



**Proposed NDIS legislative improvements and
the Participant Service Guarantee**

NDIS Act Review Consultations

October 2021

SYNDROMES WITHOUT A NAME (SWAN) AUSTRALIA

SWAN is the peak not-for-profit organisation representing the estimated 2500 children born in Australia every year without a diagnosis and those children who have rare genetic conditions. Of the children who present to a geneticist with syndromic features, 40 to 60 per cent may never receive a diagnosis, which is heartbreaking, especially if the child has a regressive condition.

Our mission is to increase community awareness and understanding about the impact and prevalence of rare and undiagnosed genetic conditions.

SWAN helps reduce the isolation and emotional strain of raising a child with a chronic health condition or disability 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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SWAN 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

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

Overall, SWAN welcomes the proposed changes to the legislation. We are pleased the government has implemented a number of the Tune Review recommendations. Our members were extremely grateful and relieved that mandatory independent assessments would not be included in the draft legislation.

We were pleased that future changes to the NDIS assessments and funding model will take a co-design approach engaging people with disability and those who represent them. Participants must continue to be at the centre of everything the NDIS does.

SWAN welcomes the changes to the NDIA board, enabling people with lived experience or knowledge in a particular field to become active board members.

We are pleased that the amendments in the Bill consider the burden of red tape that is currently with participants, their families and carers. The changes to the legislation address some of the impacts this has on them. And we appreciate that many of the proposed amendments having a person-centred approach to supporting participants.

Schedule 2, proposed changes, will ensure the objects and principles of the Act make participants the central focus point of individualised supports and respect their relationships with family and the community that supports them.

We are pleased that the proposed legislation reflects all people with disability and considers all sexual orientations and gender identification. And we are pleased that more positive language is used throughout; terms like 'psychosocial disability' replacing 'psychiatric condition'. And 'to the extent of their ability' being replaced with 'inclusion and social participation'.

We were disappointed that the Administrative Appeals Tribunal (AAT) still does only has the jurisdiction to rule on the parts of the participants plan that are under review and not take into consideration a participants full plan.

The draft legislation does nothing to address the complexities of the NDIS framework, which was a missed opportunity to improve participants' level of understanding of the NDIS framework that underpins the scheme.

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

Summary of Key Issues and Recommendations

Key Issues	Recommendations
Plan Variations, Reassessments and Reviews	<ul style="list-style-type: none"> Clarify the ambiguity around plan variations with regards to being able to increase total supports for funding. More clarification is required about how plan variations will proceed.
Reasons for Decisions	<ul style="list-style-type: none"> Amend the draft legislation to ensure the NDIA is transparent about all decisions made in relation to a participant’s plan, not just for plans under a review of a reviewable decision.
Change to the “Becoming a Participant” Rule	<ul style="list-style-type: none"> Any disability that is episodic or fluctuating that vary in intensity in nature should be considered as permanent and included in the scheme.
Preventing a Provider Delivering Support	<ul style="list-style-type: none"> The list of service providers that a client cannot use should be agreed upon at the planning meeting, so a participant still has some “choice and control” over the providers they use.
Payment of Supports	<ul style="list-style-type: none"> Clarity is required under section 45 of the legislation on how new technology for payment methods will work if participants would like to use a combination of methods.
Plan Management	<ul style="list-style-type: none"> Clarity around whether price caps will be applied with the draft changes to the Plan Management option.

Introduction

SWAN is pleased to provide feedback on the proposed changes to the National Disability Insurance Scheme (NDIS) legislation and hope the proposed changes improve the experience of accessing and utilising the scheme for SWAN members

We feel there is a distinct lack of understanding about the needs of our families from the National Disability Insurance Agency (NDIA) and hope that the draft legislation improves some of the gaps for our members.

We welcome many of the Tune Review recommendations being included in the proposed legislation. We support the amendments which ensure the Act remains current and omits redundant phrases in the legislation.

We applaud the NDIA wanting to work in collaboration with people with disability, their families, and the sector that supports them, ensuring the scheme remains person-centred and will continue to provide our SWAN families to live their best lives.

1. Establish the Participant Service Guarantee - Schedule 1

a) Service Standards

SWAN welcomes the introduction of a Participant Service Guarantee, which includes a level of standards for which the NDIA must adhere to for greater accountability and responsiveness. The guarantee will improve a participant's experience of the NDIS, empowering them to obtain the supports they require to live their best lives.

The guarantee will ensure the NDIA meets specific service standards and timely decisions are made around access and plans. This will further support SWAN members in obtaining the supports they need when they need them.

SWAN is pleased the Participant Service Guarantee will enable participants who are affected by a reviewable decision to ask about the reasons for the decision.

b) Plan Variations, Reassessments and Reviews

Whilst SWAN welcomes changes to the plan review process as recommended in the Tune Review, the process is still somewhat confusing. The draft three concepts: plan variation (edits existing plan without creating a new one, similar to a light/soft-touch review), plan reassessment (when the plan is due to expire) and plan review. (review of a reviewable decision) remove the duplication of the word 'review' in s 48 and 100's, which is an improvement. However, they still have some ambiguity around them. It needs to be clarified as to whether a plan variation can increase total funding in plans or just those that include quotes for approved supports, e.g., equipment.

We appreciate a more flexible approach to plan variations for minor errors, so our members don't have to undergo a full plan review and quickly get the supports they need. Having to undergo another full plan review once a quote is received for assistive technology can be incredibly stressful for our members.

SWAN members are concerned that the NDIA can order a plan review at any time and vary a participant's plan. More clarification is required about how plan variations will work. What is clear is that SWAN members would like more transparency about why and when plans can be varied, reassessed or reviewed.

SWAN welcomes the changes to a review of a reviewable decision, enabling both the internal reviewer and the Administrative Appeals Tribunal to review the original and subsequent decisions.

c) Reasons for Decisions

SWAN applauds the decision by the government to introduce the proposed changes of s 100(1B) and (1C) to the Act, which will allow participants to request the reasons for the decisions made in their plan prior to an internal review. However, we don't think the proposed legislation changes go far enough. They should be extended 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 to a participant their decision 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.

In response to a review of a reviewable decision Section 42, Subsection 100(6), we are pleased that the words "as soon as reasonably practicable" will be omitted and 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", making the NDIA more accountable.

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

a) Children Accessing the NDIS Earlier

SWAN welcomes the proposed inclusion of legislation under Section 14 of the NDIS Act as per *Tune Recommendation 13*, which will enable children under the age of seven years who don't have an NDIS plan to access supports as soon as possible while awaiting an NDIS plan. This will allow their families to build their capacity and ability to exercise informed choice and control and assist children who may not be ready to start planning for supports under the NDIS.

b) Change to the "Becoming a Participant" Rule

We are pleased to read the draft NDIA legislation include the Tune Recommendation 8b: *the NDIA Act is amended to remove references to 'psychiatric conditions' when determining eligibility and replace them with 'psychosocial disability'*. We believe this will remove some of the stigmas that go with having a psychosocial condition.

SWAN welcomes the new subsection, 24 of the Act, which clarifies how psychosocial disability can be defined. Impairment or impairments to which a psychosocial disability is attributable can be episodic or fluctuating, or varying in intensity, and may be taken to be permanent with the person likely to require support under the Scheme for their lifetime. This is despite possible variations in their condition from time to time. Some SWAN children with a psychosocial disability and have been declined eligibility for the NDIS.

SWAN would like to see a similar adjustment made to the rules around accessing the scheme for all disabilities. Many SWAN children have undiagnosed or rare genetic conditions that are episodic or fluctuating that vary in intensity in nature. These children have been declined access to the NDIS because of a lack of understanding that their disability is permanent. We feel the NDIA have very little understanding of undiagnosed and rare genetic conditions. Unfortunately, most undiagnosed and rare genetic conditions will remain permanent unless significant progress is made with gene therapies and clinical trials and new treatment options are found. There are often no appropriate treatment options for our families.

c) Preventing a Provider Delivering Support

There are safeguards in place to protect NDIS participants from NDIS providers that fail to meet NDIA standards. The NDIS has been able to include in a participants plan who should provide the support. Now it appears that the NDIA will be able to dictate what providers 'cannot provide the support'. SWAN feels that the NDIA is not always best placed to know what providers are suitable matches for participants. What process will be used to conduct due diligence on the support provider if they are either included as a stated provider or listed as an excluded provider? This rule has the potential to limit the amount of "choice and control" a participant has. It may also mean the plan is not individualised for the participant.

d) Payment of Supports

SWAN welcomes the proposal to change the wording of section 45 of the Act. This will enable the NDIA to pay service providers for services participants use irrespective of their plan management type. This will mean self-managed participants are no longer required to pay for services upfront and later claim for reimbursements. However, the proposed "tap and go" smartphone app system recommended for self-managing participants does give some rise to concern. Not everyone has access to a smartphone, and it is not clear under section 45 how this will work if participants want to use a combination of payment methods. It is also unclear if providers will have to wait longer for payments to go through using this new technology.

e) Plan Management

SWAN is pleased that the risk satisfaction assessment criteria currently used to assess if someone can Self Manage their NDIS plan, will also be used for Plan Managers. It offers another layer of protection for those wanting to use a registered Plan Manager. It is unclear whether price caps will be applied with this proposed change to the legislation.

3. The NDIS at Full Scheme – Schedule 3

SWAN is pleased that the legislation will be updated to reflect the current law and NDIS status. It is timely as the trial and transition phases are no longer relevant to the current legislation as the scheme is now fully rolled out across the nation. We are grateful that these changes will have no impact on SWAN members or others with disabilities.



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