



Syndromes Without A Name (SWAN) Australia

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Submissions

The National Disability Insurance Agency (NDIA)

20 February 2021

Re: Access and Eligibility Policy for Independent Assessments

To whom it may concern,

Thank you for the opportunity to provide feedback on the access and eligibility policy for independent assessments submission. SWAN Australia provides information, support and systemic advocacy for families caring for a child with an undiagnosed or rare genetic condition. About half of our families have children under the age of ten years old so this consultation paper is very relevant for our families.

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 NDIA.

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. Many of our SWAN children are thriving thanks to the NDIS.

We have addressed the consultation questions on the following pages along with our key issues and recommendations.

Kind regards

Heather Renton
Chief Executive Officer
Syndromes Without A Name (SWAN) Australia

KEY ISSUES AND RECOMMENDATIONS

<p>Consultation and pilot programs</p>	<p>The NDIA should consult with people with disabilities and their families, disability organisations and people who work in the disability industry before making changes to the NDIS.</p> <p>Pilot programs should be developed in consultation with people with disability and the disability sector. They should be reviewed, completed and assessed by people with disability and the sector, prior to going out for further consultation.</p>
<p>Presumptions</p>	<p>The NDIA has approached independent assessments as if the new legislation has been adopted. We consider this to be misleading and may be causing concern to participants unnecessarily. We recommend the NDIA stop presuming that the legislation changes around independent assessments and other changes to the NDIA Act 2013 will be passed by the government.</p>
<p>Better use of funding</p>	<p>Funds could be better spent on improving the NDIS rather than introducing mandatory independent assessments. These would include providing participants with the supports they need to achieve their NDIS goals and training staff, so they have a better understanding of disability (including undiagnosed and rare genetic conditions).</p>
<p>Review process</p>	<p>If mandatory independent assessments are introduced there needs to be a review process so participants can appeal their results from an independent assessment if they believe them not a true representation of their functional capacity. There is too much ambiguity that needs to be explained around risk and significant behaviours and how they allocate supports when a participant is non-compliant in an assessment.</p> <p>Participants can only request a second assessment where the assessment was not consistent with the independent assessment framework, or if there has been a significant change to their functional capacity or circumstances. We disagree with this decision as participants can perform better on some days than others.</p> <p>Unless another independent assessment shows a change in functional capacity, it will be very difficult to gain additional funds in a participant's plan to support their needs and goals. The AAT cannot review independent assessments so it will be difficult to gain more funding as budgets are linked to independent assessments. SWAN considers this a big flaw in the review process because it is favours the NDIA all the way!</p> <p>SWAN recommends that independent assessments 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 preventing them from getting the supports in their plan they need to be able to achieve their NDIS goals.</p>
<p>Evidence letters and reports need to be considered</p>	<p>Reports and letters provided to the NDIS that are written by clinicians, allied health professionals and service providers need to be taken into consideration when allocating support and funding in plans. These reports are written by "experts" in their field. These service providers have a much better understanding of participants' support needs and goals than someone who has never worked with the participant. This is particularly important when supporting participants who have an undiagnosed or rare genetic condition, as often there is very little information about the condition.</p>

Support budgets	Support budgets should not be allocated solely on the results of independent assessments. Instead, conversations need to be had with participants or their representatives to find out from them how they wish to be supported and professional reports need to be considered.
Transparency	<p>The NDIA needs to be more transparent about independent assessments, including how NDIS assessments will be independent when the NDIA is the one in charge of the tender process.</p> <p>The NDIA needs to state the maximum number of times they will allocate for an independent assessment to be completed.</p> <p>The NDIA needs to say what the criteria and professional qualifications are for administrating independent assessments as it currently states it is not limited to the listed professions.</p>
Thin markets	The NDIA should state how they intend to address the shortage of allied health professionals, particularly in rural areas, due to allied health professionals leaving their profession to become independent assessors.

CONSULTATION QUESTIONS

Overview of Independent Assessments

SWAN is vigorously opposed to independent assessments in most scenarios and hope that by doing this consultation that the NDIA realise that the introduction of mandatory independent assessments is not the way to improve the NDIS. We feel the money would be better spent in other areas of the NDIS such as on the participants supports (many of our members have inadequate plans), or on staff training as many ECEI Coordinators, LAC and Planners have little understanding of what is like to be a participant with an undiagnosed or rare genetic condition.

SWAN is disappointed that the NDIS plans to introduce independent assessments without the pilot program fully completed or enough consultation lead time. To put a consultation out just prior to Christmas when everyone is exhausted from a very tough year and want responses a few weeks after people return to work is insensitive. Like other disability organisations, SWAN feels disappointed in the approach and questions the degree of consultation that the NDIS wants to engage in.

The Tune review supported providing the NDIA with discretionary powers if a prospective person or participant undergoes an assessment for the purposes of decision-making under the NDIS Act. There was no mention of functional assessments being used at the review meeting and that was not the intention of Tune recommendation 7.

We have concerns that the legislation around independent assessments has not been passed in parliament yet and the NDIS presumes that 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 this consultation paper is written.

Budgets from independent assessments should not be used to determine plan budgets alone. Instead, LAC's and Planners should be in a position to adjust budgets based on participants needs and individual reports so that participants can secure all the supports they need in their plan to assist them with meeting their plan goals and aspirations. It is unclear if this will be the case.

Reports and letters provided to the NDIS written by clinicians, allied health professionals, and service providers who are working with participants should be considered in the planning and budgeting process. These service providers should be classified as the "experts" in their field as they understand a participants support need. These experts often have a long-standing relationship with participants and have built trust with them over time. They are in a well placed position to identify supports and goals.

Planning meetings are meant to be two way conversations about what supports participants would like in their plan, and their goals and aspirations. From these conversations, budgets should be derived based on a participant's needs. Instead, the new approach the NDIA is recommending is that the LAC or Planners show participants a draft budget that has been derived mainly from their independent assessment and can only be changed under specific circumstances with very little avenue to review.

To SWAN 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.

The NDIS is proposing participants have a planning meeting after their draft plan has been developed by the LAC or Planner and shown to a participant. Not every participant will have the capacity to read it, let alone understand a draft plan. These should be available in Easy English when the plan is in draft format and again when the plan is finalised for a person who requires it, but the NDIA has made no reference to whether they will.

The planning meeting may focus on trying to fit supports into budgets if the draft supports in their plan are not what the participant wants. This is concerning for our SWAN families who have a child with unpredictable needs. It may mean a participant may not receive the supports they need to maintain or increase their child's functional capacity or the budget in their plan to purchase the supports they need. The NDIS is meant to be tailored to the individual participant's needs and we worried that this will no longer be the case if the proposed changes go ahead. Participants have to be involved in planning discussions prior to receiving a copy of their draft plan.

We believe plans will be more difficult to be appealed because of the difficulty in reviewing plan budgets linked to independent assessments. It is very difficult to lodge a review of an independent assessment. A second assessment will only be granted where the assessment was not consistent with the independent assessment framework, or if there has been a significant change to a person's functional capacity or circumstances. So unless another independent assessment shows a change in functional capacity, it will be very difficult to gain additional funds in participants plan to support their needs and help participants meet their NDIS goals. Even if participants lodge an appeal at the AAT, they cannot review independent assessments so it will be difficult to gain more funding as budgets are linked to independent assessments. Independent assessments should be easier to appeal if a participant believes they have not accurately assessed their functional capacity. We think the decision to make the review process so difficult is skewed towards the NDIA all the way!

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 and aspirations.

Learning and Access to the NDIS

People struggle to even learn about the NDIS and how to access the scheme. Once you have submitted reports to access the scheme, the NDIS will arrange an independent assessment to confirm you meet the scheme's criteria. One of the key issues with that process is that many participants cannot afford to pay for reports upfront so they may be disadvantaged.

SWAN does not have issues with removing the scheme access lists in the operational guidelines as we considered them to be unfair. Some genetic conditions were listed but most were not. We realise it is impractical to list over 3500 genetic disorders that cause disability but to list a few so people with those conditions gained easier access to the NDIS, made it more difficult for our SWAN families.

SWAN members are sometimes denied access to the NDIS. The NDIS Act 2013 is very clear in setting out the scheme's access requirements, yet even when our SWAN families have one or more impairment; intellectual, cognitive, neurological, sensory or physical impairments that are likely to be permanent they have still been declined onto the scheme.

One of our SWAN families has three children, two were on the NDIS because they accessed the scheme under the ECEI requirements. Their third child was over seven, so did not qualify under ECEI and was denied access to the scheme, despite showing similar symptoms and disability to their siblings. We can only presume that they were denied entry to the scheme because they had an undiagnosed rare genetic condition because the access team did not understand the complexities of their condition because some of the symptoms were episodic. The lack of awareness and training of this team has caused problems for some of our SWAN families.

One of the issues we know exists for our SWAN families is that the NDIS sometimes struggles to understand medical reports. For example, if one of our members submits a lab report with their application which states “most likely pathological cause of the genetic condition to a gene change on the KAT6A gene”, the access team would be unlikely to have any idea what that means or its possible impacts on functional capacity. And there lies one of the issues with undiagnosed and rare genetic conditions. Even clinicians often do not know the implications of many rare diseases because they may have only been discovered in a few years and are, as the name suggests they are “rare”. Our members can not always provide information about the rare condition that may lead to more complicated health conditions and disability occurring. And then we have the other issue where we hear that our families have submitted medical reports or allied health reports and the NDIS has not read them. We even had an example of this when an NDIS reviewer phoned a SWAN participant’s parent to conduct S100 review. The parent asked the reviewer what they knew about their child’s rare condition and the reviewer replied that they knew nothing about it. They had clearly not read the plain English fact sheet about the rare genetic condition that the parent had uploaded to their child’s NDIS portal. A LAC told one of our members, “we can submit reports, but there is no guarantee the Planners will read them”. There needs to be greater assurance that Planners take evidence provided in reports into consideration when preparing plan budgets and independent assessments should not be relied on solely for budgeting purposes.

Because rare conditions are so rare, clinicians cannot always guarantee that disability will be permanent. Clinical trials, research, gene therapies and gene editing techniques such as CRISPR-Cas9 are evolving all the time.

When looking at the distinction in medical terms, such as chronic, acute and palliative care, these terms should be explained to patients by medical experts, not the NDIS employees who will likely not have any medical training. The NDIS needs some level of understanding of these terms as they will come up in reports and planning meetings.

The NDIS should use reputable definitions for health conditions such as the World Health Organisation or government definitions. It is important to realise that there is a distinction between palliative care in adults and palliative care in children when you are discussing palliative care. They should use such definitions such as:

Chronic Condition

“Chronic conditions’ encompasses a broad range of chronic and complex health conditions across the spectrum of illness, including mental illness, trauma, disability and genetic disorders.”¹ “Chronic diseases are long lasting conditions with persistent effects.”²

Acute Conditions

“In a hospital or other medical environment, Acute Care is the opposite of chronic care and refers to care where there is time pressure. Where chronic care deals with patients that have long-term illnesses.”³

Paediatric Palliative Care

“Palliative care for children and young people with life-limiting conditions is an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite, and care through death and bereavement.”⁴

¹ <https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf>

² <https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/chronic-disease/overview>

³ <https://www.opencolleges.edu.au/careers/blog/what-acute-care-and-why-work-within-it>

⁴ <https://www.racgp.org.au/afp/2014/april/paediatric-palliative-care/>

Adult Palliative Care

"Palliative care supports people with life limiting illness and their families to live, die and grieve well."⁵

Undertaking an independent assessment

Many of our SWAN members have reported they are fearful of independent assessments. They are causing anxiety amongst participants and their families. Meeting with a stranger who does not know our child's strengths and weaknesses is of huge concern for our community. Our families have enough anxiety living with the unknown, and they don't need anything more to add to their worries. There is already too much unknown 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 can occur.

Parents have reported that they are concerned that their SWAN child will be non-compliant in their assessment. We are worried if this is the case as assessments are linked to plan budgets, where does it leave many of our SWAN participants? We don't know what the plan budget amount is for participants who receive a non compliant assessment. Will it be that NDIS just allocated an amount based on their review of reports and conversation at the planning meeting. If this is the case, why not just conduct a meeting this way in the first place and don't use independent assessments as these will be a waste of time and resources. The process is very confusing for our members.

On the NDIS website, it states "Your assessment will be free. The assessment will take around 3 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"⁶ 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 x 3-hour timeslots 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, which state the number of times you can meet with your assessor to complete the assessment tasks.

We are worried that families will struggle to select what health discipline to choose their independent from because of their child's complex disabilities. We think that some of the proposed assessments are best performed by a psychologist or educator rather than allied health professionals or others who has little experience conducting such assessments. In most cases, a multidisciplinary assessment would be required to provide a full understanding of the child's daily function.

SWAN is concerned about our parents with limited English who may need help with completing parts of these assessments, such as the Vineland test. We are worried that there may not be enough language prompts or in an Easy English version to help families understand the questions. From our knowledge of using interpreters in genomics projects, interpreters do not always translate information correctly and there is not always an equivalent word in English. Some of our members who have completed the pilot assessments have reported language issues. They reported that there was terminology in the assessments that they didn't understand such as "restrictive practice". Not understanding terminology could lead to inaccurate assessments taking place.

Life is difficult enough when you have a child with a rare genetic condition. Many of them already undergo extensive testing in the health system, our members do not want to undergo further testing that may be unnecessary. Many children have difficulty concentrating for extended periods and will be unable to participate actively in assessments and score "non-compliant". Families do not want to feel bad when their child cannot complete a task.

⁵ <https://www.pallcarevic.asn.au/families-patients/about-palliative-care-2/>

⁶ <https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-process>

We are concerned that an independent assessor might feel vulnerable or helpless when conducting an assessment, such as if one of our SWAN children has a seizure or an aggressive outburst and the assessment has to come to an abrupt halt. It can be confronting to be in these situations and we are assessors may leave assessments traumatised by what they have witnessed. They may not even feel comfortable with continuing with the assessment. It is unclear what will happen then. Will another stranger need to be introduced to continue the assessment, causing more angst for the participant and their families?

Independent Assessments will only demonstrate a child's capacity in the environment in which they are assessed. We are concerned that they will be unable to provide a comprehensive picture of functional capacity across settings, including at home, at school and in the community. How can social skills with peers possibly be assessed at home? And while a child may be able to perform a function at home, it may be very different at school or in other busy environments.

We are struggling to understand how assessors can be independent if the NDIA appoints them. We are concerned that the proposed assessors are from a range of health professionals but are not limited to the list specified by the NDIS. Does that mean a person with no qualifications in disability or health, or lived experience in disability can administer and interpret these assessments? Will we see these assessments be administered by LAC's and Planners, many of whom have no 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 to meet their NDIS goals.

If allied health professionals are being used as independent assessors, it will leave a shortfall of allied health professionals for participants to access as part of their capacity building supports. We already know there is a shortage of these service providers in rural areas.

Many undiagnosed and rare genetic conditions have autism or autistic traits as part of their symptoms, where high levels of anxiety impact their functional capacity. Will a participant with autistic traits have a choice as to whether they are assessed with the PEDICAT (Speedy) or PEDICAT ASD (Speedy)? Depending on circumstances, a participant with autistic traits, may appear more autistic than a person with an ASD diagnosis at times.

SWAN is concerned that the introduction of independent assessments will be used as a way for participants to exit the scheme prematurely, which shifts away from where you are a participant for life if you have a permanent disability.

Exemptions

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, 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 stopped or not attempted at all. This should not have a negative impact on the amount of funding they receive in their plan for supports.

Review process

One of our major concerns is that there is no avenue to request a review if you disagree with the independent assessment, which could impact eligibility or determine your plan budget. We believe this is wrong. The assigned budget aligned to your plan as a direct result of these independent assessments may not be enough to support a participant's 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.

It is important that the NDIS consider "expert" reports from service providers that support participants. They are better positioned to understand the supports participants needs in either maintaining or improving their functional capacity. There is still so much unknown about rare genetic conditions that an assessment such as those proposed by the NDIS will not capture many of our SWAN children and their families' needs. Some rare diseases 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.

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 the reference in the independent assessment framework as to what constitutes as "significant change" in a person's capacity or circumstances and this concerns us as it may be subjective.

It appears only a delegate can make a decision 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.

It is unclear about the grievance process for applicants who are dissatisfied with an independent assessment, their assessor, or the assessor 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 AAT. 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 are only allowed under special circumstances.

Independent assessments 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 preventing them from getting the supports in their plan they need to be able to achieve the goals in their plan and aspirations.

Communications and accessibility of information

There is limited information about how these assessments will be administered if families have little grasp of English or require the assessments to be provided in Easy English or with visual supports? SWAN doesn't believe that the NDIA has spent enough time considering participants' needs and values from culturally diverse backgrounds. From our conversations with our families from some cultures, they fear they will be sent back to their homeland by the government if their child does not perform well in these assessments. This adds to their already heightened anxiety and stress levels.

Participants should be able to choose between receiving their independent assessment either as a summary report or a full report. The NDIS has to be transparent about how they propose to allocate support budgets to independent assessments and how much will be allocated to the different assessments tests and their scores.