but the majority of people responded that they did not have the energy capacity to assist within the tight timeframe.

This is inaccessible and unfair. The Bill must be rejected so that co-design of crucial legislative changes can occur.

Concerns About the Contents of the Bill

Many disability organisations, advocates and disabled people have raised serious concerns about the Bill and the impact that it will have on disabled people. The Bill is also inconsistent with the recommendations of the NDIS Review, a review that the disability community had substantial input into.

My concerns include:

1. **Co-design is not required:** The Bill itself fails to require co-design in the development of the Rules and policies developed to implement the Bill. The Bill requires the Minister to *consider* co-design principles. It does not make this a legal requirement. It is essential that the disability community are involved in co-designing the scheme to ensure the best outcomes for disabled people. This is best practice. The attempted introduction of "Independent Assessments" by the Coalition government is a good example of how a lack of co-design lead to conflict with the disability community and the eventual throwing out of the proposal. I think that meaningful co-design must be enshrined in any NDIS legislation.

2. **Does not take a Whole of Person Approach**: Disabled people often have multiple impairments. For example, many Autistic adults have co-occurring physical disabilities caused by conditions such as ME/CFS or EDS, and stroke survivors can have cognitive, physical and sensory impairments. Because of this, the NDIS Review recommended that the NDIS moves away from its focus on funding medical diagnosis to needs.

   This Bill moves in the opposite direction – making the NDIS approve and fund individual impairments only. It is impractical and frankly impossible to split off a disabled person's impairment. For example, during a functional assessment with an OT, I was asked to answer a questionnaire based on my physical impairment only and not my Autism. While I can say how I function on a given task such as communicating with others, it is impossible for me to determine how much my physical impairments vs Autism are contributing to my difficulties. They are intertwined and inseparable. It is also irrelevant – if I am struggling with an activity such as communicating, regardless of the cause, I need support.

   The NDIS needs to take a whole of person approach and fund disability supports for all of a participant's needs (as recommended by the NDIS Review).

3. **Unclear review and appeal rights:** The Bill lacks a clear way for participants to appeal or replace the mandated needs assessment or to challenge their allocated budget. This will lead to participants being allocated inadequate or inappropriate funding for many years without any avenue of review/appeal. This is procedurally unfair and will leave participants without essential disability supports. It is essential that participants' rights of review and appeal are enshrined in any NDIS legislation.

4. **Broad powers to require assessments**: The Bill provides the NDIA with broad powers to require participants undergo assessments. The details of these assessments are not provided in the Bill – who and how many people will conduct these assessments, what assessment tool(s) will be used, how long assessments will take, and what choices, input and rights participants have about the assessments. These details are important because they ensure fairness, flexibility and thoroughness in a process that will be used to determine participant budgets.

   For example, because I have multiple, non-traditional disabilities, it has taken me 4 years and trialling multiple occupational therapists (OT) to find someone who understands the NDIS and my disabilities. I have experienced OTs completing the wrong paperwork, writing reports that are unsuitable for the NDIS, refusing to work with me, and struggling to assess me because my presentation is outside their area of competency and standard disability assessment tools have not been designed for my disabilities. Because OT assessments are required to access funding, this has meant that my NDIS funding has been inadequate for 4 years. My story is not unique – I've heard it repeated by many other disabled people in the ME/CFS, neurodivergent and psychosocial disability communities.

   I believe that the mandated assessment process proposed by this Bill will worsen these existing problems with the NDIS. The NDIS Review made multiple recommendations to address this problem and about how best to implement Needs Assessments. These recommendations should form the basis of assessment co-designed with the Disability Community. Only then, should the principles of these assessments be written into the NDIS legislation.

5. **Limits on Support and Spending:** Instead of participants being able to spend their NDIS funds on anything that meets the Can I Buy It Checklist or is recommended by an allied healthcare professional as they do now, under the new Bill the Minister would develop a specific list of what participants can and cannot buy. Non-disabled, non-disability trained professionals should not be making decisions about what supports are and are not funded by the NDIS. They don't have the knowledge to do this and they cannot possibility be across every disabled individual's unique needs and situation, or changing technologies and techniques.

For example, the disability needs of people with ME/CFS are rarely catered for by disability equipment providers. People with ME/CFS often need to make do with purchasing off-the-shelf items not designed as assistive technology – using a hairdresser's stool to facilitate preparing meals in the kitchen, using a "luxury" quick-drying bathrobe to allow someone to dry themselves after washing, or using an apron to prevent mess when eating in bed. I am concerned that a set list of what is and is not an NDIS support will limit participant's ability to fund non-standard essential supports.

Having the Minister decide what NDIS participants can spend their funds on allows for moral-judgements and political whim to influence how disabled people are allowed to live their lives. For an example of this, see Bill Shorten's plans to prevent NDIS funding being spent on Sex Therapists. Access to disability supports should be based on research, best practice, and the personal needs and outcomes of disabled people.

6. **Punitive measures against participants:** The Bill gives the NDIA new powers to change how participants' plans are managed and to raise debts against participants if they decide funding has been misused. The problem is that the NDIS requires that the service is provided first then payment can be claimed from the Plan. There is no process for pre-approval of spending. So participants will only find out that their spending was inappropriate after the money has been spent. There is also no process for providing participants with a warning or education about appropriate spending (as recommended by the NDIS Review).

   Some invoices for disability supports are huge – for example, a family with 2 disabled children who use respite services for a week would have an invoice of $30,000+. Most disabled people cannot afford to pay for disability supports without the NDIS and would not be using the supports without having NDIS funding.

   The Bill fails to offer participants any right of appeal or review against these debts. In cases where the NDIS will reject a claim prior to payment, participant will be left on their own to manage the unpaid invoice with provider and their debt collectors without any oversight or help.

   This essentially legalises Robodebt and will likely lead to similar horrific outcomes for disabled people as Robodebt. These punitive measures will place unnecessary stress and fear on NDIS participants, and further the adversarial relationship between the NDIS and participants. This is inconsistent with the recommendations of the NDIS Review which said the NDIS should switch to taking a collaborative, educational approach with participants.

In response to this Bill, I have witnessed disabled people discussing: rioting in the streets, leaving the NDIS, and accessing assisted dying. The disability community does not want this Bill to be passed. It must be rejected to maintain the integrity of the NDIS. It must be rejected to prevent harm to disabled people. It must be rejected so that co-design of the detailed changes of the scheme may occur first and then co-design of associated legislative changes can occur.

Regards,