



# Submission to the Senate Standing Committees on Community Affairs Inquiry:

## National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions]

May 2024

**Kiind** | operated by Parents of Children with Special Needs Inc

Ground Floor, Family Resource Centre

### Perth Children's Hospital

15 Hospital Ave, Nedlands WA 6009

C/- Child and Adolescent Health Service, Locked Bag 2010, Nedlands WA 6909

Phone

Email

Web [Kiind.com.au](http://Kiind.com.au)



*Kiind is endorsed as a deductible gift recipient (DGR) under item 1 of the Income Tax Assessment Act 1997*



## Contents

We are Kiind.....	3
Response to the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions] .....	3
First impressions matter .....	3
The devil is in the detail.....	4
‘Trust us’ doesn’t cut it.....	4
New framework plans .....	4
Challenging NDIS decisions.....	5
Where will the children go?.....	5
The supports landscape is not yet mapped .....	6
Protecting our choice and control.....	6
Nothing about us without us.....	7
Final impressions .....	7



## **We are Kiind.**

Kiind is a family-led, independent peer support organisation with 36 years of operation in Western Australia (WA).

We support families across WA raising children living with a disability, developmental delay, autism, genetic, rare, undiagnosed and/or chronic condition, from birth to age 25.

The goal of our systemic advocacy is to represent our more than 6,500 member families so their voices can be heard about the issues that affect their lived reality and wellbeing.

## **Response to the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 [Provisions]**

In the discussion below, Kiind provides commentary on the National Disability Insurance Scheme Amendment (Getting the NDIS Back on Track No. 1) Bill 2024 (NDIS Bill), tabled in Parliament on 27 March 2024.

We include our recommendations for a more collaborative and detailed NDIS bill that balances fairness, flexibility, choice and control with the powers of the NDIS.

### **First impressions matter**

The NDIS Bill is not easy for a layperson to unpack. The deadline for submissions, while we appreciate this was extended, is still too short to allow proper consultations with Kiind's membership. Given that people with disability and their families are the core stakeholder group affected by the proposed legislative changes, we need to see better efforts to make the information in the bill, and the consultations around it, more accessible.

The NDIS bill heralds a major re-design of the scheme. The re-design process must be collaborative, with protections in the legislation to ensure meaningful co-design. But this bill is delegated legislation, and the rules and other details are delegated to the Minister and/or CEO of the NDIA (National Disability Insurance Agency) to be figured out at a later stage without the need to go through parliamentary processes. This delegated authority is not democratic, and it is not co-design. Even if there is a good faith intention to use co-design methodology, the delegated power is held with the Minister, who could override any co-design process.

Kiind acknowledges that the current NDIS Act was rushed to implementation and difficult to administer, there are inconsistencies and inequities in participant funding and supports, and the sustainability of the scheme is in question. We want to help the NDIS improve the scheme for participants and their families and make it easier to operate. However, the NDIS risks making the same mistakes if the government rushes to new legislation without adequately involving the community in the decisions that affect them.



### **Recommendation:**

- Remove the delegated power of the Minister to determine the details of the legislation outside of community and senate scrutiny.

### **The devil is in the detail.**

Because this bill is delegated legislation, it contains few details of the proposed legislative changes. Several key elements of the new NDIS, such as the definition of NDIS supports, the framework for making decisions about assessment for eligibility, and the method and technical tools for converting needs assessments into funding packages, are yet to be decided. Given that there is so much detail yet to be figured out, it is difficult to comment on what's in the NDIS bill at present, as there isn't much detail in it at all.

However, while the details are scarce, the powers of the Minister and CEO in this bill are too broad. We are being asked to approve the details that are not yet written, based on trust that the government will 'do right by us'. Delegated legislation is not right for developing rules and determinations. We could end up with technical tools that are not fit for purpose, with no avenues for contesting them.

The disability community cannot understand the full impact of the Bill and the changes it proposes because the new rules, technical tools, and the foundational supports strategy are yet to be decided. We need the commonwealth to slow down the introduction of this bill to allow for meaningful co-design with the disability community, and the states and territories, to develop the foundational support strategy and the new NDIS Rules. We need more detail and more clarity in the NDIS Bill before the legislation is passed.

### **Recommendations:**

- Draft the new NDIS Rules and release for comment prior to passing new legislation.
- Provide the public with opportunity to respond to and ultimately reject the rules and determinations when they are developed. Do not allow legislation after.
- Include the new NDIS Rules in the NDIS Bill
- Develop the foundational supports strategy with the disability community, states and territories prior to passing the new NDIS legislation.

### **'Trust us' doesn't cut it.**

#### **New framework plans**

Kiind supports the goal of the NDIS review to improve equity and fairness in the scheme by introducing a new standardised approach to assessment, planning and funding. We are pleased to hear that budgets will be simplified to be more flexible, not dictated by rigid line items. We support longer-term plans that reduce the administrative load for families.

However, families and children need protections from unintended consequences. We want to see the new framework plans before they become legislated. Families need assurance that we are not getting the tools that we already rejected, such as the independent assessments that were proposed by the previous government in 2021. The current NDIS Bill leaves this open to happen.



Other issues to consider are quality control, rights to appeal, and reassessment - currently the NDIS Bill suggests that the CEO of the NDIA has the power to order replacement assessments, but families/participants do not. The NDIS Bill needs to define the tools and methods of assessment, not delegate determinations for the Minister to decide later.

#### **Recommendations:**

- The NDIS Bill must not be delegated legislation.
- The new framework plans and assessment tools must be co-designed with the disability community, and details of the designs included in the NDIS bill.

#### **Challenging NDIS decisions**

People with disability must have their rights upheld and this includes the right to challenge a decision made about them and the supports they are entitled to. The circumstances in which someone can challenge a needs assessment is not yet decided, and the NDIS bill is vague regarding whether there even exists a right to appeal. The NDIS bill is not complete if it does not include a process or circumstance in which a decision made in the NDIS can be challenged.

#### **Recommendation:**

- Develop, define and legislate a clear mechanism/s for NDIS applicants and participants to appeal or challenge any assessment decisions made by the NDIS.

#### **Where will the children go?**

There is concern among many families and carers of children with disability that their NDIS access may be denied or revoked. In the current NDIS Bill, assessment decisions cannot be challenged by participants or their families but there is strong provision for the CEO to initiate reassessment processes, which can ultimately lead to decisions to exit participants from the scheme. In the early intervention pathway, reassessments will occur periodically with the NDIA having new powers to request information or documents from participants.

Reassessments will include a 90-day period (or longer) within which approved reports must be supplied to the NDIA, or children risk being exited from the scheme. While there is provision for longer periods than 90 days, and protection from exiting where there is a reasonable explanation for not submitting reports within that period, we feel that this exerts undue pressure on families to supply reports to justify their continuing need for services. It is not clear in the bill who pays for these reports.

The reason that so many families are seeking diagnosis and applying for the NDIS is because the NDIS is 'an oasis in the desert' - it is the only avenue for many families to get the supports they need.

**"Are the states and territories going to irrigate the desert, or just hose some sand?" - Dr Darren O'Donovan, La Trobe Law School.**

Before exiting children from the NDIS, the states and territories - in collaboration with the commonwealth - must build the foundational supports system. Before passing any new



legislation on the NDIS, the commonwealth must get the states and territories to agree to providing supports in the community and sectors outside of the NDIS, with no gaps between commonwealth-funded NDIS services and state-funded foundational supports.

**Recommendation:**

- Define NDIS supports and foundational supports in the legislation, ensuring there are no gaps in services or supports for any person with disability of any age.

**The supports landscape is not yet mapped.**

The rules regarding which supports are classified as NDIS supports and which are foundational supports will be determined through a delegated process of negotiation between the commonwealth and states and territories.

**“Why are we slicing up need rather than dividing up responsibilities and working together?” – Dr Darren O’Donovan, La Trobe Law School.**

Families and advocates are worried there will be significant gaps between what the NDIS will support, and what supports the states and territories will agree to support. Kiind’s concern is that children and young people will fall through these gaps. Indeed, there are already significant tensions and gaps in services for children between the NDIS and the health and education sectors. The public cannot reasonably be expected to support the NDIS Bill before such details are worked through and explained.

**Recommendations:**

- Co-design the foundational supports strategy concurrently with new legislation.
- Complete all negotiations with states and territories prior to introducing new bill.
- Include the finalised definition of NDIS supports in the new legislation.

**Protecting our choice and control**

The NDIS Bill in its current iteration does not adequately safeguard participant choice and control and seems to mainly focus on reducing eligibility to the scheme. If the definition of NDIS supports and the new rules are too narrow, this may lock people out of receiving NDIS funding for what they need. There are also provisions in the bill that give the NDIA broad powers to stipulate which supports participants must utilise their plans for. The NDIS Bill should be written in a way that protects choice and control, and enables people to access the supports they need, with the dignity to choose supports and interventions that respond to their individual circumstances and preferences.

**Recommendations:**

- Include protections for participant choice and control in the NDIS Bill and ensure choice and control cannot be overridden in any new rules or determinations.
- Develop instruments and methods that support participant choice and control
- Enshrine participants’ right to choice and control in the NDIS supports they access



## Nothing about us without us.

We have been promised a grounded, world-leading process co-designed with people with disability to capture support needs based on what they can and can't do at a daily living level, but the working out method for converting the needs assessment into a funding amount is to be determined by the Minister, sometime in the foreseeable future.

Minister Shorten has assured us that genuine consultation and collaboration with the disability community will be central to the design of the Rules, technical assessments, and Ministerial determinations, however a requirement for co-design is not written into the legislation. There is no consequence if the Minister decides not to follow through on these promises. There is an opportunity now to legislate transparency and accountability through a legal requirement for meaningful co-design with the disability community.

### Recommendations:

- Amend the NDIS Act to include a commitment to and definition of co-design.
- Legislate the requirement for the use of co-design methodology to develop all technical tools, methods, and NDIS rules, with consequences for not doing so.

## Final impressions

Through our analysis of the NDIS Bill, listening to commentary in the community and from lawyers and disability rights experts, our impression is that the NDIS Bill in its current iteration does not adequately:

- Bring people with disability into the decisions that affect them,
- Protect participant choice and control in the NDIS,
- Require meaningful co-design and power-sharing with service users, nor
- Safeguard against a barren landscape of disability supports outside the NDIS.

We cannot dismantle the current system until the new system is designed and built. This NDIS Bill, if passed, will allow the dismantling of the old system, with the details and definitions in the new system to be decided later (by those in power). This is against the stated intent of the NDIS Review and all the rhetoric from Minister Shorten that we would be included and involved in all decisions at every stage.

Kiind looks forward to seeing a refreshed NDIS Bill that adequately protects participant choice and control, defines 'what is' an NDIS support, provides assurance that foundational supports will cover 'what is not' in the NDIS, and outlines the details of the new NDIS rules.