



Draft Lists of NDIS Supports

August 2024

NDIS Consultations Team
Department of Social Services
GPO Box 9820
CANBERRA ACT 2601
NDISConsultations@dss.gov.au

Dear NDIS Consultations Team,

Syndromes Without A Name (SWAN) Australia thanks you for the opportunity to comment on the draft list of the National Disability Insurance Scheme (NDIS) Supports related to section 10 to the *National Disability Insurance Scheme (Getting the NDIS Back on Track No. 1) Bill 2024* ('NDIS Amendment Bill').

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. Over 98% of SWAN children have disability as part of their undiagnosed or rare genetic condition and almost all of SWAN children are participants of the NDIS.

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.

This submission has been prepared by Maya Pinn, from SWAN Australia maya@swanaus.org.au | 0466 122 290 in consultation with SWAN members and members of our community advisory group. Our main concerns are outlined in this submission in the subsequent pages.

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



Table of Contents

1. TABLE OF CONTENTS	3
2. EXECUTIVE SUMMARY	5
3. SUMMARY OF KEY ISSUES AND RECOMMENDATIONS	6
e) STA & Holiday Rental - (High Intensity Participants)	6
f) Disability Related Health Supports	6
g) Assistive Technology	6
4. INTRODUCTION	8
5.....	LACK OF CONSULTATION AND CODESIGN.....
a) Key Issue: No time for appropriate co-design with the disability community and lack of accessibility to the NDIS Draft List	9
b) Recommendations	9
i. <i>Extend the consultation period for the NDIS Draft List to allow for a thorough and inclusive co-design process with the disability community.</i>	9
ii. <i>Provide accessible formats of the NDIS Draft List in multiple languages and formats, including Easy English.</i>	9
6.....	LACK OF CHOICE AND CONTROL.....
a)Key Issue: List approach to NDIS supports is inappropriate and takes away ‘Choice and Control’	9
b) Recommendations	10
iii. <i>The NDIS maintains a flexible and ‘needs-based’ approach with a co-designed guide to determine the level of supports.</i>	10
7.....	AMBIGUITY AROUND CHANGE OF CIRCUMSTANCES
a)Key Issue: Unclear ‘Change of circumstances’ increases risk and safety of vulnerable children	10
b) Recommendations	11
iv. <i>Clear guidelines for “change of circumstances provisions.</i>	11
8.....	MAINSTREAM SUPPORTS ARE UNCERTAIN FOR CHILDREN WITH COMPLEX NEEDS
a)Key Issue: Mainstream supports create uncertainty for families with complex children	11
b) Recommendations	11
v. <i>Adoption of a more flexible and individualized approach.</i>	11
9. ADDITIONAL CONCERNS FOR SWAN FAMILIES.....	11
a) Key Issue: Afterschool Care Programs for Children with Disability	11
b) Key Issue: Eating Disorders	12
c) Key Issue: Menstrual Products	12
d) Key Issue: Specialist Disability Accommodation	12
e) Key Issue: STA & Holiday Rental - (High Intensity Participants)	12
A flexible ‘Reasonable & Necessary’ approach must continue with STA. Many NDIS Participants with High Intensity support needs due to complex disabilities, do not have readily available access to SDAs (for STA/Respite) due to the individual’s 24/7 complex care needs & availability of trained staff. Flexible STA by utilising ‘Accessible Holiday Rental’ is often Value for Money in comparison to a SDA & will enable the continuation of respite through accessible accommodation options, enabling the NDIS Participant’s to use their own known, reliable, confident & knowledgeable 24/7 High Intensity Disability support team.	12

f) Disability Related Health Supports.....	13
The NDIA must not push (direct) a disability related health support to Mainstream &/or Acute Care Services if the NDIS support is:.....	13
• Working Well.....	13
• Takes into consideration the NDIS Participants individual needs	13
• Geographical living situation.....	13
• NDIS Act Section 34.....	13
~ Professional Evidence states it is:	13
• Reasonable & Necessary	13
• Effective & Beneficial to the Participant & systems	13
• Value for Money for the NDIA to fund this support	13
g) Key Issue: Assistive Technology	14
h) Recommendations	14
vi. Afterschool Program for Children with Disability.....	14
vii. Eating Disorders	14
viii. Menstrual Products.....	14
ix. Specialist Disability Accommodation.	14
x. Assisted Technology.....	14

Executive Summary

Thank you for the opportunity to provide feedback on the draft list of the National Disability Insurance Scheme (NDIS) Supports related to section 10 to the *National Disability Insurance Scheme (Getting the NDIS Back on Track No. 1) Bill 2024* ('NDIS Amendment Bill'). It is important that we express the views of our SWAN members in this submission.

Whilst SWAN members agreed with many of the inclusions on the draft list, there were some items that were not included that we felt should have been.

We are concerned that true choice and control will be taken away from participants. We are also concerned that some flexibility will also be waived around supports. There are definitely mainstreams supports such as sensory items and targeted play equipment used in therapy that are very much needed for participants to live their best lives. Not everyone will be able to afford sensory equipment and assistive technology that they need which can help build their independence. Items that will make our members lives easier, may not be funded under the revised scheme and this is concerning.

We urge the government to reconsider including some mainstream items and give participants the flexibility, and the choice and control that they deserve.

Summary of Key Issues and Recommendations

Key Issues	Recommendations
<p>1. Lack of Consultation and Codesign</p> <p>No time for appropriate co-design with the disability community and lack of accessibility to the NDIS Draft List.</p>	<p>i) Extend the consultation period for the NDIS Draft List to allow for a thorough and inclusive co-design process with the disability community.</p> <p>ii) Provide accessible formats of the NDIS Draft List in multiple languages and formats, including Easy English.</p>
<p>2. Lack of Choice and Control</p> <p>List approach to NDIS supports is inappropriate and takes away 'Choice and Control'.</p>	<p>iii) The NDIS maintains a flexible and 'needs-based' approach with a co-designed guide to determine the level of supports.</p>
<p>3. Ambiguity around Choice and Control</p> <p>Unclear 'Change of circumstances' increases risk and safety of vulnerable children.</p>	<p>iv) Clear guidelines for "change of circumstances provisions.</p>
<p>4. Mainstream Supports are Uncertain for Children with Complex Needs</p> <p>Mainstream supports create uncertainty for families with complex children.</p>	<p>v) Adoption of a more flexible and individualized approach.</p>
<p>5. Additional Concerns for SWAN Families</p> <p>a) School aftercare programs for children with disability.</p> <p>b) Eating disorders.</p> <p>c) Menstrual products.</p> <p>d) Specialist Disability Accommodation.</p> <p>e) STA & Holiday Rental - (High Intensity Participants)</p> <p>f) Disability Related Health Supports</p> <p>g) Assistive Technology</p>	<p>vi) Suitable supports to be funded through the NDIS to support students' who are NDIS participants with sensory needs in afterschool care programs based in schools.</p> <p>vii) Mainstream supports such as those that can support NDIS participants with food aversions to be funded by the NDIS.</p> <p>viii) Mainstream supports such as period underwear and bathers to be funded by the NDIS for females NDIS participants.</p> <p>ix) SDA be included in the list of approved supports for travel.</p> <p>x) STA needs to be included for true 'Value for money' and safety purposes for complex participants</p> <p>xi) The NDIA must not push (direct) a disability related health support to Mainstream if the current services are appropriate and sustaining quality care</p>

	xii) A flexible approach needs to be considered when funding Assistive Technology item
--	--

Introduction

SWAN is pleased to provide feedback draft list of the National Disability Insurance Scheme (NDIS) Supports related to section 10 to the National Disability Insurance Scheme (Getting the NDIS Back on Track No. 1) Bill 2024 ('NDIS Amendment Bill'). We hope the our feedback is considered and will improve the experience SWAN children who are participants of the National Disability Insurance Scheme.

We feel that the short time frame given to review the draft lists will mean that many members of the disability community will be unable to provide feedback to the NDIS consultation team.

We are concerned that many mainstreams supports will no longer be covered by the NDIS and we urge the NDIA to reconsider them as funded items.

We hope that the draft rules which will accompany the NDIS legislation will have wide community consultation and be codesigned and we look forward to providing feedback on them. We want the NDIS to continue to remain person-centred so SWAN children and their families can flourish and live their best lives.

1. Lack of Consultation and Codesign

a) Key Issue: No time for appropriate co-design with the disability community and lack of accessibility to the NDIS Draft List

The development of the draft lists has been conducted without adequately involving people with disability, whose expertise and lived experiences should be central to the process. It is crucial that people with disabilities take on a leadership role in both the design and implementation of guidelines that govern the funding of supports under the NDIS.

Properly assessing how these lists distinguish between fundable and non-fundable supports requires the direct input of people with disability, their families, and advocates. Their insight is essential to understanding the real-world implications of these decisions. However, the brief consultation period has severely limited the opportunity for thorough examination, particularly given the complexity and technical detail involved.

b) Recommendations

i. Extend the consultation period for the NDIS Draft List to allow for a thorough and inclusive co-design process with the disability community.

Extend the consultation and review the proposed lists of supports to ensure that disability organisations are heard. This will create appropriate time to consider the implications of supports for NDIS participants without impacting their day-to-day lives. This extension will enable the meaningful involvement of people with disabilities, their families, and advocates, ensuring that their expertise informs the final version of the list.

ii. Provide accessible formats of the NDIS Draft List in multiple languages and formats, including Easy English.

The government must prioritise the creation of accessible versions of the draft list, including Easy English, Auslan, and translations into multiple languages, to ensure that all members of the disability community have the opportunity to participate in the consultation process.

2. Lack of Choice and Control

c) Key Issue: List approach to NDIS supports is inappropriate and takes away 'Choice and Control'

The key principles we believe must be included for NDIS supports are:

- Reasonable and necessary
- Related to a person's disability
- Take into account what is provided by other government supports
- Represent value for money

Proposing a 'certified' list of NDIS supports that are 'In' and NDIS supports that are 'Out' undermines the original principles outline in the NDIS, thus not providing the appropriate care for individuals with a NDIS package. This list takes away choice and control from families to provide supports and services for their child to thrive and therefore may decrease their safety.

SWAN parents struggle to justify their child’s need due to their complex nature. SWAN children do not fit into the typical tick box in most situations and therefore will again, miss out on much needed supports and services if the proposed NDIS draft list is confirmed without further consultation of the rare disease community.

The government should reconsider the use of a rigid list-based approach to NDIS supports, as it undermines the foundational principles of the NDIS—namely, that supports should be **reasonable and necessary**, related to an individual’s disability, and should take into account other government-provided supports while representing value for money.

We are concerned that the Day-to-day living costs categories and items are vague, and we are concerned that SWAN children will miss out on supports. Such as suitable sensory tools/toys/equipment at the discretion of the planner. The types of equipment that can be funded under Assistive Technology remains unclear. Some mainstream equipment e.g. headphones, pop-its, hammocks may be excluded from funding, despite a participant’s sensory needs. Many SWAN children rely heavily on sensory resources and toys to regulate their emotions.

d) Recommendations

iii. The NDIS maintains a flexible and ‘needs-based’ approach with a co-designed guide to determine the level of supports.

*The government should reconsider the use of a rigid list-based approach to NDIS supports, as it undermines the foundational principles of the NDIS—namely, that supports should be **reasonable and necessary**, related to an individual’s disability, and should take into account other government-provided supports while **representing value for money**.*

We recommend that the NDIS maintain a flexible, individualized approach to determining supports, rather than relying on a restrictive list of "In" and "Out" items. This approach fails to capture the complex and varied needs of individuals, particularly children with rare and undiagnosed conditions, who do not fit into typical categories. The proposed list, if implemented without input from the rare disease community, risks excluding these individuals from much-needed supports and services. A more inclusive and adaptive framework should be developed, with direct consultation from the disability and rare disease communities, to ensure that all participants receive appropriate and personalised care.

3. Ambiguity around Change of Circumstances

e) Key Issue: Unclear ‘Change of circumstances’ increases risk and safety of vulnerable children

SWAN is concerned that specific equipment is utilised as safety devices for SWAN children. For example: Smart watches have fall detection which is a safety option for participants with epilepsy. Tracking devices can be useful for children that run away.

“Home security, fencing, gates, repairs - I would like to keep my 10 year old (level 3 autistic with severe intellectual disability and behaviours of concern) living at home as long as possible. He requires 1:1 constant supervision or 2:1 constant supervision if the property wasn't secured with fencing and special gate locks.”

f) Recommendations

iv. Clear guidelines for “change of circumstances provisions.

We recommend that clear guidelines be established for 'change of circumstances' provisions to ensure the safety of vulnerable children, such as funding for necessary items like fences to prevent escape behaviour.

*We recommend expanding the criteria for 'change of circumstances' to include supports that address **urgent safety needs**, ensuring that vulnerable children receive timely interventions and protections.*

4. Mainstream Supports are Uncertain for Children with Complex Needs

g) Key Issue: Mainstream supports create uncertainty for families with complex children

SWAN children should have the flexibility to purchase suitable mainstream supports. To have a division about what constitutes a mainstream support and a disability support is an ableist approach. The government should move away from a rigid list-based approach to NDIS supports, recognising that supports should simply be supports. These should be funded appropriately to enable NDIS participants to achieve their goals. The focus should be on providing flexible, individualised support tailored to each participant’s unique needs, rather than restricting access based on predefined categories. This ensures that all participants receive the necessary assistance to live fulfilling lives and achieve their personal goals, without being constrained by a one-size-fits-all framework.

Many SWAN children have autism, sleeping disorders, epilepsy and eating disorders as part of their rare genetic conditions. Flexibility within the list of supports needs to be considered to support SWAN families around these challenges in and out of the home whether it be a childcare setting or school environment. No consideration into post-school option transition supports are on the list. Not every SWAN young adult has the capacity to transition into the workplace or day service without supports in place. Failing to include transition supports in the draft list is an oversight.

h) Recommendations

v. Adoption of a more flexible and individualized approach.

We recommend that the government adopt a more flexible, individualised approach that allows NDIS participants to access the supports they need—whether they are traditionally considered mainstream or disability-related. This flexibility should extend to all aspects of life, including childcare, school environments, and post-school transitions.

5. Additional Concerns for SWAN Families

i) Key Issue: Afterschool Care Programs for Children with Disability

Many of the afterschool care programs provided at mainstream schools are not suitable for SWAN children due to their high sensory needs. For example, there may be too much light or noise stimulation or not enough space or support for a child to remove themselves from the room to regulate their emotions. And augmented communication may not be offered to those who could benefit from it.

“The majority of level 3 autistic children don't cope in after-school care facilities. The facilities are too loud, the staff not suitably trained with non-verbal children, facilities are not suitably secured. The children are not able to learn skills in these environment and their behaviours of concern increase as a coping mechanism. It is cruel to force this on children. They need support workers. Parents need to be able to work for financial and mental health reasons.” - SWAN Parent

j) Key Issue: Eating Disorders

Many SWAN children have food aversions and need to work closely with speech therapists, occupational therapists and dieticians to increase their food range and increase the number of different textured food and variety of foods they can tolerate.

“It's estimated that 70-90% of autistic children have restrictive eating patterns. My son is a recovered ARFID (avoidant/restrictive food intake disorder) - at one point he had lost over 10% of his body weight and was only eating a handful of foods. He wasn't able to tell me why. It took a dedicated home program, with specialist advice and hours and hours of trained support workers to help him recover. Medicare does not provide enough sessions to cover the complexity of an autistic child with feeding issues.” -SWAN Parent

k) Key Issue: Menstrual Products

Wearing period underwear can be less stressful for females with intellectual disability and/or autism. It can be less embarrassing for them when they have their period, particularly when they at school and be much easier for them to manage their menstrual cycle. Many SWAN adolescents report struggling to use tampons and find pads uncomfortable and have sensory aversions to wearing them. Period bathers should also be recognised as a mainstream resource suitable for females with disability and should be able to funded accordingly.

“Many females with intellectual disability find menstruation a challenge. Period underwear is more hygienic and manageable for them than pads or tampons. These support their right to dignity and independence.” - SWAN Parent

l) Key Issue: Specialist Disability Accommodation

We strongly recommend that Special Disability Accommodation (SDA) be included in the list of approved supports for travel. SDA is currently categorized into four design types— Improved Livability, Robust, Fully Accessible, and High Physical Support—each catering to the diverse needs of NDIS participants.

SWAN children often present with physical, behavioural, and/or medical complexities that require a higher level of support than children with other disabilities. For many families, ***suitable accommodations during travel are not a luxury but a necessity to ensure safety, accessibility, and proper care.*** Excluding SDA from the list of approved supports for travel fails to acknowledge the unique and often intensive needs of SWAN children.

Incorporating SDA as an approved support for travel would provide essential flexibility and peace of mind for families, allowing them to access appropriate accommodations that meet their children's specific requirements. This recommendation aims to ensure that all participants, especially those with complex needs, can travel safely and with the support they need.

m) Key Issue: STA & Holiday Rental - (High Intensity Participants)

A flexible 'Reasonable & Necessary' approach must continue with STA. Many NDIS Participants with High Intensity support needs due to complex disabilities, do not have readily available

access to SDAs (for STA/Respite) due to the individual's 24/7 complex care needs & availability of trained staff. Flexible STA by utilising 'Accessible Holiday Rental' is often **Value for Money** in comparison to a SDA & will enable the continuation of respite through accessible accommodation options, enabling the NDIS Participant's to use their own known, reliable, confident & knowledgeable 24/7 High Intensity Disability support team.

n) Disability Related Health Supports

The NDIA must not push (direct) a disability related health support to Mainstream &/or Acute Care Services if the NDIS support is:

- Working Well
- Takes into consideration the NDIS Participants individual needs
- Geographical living situation
- NDIS Act Section 34

~ *Professional Evidence states it is:*

- Reasonable & Necessary
- Effective & Beneficial to the Participant & systems
- Value for Money for the NDIA to fund this support

o) Key Issue: Assistive Technology

Assistive Technology such as upgrades to standard household items such as dimmer switches, shower and bathroom mixer taps, automatically fingerprint locks, and key lock safes and automated blinds, which can help build a participant's independence as well as keep them safe and cannot be ignored and should be included in flexible items.

Play equipment that is specialised sensory equipment should be funded under Assistive Technology.

Additional insurance for support workers to drive a participants modified vehicle should also be considered.

p) Recommendations

vi. Afterschool Program for Children with Disability

Suitable supports to be funded through the NDIS to support students who are NDIS participants with sensory needs in afterschool care programs based in schools.

vii. Eating Disorders

Mainstream supports such as those that can support NDIS participants with food aversions need to be funded by the NDIS.

viii. Menstrual Products

Mainstream supports such as period underwear and bathers should be funded by the NDIS for females NDIS participants.

ix. Specialist Disability Accommodation.

SDA should be included in the list of approved supports for travel.

x. Assisted Technology

A flexible approach needs to be considered when funding Assistive Technology items as some mainstream items can make a big difference in building a participant's capacity to become independent and regulate their emotions.



swanaus.org.au



[@SWANAustralia](https://www.facebook.com/SWANAustralia)



[@swanaus](https://twitter.com/swanaus)



[linkedin.com/company/swanaustralia](https://www.linkedin.com/company/swanaustralia)



[instagram.com/swanaus/](https://www.instagram.com/swanaus/)



[youtube.com/c/SwanausAus](https://www.youtube.com/c/SwanausAus)