



Syndromes Without A Name (SWAN) Australia

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Submissions

The National Disability Insurance Agency (NDIA)

20 February 2021

Re: NDIS Planning Policy for Personalised Budgets and Plan Flexibility

To whom it may concern,

Thank for the opportunity to provide feedback on the Planning Policy for Personalised Budgets and Plan Flexibility 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>Planning Process and Budgets</p>	<p>If independent assessments are to be mandated, we recommend that support budgets not be determined by the results of independent assessments alone. 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.</p>
<p>Planning Meeting</p>	<p>Planning meetings should place participants at the centre and be led by participants or their representatives. Participants or their representative should be supported to lead a discussion on what supports they would like in their plan and what their goals and aspirations are. Reports supplied by professionals also need to be considered and taken into account when developing plan budgets as they are the “experts” in their field and are well placed in understanding participants’ needs.</p> <p>Draft plans cannot be predetermined prior to having a planning conversation with the participant or there representative. The planning meeting needs to be about discussing participants support needs, goals and aspirations and then a draft plan derived by the LAC or Planner for further discussion. The meeting should not be used to work out how the budget can best meet a participant’s needs.</p>
<p>Plan Implementation and Usage</p>	<p>Funds should not be released on a monthly or quarterly basis. This will not work for SWAN families with vulnerable children who may need intensive therapies at certain times of the year and/or may not be able to access therapies at other times during the year, i.e., for reason of illness or needing to take a break over holidays. To ensure equitable access and plan flexibility, funds must be reimbursed as they are spent, without limitation.</p>
<p>Review Process</p>	<p>There needs to be a clear and fair review process if mandatory independent assessments are introduced if they believe them not a true representation of a participant’s functional capacity. Ambiguity around them needs to be explained, particularly around risk and significant behaviours and how they allocate supports when a participant is non-compliant in an assessment.</p> <p>Participants should be able to request a second independent assessment if they, or their representative believe the assessment was not an accurate representation of their “usual” functional capacity.</p> <p>It will be very difficult to gain additional funds in a participant’s plan to support their needs if independent assessments are solely used to develop plan budgets as independent assessments themselves cannot be appealed and they are linked to plan budgets. We recommend a fairer and transparent review process where participants can appeal their independent assessments or request additional funding to support their needs and assist them with meeting their NDIS goals and aspirations.</p>

CONSULTATION OVERVIEW

Planning Process and Budgets

SWAN is concerned about the planning process for NDIS plans being driven by budgets based on independent assessments. We are worried that independent assessments will not provide enough detail and context about people's lives. They will relegate and devalue people with disabilities and their families' expertise if there is not enough consultation with participants or their representative when developing plan budgets.

Budgets associated with independent assessments **should not be used to determine plan budgets alone**. If independent assessments are to be mandated, LAC's and Planners should be able to adjust budgets based on participants' needs and individual service providers 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. Independent assessments need to be considered with less weighting and more emphasis put on a discussion with participants about understanding their support needs and goals and specialist reports.

The NDIA is yet to share evidence that supports functional capacity assessments as proven tools for determining support needs and budgets. Nor has it demonstrated how these assessments would be translated into budgets or even what these budgets are. We cannot have a one size fits all approach to budgets for plans. The NDIS is meant to be individualised and tailored to a participant support needs, goals and aspirations. This will be more difficult to achieve if budgets are linked to individual assessments alone, and the supports are then built around the budget limitations. We are concerned that the amount of funding needed for a participant to reach their goals and receive requested supports will not be within the allocated plan budget. We fear it will be difficult to increase the budget to include more supports unless a new independent assessment is undertaken, which is only permitted under very limited circumstances.

SWAN represents many vulnerable children with undiagnosed and rare genetic conditions. Some of these conditions are regressive, progressive and episodic. We are very concerned that if a participant is having a "good" day when they complete their independent assessment, it might not be a true representation of their functional capacity and their plan budget will not accurately reflect their support needs. Independent assessments alone do not understand genetic conditions and how they impact our community across different settings.

There seems little point in showing participants or their representatives their budget as many 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 their budget.

There is an issue with showing participants their draft budget before their draft plan if it can only be changed under specific circumstances. Participants cannot ask for a review of a draft budget, which may lead to more participants requesting reviews of their plans as plan budgets may not align with participants needs. If reviews increase by a set percentage each month, an advisory council that meets on a monthly basis will need to readjust the budget allocation based on independent assessments.

We do not support plan budgets being released at certain intervals throughout the plan. Funding should be reimbursed as it is spent without limitations. The NDIS are trying to limit the amount of control that participants have with how often they spend and how they spend funding. This will not work for our families!

Our SWAN families are vulnerable. Frequently our children are in hospital and unable to spend their NDIS funding. Families may not access therapy and other supports whilst their child is in hospital. Many families choose to give their child a much needed break from therapy over school holidays and not access many capacity building supports in that time. Sometime families would prefer to do intensive therapy and if they don't have enough funding released for that month, they will have difficulty paying for the support. At times our families can find it difficult to access supports so may not be able to spend some of their plan budget until well after their plan starts.

Planning Meetings

It is proposed that draft budgets and draft plans are then sent to participants prior to their planning meeting. We are concerned that not everyone will have the capacity to read and understand them. These draft plans should be available in Easy English but the NDIA has made no reference to whether they will.

For many SWAN families preparing for their child's planning meeting based around a draft budget and draft plans will be difficult. Our concern is that our families who cannot advocate for themselves could too easily accept their draft plan as their child's final plan. SWAN fears that there may not be adequate discussion around a participant's support needs and goals with their LAC or Planner.

The NDIA proposal is to draft a plan for participants prior to a planning meeting largely based on the budget attached to an independent assessment result, rather than first discussing participants' needs and goals with them or their representative. It seems to us that the NDIA are trying to shy away from a participant led scheme and are happy to pre-empt participants needs without a conversation. This goes against the philosophy of the scheme as this should be driven by participants or their representatives, **not** the LAC or Planner.

We are baffled as to why a LAC or Planner would draft a plan without first having a conversation with a participant or their representative about what support needs they require or their goals or aspirations. This is a waste of time if they do not know the participant, they may be guessing and not understand their needs at all. Draft plans need to be shown to participants after a planning conversation has taken place between the LAC or Planner and the participant. Then there should be the opportunity for further discussion. Reports written by service providers also need to be considered as these people are "experts" in their field and often have long standing relationships with participants.

It seems that participants' will have the planning meeting and then have to work backwards 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 not have the budget in their plan to purchase the supports they need.

Participants and their representatives should be at the centre of planning meetings. These meeting should be about conversation and supporting participants to help planners understand their support needs, goals and aspirations. They cannot just be about how to get budgets to fit with what the Planner thinks is the ideal plan. Given it will likely be the first time they have met with the participant, how could they possibly know what supports the person wants and needs in their plan. Presuming this, may make participants upset and cause greater anxiety for them in which is often a very stressful time for a participant and their families lives.

SWAN is concerned that the quality of NDIS plans depends on participants' or their representatives' capacity to understand the NDIS and advocate for their support needs. We know there are inconsistency with plans and often, it comes down to the knowledge and expertise of a LAC and Planner. This is very apparent with plans for undiagnosed and rare diseases, their skill and knowledge need to improve. We had one SWAN member who had a child who was the same age as another SWAN child, with very similar needs and functional capacity. One met with a LAC for their planning meeting, the other with a NDIS Planner. The member who met with the Planner received double the funding compared to the member who met with the LAC, despite both members using a very similar preplanning document that highlighted their needs. Both had the same goals. This just confirmed the inconsistency with the scheme. More staff training has to occur so they can gain a better understanding of participants needs.

Plan lengths should be discussed with participants at the meeting stage, so they can meet participants needs. Some participants might not want a longer plan, particularly if their condition is episodic, fluctuates and may lead to deterioration of their functional capacity.

Plan Implementation and Usage

Support coordination and LAC's will need to support people to use their new plan flexibly and if desired more innovatively. Many participants require an engaged LAC or support coordinator to assist them with utilising their plan. However, we have heard, it is difficult for participants who self manage their plan to receive support coordination. People experiencing disadvantage, isolation and financial hardship may find it harder to use their plan without support. And we know people have difficulty finding supports in thin markets for services, particularly in rural, regional and high-growth areas. Even in metropolitan areas, for many of our SWAN families, appointments with allied health professionals after school or Saturdays are few and far between. Most of the well regarded allied health professionals have long waiting lists. This creates problems for people being able to spend their funding.

Good support coordinators who have a good understanding of SWAN children are difficult to find. Many of them have a limited understanding of undiagnosed and rare genetic conditions, and in particular their impacts on functional capacity. There are many participants who could benefit from support coordination in their plan but are not receiving it. They then struggle to understand their plan and find supports.

We don't think there is enough allocated time for LAC's to assist participants with understanding their plan. It is not unheard of for participants to contact them without a response. This is often because the LAC has left their role but the participant is unaware they are no longer their LAC. There seems to be a very high staff turnover. A participant's new LAC's may be slow to introduce themselves and we often hear that there is no interaction with a new LAC until it is time to set up a planning meeting.

It would be helpful if plans could be set out with examples specific to the participant's goals to make it easier for participants to understand what supports they can purchase with their plan. We are concerned that there may not be enough structure in their plans for some participants, and they may struggle to know what supports they can spend their plan budget on.

The pricing guide is long, not laid out well and difficult to read. The language in it, differs to that of plans and the portal. Greater consistency of more intuitive language needs to be used around Core, Capacity Building and Capital supports and more examples given.

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.

If independent assessments are to be mandated, it is important that the NDIS also consider "expert" reports from service providers that support participants, particularly when planning budgets and allocating supports in plans. 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 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. However, 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. 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 you take the review to the AAT, they cannot review independent assessments so it will be difficult to gain more funding as budgets are linked to independent assessments. 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. SWAN considers this to be non-sensical and wholly inequitable!

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.

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