



Syndromes Without A Name (SWAN) Australia

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NDIS Consultations
Department of Social Services
GPO Box 9820
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30 October 2019

Mr Tune AO PSM,

RE: The NDIS Act Review and NDIS Participant Service Guarantee Discussion Paper

Thank you for considering our submission that represents the NDIS planning experience of many of our Syndromes Without A Name (SWAN) Australia families who have children on the National Disability Insurance Scheme (NDIS).

Background

About Syndromes Without A Name (SWAN) Australia

Syndromes Without A Name (SWAN) Australia is a not for profit organisation and the peak body supporting 440 families who care for a child with an undiagnosed or rare genetic condition, many of whom have disabilities. Our mission is to support and empower SWAN families to ensure no one feels unsupported or isolated on their journey. We provide opportunities for our members to engage in peer-to-peer support activities, workshops and events. We aim to limit the isolation, frustration and anxiety often felt by SWAN families.

We have a parent support telephone line that receives many questions about the NDIS and, in particular, around planning issues experienced by our parents when requesting “reasonable and necessary” supports for their SWAN child under the NDIS. SWAN itself is not a registered NDIS provider and offers NDIS information and support as a free service to its members.

We have addressed the suggested submission headings and questions on the subsequent pages and have included our key recommendations. We would be happy to discuss the content of this submission further.

Yours sincerely

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

Key Recommendations:

Principals for the NDIA service standards

- NDIS and LACs require hands on training in a range of disabilities with regards to understanding how a disability impacts people lives.
- Flexibility needs to be applied when funding is a matter of urgency, with requirements to review urgent cases within 7 days of the request.
- Accountability and transparency need to be demonstrated by the NDIS, so participants understand why funding requests are rejected if they do not meet the criteria of section 34 of the NDIS Act 2013.

Eligibility and Access

- Review the use of accessibility lists in the Operational Guidelines as they can discriminate against rare genetic conditions.
- Include reference groups to provide information on rare genetic conditions to address eligibility and access criteria concerns.
- Provide templates and useful information to clinicians, GP's and allied health professionals to assist them with writing letters of support for participants accessing the scheme.

Planning Process

- Improve training for LACs and NDIS Planners to ensure they have a thorough understanding of a range of disabilities.
- Ensure that evidence provided is read, understood and acted upon.
- Introduce a consistent approach to decisions making and a more defined approach to what is considered "reasonable and necessary", including for different stages of development and life.
- Participants with undiagnosed and complex rare genetic diseases should be eligible for the complex needs support pathways.
- Participants to have their planning meeting with a planner rather than a LAC and LACs should act as support coordinators and plan interpreters. Plan review meetings should be held with senior NDIA Planners.
- Introduction of draft plans and have the option to comment, provide further evidence if required and make changes together with the NDIS Planner if participants are not happy with their plan.
- Light touch reviews where a participant can have their plan adjusted slightly without going through a review of a reviewable decision.
- Use consistent language in plans – it should be the same terminology on the portal, in the pricing guide and on a participant plan.

Key Recommendations:

Appeals

- The length of time the NDIA respond to review of reviewable decisions needs to be revised and the words “reasonably practical” removed from the NDIS Act 2013 and replaced with definitive number of days.
- LACs and NDIS Planners to be able to make light touch reviews to plans to avoid reviews.
- Participants need to be supported to make appeals, not discouraged.
- Participants should not risk losing supports if their plan is appealed.
- Participants should be able to only request certain sections of the plan to be reviewed as part of the appeals process rather than the whole plan.
- Too many cases are settled just prior to going to the ATT to avoid setting precedents – this needs to change and there needs to be transparent data around this.
- A fairer system – the NDIA uses lawyers to debate appeals, participants have to self-fund their own legal services or engage advocacy agencies if they are not already at capacity.

Legislation

- Terminology such as “reasonably practical” need to be removed from the NDIS Act 2013 and replaced with definite time frames.
- It must be compulsory for board members to have some lived experience of disability, either personally or through a family member.
- Section 48 of the NDIS Act 2013 should include the introduction of *Urgent reviews* to support participants with life limiting conditions.
- Have clear guidelines on Section 48 of the NDIS Act 2013 as to what constitutes “reasonable and necessary”

Possible principles for NDIA service standards

Key discussion questions:

- 1. Which of the above principles do you think are important for the NDIA to adhere to, and why?**

All the listed principals are important. SWAN has commented on each principal below:

Timely

Plan reviews need to be prompt to ensure participants don't experience funding gaps in their plans. Currently there is still a back log of plan reviews that leave participants with no firm idea of when their review will be held. This can have an impact on paying and keeping support workers if participants don't know when their plan will be reviewed.

Engaged

It is absolutely vital that the NDIA engage with people living with a disability, their families and carers when developing policy and operational procedures and processes. These people are living with disability every day.

The NDIS must also be equitable. List A and List B of the operational guidelines select certain conditions to make entry into the NDIS easier for those people with those conditions. Rare Diseases as a collective, however, affect more people than diabetes and constitute 6-8% of the population, yet most of these conditions are not included on the Lists of the Operational Guidelines. The NDIS is intended to provide support to all people with significant and permanent disabilities, caution must be taken to ensure it does not end up providing access only to people with more common or known disabilities (as has occurred in the past).

Expert

Training for NDIS staff is required in order for them to fully understand (or learn how to access an understanding of) participants' conditions and situations so that participants get much needed and requested supports in their plan. The expertise and qualifications of Local Area Coordinators (LACs) and NDIS Planners vary considerably. There are no formal qualifications required to be an NDIS Planner, as is evidenced by variance in knowledge and expertise of LACs that work for different organisations. It is clear that not enough support, education or training of LACs has taken place. If participants are to get the best plans to support their needs, planners need to have a first-hand experience of disability.

Connected

SWAN believes LACs or NDIS Planners need to understand the different disability groups they are writing plans for. Without an in depth understanding of Rare Disease participants, including those living with complex disabilities and life limiting conditions, SWAN families will continue to miss out on the supports they need.

Valued

SWAN families are often the expert when it comes to their child's undiagnosed or rare genetic condition. For SWAN participants to get the best and most supportive plan, SWAN parents and carers need to be listened to and valued as equal partners in planning meetings.

Decisions are made on merit

It is important for any decisions made by the NDIS are made with good reason and are fully justified. If evidence is not accepted and/or requested funding is refused the NDIS needs to be transparent as to the reasons why. If further evidence is required, the participant should be accorded the opportunity to obtain that evidence before a decision is made. It is understandable that evidence may be required to support the funding request but sometimes the voice of an “expert” – the parent or carer - should be just as valued and carry as much weight as a report from an expert in their field.

Accessible

NDIS literature needs to be provided in accessible format so participants can understand the information required to write a pre-plan (planning document in preparation for their planning meeting), understand what is being asked of them in a planning meeting, and interpret and understand their plan once it is approved. Without accessible information, the scheme will fall significantly short of participants living a full life under the NDIS. The NDIS needs to have an Easy English version of their website.

2. In your experience with the NDIA, do you think they fulfilled the above principles? If not, how are they falling short?

Timely

A decision around access into the scheme should be made within 14 days not within 21 days as stated in Section 21 of the NDIS Act 2013. Supports are crucial for SWAN families who have children with undiagnosed and rare genetic conditions particularly those with life limiting conditions.

The NDIA need to make decisions in a timely and responsive manner. SWAN has suggested below amendments to the number of days to what was listed in Appendix A of the NDIS Act 2013 and also added new clauses in italics:

- Once the NDIA has appropriate information, Access Requests are made in **14** days.
- Participants are offered a planning meeting within **28** days of receiving their access met decision.
- First plan approvals take less than **21** days after their access decision.
- *Draft plans are submitted to participants within 7 days of their planning meeting.*
- *Final plans are submitted for approval 7 days after a participant has reviewed their draft plan and provided feedback.*
- Plans are approved within **7** days of the approved draft plan being submitted, following the provision of all necessary evidence.
- Plan amendments are considered within **14** days of the request.
- Plans involving SDA or AT requests are made within **21** days of the information being provided.
- Participants who request an internal review of a decision are contacted within **14** days of the request.
- *Review of reviewable decisions planning meetings are held within 28 days of being requested*
- *Decisions of review of reviewable decisions to be made within 7 days of the review meeting taking place*

- *Urgent review meeting requests to be approved within 7 days with an urgent planning meeting to be followed within 7 days of the request, following the provision of all necessary evidence.*

Engaged

People living with a disability, their families and carers can offer valuable firsthand experience and feedback about utilising the NDIS and provide insight as to what is and is not working well. Nobody understands disability as well as someone living with it day in and day out and this is where the NDIS falls short as many of the LACs and NDIS Planners have no lived experience of disability.

Expert

Many LACs and NDIS Planners, had no life experience of disability, qualifications or even experience with working with people with disabilities. The lack of experience and qualifications of LACs and NDIS Planners is clearly reflected in the number of plans that need to be reviewed. Many SWAN families reported that their plans did not have adequate funding and supports in place for their children to even meet their NDIS goals.

We estimate that 30% of SWAN families have requested a review of a reviewable decision as a direct result of not having adequate funding for their much needed supports, therapy and equipment in their plan. This is particularly the case when applying for equipment for those children aged under five years old.

We do not expect every LAC or NDIS Planner to know something about every one of the estimated 7000 rare diseases but we do expect them to have the training as to where they can seek further information about the impact of a particular undiagnosed or rare genetic condition has on a participant.

Direct experience with disability and complex special needs in children should be required in order for LACs and NDIS Planners to have “on the ground” day-to-day knowledge of the challenges faced by SWAN families in caring for their child. No written descriptions can replace the direct experience of the constant daily challenges these children and their families face. This is especially relevant in relation to the constantly and rapidly changing needs of SWAN children as they grow and develop with their complex special needs. An appreciation of how different this is to a typical developing child is essential for the planners to grasp. A reference group could assist in educating NDIS Planners around the complexities of rare diseases and complex issues.

Well trained NDIS Planners should be conducting plan reviews and not LACs. LACs should act in a support coordination role and also be responsible for interpreting a participant’s plan once they are approved. Many LAC’s do not have enough knowledge of the NDIS Act 2013, Operation Guidelines, and the rules or quality and safeguards standards to be meeting with participants and developing plans.

Connected

SWAN does not believe LACs or NDIS Planners are connected enough with Rare Disease participants who have significant disabilities, complex support needs or mental health issues. LACs and NDIS Planners are not offered any training with the Rare Disease Support groups to try and understand more about rare disease and how disability impacts them. The rare disease field is constantly changing with advances in genetic and genomic testing and LACs and NDIS planners should be encouraged to stay informed of any significant changes in this area and be guided by rare disease experts about the impact they can have on the daily lives of their participants. Health and disability are not black and white areas and they need to overlap as does disability and education.

Valued

SWAN does not believe that the contribution that SWAN participants and their families can make at their planning meeting is valued enough. Parents and carers need to be respected as often they know what is best for their child. Participant and carers statements need to be read and understood as they reflect the participants and carers situation. In our experienced they are often disregarded after the first planning meetings. Allied health professionals reports also need to be read and considered when making decisions. Too many times “expert” reports are requested at a cost to a participant and then disregarded and sometimes not even read by the LAC or NDIS Planner. When funding decisions are made that are contrary to recommendations in these reports, reasons are rarely given.

Decisions are made on merit

Decisions are falling short because participants are not provided feedback as to why a requested support is declined. If there is not enough evidence to support the request this needs to be relayed to the participant. Funding has to be “reasonable and necessary” in accordance with section 24 of the NDIS Act 2013, but this flexible approach leads to different interpretations by planners as to what constitutes “reasonable and necessary”. Ideally participants should work together with a well trained LACs And NDIS Planner. LACs should not be writing plans as requests can get misinterpreted when too many people are involved in the planning process.

Participants with undiagnosed and complex rare genetic diseases should be eligible for the complex needs support pathways and should have their plan review meetings with senior NDIS Planners.

Accessible

There is a lot of NDIS literature provided in accessible format, however participants plans are not provided in “Easy English” for participants to understand. LACs do not always have the skills to explain participant’s plans in a way people with disabilities, or culturally and linguistically diverse backgrounds can understand.

3. What other key principles are important for the NDIA to follow, that could be included in a Participant Service Guarantee?

Flexibility

The NDIA needs to take a more individual and flexible approach when it comes to:

- Plan reviews – time between receiving one plan and receiving the next needs to remain flexible. Participants with rare diseases may require a plan review more frequently than the standard 12-month review. Participants should also be offered longer plans if they do not think their needs will change much over the next few years.
- Urgent reviews – for participants who require supports or equipment they cannot wait if their condition has deteriorated or circumstances have changed. The urgent review request should be considered within **7** days of requesting an urgent review and the review planning meeting should be held within **7** days of approving the request for an urgent review. This should be documented under section 48 of the NDIS Act 2013
- SWAN children with life limiting conditions cannot wait extended periods of time for equipment to be approved that should have been funded at the original planning meeting.
- Light touch reviews where a participant can have their plan adjusted slightly without going through a review of a reviewable decision.

Accountability and Transparency

The NDIS needs to be accountable for its decisions and be transparent as to why they have made the decisions they have when it comes to a participant plan. SWAN families do not understand why many of their funding requests are refused when they deem them as “reasonable and necessary” for their child.

- 4. One way to measure these principles is through a set of ‘Service Standards’. Some ideas for what these Service Standards could be are listed in Attachment A. Do you think these Service Standards are fitting? Are there other standards you believe should be included?**

The below service standards need to be included under timely principle:

- Draft plans are submitted to participants within **7** days of their planning meeting.
- Final plans are submitted for approval **7** days after a participant has reviewed their draft plan and provided feedback.
- Review of reviewable decisions are held within **28** days of being requested.
- Decisions of a review of reviewable decisions to be made within **7** days of the review meeting taking place. (subject to the need for further evidence)

- 5. Do you have any ideas on how we can measure how well NDIA has delivered on each of the principles?**

Conduct participant satisfaction surveys after people have received their plans and ask participants to rate their experience 1-10 against each principle.

Data needs to be transparent and measured at the right time. For instance, satisfaction of participants experience of the NDIS was measured prior to participants receiving their plan. The NDIS needs to be more transparent about what, when and how they are measuring data.

Getting started: Eligibility and application

Key discussion questions:

- 6. What are some of the significant challenges faced by NDIS participants in the access process?**

The team that assesses eligibility criteria do not have a good enough understanding of rare genetic conditions. They improperly rely on the operations guidelines that lists limited genetic conditions. The use of these lists needs to be reviewed and possibly abolished. There needs to be a reference group that assessors can contact if they require further information about a rare genetic disease.

- 7. The NDIS Act currently requires the NDIA to make a decision on an access request within 21 days from when the required evidence has been provided. How long do you think it should take for the NDIA to make an access decision?**

Once the NDIA has appropriate information, an Access request decision should be made in 14 days to close the time gap that participants are waiting for supports. If further evidence is required to access the scheme, participants should be accorded a further 60 days to provide this evidence (given the time it can take to access reports from experts) An Access request decision should then be made within **14** days of this evidence being submitted.

8. What do you think the NDIA could do to make it quicker or easier to access the NDIS?

Have a dedicated access review team who are experienced and understand a number of genetic conditions and how they impact on participants daily lives. The current operational guidelines do not recognise a large percentage of rare diseases.

Chronic conditions need to be better understood to ensure quicker access to the NDIS.

9. Does the NDIA provide enough information to people when they apply for access to the NDIS? If not, what else could they provide that would be helpful?

It would be helpful if clinicians, GP's and allied health professionals could be provided with templates they could complete to assist participants accessing the scheme if they meet the access criteria. Many of them are not familiar with the terminology used in the NDIS Act 2013. Many health care providers and disability support organisations like to focus on the positive aspects of the participant, instead participants once again need to focus on a "worst day" scenario often to gain access to the scheme and receive the supports they require.

10. Is the NDIA being transparent and clear when they make decisions about people's access to the NDIS? What could the NDIA do to be more open and clear in their decisions?

NDIA need to have a conversation with the participant to explain their reasoning for refusing them onto the scheme. They should also ensure that participants are familiar with the appeals process if they wish to appeal the decision.

Planning Process 1: Creating your Plan

Key discussion questions

11. What are some of the significant challenges faced by NDIS participants in the planning process?

Lack of continuity and consistency

There is a lack of consistency amongst LACs and Planners as there seems to be a high staff turnover. This means that participants are having to repeat their story yet again. It also means that there has been no continuity of LACs touching base with the participant throughout their plan and we hear many stories of SWAN families leaving numerous messages for their LAC to assist them with finding supports only to find out later that their LAC had left and nobody had taken over supporting their child with their NDIS plan. Better communication in this area is definitely required.

The impact of plan gaps is immense and far too frequent. Plan gaps have direct and severe consequences on participants with complex needs and disabilities.

- Therapy has to be discontinued, resulting in a plateau or regression or families self-funding therapy;
- Support workers are not able to work losing their income;
- Socialisation and community participation for the participant is reduced, compromising relationships, learnings and mental health;
- Equipment and consumables cannot be funded during this time, leading to reduced outcomes and quality of daily living for participants.

The ramifications of plan gaps and inadequate funding often mean children have to either take a break from the therapy and risk their development regressing, or families have the financial burden of funding therapy until sufficient funding is provided in their plan. Families are torn between wanting their child to continue to improve their skills and being financially worse off. Some SWAN families simply cannot afford the therapy required for their child to meet their NDIS goals.

NDIS goals

Participants struggle to write achievable goals, particularly when it is a first plan. Some SWAN families tell us they have set goals with their LAC or NDIS Planner only to have received plans with different goals that were not discussed in the planning meeting. It can at times be difficult for participants with undiagnosed and rare genetic conditions to set goals because they do not know what the future holds for them or have any idea of what goals are even reasonable for them to be able to achieve.

Many of our SWAN families are telling us that LACs and NDIS Planners are not allocating enough funds for participants to achieve their goals. One SWAN participant's family reported their 13-year-old child only received 4 hours of community access per month, making it impossible to achieve her daughter's goal of becoming more independent.

Supports

New participants struggle to know what supports they can ask for to assist them to meet their NDIS goals. Participants also struggle to secure supports again if they have not used them in their current plan, often because they found it extremely difficult to access a support so they could meet their NDIS goals.

Different LACs and NDIS Planners give conflicting information. For example, one SWAN family reported that a LAC told them that they could not self-manage Capacity Building – Improved Relationships but other LACs and NDIS Planners allow participants to self-manage this component of the plan. The NDIS ACT 2013 and (quality and safeguards standards) allow participants to self-manage Capacity Building - Improved Relationships unless restrictive practices and a behaviour support plan is in place, in which case this component of the plan needs to be NDIA managed.

Often participants do not know they need to provide evidence from allied health workers to support their NDIS goals. These evidence letters should be provided at the start of the planning process but participants may not have the funds to pay for these reports prior to being accepted onto the scheme. Participants also might lack the best language to use when discussing and requesting supports to access the scheme.

Ways that participants can manage their plan is often not explained properly and participants feel they are put on the spot, without really understanding what each plan management option means.

12. Are there stages of the planning process that don't work well? If so, how could they be better?

The fact that participants do not always see a copy of their draft plan, means they do not have the option to see it and can't amend their plan before its final approval. This leads to many participants lodging reviews of reviewable decisions. Every review undertaken risks losing current supports in the plan and as a result many people don't request a review. Some SWAN members have informed us that some LACs are not recommending participants request a review of a reviewable decision because of the length of time it takes to get a review meeting, the amount of work it takes to submit a review or the risk that they may lose a current support that is working well for the participant in their plan.

SWAN has been informed by some of our members that some participants are struggling with the planning process as a direct result of LACs and NDIS Planners lack of training and therefore their inability to properly support the participant through the planning process. There is no guarantee that a LAC will advocate for a participant the same way a family member, carer or the participant themselves would do. It appears to be random chance as to whether a participant's LAC can understand and translate the participant's requested supports the way they, a family member or carer could. Dealing with a LAC creates a communication layer once removed from the NDIS Planner, who is making the funding decisions and it is incredibly time consuming for participants and their families often under great duress. SWAN proposes that participants should meet directly with a NDIS Planner and have LACs focus on supporting families once they have received their plans in a support coordination and interpretation role.

There seems to be "internal rules" that LACs and NDIS Planners implement in plans such as only funding 10 allied health sessions. These "internal rules" are not stated in any format or place participants can access and there is no documentation in the NDIS rules stating how many sessions of allied health a participant can have. More transparency and accountability are required about the NDIS internal rules and these rules should not override expert recommendations or a participant's individual needs.

The NDIS is falling short in the area of transparency. For example, Core Support categories are interchangeable with other Core Support categories unless they are explicitly marked as Stated. One SWAN member, reported this was not the case and only realised when they tried to upload a claim to the portal and the request was refused. When they rang the NDIS, they were told they had used all their funding in Core – Daily Activities and just to put it under Core – Social and Community Activities. The participant then proceeded to ask how much funding was in each category and was told different amounts had been allocated to different Core Support categories, none of which were documented in their plan approval letter or on the portal. Core supports are interchangeable if self-managed and should not be capped unless marked as Stated.

Complaints are another area in which the planning process are not working. A SWAN member put in two separate complaints, one about a planner and one about a portal process that was not working well. These were thoroughly documented but were not followed up by the complaints department after the initial phone call to clarify the complaint. The person they spoke to confessed that they had only been in their role for 5 weeks and told the SWAN member that they knew much more about the NDIS than they did. They clarified that the complaint that was written was actually the complaint in question and then said they would let their supervisor know. If people put in complaints about the planning process they need to be followed through and a response put in writing as to what the outcome of the complaint will be. There is very little point in people complaining if processes and systems are not changed to address the need.

13. How long do you think the planning process should take? What can the NDIA do to make this quicker, remembering that they must have all the information they need to make a good decision?

Participants could be encouraged to submit their pre-plan (including participants statements, carers statement, weekly schedule, goals, requested supports and evidence) 14 days prior to their planning meeting, if they are confident to do so. Otherwise they could just submit a brief tick box questionnaire asking them:

- If they had adequate supports in their plan to assist them with meeting their NDIS goals?
- Did they manage to find suitable supports to meet their NDIS goals?
- What NDIS goals would they like to work towards in their next plan?

- Did they utilise the majority of funding in their plan, if not why not?
- What supports would they like to have in the next plan to assist them with achieving their next NDIS goals?

Other measures to speed up the planning process could include:

- Continuity of LACs and NDIS Planners to allow them to build a relationship with the participant.
- Better trained LACs and NDIS Planners so they have a better understanding of disability and the participant needs.

14. Is the NDIA giving people enough, and the right type of information, to help them prepare for their planning meetings? If not, what else could they provide?

Many participants need guidance to assist them prepare for their planning meeting. This includes assistance with the following tasks prior to going to a planning meeting:

- Writing a participant statement.
- Assisting the carer to write a carers statement.
- Writing the participants weekly/fortnightly schedule.
- Writing the participants goals.
- Requesting supports and ensuring what they are requesting are “reasonable and necessary” and will assist them to reach their goals.
- Ensuring that participants have suitable evidence to support their funding requests and support the goals they are working towards.
- Understand why and be prepared to address in the planning meeting any reasons for participants not meeting their goals.
- Understand why and be prepared to address in the planning meeting any the reasons why participants didn’t use all their funding allocated to supports.

15. Is the NDIA being responsive and transparent when making decisions in participants’ plans? If not, how could this be improved?

Currently participants do not receive any feedback as to why a funding request was refused. This needs to change and the NDIS needs to be more transparent. One SWAN member reported that their LAC emailed them what supports they had requested on behalf of the participant to the NDIS Planner and the NDIS Planner’s response. It became very clear from the NDIS Planner’s responses that they had not read the evidence provided, as they made statements about activities the participant was no longer doing. The plan also said the participant took student transport to school. This was not the case as the participant lived outside the designated school transport zone. The participants nominee had submitted a letter to the LAC stating the reasons why their child had changed schools and included a written explanation as to why they were seeking funding for student school transport in their child’s plan. They wanted their high school child to be able to travel independently to and from their special school.

Another SWAN member reported that a piece of equipment was released 3 months into their plan and then their plan was reset with a pro rata amount of funding from the original funding in the new plan. They could not seek an explanation as to why this had occurred and there is nothing in the NDIS Act 2013 Operational Guidelines or Rules about this happening.

Other SWAN members reported inconsistencies in planning decisions. For example, one participant was told by their LAC that NDIS Planners did not give 2 year plans for children under 14 years of age, yet another SWAN member reported receiving a 2 year plan for their 10 year old. There is nothing in the NDIS Act 2013 that states what the time frame should be between one plan and the next plan.

Planning processes 2: Using and reviewing plans

Key discussion questions

16. If you have been in the NDIS for more than one year, is it easier to make a plan now than when you first started? What has the NDIA improved? What still needs to improve?

Some participants have utilised templates developed by providers and other organisations, or developed their own templates which include:

- Writing a participant statement.
- Assisting the carer to write a carers statement.
- Writing their weekly/fortnightly schedule.
- Writing their goals.
- Requesting supports and ensuring what they are requesting are “reasonable and necessary” and will assist them to reach their goals.
- Ensuring that participants have suitable evidence to support their funding requests and support the goals they are working towards.
- Understand why and be prepared to address in the planning meeting the reasons why participants didn’t meet their goals.
- Understand why and be prepared to address in the planning meeting the reasons why participants didn’t use all their funding allocated to supports.

Many participants, still struggle to follow the planning process, particularly if they do not have the cognitive ability or supports to do so. The lack of support coordination given in plans and the lack of time and capacity of LACs, have added to the problem of participants not being fully prepared for their next planning meeting.

Some participants should be allocated a person to support them in preparation for their next planning meeting and have someone to support and advocate for them in their planning meeting. For many participants this is not an option as they don’t have support coordination in their plan, they do not know any advocates or support people to accompany them to the meeting, and they do not have the ability to ensure they have a pre-plan ready for their planning meeting. A participant should not be at a disadvantage if they are poorly educated, have a cognitive impairment, are from a CALD background, are an Aboriginal and/or Torres Strait Islander, are in the LGBTQTIA+ community, or come from a lower socioeconomic background.

17. What are some of the significant challenges faced by NDIS participants in using the supports in their plan?

There are many challenges faced by NDIS participants with regards to utilising the supports in their plan. A key issue is that the participant simply does not understand how to use their plan and receives little guidance on how to do this. Plans are not written in Easy English, which is necessary for participants who cannot understand the wording and phrasing used in their

plans. The other main issue is that the support and services market does not actually fulfil the demand for supports.

For example, many allied health professionals have limited places for therapy after school and on weekends so SWAN parents/carers have to make a decision as to whether they can take children out of school to attend therapy (not always practical because of work commitments or other responsibilities) or do they go on a wait list for afterschool therapy and miss out on using the allocated funding for therapy.

One rural SWAN family told us that they have two children on the NDIS and were seeing 6 different allied health professionals between the children on different days of the week. It took them 18 months to condense it to three therapists over three days and have back-to-back appointments for their two children. In the ideal world, this would have been offered from the start.

Many psychologists are not registered with the NDIS making it difficult for participants who are not self-managing to engage a psychologist. Moreover, many psychologists have a 6 month waiting list making it difficult to utilise the allocated 12 months worth of funding in 6 months.

From interviewing SWAN families, there seems to be not only a shortage of therapists and psychologists but a shortage of appropriate NDIS support workers. Not every family we spoke to has the ability or capacity to seek out their own services and many felt let down by their support coordinators. Truth be told - there is still a paucity of truly inclusive programs for children with disabilities. Until the workforce and mainstream services cater inclusively for people with disabilities and catch-up with the demand for their service, SWAN participants will continue to have this problem.

It becomes more difficult for families to justify they need the same level of support in their plan when they have not spent their current support budget when it comes time for a plan review. Often it simply comes down to a lack of available services for NDIS participants to use their allocated funds and is not an excess of funding issue which is the view of some LACs and NDIS Planners.. Obtaining disability support workers through Core Supports is also an issue for SWAN families with children in year 7 through to year 12. Many are being denied Core Support funding as looking after their child around the clock is still deemed “parental responsibility”. A typical year 7 student gets themselves to school independently and can be left at home by themselves afterschool and during the day in school holidays. Almost all SWAN children with a disability cannot. I think until it becomes mandatory that NDIS planners participate in 2 weeks work experience with a variety of NDIS clients, many will never grasp what it is like to have a disability and the need for supports.

Lastly and importantly, SWAN families caring for their children with undiagnosed and rare genetic conditions often find it more difficult to have their children’s needs under the NDIS understood. This tragically means they miss out on necessary services due to the complexities of their child’s disability and high support needs. SWAN would like to see a reference group formed on rare genetic conditions to help educate and inform NDIS planners around the complexity of rare disease and the challenges a child faces with a rare condition or a lack of diagnosis.

18. Is the NDIA giving people enough, and the right type of information, to help them use their plan? If not, what other information could the NDIA provide?

Participants need to know where to find supports to assist them with meeting their NDIS goals. Many participants do not have the ability, time capacity, or motivation to self-drive this process and become overwhelmed with trying to find supports.

Participants should be given a list of suitable supports when they have a meeting with their LAC to go over their new plan. Many SWAN families reported not even receiving a phone call

let alone a post planning meeting to assist them with interpreting their plan. Others reported LACs giving them incorrect information such as *“you can just pay your support workers out of your improved relationships category, so long as you are meeting the participants goals in accordance with page 8 of the Self-Management Support Guidelines, you are fine”*.

LACs and support coordinators have a high staff turnover and SWAN has heard on numerous occasions that participants are unaware that a new LAC has been allocated to their child until their next planning meeting. Better communication between LACs needs to be addressed so participants know who to ask for when seeking guidance with utilising their plan.

There is also confusion amongst SWAN members when interpreting their plans as often the language in support categories outlined in the plan letter, is written differently to that on the portal, and different again in the pricing guide. Consistent language needs to be used.

There is no process for reversing an incorrect amount claimed or incorrect category claimed when uploading claims to the NDIS Portal if you self-manage your plan. One SWAN member contacted the NDIS to say they had accidentally uploaded a claim to the incorrect support category, only to be told, *“just load up less next time”*. There needs to be away participants can easily reverse a mistake like this. One wonders how the NDIS can audit self-managed clients if this is the information they are telling participants.

19. What other advice, resources or support could the NDIA provide to help participants to use their plan and find supports?

Support coordination needs to be offered to everyone at every planning meeting. Whether this is offered through utilising a support coordination provider or through the LAC, would depend on the complexity of the participant’s needs and supports. There needs to be enough funding to support the participant in accessing their supports and the standard 10-12 hours that many SWAN families receive in their first plan is simply not enough. Even for people self-managing, circumstances change and it may be the case that a parent has gone back to work and does not have the time capacity to seek supports for their child. Just because you have had support coordination in your first plan, does not mean that you do not require it in subsequent plans.

20. What are some of the significant challenges faced by NDIS participants in having their plan reviewed (by planned or unplanned review)?

Our SWAN members have reported that the average time to write up a pre-plan for their planning meeting is 6 hours. Then there is the added time of requesting therapy and other support letters to support their child’s goals moving forward into the next plan. Many parents do not have the time capacity or the know how to write up a pre-plan, which will assist them with getting the supports they need. They might not know people who are experienced with the NDIS and therefore are isolated and become overwhelmed by the planning process.

Sometimes there is not enough time allocated before a planning meeting to compile a pre-plan, particularly if the planning request has been at short notice or the participant is caught off guard by an unplanned review.

21. What can the NDIA do to make this process easier or more effective?

Participants should be able to request a LAC or support coordinator assist them with preparing for their planning meetings. For some people, reading a document on the NDIS website is not enough and they would benefit from a person sitting with them and supporting them with preparing a pre-plan for their NDIS planning meeting. People should be able to access planning support if they require so no participants are disadvantaged in their planning meetings.

22. How long do you think plan reviews should take?

Plans reviews should take between 1-2 hours on average depending on the complexity of the child. Participants should not be made to feel rushed or inadequate. The use of survey questions, such as the pedicad, should not be deemed more useful and relevant than the information directly sourced from a discussion with the participant or their family or carer. This test is often performed by people inexperienced with using this test. There is inconsistency with the use of these tests as some LACs engage the participant or their family or carer in doing this test and others perform this without the participant or their family or carer being involved. This test should not be used at all in in NDIS meetings or behind the scenes.

As discussed above:

- Participants who request an internal review of a decision should be contacted within **14** days of the request.
- Review of reviewable decisions planning meetings should be held within **28** days of being requested
- Decisions of review of reviewable decisions should be made within **7** days of the review meeting taking place, following the provision of all necessary evidence.

If participants attended planning meetings with a well documented pre-plan that is submitted with supporting evidence **7** days prior to their planning meeting, then this would condense the plan review time.

Appealing a decision by the NDIA

Key discussion questions

23. What are some of the significant challenges faced by NDIS participants when they seek a review of an NDIA decision?

SWAN families have reported that their LACs or NDIS Planners have discouraged them from lodging a review of a decision for the following reasons:

- The lengthy time it takes to have a decision reviewed.
- Sometimes the plan is up for review before the review of the reviewable decision is actioned.
- The difficulty in writing a review and the time taken to submit a review is lengthy.
- The risk that they might lose funding in their current plan if the plan is reviewed.

One of the issues is that the whole plan is reviewed and not just the components of the plan that triggered the review. The system could be improved if participants could just have the component of the plan that was not meeting their needs reviewed.

Many cases are discouraged from reaching the AAT and many appeals are settled just prior to reaching the AAT to avoid setting precedents. You are disadvantaged if you cannot pay for a legal team to support you at the AAT level. Many advocacy agencies are at capacity and cannot support many people who require their services. There are no statistics to show how many cases are settled just prior to going to the AAT level. The NDIA need to be transparent with this figure.

Participants are not made aware of how many cases are settled prior to reaching the AAT. One of the reasons the NDIA settles cases prior to them reaching the AAT is so precedents are not set for subsequent cases. Only 2.4% of cases reach the AAT and around 56 decisions have

been published as a result. Appropriate KPIs need to be reported on and transparency needs to be improved. Too frequently LAC's and NDIS planners discourage participants from lodging an appeal.

Allowing direct communication between the participant and their NDIS Planner at the planning stage would reduce the number of AAT referrals. There needs to be greater transparency of the planning and review process to allow participants to monitor the progress of their reviews and communicate with their planners if vital information has not been considered or other legal errors may have been made. Providing participants with a clear decision-making framework around their plans and reviews and involving participants as active partners in the process will decrease referrals to the AAT. Again, clear transparent communication of the progress when an AAT appeal has been lodged, is vital for the participant to understand and more readily accept the outcome.

Advocacy agencies are at capacity to represent NDIS participants at the AAT. Many people do not know how to access an advocacy agency. This makes you wonder how many more cases would come before the AAT if advocacy were available to more participants in a timely manner. However, many advocates do not have a legal background.

Many participants cannot afford the high legal costs involved with having a case brought before the AAT. The NDIA has legal counsel representing them at the AAT which makes it an unjust system.

24. Are there other issues or challenges you have identified with the internal and external review process?

The main issues and challenges are around:

- Language
- Transparency
- Process
- Turnaround times

Language

The language around the review is confusing for people. The terminology around the review process is very confusing. We hear terms that do not have a lot of meaning to participant and their families and carers such as:

- A review of a reviewable decision or S100
- An internal review
- An unscheduled review or S48
- An NDIS internal review (just within the NDIS team)
- Appeal

Transparency

Clear guidelines and transparency are required about how to lodge a review, particularly around the language used for an appeal to ensure the process does not disenchant participants. Participants need to be able to track where their review is at, in the process. Ideally an online tracking system attached to the NDIS participant's MyGov portal needs to be used along with the opportunity to respond and be responded to. This will reduce miscommunication and will streamline the process through a better understanding of participant's requirements and the time frame for these requirements.

Participants want clear reasoning in writing as to why funding was declined if that is the case. They want guidance as to what further support evidence is required from them to obtain the supports that have been declined.

Process

We have heard from a number of SWAN families who have no idea as to the progress of their review, despite their best efforts to try and find out by writing several emails to the NDIS, lodging complaints, and even going to their local members of parliament. This lack of transparency is a big issue.

SWAN families have reported being asked to accept an unscheduled review or a plan review in place of an internal review. This in itself is an issue as many participants take the early unscheduled review as it provides them with the opportunity to get the funding they require rather than waiting for their case to be heard by the AAT. This means the true indicators of how many people are not happy with their plans are not reflected in the NDIS reported KPIs. It also means that fewer precedents are set to guide future decisions on.

Turnaround Times

We have heard from a number of SWAN families who had their review of a reviewable decision request heard at the same time as their 12 month plan review. By that time, many of them had run out of funding for their child to adequately meet their NDIS goals. There was little to no communication in this time with regards to what was happening with their requested review. It is imperative that clear communication is provided to participants, as to where their review cases are at in the process of being reviewed.

Faster turnaround time frames for review of reviewable decision meetings are needed so participants do not miss out on much needed supports to assist them with achieving their NDIS goals and the quality of life they deserve.

25. How could the NDIA improve the decision review process?

Specific wording around time frames of section 48 of the NDIS Act 2013

Participants have 3 months from their plan start date to lodge a review. If a participant requests a review of their plan, the NDIA have up to **14** days to decide whether or not to accept the review (Section 48 (2) of the NDIS Act). If there is no response, the decision is taken as the review was not accepted. If the NDIA do accept the review Section 48 (3) of the NDIS Act, states that the CEO must complete the review *“as soon as reasonably practicable”*. *“As soon as reasonably practicable”* should be reworded with a defined time frame of a *“within a 28 days”* in Section 48 (3) of the NDIS Act 2013.

Decreased waiting times

Long waiting times to have a review meeting makes it evident that more planners need to be dedicated to the review process. A triage system is required whereby the participant and their care support team can indicate how urgent the review needs are. They can then provide a more detailed context to the planner of the participant’s situation and the consequences of not reviewing the plan in a timely manner. Many SWAN children in the Early Childhood Intervention Category have experienced a long drawn out process to receive their requested changes to their equipment needs.

Clear communication

Clear communication needs to be had with participants and transparency of the review process must be maintained. This includes where reviews are at in the review process, including an online tracking capability through MyGov.

Improved process

A clear flowchart of the steps taken to appeal an NDIS Plan, including which process sits with which position in the NDIA and what supporting evidence might be required to support the review process.

The legislative framework

Key discussion questions

26. How long do you think reviews of decisions should take?

- Participants who request an internal review of a decision should be contacted within **14** days of the request.
- Review of reviewable decisions should be held within **28** days of being requested.
- Decisions of review of reviewable decisions should to be made within **7** days of the review meeting taking place.

27. Do you think there are parts of the NDIS Act and the Rules that are not working or make things harder for people interacting with the NDIS?

SWAN agrees with Attachment C: COAG's agreed amendments from the 2015 Act Review, but feel there are a number of sections under the NDIS Act 2013 that need addressing and should be followed (currently some are not being instrumented despite legislation).

Section 4 - General principles guiding actions under this Act

These include:

- (5) People with disability should be supported to receive reasonable and necessary supports, including early intervention supports.
- (11) Reasonable and necessary supports for people with disability should:
 - (a) support people with disability to pursue their goals and maximise their independence.
- (12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected.

If these principles were followed less SWAN families would request a review of a reviewable decision. Many SWAN families are told caring for their child 24/7 is a "a parental responsibility". A number of SWAN children with disabilities, however, require a significantly a higher level of care than a "typical" child due to the complexity of their disabilities and genetic condition.

Section 5 - General principles guiding actions of people who may do acts or things on behalf of others

- (a) people with a disability should be involved in decision making processes that affect them, and where possible make decisions for themselves;

SWAN families sometimes feel that LACs have too much influence on what they put in the plan. One SWAN family reported that the LAC told the participant that they would have to choose between two different requested supports as they did not think the NDIS would fund both supports. The participant's family thought both supports were "reasonable and necessary" and had evidence to support both funding requests but the LAC told them she would only request one of them from the NDIS Planner. This was not the LACs decision to

make and families can feel they are not involved in the decision-making process when they feel bullied into making decisions.

Section 26 - Requests that the CEO may make

- (2) If:
 - (a) information or one or more reports are requested under subsection (1); and
 - (b) the information and each such report are received by the CEO within **28** days, or such longer period as is specified in the request, after that information or report is requested;

Participants who cannot afford to pay for these reports will be disadvantaged when trying to enter the scheme. The NDIS does not pay for reports when people with disabilities are not participants of the scheme. If people then become participants of the scheme, the money required for such reports should be reimbursed from the funding of their first plan.

31 - Principles relating to plans

The preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:

- (b) be directed by the participant; and

As in section 5 of the NDIS Act 2013, SWAN families sometimes feel that LACs have too much influence on what they put in the plan. Participants may feel that the LAC knows best as they are meant to be experts in their case, however this is clearly not the case otherwise we would not have a high number of participants unhappy with their plans.

- (c) where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant; and
- (d) where possible, strengthen and build capacity of families and carers to support participants who are children; and

Too many times we hear that SWAN families do not receive enough funds in the Core Supports areas of their plan to enable parents to work. Most special schools and developmental schools finish their day at 3:00pm and do not offer after school care programs. There are very few school holiday programs that meet the needs of children and teenagers with disabilities, making it extremely difficult for parents to work without substantial Core Supports in their child's plan to enable them to do so.

- (i) maximise the choice and independence of the participant

Participants should be able to choose to travel to school independently. Currently participants are not receiving school transport funding unless they live in the designated school transport zone if they attend a special school or special development school. SWAN participants are missing out on this funding and are not being given the opportunity to travel independently to school as their parents need to transport them. The NDIS asked for submissions into school transport in August 2018 and a decision was scheduled to be made for implementation in 2020, which has now been postponed until 2023. SWAN families have been told by LACs and NDIS Planners that school transport is a "parental responsibility", however, a typical secondary school aged child can get themselves independently to school. Without transport funding participants are not being able to maximise their independence.

33 - Matters that must be included in a participant's plan

- (1) A participant's plan must include a statement (the ***participant's statement of goals and aspirations***) prepared by the participant that specifies:
 - (a) the goals, objectives and aspirations of the participant

SWAN families have told us that the LACs and NDIS Planners have manipulated the statement of goals. This is a serious issue as when they have received their plan the goals listed are ones that weren't agreed to in the planning meeting. There is also conflicting advice from LACs and NDIS Planners around the number of goals a participant can have, some saying only 1-2 short term goals are appropriate whilst others list several. Some families feel that their child's goals are not respected or achievable.

- (4) The CEO must endeavour to decide whether or not to approve the statement of participant supports as soon as reasonably practicable, including what is reasonably practicable having regard to section 36 (information and reports).

The wording in this part of the NDIS Act 2013 is too ambiguous and is open to interpretation. The CEO must approve the statement of participant supports within **7** days of the planning meeting.

34 - Reasonable and necessary supports

SWAN has an issue with the terminology "reasonable and necessary" supports because they are open to interpretation. What one person deems as "reasonable and necessary" another may not and therein lie the problem with a number of plans. Whilst a LAC might think supports are "reasonable and necessary" and put them in a participant's plan for the NDIS Planner to approve, the NDIS Planner may not. NDIS Planners need to be transparent as to why they didn't think the support was as "reasonable and necessary" and the reason needs to be given to the participant. SWAN recommend that there are clearer guidelines as to what is considered as "reasonable and necessary" for different stages of development and life. The Independent Advisory Council to the NDIS published some excellent guidelines, Reasonable and Necessary Support across Lifespan: An Ordinary Life for People with Disability guidelines in October 2014. These guidelines need to be referenced more by LACs and NDIS Planners.

36 - Information and reports for the purposes of preparing and approving a participant's plan

- (2) The requests the CEO may make are as follows:
 - (b) that the participant do either or both of the following:
 - (i) undergo an assessment and provide to the CEO the report, in the approved form, of the person who conducts the assessment;

One of the issues SWAN families reported was that LACs requested reports to be included as evidence for supporting a participants goals however participants felt that these "expert" reports from therapists were disregarded when developing a participants plan. The NDIA needs to understand that allied health workers are experts in their field and should be respected for their expertise. It is also noted that the NDIA funded these reports in the first place only to ignore them.

37 – When the plan is in effect

- (2) A participant's plan cannot be varied after it comes into effect but can be replaced under Division 4.

It would be less stressful, less time consuming and cost less money if LACs or NDIS Planners had the ability to make light review touches to a participants plan rather than go through an

internal review. A light touch review could mean adjusting dollar amounts to the support categories without changing the total amount of funding allocated in the plan.

48 - Review of participant's plan

- (2) The CEO must decide whether or not to conduct the review within **14** days after receiving the request. If the CEO does not make a decision within that period, he or she is taken to have decided not to conduct the review.

SWAN families have reported hearing nothing as to whether their plan will be reviewed. The way the NDIS Act 2013 section 48 (2) reads, it is interpreted that if a participant does not hear anything within **14** days of lodging a review, the review has been declined. However, SWAN families have reported hearing nothing and their plans had been put in the review process without their knowledge. It would be best practice to communicate to the participant the reasons why their plan would not be reviewed, after **14** days of receiving the request.

- (3) If the CEO decides to conduct a review under subsection (1), the CEO must commence to facilitate the review within **14** days after so deciding and must complete the review as soon as reasonably practicable.

Stating the CEO must complete the review as soon as reasonably practicable is too vague. It needs to state a set time frame of **28** days.

- 5 The CEO must conduct a review of a participant's plan before the plan's review date and in the circumstances, if any, specified in the plan.

Despite the NDIS Act 2013 stating that the CEO must conduct the review of a participant's plan before the plan review date, SWAN knows a number of participants who have had their review heard the same time as their regular plan review.

There needs to be provision in the NDIS Act 2013 for urgent reviews to be accepted within **7** days and a review planning meeting to occur within **7** days of an accepted urgent review so participants who have deteriorated in health or circumstance have changed can be reviewed, particularly for requests for equipment and supports.

50 - Information and reports for the purposes of reviewing a participant's plan

- (2) The requests the CEO may make are as follows:
 - (a) that the participant, or another person, provide information that is reasonably necessary for the purposes of reviewing the participant's plan;

SWAN participants have reported being asked for these reports and assessments, which they have provided at their own expense, only to have the requested funding declined. Expert reports need to be valued as they are the experts in their field.

100 - Review of reviewable decisions

- (6) The reviewer must, as soon as reasonably practicable, make a decision:
 - (a) confirming the reviewable decision; or
 - (b) varying the reviewable decision; or
 - (c) setting aside the reviewable decision and substituting a new decision.

"Reasonably practicable" is too vague. A decision should be made within **7** days of the review meeting.

127 - Appointment of Board members

- (2) A person is eligible for appointment as a Board member only if the Minister is satisfied that the person has skills, experience or knowledge in at least one of the following fields:
 - (a) the provision or use of disability services;
 - (b) the operation of insurance schemes, compensation schemes or schemes with long-term liabilities;
 - (c) financial management;
 - (d) corporate governance.;

It should be mandatory that all NDIA Board members should be required to have lived experience of disability, either personally or through caring for a family member. A NDIA Board member should also have skills, experience or knowledge in one of the following areas:

- either operation of insurance schemes, compensation schemes or schemes with long-term liabilities
- financial management
- corporate governance

28. What changes could be made to the legislation (if any) to:

SWAN's recommended changes to legislation have been detailed in the above sections along with the reasons why the legislation needs to change.

Plan amendments

Key discussion questions

29. What are the significant challenges faced by NDIS participants in changing their plan?

There should be the ability for LACs and NDIS Planners to make light touch adjustments or the proposed plan amendments. These would be made at the request of the participant and do not require a full-scale internal review.

Participants should also be able to request that just one component of their plan be reviewed if they are not happy with it and the other components of the plan remain untouched. Too many participants refrain from asking for a review for fear they will be worse off and lose existing funding supports.

30. How do you think a 'plan amendment' could improve the experience for participants? Are there ways in which this would make things harder or more complicated for people?

SWAN thinks plan amendments would save a lot of time, resources, and stress for participants. We also believe light touch reviews, which are slight funding adjustments, should be able to be conducted by LACs and NDIS Planners to decrease the number of NDIS plan review requests.

31. How long should people have to provide evidence that they need the changes they are requesting in a plan amendment?

They should have at least **28** days to provide the evidence required for a plan amendment.

32. Are there other situations during the planning cycle where a quicker and easier way to make changes may be necessary?

A LAC or NDIS Planner should be able to make slight adjustments to a plan. For example, moving funding from one section of a plan to another, or adjusting how a section of the plan is managed or rectifying clear and agreed errors.

33. How else could the NDIA improve the process for making changes to a plan?

The NDIS needs to introduce draft plans that the participant can provide feedback on prior to the plan being approved. If they are unhappy with the draft plan participants should be able to request the plan once again be reviewed.