

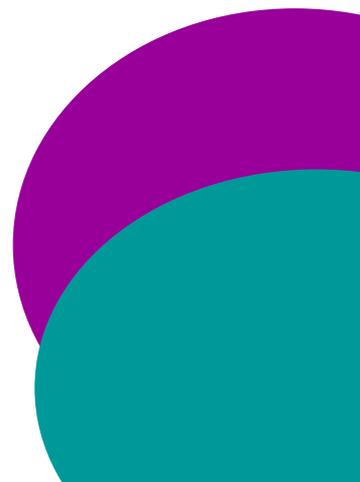


# Current Scheme Implementation and Forecasting for the National Disability Insurance Scheme (NDIS)

## Joint Standing Committee on the National Disability Insurance Scheme

### October 2021

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

GUARD Collaborative Australia comprises 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 community.

GUARD members work independently of each other fulfilling their own responsibilities and roles and come together to provide systemic national 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.

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 organisational objectives.

### **GUARD Collaborative Australia**

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



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## Executive Summary

GUARD welcomes the opportunity to provide feedback on the Implementation and Forecasting Submission for the National Disability Insurance Scheme (NDIS).

Current conservative estimates indicate that 6-8% of Australians are affected by a rare condition,

80% of which are genetic in origin. There are approximately 8000 rare diseases. Recently the

Australian Bureau of Statistics reported that the number of people in Australia with a rare

condition is equal to that of people living with diabetes.

As many of our community have conditions which manifest disability, our community needs a consistent, responsive and inclusive NDIS system to support quality of life.

The NDIS inspires hope and the NDIA can lead the way to positive change by supporting community organisations to create a more inclusive society. This will impact not only people with disability, their family and friends and also the wider community.

Currently, anecdotal evidence reveals variations in plans based on geography with clear differences between metro, rural, regional and remote areas and the level of support. Inconsistencies are also experienced between individual supports who appear to have very similar circumstances for assessment. This leads to mistrust of the NDIS overall.

There remains a lack of understanding of undiagnosed and rare genetic conditions among, Early Childhood Approach partners, Local Area Coordinators and Planners. This has been an issue since inception. We hope that the NDIA will access specialist patient support organisations like the GUARD organisations to assist with upskilling and educating staff about some of the challenges our community lives with.

We are cognizant that the NDIS is still developing, and we are pleased that many of the Tune Reviews recommendations will be implemented over the next 24 months. We sincerely hope that changes to the NDIS, such as core and capacity building funding become interchangeable.

It is also important that draft plans are provided to participants for discussions at three-way planning meetings between local area coordinators, planners, and participants. This will greatly assist in reaching agreed plans and plan outcomes.

Duration of plans and timely reviews where critical such as degenerative conditions and life course milestones are also imperative for an effective NDIS.

## Summary of Key Issues and Recommendations

KEY ISSUES	RECOMMENDATIONS
<b>The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding</b>	
<b>Community Based Supports</b>	<ul style="list-style-type: none"> <li>• NDIA to work closely with community and mainstream services to assist them with becoming more inclusive of people with disability.</li> <li>• Introduce a rating system for hospitality venues to encourage more places to be more inclusive of people with disability.</li> </ul>
<b>Information, Linkages and Capacity Building Grants Program</b>	<ul style="list-style-type: none"> <li>• Ensure ILC grants are widely advertised to include applications from mainstream organisations</li> <li>• Encourage ILC recipients to continue their work in supporting people with disability.</li> </ul>
<b>The reasons for variations in plan funding between NDIS participants with similar needs</b>	
<b>Drivers of Inequity</b>	<ul style="list-style-type: none"> <li>• Incentives offered to service providers, particularly allied health professionals to work in the area.</li> <li>• Increased funding for travel and transport in plans for people who live in rural, regional and remote areas.</li> <li>• NDIA to consult with a genetic, undiagnosed and rare condition advisory group, such as the GUARD Collaborative Australia.</li> </ul>
<b>The ongoing measures to reform the scheme</b>	
<b>New Early Childhood Approach</b>	<ul style="list-style-type: none"> <li>• More transparency and support required to transition participants out of the NDIS.</li> <li>• More core funding in NDIS plans to support families who have children in the scheme.</li> </ul>
<b>Planning Policy for Personalised Budgets and Plan Flexibility</b>	<ul style="list-style-type: none"> <li>• Core and Capacity Building supports able to be used interchangeably.</li> <li>• Introduction of three-way planning meetings between participant, LAC and planners availability of a draft plan to review and discuss and be adjusted to meet needs if required.</li> <li>• Less frequent plan reviews unless a participants circumstances change or are likely to change.</li> </ul>

## Introduction

GUARD Collaborative Australia is pleased to provide feedback to the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) around the General issues around the Implementation and Forecasting of the NDIS.

We applaud the National Disability Insurance Agency (NDIA) for their hard work in managing the NDIS, which "As at 30 June 2021, there are 466,619 participants across Australia in the Scheme, including 245,274 receiving supports for the first time".<sup>1</sup>

Due to resource restraints and the short turnaround time required for this submission, we could not address all the terms of reference in this inquiry or consult more broadly with our genetic, undiagnosed and rare disease community. We hope to undertake this consultation to contribute further to the next call for submissions in this area in February 2022.

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<sup>1</sup> <https://www.ndis.gov.au/about-us/publications/quarterly-reports>

### 1. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding

#### 1. Community Based Supports

GUARD are aware through anecdotal evidence that the community supports are not always inclusive of people with disabilities. SWAN has reported that:

*“One of their members reported three times to their local government leisure centre that there was a distinct lack of visual signs with images of how to act around the pool. For example, the pool had a ‘No play, no swim zone sign’ at one end of the swim ramp, which pool patrons use to access the deep pool. Not only was this sign located at just one end of the ramp, but there were also no visual images incorporated in the sign. This meant that anyone who could not read would not understand the sign. Local governments should lead by example in this area.”*

This is just one example of how many organisations, public and private, are not supporting people with disability.

Another example would be cafes and restaurants. The introduction of a public rating system applied to the hospitality setting would encourage venues to be more inclusive and also be informative to people with disability, their friends and family. Accommodation venues increasingly rate their facilities and publish ratings of inclusiveness of people with disability. This model could be adapted for hospitality venues. A rating system could be developed to include: a) wheelchair accessibility, including toileting facilities; b) stairs for access with number and c), a sensory sensitivity rating as many people with genetic, undiagnosed and rare conditions have sensory needs around light and noise. Ratings such as these would inform choice and reduce stress around outings for people with disabilities and families.

#### **Recommendation:**

NDIA to work closer with community and mainstreams services to assist them with becoming more inclusive of people with disability.

Introduce a rating system for hospitality venues to encourage more places to be more inclusive of people with disability.

#### 2. Information, Linkages and Capacity Building Grants Program

This program is a wonderful program with a low awareness, particularly outside the disability sector. This must be addressed to invite mainstream organisations to access funding for initiatives to assist them in supporting people with disability.

Success grant applications appear to generally favour the same well established large disability organisations over smaller, less established ones. It would be good to encourage integrative projects where fabulous work continues improvements to accommodate people with disability further

**Recommendation:**

Ensure ILC grants are widely advertised and are able to be known about for mainstream organisations to apply for.  
Encourage ILC recipients to continue their work in supporting people with disability.

## 2. The reasons for variations in plan funding between NDIS participants with similar needs

### 1. Drivers of Inequity

#### I. Rural, regional and remote areas

One of the key drivers of inequity experienced by our community living is geography. Access to services and supports is much more difficult in rural and remote areas. There are simply not enough service providers in some of areas. Unless the workforce is developed and maintained in these areas, this will continue to be a problem.

Participants may receive funds they cannot spend in their plan. The risk is that less funds are then received in subsequent plans because they have not spent the funds in their current plan.

#### II. Lack of understanding of undiagnosed and rare genetic conditions

Since the NDIS inception, GUARD has been receiving feedback that many of the Early Childhood Early Intervention (ECEI) partners, Local Area Coordinators (LAC's) and Planners they meet do not have a good understanding of genetic, undiagnosed and rare conditions. There is also a high turnover of these planners, and it is not uncommon for NDIS participants to report they have had two to three staff allocated to their plan before their next planning meeting. So once again, our community need to retell their stories.

**Recommendation:**

Incentives offered to service providers, particularly allied health professionals to work in the area.

Increased funding for travel and transport for people who live in rural and remote areas.

For the NDIA to consult with an undiagnosed and rare genetic condition advisory group, such as the Genetic Undiagnosed and Rare Disease (GUARD) Collaborative Australia.

## 3. The ongoing measures to reform the scheme

### 2. New Early Childhood Approach

The new Early childhood approach includes giving any child with developmental concerns access to the NDIS with or without a referral. Having a broader scope and easier access to the NDIS will assist and support families to build their child's capacity to develop. It can provide the tools for families to use and build on to address and support their child's

developmental concerns. Timely early childhood intervention has been proven to give children the best outcomes in life. Depending on the child and individual circumstance it may mean they are less reliant on supports in the future, saving the scheme money. We are supportive that entry to the Early Childhood Approach is not diagnosis based. We estimate there up to 350,000 children in Australia under the age of 18 years living without a diagnosis, or a diagnosed genetic rare condition so we are pleased that the Early Childhood Approach is not reliant on a diagnosis. Too often, we believe the NDIS relies on a diagnosis to access and gain suitable supports in the scheme instead of basing it on a participant's needs.

We welcome the early childhood best practice approach, which provides advice on supporting a child, increasing inclusion and participation of a child in mainstream and community supports to assist families in helping their child meet their goals. We are pleased the approach includes building the capacity of mainstream services that support a child with delay. We are concerned that very few of families with children under the age of 16, receive adequate core support funding unless it is for low technology items. Many of our families need respite and a chance to recharge for their caring role. Previously they would have received it as part of the Home and Community Care funding under the old model of providing supports to families of children with disability.

The new approach to early childhood early intervention means that a family who has a child with delay can get assistance from an Early Childhood Approach partner to enter the full scheme as a participant if they meet the criteria. This is important as it can be an overwhelming experience for so many.

However, funding and support to assist children to transition out of the NDIS requires consideration and people with disabilities would benefit from more focus, greater transparency, and support. Our concern is that if so, many more children are going to receive short term early interventions for a period of up to 12 months, that does not give them enough time to benefit from supports and assist and prepare them to transition out of the scheme at the same time. The approach to how this transition phase will be done and supported is not clear.

We are pleased that many of the recommendations and guidelines for the early childhood approach are currently being updated, including extending the early childhood approach until nine years of age over the next 24 months, a welcome change in supporting young children.

**Recommendation:**

Introduction of three-way planning meetings between participant, LAC and planners  
More core funding in NDIS plans to support families who have children in the scheme.

### **3. Planning Policy for Personalised Budgets and Plan Flexibility**

On the 14 November the Honourable Stuart Robert MP, who was at the time Minister of the NDIS and Minister for Government Service released a plan to deliver the last phase of the NDIS. A number of flexible approaches were announced but are yet to be implemented in practice such as:

*"From 1 July 2020, and in line with functional assessments, we will aim to remove the distinction between core and capacity building so that participants and their families can use plan funding more flexibly on those supports that best meet their needs."*

*"In order to reduce requests for plan reviews the NDIA will also commence the national rollout of joint planning meetings and the provision of draft plan summaries from April 2020"*

*"We will also look to extend plan duration even further so that wherever possible and appropriate plan reviews are only initiated in line with significant life milestones, such as starting school and finishing school, getting a job, moving house or other changes in support needs." <sup>2</sup>*

On the 24 July 2020, Scott McNaughton (General Manager at the NDIA) confirmed at an NDIS virtual forum facilitated by Every Australian Counts, that three-way planning meetings and draft plans had been held up because of COVID-19 and that the NDIA was still working on how to make Core and Capacity Building Supports interchangeable.

After almost 18 months, neither of these flexible approaches have been implemented and no update has occurred. We are still waiting to have greater flexibility within plans between Core and Capacity supports. We need to remove the "stated supports" to give participants greater flexibility within their plans and offer participants full choice and control of spending their budgets to meet their NDIS goals.

As for the duration of plans, this area seems to be inconsistent between participants of the same age and participants in general. Some participants are given a three-year plan, even if they will be entering a transition phase in that time period, whilst others are not. Individuals have reported they requested a two-year plan and received a one year plan. It seems to be completely random decisions. The participant's request for the plan's duration appears in many cases not to be even considered in the plan duration process. The fact that plan reviews were going to be initiated in line with significant milestones has not happened.

**Recommendation:**

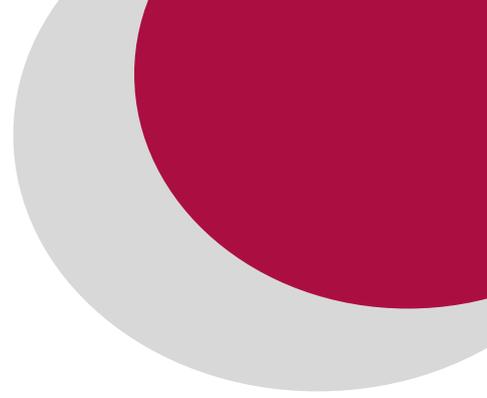
Core and Capacity Building supports able to be used interchangeably.

Introduction of three-way planning meetings between participant, LAC and planners so there is the opportunity to be shown a copy of their draft plan, review and discuss it and adjust it to meet their needs if required.

Less frequent *plan reviews unless a participants circumstances change or are likely to change.*

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<sup>2</sup> <https://formerministers.dss.gov.au/18955/the-ndis-plan/>



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