



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

**Joint Standing Committee on the National Disability
Insurance Scheme**

October 2021

SYNDROMES WITHOUT A NAME (SWAN) AUSTRALIA

SWAN Australia provides information, support and systemic advocacy for families caring for a child with an undiagnosed or rare genetic condition. We are the peak not-for-profit organisation representing approximately the 2500 children born without a diagnosis every year, and around 1 in 12 children are diagnosed with a rare genetic disorder. This equates to 350,000 children across Australia, at any one time. Our mission is to increase community awareness and understanding about the impact and prevalence of rare and undiagnosed genetic conditions.

Of the children who present to a geneticist with syndromic features, 40 - 60% may never receive a diagnosis. This is especially difficult if the child has a regressive or life-limiting condition.

We are here to help reduce the isolation and emotional strain of raising a child with different needs by helping parents connect with other SWAN families. We provide parent information seminars and workshops, peer support events and social networking opportunities where SWAN families can form lifelong bonds. SWAN also advocates for improved disability support services, free and equitable genetic and genomic testing, and increased research funding to ensure more children can obtain a diagnosis.

We provide a public voice for our families, campaigning for better community education and improved resources and pathways so that SWAN children can thrive.

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Table of Contents

Executive Summary	4
Summary of Key Issues and Recommendations	5
Introduction	6
1. The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding.	7
a) Community Based Supports	7
b) Information, Linkages and Capacity Building Grants Program	7
2. The reasons for variations in plan funding between NDIS participants with similar needs.	8
a) Drivers of Inequity	8
I. Rural, regional and remote areas	8
II. Lack of understanding of undiagnosed and rare genetic conditions	8
3. The ongoing measures to reform the scheme.	9
a) New Early Childhood Approach	9
b) Planning Policy for Personalised Budgets and Plan Flexibility	10

Executive Summary

Thank you for the opportunity to provide feedback on the Current Scheme Implementation and Forecasting for the National Disability Insurance Scheme (NDIS) submission. It is important that we express the views of our SWAN members in this submission.

There are still opportunities for community organisations to be supported to create a more inclusive society. The NDIS can lead the way with this and make positive changes for not only people with disability, their family and friends and the wider community that supports them.

Plan variations between metro, rural, regional and remote areas still occur, as do variants for plan funding for children of very similar ages and needs. There is a distinct lack of understanding of undiagnosed and rare genetic conditions among Early Childhood Approach Partners, Local Area Coordinators and Planners. We hope that organisations like SWAN can assist with upskilling staff and education around some of the challenges our families experience.

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 making core and capacity building funding interchangeable, soon become an option for participants. Draft plans need to be provided to participants for discussions at three-way planning meetings between Local Area Coordinators, Planners, and Participants. We look forward to the day when plans are made longer in duration, except for when participants are approaching life milestones such as a transition phase. This will limit the stress and anxiety so often felt by our members in the lead up to their child's planning meeting.

Summary of Key Issues and Recommendations

Key Issues	Recommendations
The impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding	
Community Based Supports	<ul style="list-style-type: none"> • NDIA to work closely with community and mainstreams services to assist them with becoming more inclusive of people with disability. • The introduction of a rating system for hospitality venues to encourage them to be inclusive of people with disability.
Information, Linkages and Capacity Building Grants Program	<ul style="list-style-type: none"> • Ensure ILC grants are widely advertised and can be known about for mainstream organisations to apply for • Encourage ILC recipients to continue their work in supporting people with disability.
The reasons for variations in plan funding between NDIS participants with similar needs	
Drivers of Inequity	<ul style="list-style-type: none"> • Incentives offered to service providers, particularly allied health professionals, to work in regional, rural and remote areas. • Increased funding for travel in participants plans who live in rural, regional 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 with regards to uncertainty about conditions.
The ongoing measures to reform the scheme	
New Early Childhood Approach	<ul style="list-style-type: none"> • More transparency and support required to transitioning participants out of the NDIS. • More core funding in NDIS plans to support families who have children in the scheme.
Planning Policy for Personalised Budgets and Plan Flexibility	<ul style="list-style-type: none"> • Core and Capacity Building supports able to be used interchangeably. • Introduction of three-way planning meetings between participants, LAC and planners, so there is the opportunity for participants to be shown a copy of their draft plan, review it 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 as part of a transition phase in their life.

Introduction

SWAN 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".¹

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. We hope to contribute further in the next call for submissions in this area in February 2022.

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

Terms of Reference

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

a) Community Based Supports

SWAN has heard from our members that the community supports they access are not always inclusive of people with disability. One of our 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 of mainstream services not adjusting to the needs of people with disability would be cafes and restaurants. SWAN would like to see a rating system applied to the hospitality setting. More and more accommodation venues (including Airbnb's) can rate their facilities as being inclusive of people with disability. Unfortunately, the same cannot be said with regard to hospitality venues. SWAN would like to see a rating system applied in a few different ways:

- 1/ For hospitality venues that claim to be wheelchair accessible but don't have a toilet cubicle that can practically accommodate a wheelchair.
- 2/ For hospitality venues to state if stairs need to be used to access their venue.
- 3/ For hospitality venues to apply a sensory rating system. Many of our members have sensory needs both with light and noise. They may also have a seating preference (outside or inside). Many autistic people would also benefit from knowing how hospitality rates in this area.

Recommendation:

- *NDIA to work closer with community and mainstreams services to assist them with becoming more inclusive of people with disability.*
- *The introduction of a rating system for hospitality venues to encourage them to be inclusive of people with disability.*

b) Information, Linkages and Capacity Building Grants Program

As much as it is great to have an Information, Linkages and Capacity Building Grants Program to build organisations and businesses capacity to be more inclusive of people with disability, we don't think those outside the disability sector widely know much about the initiative. We fear that many organisations may think it is too difficult and/or too expensive to make their business more disability inclusive, so nothing changes.

We have witnessed some ILC grant recipients do fabulous work with their grant funding. However, once their funding has ceased, some organisations have struggled to make further improvements to ensure the inclusion of people with disability.

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.

a) Drivers of Inequity

I. Rural, regional and remote areas

One of the key drivers of inequity experienced by our members living in rural and remote areas is access to services and supports. There are not enough service providers in some of the places our members reside. Unless the workforce develops in these areas, possibly with incentives, this will continue to be a problem. Participants may receive funds they cannot spend in their plan. We hear from our members that they receive less funds in their subsequent plans because they have not spent the funds in their current plan.

II. Lack of understanding of undiagnosed and rare genetic conditions

Our members report that many of the Early Childhood Early Intervention (ECEI) Partners, Local Area Coordinators (LAC's) and Planners they meet with do not have a good understanding of undiagnosed and rare genetic conditions. There is also a high staff turnover, and it is not uncommon for our members to report they have had two to three staff allocated to their child's plan before their next planning meeting. So once again, our members need to retell their stories.

A case study illustrating inconsistent planning decisions

One of our SWAN members did some pre-plan work in preparation for their child's planning meeting. They gave their pre-plan work to their friend (also a SWAN parent) who has a child of the same age with very similar needs. The friend met with an NDIA Planner whilst the member who did the pre-plan work met with an LAC. The friend who met with the NDIA Planner got double the amount of funding compared to our member who met with the LAC. There was not double the need for the funding to meet their child's needs to live their best life.

The above case study demonstrates the lack of understanding by the NDIA of undiagnosed and rare genetic conditions.

Recommendation:

- *Incentives offered to service providers, particularly allied health professionals to work in regional, rural and remote areas.*
- *Increased funding for travel in participants plans 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 with regards to uncertainty about conditions.*

3. The ongoing measures to reform the scheme.

a) 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. 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 are 31,500 SWAN children in Australia under the age of 18 years living without a diagnosis, 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. However, we are concerned that very few of our families with children under the age of 16 receive sufficient core support funding in their NDIS plan unless it is for low technology items. Many of our families need respite and a chance to recharge from 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. Many of our SWAN families struggle in their caring capacity without some time away from their caring role. Carers need support under the NDIS too.

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 applying to access the NDIS can be an overwhelming experience for so many.

However, we have concerns about the lack of funding and support to assist children in transitioning out of the NDIS. We feel this is an area that could include more focus, greater transparency, and support. Our concerns are that if so many more children are going to receive short term early interventions for a period of up to 12 months, it does not give them enough time to benefit from supports, or 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:

- *More transparency and support required to transitioning participants out of the NDIS.*
- *More core funding in NDIS plans to support families who have children in the scheme.*

b) Planning Policy for Personalised Budgets and Plan Flexibility

On 14 November, the Honourable Stuart Robert MP, who at the time was 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 still 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." ²

On 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.

Fast forward to late October 2021, neither of these flexible approaches has been implemented. No more information has come forward about when draft plans and three-way meetings between LAC's, planners and participants will occur. 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 are entering a transition phase in that time period, whilst others are not. Some of our members have requested a two-year plan and have been given a one year plan. It seems to be completely random and inconsistent decisions. The participant's request for the plan's duration appears in many cases not to be even considered in the planning 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 participants, LAC and planners, so there is the opportunity for participants to be shown a copy of their draft plan, review it 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 as part of a transition phase in their life.*

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



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