



## **INDEPENDENT ASSESSMENTS**

SWAN Submission to the Joint Standing  
Committee on the NDIS Inquiry

**March 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. We feel there is a distinct lack of understanding about the needs of our families from the National Disability Insurance Agency (NDIA).

SWAN helps reduce the isolation and emotional strain of raising a child with 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 was prepared by Heather Renton, CEO - Syndromes Without A Name (SWAN) Australia.

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



Syndromes **Without A Name** (SWAN) Australia



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## Executive Summary

SWAN is vigorously opposed to mandatory independent assessments. We hope that by undertaking this consultation the National Disability Insurance Agency (NDIA) realise that the introduction of mandatory independent assessments is not the way to improve the National Disability Insurance Scheme (NDIS) and will be detrimental to the scheme. We recommend funds be better spent and more effectively allocated to other areas of the NDIS, such as on participants' supports (many of our members have inadequate plans), or on staff training as many Early Childhood Early Intervention (ECEI) Coordinators, Local Area Coordinators (LAC) and Planners have little understanding of the functional capacity or support needs of it NDIS participants with undiagnosed or rare genetic conditions.

SWAN is disappointed that the NDIS plans to introduce independent assessments without the pilot program fully completed and with very little consultation with people with disability, their family and carers or the disability sector that supports them. Any changes to the NDIS need to involve codesign and consultation with the disability community. Together we can make practical improvements to the NDIS to make the scheme more equitable for everyone.

It is important that the NDIS consider assessments and reports from specialists, therapists and service providers that identify a participant's functional capacity as well as their goals and support needs. These support providers have established trust and built relationships with an understanding of their clients' needs over time. Furthermore, they are also experts in their field so their reports should have a considerable weighting and shed significant insight into a participant's functional capacity and support needs.

Some undiagnosed and rare genetic conditions are regressive, progressive and some are episodic, so if a SWAN child was assessed on a "good" day, they might receive a very different score on their assessment than on a day where the condition impacted their disability more. Progressive conditions along with other health concerns are not uncommon among our members and daily function can decline very rapidly. There is still so much unknown about undiagnosed and rare genetic conditions that the toolbox of individual assessments that the NDIA are proposing may not capture an accurate assessment of many of our SWAN children and their families' functional capacity. Symptoms may be lacking or masked at the time of the independent assessment but that does not mean they do not exist. On a difficult day, our children require an intensive level of support by either a family member or someone who knows their child well, such as a highly skilled and trusted, and trained support worker or therapist.

We simply cannot have a one size fits all approach to the NDIS. The intention of the NDIS was to put the participant first and at the centre of any conversation. The approach to working backwards, linking plan budgets to independent assessments to determine the level of support in a participant's plan and then deriving draft plans to fit the budget is not feasible and simply cannot happen. A two-way conversation needs to occur between the participant and planner first to understand their goals, aspirations and support needs prior to a plan being drafted.

**Summary of Key Issues and Recommendations**

KEY ISSUES	RECOMMENDATIONS
<p><b>a/ Reasons and justifications for the introduction of NDIS independent assessments</b></p>	<ol style="list-style-type: none"> <li>1. The Federal government delay drafting legislation to introduce NDIS mandatory independent assessments until the results from the second pilot study have been evaluated.</li> <li>2. NDIA and government representatives consult and converse with people with disability, their families and the sector that supports them and involve them in codesign prior to any radical changes to the NDIS.</li> <li>3. If independent assessments are to be introduced, they should not be mandatory and should only be used in a voluntary capacity to access the NDIS.</li> </ol>
<p><b>c/ Human and financial resources needed to effectively implement independent assessments</b></p>	<ol style="list-style-type: none"> <li>4. The NDIA does not subcontract the task of conducting independent assessments outside of the NDIA.</li> <li>5. The NDIA address the workforce issue of thin markets when it comes to allied health professionals, psychologists, counsellors and social workers, particularly in regional, rural and remote areas. This has to be done prior to even attempting to use this workforce to conduct independent assessments.</li> <li>6. The NDIA does not link the number of independent assessments conducted in one week to an assessors KPI's and does not put limits on the number of times the same independent assessment can be completed in relation to the review meeting.</li> <li>7. The NDIA does not ask parents to complete an assessment task away from their child on the day of the independent assessment.</li> </ol>
<p><b>d/ Independence, qualifications, training, expertise and quality assurance of assessors</b></p>	<ol style="list-style-type: none"> <li>8. The NDIA keep consistent information on the NDIA website.</li> <li>9. The NDIA ensures independent assessors have minimum of three years training both in conducting assessments and within their healthcare profession.</li> <li>10. The NDIA ensure independent assessors communicate with NDIS participants in the participants usual method of communication such as Key Word Sign.</li> <li>11. The NDIA does not allow independent assessments to be rushed, every participant deserves the right to complete their independent assessments at their own pace and over multiple days (if required).</li> </ol>

KEY ISSUES	RECOMMENDATIONS
<p><b>e/ Appropriateness of the assessment tools used for independent assessments to determine plan funding</b></p>	<p>12. The NDIA not conduct pilot studies without first consulting and codesigning a study with NDIS participants, their families, and the disability sector.</p> <p>13. The NDIA ensures evidence from pilot studies is properly reported and evaluated on prior to hastily making any recommendations or changes to the NDIS.</p> <p>14. The NDIA consult with NDIS participants, their families and the disability sector before implementing any changes to the NDIS.</p> <p>15. The NDIA ensure that participants are the focal point of any planning or review meeting. The NDIS needs to remain person centred.</p> <p>16. The NDIA base planning meetings around the participants’ goals and aspirations and utilise assessments and reports provided by specialists, allied health reports and service providers who have a good understanding of a participants needs so that information can be transposed into draft plans.</p> <p>17. If independent assessments are to become mandatory (we sincerely hope they don’t), they should be conducted by health professionals already working with participants and additional funding should be included in participants’ plans to pay for them.</p> <p>18. The NDIA needs to state what happens when a participant is non- compliant or unable to complete the assessment tasks.</p>
<p><b>f/ Implications of independent assessments for access to and eligibility for the NDIS</b></p>	<p>19. The NDIA does not use mandatory independent to access the NDIS.</p> <p>20. The NDIA introduce voluntary independent assessments if participants require assessments to enter the scheme when they cannot provide enough supporting evidence to access the scheme.</p> <p>21. The NDIA does not make access to the NDIS more stressful than it needs to be.</p> <p>22. The NDIA to be transparent about the full cost of independent assessments when they are used for participants to enter the scheme.</p> <p>23. The NDIA needs to clarify what they will do if a participant is unable to complete the assessment.</p>

KEY ISSUES	RECOMMENDATIONS
<p><b>g/ Implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports</b></p>	<p>24. The NDIA does not align plan budgets to independent assessments alone. They need to take into consideration the participants support needs and goals, and assessments and reports from specialists and therapists provided at their planning meeting.</p> <p>25. The NDIA cannot rely on independent assessments alone to determine a participant’s functional capacity or plan budgets.</p>
<p><b>h/ Circumstances in which a person may not be required to complete an independent assessment</b></p>	<p>26. When taking into consideration what constitutes a behaviour of concern, the NDIS recognise that either a participant, their family, specialist, or therapists is best placed to identify these. If behaviours of concern have the potential to arise or do arise, the independent assessment will need to be aborted immediately.</p> <p>27. The NDIA should define what constitutes “significant risk and behaviour”.</p> <p>28. The participant should be able to dictate how many attempts they can have at an independent assessment per plan review.</p>
<p><b>i/ Opportunities to review or challenge the outcomes of independent assessments</b></p>	<p>29. The NDIA needs to be more transparent about the review process (or lack of it) for independent assessments if participants wish to challenge their assessment.</p> <p>30. The NDIA need to allow independent assessment results to be reviewed more easily.</p> <p>31. The NDIA needs to define what constitutes a “significant change” in a person’s capacity or circumstances.</p> <p>32. The NDIA must be transparent about the grievance process for NDIS applicants or participants who are dissatisfied with an independent assessment, their assessor, or the assessor’s organisation.</p>
<p><b>j/ Appropriateness of independent assessments for particular cohorts of people with disability</b></p>	<p>33. The NDIA needs to avoid using terminology in independent assessments that participants may not understand.</p>

KEY ISSUES	RECOMMENDATIONS
<p><b>k/ Appropriateness of independent assessments for people with particular disability types</b></p>	<p>34. The NDIA should not have a one size fits all approach to independent assessments when determining a participant’s functional capacity, particularly when assessing a participant with an undiagnosed or rare genetic condition.</p> <p>35. The NDIA does not use independent assessments that involve parents being separated from their children.</p>
<p><b>l/ Other related matters</b></p>	<p>36. The NDIA stop presuming that independent assessments will become part of the NDIS when the legislation is yet to be passed by parliament.</p> <p>37. Ensure participants can receive a full copy of their assessment report not just a summary if they request it.</p>

## Introduction

Thank you for the opportunity to provide feedback to the Joint Standing Committee on the NDIS inquiry into independent assessments. It is important that we express the views of our SWAN members in this submission. Mandatory independent assessments will have the potential to have a negative impact on our community due to the uncertainty and very nature of undiagnosed and rare genetic conditions. Undiagnosed and rare genetic conditions often present as being episodic and progressive and often involve a range of disabilities and health concerns. We are extremely concerned that our members functional capacity is subject to change frequently, depending on their genetic condition and their capacity on the day.

Whilst we are strongly opposed to mandatory independent assessments, we do think there is a place for voluntary independent assessments when there is uncertainty about a participant's functional capacity or in the case where a participant cannot afford assessments and reports from a health specialist, allied health provider or other support service providers. In these circumstances, voluntary assessments should only be administered by well trained and experienced health professionals of a participant's choosing (ideally already known to the participant).

Codesign and consultation with people with disability, their families and carers and the disability sector prior to any radical changes being made to the NDIS is essential. Participants must continue to be at the centre of everything the NDIS does.

## Terms of Reference

### a. the development, modelling, reasons and justifications for the introduction of independent assessments into the NDIS;

#### RECOMMENDATIONS:

1. The Federal government delay drafting legislation to introduce NDIS mandatory independent assessments until the results from the second pilot study have been evaluated.
2. NDIA and government representatives consult and converse with people with disability, their families and the sector that supports them and involve them in codesign prior to any radical changes to the NDIS.
3. If independent assessments are to be introduced, they should not be mandatory and should only be used in a voluntary capacity to access the NDIS.

## THE ISSUES

### Lack of understanding of a participant's needs

SWAN Australia is extremely concerned about the introduction of mandatory independent assessments and the reasons that the NDIA and the Federal government have provided for their proposed introduction. One of the arguments for independent assessments is that it will be cost saving as participants will not have to produce reports and assessments written by clinicians, allied health professionals and support organisations. However, what they fail to see is that these reports are written by professionals who are experts in their field and work with our SWAN children. They gain a good understanding of their support needs and build positive relationships and trust with them over time. We fear that our SWAN children's needs and functional capacity will not be well understood by an assessor who meets with our children once, particularly in a setting that the child or their family may not feel comfortable in. SWAN Parents and clinicians can struggle to know the full impacts of a child's genetic condition, so we do not understand how a complete stranger can be the best placed to evaluate a child's functional capacity.

### Lack of evidence to support independent assessments

There is no evidence that the tool kit of assessment tools decided on are the most suitable assessments for a social model of disability supports. We do not feel the small number (513)<sup>1</sup> of NDIS participants who participated in the first Independent Assessment was a broad enough sample to confirm the selected assessments were the right tools to use. The first pilot also only included 71% of participants with a high level of function who had either Autism Spectrum Disorder, intellectual disability or psychosocial disability. SWAN does not know of any members who participated in the first pilot study which suggests the proposed assessments have not been tested on NDIS participants from the undiagnosed and rare disease community.

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<sup>1</sup> <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-pilot>

The second pilot study aims to draw on the experience of 4000 pilot participants and is yet to be concluded. SWAN has heard from some of our members who have been invited to participate. The lack of interest in registering for the pilot study, is evidence that people with disability are anxious, fearful, and concerned about independent assessments. We now have the NDIS offering some participants an incentive of \$150.00 to participate, whilst others are not being offered any financial incentive to participate.

### **Case Study**

*“We tried to reschedule our pilot independent assessments and were told that we were not allowed to reschedule appointments, despite the NDIA website saying you could request a change of appointment<sup>1</sup>.”*

SWAN feels that there is little justification for independent assessments without the supporting evidence to demonstrate that independent assessments, as proposed are the most appropriate tool be used to support a social model of disability.

In August 2020, the government’s responded to the Tune Review Recommendation 7, stating that:  
b) provide discretionary powers for the NDIA to require a prospective participant to undergo an assessment for the purposes of decision-making under the NDIS Act, using NDIA-approved providers in a form set by the NDIA.

The Tune Review recommends the Act is amended so the NDIA can apply discretionary powers to require prospective participants to complete an independent assessment. This is very different to what the NDIA is proposing with the NDIA wanting to introduce mandatory independent assessments to access the NDIS and again at every review meeting.

### **Lack of consultation with people with disability, their families and the sector**

It appears there has been little consultation with people with disability, their families and the disability sector that supports them. It was our understanding that the process for implementing independent assessments would be determined based on the experience of the recent trials and would occur in consultation with people with disability, their families, and the disability sector. Judging by the number of people with disability, their families and the disability sector’s disappointment with the NDIA’s proposed mandatory use of independent assessments, it is clear that not enough consultation has taken place. We are disappointed the NDIA is assuming the legislation will be passed without waiting for the results of the second pilot project. Codesign and consultation with people of people with disability, their families and the disability sector that supports them, needs to occur prior to any hasty changes being made to the NDIS.

### **Legislation is yet to be passed**

The draft legislation around independent assessments has not been tabled in parliament so we recommend that the NDIA stop acting as if the amendments to the NDIS Act 2013 have already been passed; they haven’t.

## **b. the impact of similar policies in other jurisdictions and in the provision of other government services;**

SWAN does not wish to comment on this question.

**c. the human and financial resources needed to effectively implement independent assessments;**

**RECOMMENDATIONS:**

4. **The NDIA does not subcontract the task of conducting independent assessments outside of the NDIA.**
5. **The NDIA address the workforce issue of thin markets when it comes to allied health professionals, psychologists, counsellors and social workers, particularly in regional, rural and remote areas. This has to be done prior to even attempting to use this workforce to conduct independent assessments.**
6. **The NDIA does not link the number of independent assessments conducted in one week to an assessors KPI's and does not put limits on the number of times the same independent assessment can be completed in relation to the review meeting.**
7. **The NDIA does not ask parents to complete an assessment task away from their child on the day of the independent assessment.**

**THE ISSUES**

**Assessment tools**

SWAN is worried that the utilisation of independent assessments at every plan review will be a burden of both human and financial resources to the scheme. It will be an expensive process to train assessors on a number of different assessment tools.

**High staff turnover**

Assessors are likely to experience a high level of emotional burnout and fatigue as they hear about what it is like to live with a disability. In the case of members who are living with undiagnosed and rare genetic conditions, including complex disability, hearing our communities stories can be challenging but it does provide a better understanding of our SWAN participants' needs. We are concerned that there will be a high staff turnover among assessors like there is with LAC's and planners, as they realise that it is not the vocation for them. High staff turnover costs money, that could be better spent on participants.

**Thin markets**

SWAN members report that there is frequently a 6 -12 months waiting list to see an allied health professional, psychologist, counsellor or social worker. Some members have mentioned a number of services have even closed their waiting lists, including those in the Melbourne metropolitan area. We know that there are thin markets with this workforce. This is particularly true in regional, rural, and remote areas, where there are already delays and service gaps due to limited local services and long waiting lists. We are extremely concerned that the mandatory introduction of independent assessments will exacerbate the problem.

We are also concerned that independent assessments may end up being administered by LAC's and Planners, once the NDIA realises it cannot get enough health professionals to administer independent assessments. Already we have a number of LAC's and planners who have had little training or lived experience in disability. The lack of lived experience and training in disability among LAC's and Planners already causes issues for our families trying to obtain funding in their child's plan to meet their NDIS goals.

### **Time consuming to implement**

The recommended time to conduct an assessment is 20 minutes to 3 hours. This is a lengthy time for a child and parent to engage. The NDIA have not been clear about how many times the one assessment can be attempted or how many times the assessor will be willing or able to return to complete the assessment. If an assessor has to conduct an assessment over a number of days, this will be costly as the assessor will claim for travel as well as their hourly rate. SWAN wonders if the number of individual assessments conducted will be linked to assessors KPI's?

On the NDIS website, it states "Your assessment will be free. The assessment will take around three hours. You can choose to do the assessment in the way that best suits you, like on the same day, or over a number of days"<sup>2</sup> However, the SWAN NDIS participants we have spoken to who have been asked to participate in the pilot study have been told they have only been offered two options, one for three hours or two separate time slots. Due to their medical condition and disability, many of our SWAN children will not be able to focus for long before they fatigue. There is no definitive maximum number of times set out by the NDIS to complete the assessment tasks.

### **Environment**

It is important that participants who complete independent assessments are able to select the location and environment in which they are take place. A person's functional capacity and needs can vary depending on what setting they are in, whether it be at school, out in the community or at home. Ideally assessments should take place across a number of settings.

### **Supervision of participants**

The Vineland test is required to be completed when the participant is in a different room. Does that mean that the assessor will bring a support person with them to care for the child whilst their parent completes the assessment tasks? Very few SWAN children can be left unattended without supervision. Who will pay for the medically trained carer to supervise SWAN children whilst their parent completes the assessment task? Many of our SWAN children have anxiety and are not comfortable talking to or being observed or cared for by strangers. It is unclear if the NDIA will provide additional funding for a participant's regular carer (if they have one funded) to be present on the day. Many of our SWAN children only receive capacity building supports in their plan and not core funding as the NDIA argue looking after your child is a "parent's responsibility".

## **d. the independence, qualifications, training, expertise and quality assurance of assessors;**

### **RECOMMENDATIONS:**

- 8. The NDIA keep consistent information on the NDIA website.**
- 9. The NDIA ensures independent assessors have minimum of three years training both in conducting assessments and within their healthcare profession.**
- 10. The NDIA ensure independent assessors communicate with NDIS participants in the participants usual method of communication such as Key Word Sign.**
- 11. The NDIA does not allow independent assessments to be rushed, every participant deserves the right to complete their independent assessments at their own pace and over multiple days (if required).**

<sup>2</sup> <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-process>  
SWAN Australia - Submission to the Joint Standing Committee on the National Disability Insurance Scheme  
- Inquiry: Independent Assessments.

## THE ISSUES

### NDIA website information

Previously on the NDIA website it stated that independent assessors were not limited to allied health care professionals, psychologists, counsellors and social workers. This information has now been clarified to read “the assessors will be from a range of health care professionals”. Information about independent assessments can change rapidly on the NDIA website and we are concerned that information might change without the community being aware of the changes.

The fact that information can be changed from one day to the next is concerning and provokes a lack of trust with regards to how independent assessments will evolve over time. Previous information also stated that you could choose from the assessor list what medical discipline your independent assessor would be from. Now it seems you can only choose from the following:

- where and when your assessment happens
- if your assessor is male or female
- if you'd like your assessment done in one session, or over a number of days

### Lack of training

We are concerned that to become an assessor you are only required to have “a minimum of 12 months experience full time clinical experience (post registration) working in their field...”<sup>3</sup> The lack of minimal training required to administer these assessments is concerning as many assessors will have very limited experience of liaising with children with undiagnosed and rare genetic conditions. We are dubious that in 12 months potential assessors would have been exposed to a range of assessment tools or a number of rare genetic conditions, to develop the skills and gain the expertise needed to be able to support our SWAN children. We also wonder if assessors will be trained in using the child's communication device as many of our SWAN children are nonverbal.

### Lack of understanding and awareness of undiagnosed and rare genetic conditions

We are concerned with the distinct lack of understanding and training that ECEI coordinators, LAC's and planners have, with regards to undiagnosed and rare genetic conditions. We have little faith that independent assessors will have any better understanding of our SWAN families' daily lives or needs. Undiagnosed and rare genetic conditions can be episodic, or present with fluctuating disabilities, they can be progressive and often co-existing with a number of other chronic health conditions. A SWAN child's functional capacity can change very rapidly, minute to minute, hour to hour, day to day or week to week. If an independent assessor performs assessments when a child is having a “good day”, it may not be a true indication of their general overall functional capacity.

### Outsourcing expertise has not previously worked

In the early stages of the development of the NDIS one of the thoughts was that if you had a child who was in primary school, you would meet with a planner experienced with working with primary school age children with disability, however sadly this was not the case. We know by the lack of training among Planners, LAC's and ECEI coordinators that there is a distinct lack of understanding of participants needs and disabilities. The NDIS needs to learn from its mistake of outsourcing planning meetings to LAC's. It has just led to a large number of reviews, causing high anxiety and frustration for participants, particularly among our SWAN members.

### Case study

*“Our LAC confessed straight up ‘I am an accountant from Malaysia and this is my first job in Australia’, this did not give us a lot of faith our child will receive a plan that would support their goals. Needless to say, we had to lodge a review of a reviewable decision.”*

<sup>3</sup> <https://www.ndis.gov.au/participants/independent-assessments/independent-assessors>  
SWAN Australia - Submission to the Joint Standing Committee on the National Disability Insurance Scheme  
- Inquiry: Independent Assessments.

### **Quality of independent assessments**

We are concerned that there is the potential that independent assessors will have time limits put upon them in which they will be required to conduct and complete assessments. If this becomes a reality, we are worried that assessments may be rushed and not be a true representation of a participant's functional capacity. SWAN is worried that too many assessments will be deemed "inaccessible or invalid". As a result of not being able to complete assessments, participant support budget may not be enough to support their needs.

### **e. the appropriateness of the assessment tools selected for use in independent assessments to determine plan funding;**

#### **RECOMMENDATIONS:**

12. **The NDIA not conduct pilot studies without first consulting and codesigning a study with NDIS participants, their families, and the disability sector.**
13. **The NDIA ensures evidence from pilot studies is properly reported and evaluated on prior to hastily making any recommendations or changes to the NDIS.**
14. **The NDIA consult with NDIS participants, their families and the disability sector before implementing any changes to the NDIS.**
15. **The NDIA ensure that participants are the focal point of any planning or review meeting. The NDIS needs to remain person centred.**
16. **The NDIA base planning meetings around the participants' goals and aspirations and utilise assessments and reports provided by specialists, allied health reports and service providers who have a good understanding of a participant's needs so that information can be transposed into draft plans.**
17. **If independent assessments are to become mandatory (we sincerely hope they don't), they should be conducted by health professionals already working with participants and additional funding should be included in participants' plans to pay for them.**
18. **The NDIA needs to state what happens when a participant is non-compliant or unable to complete the assessment tasks.**

### **THE ISSUES**

#### **Lack of evidence**

The NDIA is yet to share evidence that supports independent assessments to understand a participant's functional capacity, or that demonstrates they are proven tools for determining support needs and plan budgets, or even how these assessments would be translated into budgets. This radical scheme reform should not be introduced in the absence of robust evidence and evaluation demonstrating that it is indeed best practice for assessing functional capacity and support needs.

There is a lack of evidence which supports that the selected independent assessment tools, should be used to create draft plan budgets in a social model of disability. The use of individual assessments to ascertain plan budgets, moves away from an individualised approach to NDIS planning, which is participant-led, goal-orientated and puts the participant at the centre of the planning conversation.

The aim of the NDIS is to deliver person-centred supports and provide a human rights approach to disability support. It is meant to be a social model of support which focuses on supporting people with disability, their families, and carers so they can participate in social, economic and community life. More importantly it is about “choice and control”.

The proposed model of mandatory independent assessments will highlight the growing inequities of the NDIS. It will add more complexities, anxiety and stress to people with disability trying to get the supports they need to live an “ordinary life”.

### **Causing anxiety amongst participants**

Many of our SWAN members have reported they are fearful and anxious about the proposed mandatory use of independent assessments. Meeting with a stranger who does not know their child’s strengths and weaknesses is of huge concern for our community. Our families have enough anxiety living with the unknown, and they do not need more things added to their worries. There are already too many unknown issues for rare disease families. A one- size- fits- all approach will not work for the community we represent, particularly with our cohort of families where progressive and episodic symptoms frequently occur.

We have to put the participant first and conversations between planners and participants need to take place prior to any independent assessments. Planners need to gain a better understand of participants’ goals and aspirations and what supports are required to achieve them. Working backwards and creating a plan and writing goals around a budget, without talking to a participant first to find out how they want to be supported, simply will not work. It will lead to an increased number of plan reviews.

Parents have reported that they are concerned that their SWAN child will be non-compliant or unable to complete their independent assessment. We do not know how the NDIA will allocate plan budgets for participants who are unable to complete or attempt assessments, or for those who are unable to undertake them due to safety concerns. Will it mean that the NDIS will just allocate an amount based on reading the reports and assessments provided by a participant’s therapist or specialist? Or will it just be based on the conversation had between the participant and planner at their planning meeting or a combination of both? If assessments cannot be completed, then the participant or their representative should be able to state they do not want to attempt the assessment in the first place. The process is very confusing for our members.

### **Evidence from specialists reports and assessments ignored**

The NDIA has not made it clear if planners are able to add to plan budgets which are derived from assessments. We do not know whether other factors such as specialist reports and assessments can be used to form plan budgets. As far as we can ascertain, plan budgets will be derived from independent assessments alone and this is causing great angst in the disability community. Reports and assessments provided by people who support participants such as therapists cannot be ignored. They are experts in their field and have often built-up trust with a participant and their family over time and have an exceptional understanding of a participants support needs. We do not believe you can gain an accurate and true representation of a person’s functional capacity within three hours, in one setting, using inappropriate tools by assessments performed by total strangers.

### **Lead to a high number of reviews**

We are concerned that independent assessments will be linked to plan budgets with limited (if any) capacity for planners to add to a participant’s budget. From what SWAN understands, planners will need to create a draft plan based around a draft budget (which can only be reviewed under very limited circumstances).

### **Assessments tools suggested are in appropriate for SWAN families**

SWAN feels the selected independent assessments tools focus more on physical disability rather than mental, behavioural or cognitive disability. Many SWAN families have neuro diverse disability and chronic illness, therefore the selected assessment tools might not be the most suitable to support their needs or for determining access and eligibility to the scheme.

### **f. the implications of independent assessments for access to and eligibility for the NDIS;**

#### **RECOMMENDATIONS:**

19. **The NDIA does not use mandatory independent assessments to access the NDIS.**
20. **The NDIA introduce voluntary independent assessments if participants require assessments to enter the scheme when they cannot provide enough supporting evidence to access the scheme.**
21. **The NDIA does not make access to the NDIS more stressful than it needs to be.**
22. **The NDIA to be transparent about the full cost of independent assessments when they are used for participants to enter the scheme.**
23. **The NDIA needs to clarify what they will do if a participant is unable to complete the assessment.**

#### **THE ISSUES**

##### **Lack of understanding of undiagnosed and rare genetic conditions**

SWAN does not support the mandatory introduction of independent assessments to become a participant of the NDIS. We estimate around 3% of our SWAN members are rejected from accessing the NDIS the first time they apply. This was despite their child having one or more impairment; intellectual, cognitive, neurological, sensory or physical impairments. We do however support the voluntary use of independent assessments if participants require assessments to enter the scheme when they cannot provide enough supporting evidence to access the scheme.

##### **Case study**

*“We have three SWAN children, two were on the NDIS because they accessed the scheme under the ECEI requirements. Our third child was over seven, so did not qualify under ECEI and was denied access to the scheme, despite showing similar symptoms and disabilities to their siblings. We can only presume that our third child was denied entry to the scheme because they had an undiagnosed rare genetic condition, there was no reason given. We feel the access team did not understand the complexities of our child’s condition because some of the symptoms were episodic”.*

The lack of awareness and training of the NDIS access team has caused problems for some of our SWAN families. One of the issues we know exists for our SWAN families is that the LACs and planners sometimes struggles to understand medical reports.

## Case study

*“We submitted a lab report with our NDIS access application. It stated that the condition was ‘most likely pathological cause of the genetic condition to a gene change on the XXX gene’. The access team would be unlikely to have any idea what that means or its possible impacts on our daughter’s functional capacity.”*

Undiagnosed and rare genetic conditions can be episodic, fluctuating, spasmodic and progressive. Our fear is that if independent assessments alone are used as a benchmark to access the scheme, it will be even more difficult for a number of our members to become NDIS participants. Specialist reports and assessment should be used as evidence that SWAN children qualify to become NDIS participants if they meet the access criteria. However, if specialists reports and assessments cannot be provided or there is not enough evidence of our members disability, then participants should be able to undertake a voluntary independent assessment. However, if our members still fail to meet the eligibility criteria based on their first independent assessment, they should be able to undergo another independent assessment to determine their functional capacity. This is because undiagnosed and rare genetic conditions can be unpredictable and change very rapidly.

If independent assessments do become mandatory or voluntary to access the NDIS or inform plan reviews, we encourage assessors to reach out to peak organisations such as SWAN for further information. We understand that assessors cannot know everything about all types of undiagnosed or rare genetic conditions. However, peak organisations such as ours are more than willing to provide information to support assessors (and indeed LACs and planners) and build their capacity to better understand these conditions, their impacts on functional capacity and potential support needs.

The NDIS consultaton paper: *Access and Eligible Policy with Independent Assessment* 23.11 states *“disagreeing with the results of an otherwise sound and robust independent assessment is not sufficient for the NDIA to fund another assessment. Applicants can only seek a second assessment where the assessment was not consistent with the independent assessment framework, or if the applicant has had a significant change to their functional capacity or circumstances.”*

What constitutes a ‘significant change’ is currently unclear, further guidance from the NDIA is urgently required.

## Additional stress and anxiety

Just in the last month, SWAN has seen a 20% increase in emails and phone calls from members extremely concerned about independent assessments and we are worried they will lead to further anxiety and trauma among our members.

SWAN families have enough anxiety in their lives, to add another layer of complexity just adds more stress to our SWAN families which they do not need. Our families have told us they do not want to share their child’s personal information with strangers who have no understanding of what life is like for them. They do not need this traumatic and confronting experience and the stress of possible rejection to the scheme based on an independent assessment which aims to capture their child’s functional capacity in three hours. Rare genetic conditions hold more complexity than can be learned or appreciated in three hours.

Our fear is that our SWAN children will be assessed on what might look like a “good day” for them, so the assessment won’t capture what everyday life is usually like for them. It is not fair for our families to be forced to meet with strangers and undergo an assessment. Many of our children have autism or autistic features as part of their rare genetic condition. They do not cope well when they are out of the depth in unfamiliar settings or with unfamiliar people. There is a lack of trust and we are concerned that a large number of our SWAN children will be non-compliant or won’t be able to complete the assessments. Or they may demonstrate behaviours of concern. Parents will also become stressed and traumatised by the ordeal.

### **No reduction in costs**

We do not believe that the introduction of independent assessments will achieve the objective of reducing expenditure to access the NDIS. Participants still need to gather reports and assessments as evidence that they have a disability to meet the NDIS Act 2013 requirements to enter the scheme. Then if the NDIS deem them eligible for the scheme they will need to undergo an independent assessment to ensure they functional capacity is low enough to access the scheme. There is still an access barrier for people who cannot afford these reports and assessments prior to entering the scheme. We still do not know the full cost of utilising independent assessments to know whether it is a good alternative to the current model. There is no evidence that this one size fits all model will work.

### **g. the implications of independent assessments for NDIS planning, including decisions related to funding reasonable and necessary supports;**

#### **RECOMMENDATIONS:**

24. **The NDIA does not align plan budgets to independent assessments alone. They need to take into consideration the participants support needs and goals, and assessments and reports from specialists and therapists provided at their planning meeting.**
25. **The NDIA cannot rely on independent assessments alone to determine a participant's functional capacity or plan budgets.**

### **THE ISSUES**

#### **Independent assessments attached to plan budgets**

From what we understand from reading the information about plan budgets, planners are drafting participant plans based on draft budgets which are aligned to assessments (yet we still don't know how budgets will be allocated based on assessments). After the assessment the planner meets with the participant and discusses the draft plan and budget. It seems a pointless exercise to show a participant a draft budget as many participants are not familiar with the pricing guide and the cost of NDIS funded supports. The pricing guide gets updated around twice per year and there is no reference as to whether the new plans will reflect this in a participants' budget. The other issue with showing participants a draft budget before a draft plan is that it can only be changed under specific circumstances. Participants cannot ask for a review of a draft budget.

We cannot comprehend how a planner can draft a plan prior to having a conversation about what the participants goals are and what supports they need to support them in their daily life. It seems that there will be less value placed on a participant's goals and participants will have less choice and control about what supports they would like funded in their plan. This does not align with the objectives and principles of the NDIS Act 2013. SWAN is concerned that many reasonable and necessary supports that participants would like to have in their plan simply will not fit into their plan budget which has been drafted in a direct correlation to the independent assessment.

The NDIS is a not a one- size- fits -all model and this is especially the case with undiagnosed and rare genetic conditions. The proposed process is not participant focused and moves away from a personalised individualised approach which is what the NDIS was meant to be about. We fear that participants will not be happy with their plans as they won't adequately reflect their support needs or goals. This will lead to an increase in the number of reviews which come at a high emotional cost to participants and their families causing grief, high levels of frustration and anxiety. Not to mention an added expense to the NDIA!

### **May not be a true reflection of a person's functional capacity**

We are concerned that an independent assessment will not be a true indication of a person's functional capacity. The questions in the assessments lend themselves to being "black or white" answers. The assessments do not take into consideration the environment a participant might be in when completing the task e.g., they may be able to complete the task at home but not in the busy school environment. Even at the start of the PEDI-CAT, the assessor has to mark a box with regards to such things like walking devices and the options are: "walker, crutches, cane or, does not use walker, crutches or cane". There is no room to select "sometimes" or explain the circumstances.

There is a question for the assessor to complete "Has the person been diagnosed with ASD?" – there is no room to say – "awaiting diagnosis" or "traits of ASD" Many of our SWAN children have autistic traits as part of their genetic condition but they will not be able to complete the PEDI-CAT ASD.

### **Case study**

*"We were asked the question about walking up a flight of stairs – 'Walks up a flight of stairs without holding onto handrail. Please do not consider use of walking aids (walker, crutches or canes)'. I did not know how to answer it as my son can walk upstairs without holding onto the handrail, he just has to stop every second step to catch his breath so if it takes the average boy his age to walk up a flight of stairs 15 seconds, it might take my son well over a minute. There was no room for expansion on this question and it made me frustrated. I felt like my son didn't have the capacity to do the task if I answered 'no' yet I was so proud of the fact he had finally mastered going upstairs at his own pace without holding onto the handrail. How was I meant to answer this question, at the end of the day, stairs are still a struggle for him. I don't feel this question and many others captured his functional capacity because there was no room for expansion. As the test went on, I felt more and more frustrated and demoralised. How could someone know my son's capability in such a short snapshot that left no room for elaboration and conversation. To think this assessment was going to be linked to a plan budget that possibly won't be enough funding to support his goals, terrifies me".*

### **h. the circumstances in which a person may not be required to complete an independent assessment;**

#### **RECOMMENDATIONS:**

26. **When taking into consideration what constitutes a behaviour of concern, the NDIS recognise that either a participant, their family, specialist, or therapists is best placed to identify these. If behaviours of concern have the potential to arise or do arise, the independent assessment will need to be aborted immediately.**
27. **The NDIA should define what constitutes "significant risk and behaviour".**
28. **The participant should be able to dictate how many attempts they can have at an independent assessment per plan review.**

## THE ISSUES

### Behaviours of concern

If a participant is likely to be non-compliant, they should be excused from undertaking an independent assessment. Many SWAN children are unpredictable with their behaviour which are sometimes triggered by their rare genetic condition. Safety is an issue for many of our children and they may demonstrate behaviours of self-harm and/or harm to others. They may display signs of impaired mental health, including anxious behaviours or emotional outbursts. These may be triggered or exasperated by the assessment process. When safety is a concern for the participant or their family or a participant is in a heightened state, the participant or their representative should be in a position to request that the assessment be aborted immediately or not attempted at all. This should not have a negative impact on the amount of funding they receive in their plan for supports.

Behaviours of concern such as aggressive, sexual aggressive, self-harm and those in a heightened state of anxiety should be determined and identified by either the family or a professional such as a psychologist who knows the participant well.

### Significant risk and behaviour

It appears only a delegate can decide that an applicant does not need to complete an independent assessment where there is a risk to safety, or an assessment is deemed inaccessible or invalid. This is strange as surely a participant's family or support person would have a greater knowledge of what triggers aggressive and dangerous behaviour and understand a participant's emotional vulnerability and what constitutes as trauma for them, compared to someone they have never met. Severe behaviours of concern may be subjective – emotional trauma can arise after the event.

### The number of times an assessment can be completed

The participant should be able to decide on the number of times an independent assessment can be attempted per plan review. If a participant is unable to complete an assessment, it should not prevent them for getting the reasonable and necessary supports in their NDIS plan so they can meet or work towards their NDIS goals.

## **i. opportunities to review or challenge the outcomes of independent assessments;**

### **RECOMMENDATIONS:**

29. **The NDIA needs to be more transparent about the review process (or lack of it) for independent assessments if participants wish to challenge their assessment.**
30. **The NDIA need to allow independent assessment results to be reviewed more easily.**
31. **The NDIA needs to define what constitutes a “significant change” in a person’s capacity or circumstances.**
32. **The NDIA must be transparent about the grievance process for NDIS applicants or participants who are dissatisfied with an independent assessment, their assessor, or the assessor’s organisation.**

## THE ISSUES

### Review process

One of our major concerns is that there is no avenue to request a review of an independent assessment if you disagree it was a true reflection of a participant's functional capacity. This could impact eligibility to the scheme or significantly impact their plan budget. We believe this is wrong and independent assessment results should be able to be reviewed. The assigned budget aligned to a participant's plan as a direct result of these independent assessments may mean there is not enough funding to support their needs. Furthermore, the NDIA is yet to share evidence that supports functional capacity assessments as proven tools for determining support needs and budgets, or how these assessments would be translated into budgets.

The NDIA references being able to seek a second assessment where the assessment was not consistent with the independent assessment framework, or if the applicant has had a significant change to their functional capacity or circumstances, yet we could not find reference to this in the independent assessment framework as to what constitutes as "significant change" in a person's capacity or circumstances. This concerns us as it may be subjective.

It is unclear what the grievance process for NDIS applicants or participants is if they are dissatisfied with an independent assessment, their assessor, or the assessor's organisation. What does this complaints process look like? Will this form part of the quality assurance framework for the delivery of independent assessments? The fact that a delegate's decision not to grant an exception for an independent assessment will not be a reviewable decision is concerning.

We are concerned it will become harder to appeal a planning decision because support budgets are linked to independent assessment which cannot be appealed at the Administrative Appeals Tribunal. If participants do not have the funding in their plan to purchase the supports they need to meet their goals and aspirations, it will be very difficult to gain further funding without another independent assessment which will only be allowed under special circumstances.

Independent assessment results should be easier to appeal against. Participants need to be able to either request another independent assessment under less ridged appeal criteria or be able to request a review of the budget figure attached to their independent assessments if it is preventing them from getting the supports in their plan they need to be able to achieve the goals in their plan and aspirations.

Even the language used on the NDIA website is confusing for people around reviewing an independent assessment. For example, there is a question under the assessment process on the NDIA website that asks "What if I disagree with my assessment?" but then it goes onto say "if you don't agree with the decision we make based on your independent assessment, you can ask for a review of the decision". Yes, you can ask for a review of your plan BUT it is virtually impossible to ask for a review of your independent assessment. The question is misleading as participants might presume they can easily ask for a review of their independent assessment which is simply not the case under the current proposal.

- j. the appropriateness of independent assessments for particular cohorts of people with disability, including Aboriginal and Torres Strait Islander peoples, people from regional, rural and remote areas, and people from culturally and linguistically diverse backgrounds;**

### **RECOMMENDATIONS:**

33. **The NDIA should consider using assessments in Easy English that participants with intellectual disability can understand.**
34. **The NDIA needs to avoid using terminology in independent assessments that participants may not understand.**

## **THE ISSUES**

### **Independent assessments not in Easy English**

We are concerned that participants from culturally and linguistic diverse backgrounds and people with intellectual disability may not understand the questions they are being asked in the independent assessments. There is no reference to any of the assessments or draft plans or even final participants plans being presented in Easy English so participants can understand them. The assessments contain some “American” terminology that may not be familiar to people from linguistic diverse backgrounds.

### **Rural and Remote Areas**

Some of the questions in the assessments relate to things like: shopping carts, traffic lights and swimming pools which a child may never have been exposed to if they live in a rural or area. We do not feel the selected independent assessments tools are the most appropriate for people living in rural and remote areas as there will be a number of questions that will be irrelevant to this cohort of participants. The test has the capacity to make parents feel insecure and bad about the environment they are raising their SWAN child in and that can take an emotional toll on them as they may feel they are inadequate as they have not exposed their children to a number of environments or experiences.

### **Access to Technology**

From the information we received from the pilot assessments, we are led to believe that participants who choose to engage in a video health independent assessment (via video link), will be required to have good internet connectivity and an iPad size screen or larger. We are concerned that not every participant will have this option. Not every participant will want a stranger going into their home, not every participant wants to leave their house to visit a stranger, so a video link up might seem a good option, if you can afford the internet and have access to an iPad screen or larger. Once again, we will see participants from linguistically diverse backgrounds or lower socio economics backgrounds disadvantaged.

### **Environment**

According to the pilot program, independent assessments undertaken at home need to be completed in a quiet comfortable space with good lighting and with minimal distractions. We know this is not always possible, particularly for our SWAN families who may have other young children at home. Not everyone has the luxury of a quiet comfortable space with good lighting.

**k. the appropriateness of independent assessments for people with particular disability types, including psychosocial disability; and**

**RECOMMENDATIONS:**

35. **The NDIA should not have a one size fits all approach to independent assessments when determining a participant's functional capacity, particularly when assessing a participant with an undiagnosed or rare genetic condition.**
36. **The NDIA does not use independent assessments that involve parents being separated from their children.**

**THE ISSUES**

**Not appropriate for children with undiagnosed and rare genetic conditions**

SWAN is very concerned that the mandatory introduction of independent assessments will not work for our community, particularly as plan budgets will be aligned with independent assessment results.

Undiagnosed and rare genetic conditions are often episodic and/or have fluctuating disabilities along with chronic health concerns. Progressive conditions are not uncommon among our members and daily function can decline very rapidly. Symptoms may be lacking or masked at the time of the independent assessments but that does not mean they do not exist. On a difficult day, our children require an intensive level of support by either a family member or someone who knows the child well such as a highly skilled, trusted and trained support worker or therapist.

We are struggling to understand how an independent assessment can identify our children's functional capacity when they can fluctuate so much and so much is unknown about their genetic condition. And therein lies one of the issues for our SWAN families with accessing and gaining supports from the NDIS. Even clinicians often do not know the implications of many rare genetic conditions because they may have only been discovered in the last few years and are, as the name suggests, "rare".

We are concerned about the Vineland assessment which asks for someone who knows the participant well, such as the parent to complete the test away from their child. How can assessors ask for parents to remove their child from the room whilst they complete the test? Many of our SWAN children have separation anxiety and will not want to be away from their parents. It is a safety concern for many SWAN children to be left alone. Who will fund a carer to look after the child whilst the parent completes the test? And will the carer be someone known? All these questions just add to the worries, anxiety and frustration already felt by our parents.

**l. any other related matters**

**RECOMMENDATIONS:**

37. **The NDIA stop presuming that independent assessments will become part of the NDIS when the legislation is yet to be passed by parliament.**
38. **Ensure participants can receive a full copy of their assessment report not just a summary if they request it.**

## **THE ISSUES**

### **Misleading information**

We have concerns that the legislation is yet to be drafted around the mandatory use of independent assessments yet the NDIS is presuming independent assessments will become mandatory in most cases. This has been evident by seeing information around independent assessments when some of our members have participated in the participant portal review consultations and even by the way the NDIA wrote their own consultation paper requesting submissions on independent assessments.

### **Prematurely exit the scheme**

SWAN is concerned that by introducing mandatory independent assessments a number of participants will be forced to exit the scheme prematurely and without the appropriate transition in place to assist them with accessing community supports. We fear they may experience a decrease in their functional capacity without enough supports in place. This moves away from the core purpose of the NDIS, to support participants (who by definition have a significant and permanent disability) for life.

### **Full independent assessment report**

If mandatory independent assessments are introduced, participants should be able to receive a full copy of their assessment results and report and not just a summary report.



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