

# Proposed NDIS legislative improvements and the Participant Service Guarantee

## NDIS Act Review Consultations

October 2021



## **Genetic Undiagnosed And Rare Disease (GUARD) Collaborative Australia**

The GUARD Collaborative Australia comprises of the peak body organisations; Genetic Support Network of Victoria, Genetic Alliance Australia (NSW), Syndromes Without A Name (SWAN) Australia. Together, we represent the voice of people living with genetic, undiagnosed and rare disease and those who support them. We strive for a fair, equitable and collaborative approach to health, disability, education and the wellbeing for all our population members.

GUARD members work independently of each other fulfilling their own responsibilities and roles and come together to provide systemic advocacy and support for people living with genetic, undiagnosed and rare conditions and those who support them. Our advocacy is driven by values of fairness, equity and quality of life and focusses on change in the health and disability sectors.

Together we offer our united collaborative strength and provide assistance, support and services for genetic, undiagnosed and rare condition support groups, their members and the wider community seeking to influence and change current health, mental health, support services and disability policy and practice impacting our community. We strive for a fair, equitable and collaborative approach to health and wellbeing for all members of our population.

The work of GUARD is consistent with the National Strategic Action Plan for Rare Diseases, national and state genomics and precision health policies and our individual organisation objectives.

### **GUARD Collaborative**

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*The GUARD Collaborative acknowledges the Traditional Custodians of the land and pay our respects to their Elders past, present and emerging.*



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## Executive Summary

Thank you for the opportunity to provide feedback on draft changes to the National Disability Insurance Scheme (NDIS) legislation. It is important that we express the views of the community GUARD represents and support in this submission.

GUARD welcomes the draft changes to the legislation and are pleased to read so many of the Tune Review recommendations have been included. We are extremely grateful and relieved that mandatory independent assessments are not included in the draft legislation.

Participants must be central in the core principles of the NDIS and we are pleased that future changes to the NDIS assessments and funding model include co-design with people with disability, their families and the sector that supports them.

Representation on the NDIA board from people with lived experience or knowledge in a particular field is a positive change.

Amendments to the Bill remove red tape which is often experienced by people with undiagnosed, rare and genetic conditions, navigating the NDIS. And we recognise that many of the proposed amendments take a person centred approach to support participants.

We are pleased that the draft legislation considers all sexual orientations and gender, and that more positive language is used throughout the legislation.

We were disappointed that an obligation to discuss and show a participant a draft plan before their plan being approved has not been included in the legislation as this would show greater transparency in planning decisions.

GUARD supports the minor changes of the draft legislation which updates the rules around Children, Nominees and Specialist Disability Accommodation (SDA) to reflect best practice drafting standards.

## Summary of Key Issues and Recommendations

Key Issues	Recommendations
<b>Plan Variations, Reassessments and Reviews</b>	<ul style="list-style-type: none"> <li>• Further clarity around how plan variations will be delivered and whether plan budgets can be increased using this method without a full plan review.</li> </ul>
<b>Reasons for Decisions</b>	<ul style="list-style-type: none"> <li>• The NDIA needs to be transparent about all decisions made with regards to a participant’s plan, not just those under a review of a reviewable decision.</li> </ul>
<b>Change to the “Becoming a Participant” Rule</b>	<ul style="list-style-type: none"> <li>• Recognition that all disabilities that are episodic or fluctuating, that vary in intensity in nature should be considered to be permanent and included in the scheme.</li> </ul>
<b>Preventing a Provider Delivering Support</b>	<ul style="list-style-type: none"> <li>• If there is a list of service providers the planner does not wish a participant to use, they should first be discussed at the planning meeting.</li> </ul>
<b>Payment of Supports</b>	<ul style="list-style-type: none"> <li>• Ensure that a combination of payment methods can be used under section 45 of the legislation if new technology for payment methods are introduced.</li> </ul>

## Introduction

GUARD welcomes the opportunity to provide feedback on the proposed changes to the National Disability Insurance Scheme (NDIS) legislation and hope the proposed changes improve the overall experience of our community who are participants of the scheme.

We sometimes feel there is gap in knowledge about undiagnosed, rare and genetic conditions among NDIA staff and we hope that the draft legislation can address some of these gaps.

We welcome the inclusion of many of the Tune Review recommendations and support many of the proposed amendments to the NDIA Act to ensure it remains up to date.

GUARD is pleased the NDIA is committed to working collaboratively and keeping the scheme person-centred so the families we support can get the supports they require to live their best lives.

## 1. Establish the Participant Service Guarantee - Schedule 1

### a) Service Standards

GUARD supports the Participant Service Guarantee and the level of standards for which the NDIA must adhere to so it can remain responsive and accountable. This will ensure improvements to participants overall experience of the scheme.

The Participant Service Guarantee will enable participants who are affected by a reviewable decision to ask about the reasons for the decision and request a copy of their draft plan before its approval.

### b) Plan Variations, Reassessments and Reviews

GUARD welcomes the language around reviews being changed and a more flexible approach to plan variations as per the Tune Review recommendation. It remains unclear if a plan variation can increase total plan budgets or just those that include quotes.

We are concerned that the NDIA can order a plan review at any time and vary a participant's plan and we would like more clarity around how this will work. Our community would appreciate greater transparency about why and when plans can be varied, re-assessed or reviewed.

Changes to what information can be reviewed at a review of a reviewable decision, enables both the internal reviewer and the Administrative Appeals Tribunal to review the original and subsequent decisions, making it a fairer process.

### c) Reasons for Decisions

GUARD welcomes the decision to introduce the proposed s100(1B) and (1C) changes to the Act, which will allow participants to request the reasons for the decisions made in their plan prior to an internal review. We would like to see the legislation go further to include the reasons for the decisions made in plans as standard routine practice. This should be provided when draft plans are discussed and provided automatically at the final plan stage in an accessible manner to the participant.

The NDIS still does not have to justify their decision to a participant to decline or decrease supports when a review of a reviewable decision – s100 has been made. Justifications for decisions should be routine with regular plan review and when a participant has undergone a review of a reviewable decision. The NDIA needs to be more transparent when it comes to the decision-making process. This should be documented in the proposed legislation to make the NDIA accountable for their decisions.

GUARD is pleased that the NDIA will become more accountable for response to a review of a reviewable decision Section 42, Subsection 100(6). The removal of phrases such "as soon as reasonably practicable" replaced with a set time frame of "within the prescribed period of the rules or if there is no such rule, within a period of 90 days", is a positive change

## 2. Changes to the Act: Improvements to NDIS Process - Schedule 2 –

### a) Children Accessing the NDIS Earlier

GUARD is pleased that changes to the draft legislation of Section 14 of the NDIS Act will enable children under the age of seven years to access supports whilst they are awaiting their plan. This will help families to build capacity and exercise choice and control to support their children who may not be ready to start planning for supports under the NDIS.

## **b) Change to the “Becoming a Participant” Rule**

We welcome the change in terminology of referring to '*psychiatric conditions*' to '*psychosocial disability*' in the Act to reflect current terminology. The new subsection, 24 of the Act, clarifies that an impairment or impairments to which a psychosocial disability are attributed and recognises that they can be episodic or fluctuating or varying in intensity. They may be permanent, and a person is likely to require support under the Scheme for their lifetime, despite possible variations in their condition from time to time.

GUARD would like to see further amendments to this rule and apply it to all disabilities. Many undiagnosed, rare and genetic conditions are episodic or fluctuating and vary in intensity in nature. These families have been refused access to the NDIS because of a lack of understanding that their disability is permanent.

## **c) Preventing a Provider Delivering Support**

GUARD is concerned that the NDIA will now have the authority to list on a participant plan who cannot provide support for them with the propose changes to the rules. Whilst this may safeguard participants to some degree, the NDIA may have little information or knowledge about a relationship a support service has with a participant. It moves away from the foundations of the NDIS which is about 'choice and control'.

## **d) Payment of Supports**

The proposed changes to how the NDIA will pay for supports on behalf of Self-Managed or Plan Managed participants does raise some concerns. The proposed 'tap and go' smart phone app system may cause problems if participants cannot or do not have access to a smart phone. It is also unclear under the proposed wording of section 45 how a combination of payment methods will work or if providers will have to wait longer for payments to go through.

## **e) Plan Management**

Changes to the risk assessment criteria for Plan Manager brings it into line with the same risk assessment criteria for Self-Management. This is a welcome change and limits the risk to participants who utilise the Plan Management option.

# **3. The NDIS at Full Scheme – Schedule 3**

GUARD welcomes changes to the NDIS Act which update it to reflect current law and the status of the NDIS. The scheme is fully rolled out and the Act needs to be updated to reflect this.

