



Syndromes Without A Name (SWAN) Australia

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Committee Secretariat
Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra ACT 2600

5 September 2019

RE: NDIS Planning

Dear Joint Standing Committee,

Thank you for considering our submission that represents the planning experience of many of our Syndromes Without A Name (SWAN) 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 420 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, which receives many questions on the NDIS particularly 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 on the subsequent pages and have included our key recommendation. We would be happy to discuss the content of this submission further.

Yours sincerely

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

Key Recommendations:

a) The experience, expertise and qualifications of planners;

- Establish formal accredited courses, which LAC's and Planners need to complete before being qualified to do their job.
- Ensure LAC's and Planners have first hand experience of disability through working with people with disabilities or having a lived experience of disability.

b) The ability of planners to understand and address complex needs;

- Enable LAC's and Planners to have access to Rare Disease Experts who are part of a Rare Disease Reference Group. They can assist them with improving their understanding of rare genetic conditions that cause disabilities and the impact they have.
- Develop Rare Disease Fact Sheets to improve LAC's and Planners knowledge of rare diseases and the impacts they have on participants.
- Provide training and hands on experience to LAC's and Planners to develop their understanding of the challenges participants with complex needs and life limiting experience face.
- For LAC's and Planners to take into consideration and value reports from experts in their field when making planning decisions.
- For participants with complex needs to have the option of flexible plan reviews and for LAC's and Planners to honour and respect this, particularly when it comes to funding essential pieces of equipment.

c) The ongoing training and professional development of planners;

- Training to improve LAC's and Planners understanding of rare genetic conditions and give them a better understanding of how rare conditions that cause disabilities impact participants and their families.

d) The overall number of planners relative to the demand for plans;

- More Planners allocated to the review process.
- No NDIS participant to wait more than 4 weeks to see a LAC or Planner.
- Consistent LAC's and Planners from plan to plan to enable a better understanding of participants needs when plans are being reviewed.

e) Participant involvement in planning processes and the efficacy of introducing draft plans;

- Draft plans to be shown to participants for further discussion prior to plans being approved. This includes reviewing requested supports and participant's goals.
- Parents of children with rare diseases should be valued, respected and acknowledged as experts in their child's genetic condition and should be involved as much as possible in the planning process.

f) The incidence, severity and impact of plan gaps;

- NDIS Participants should never have funding gaps in their plan and they should never have to wait for essential equipment to be approved.

NDIS participants cannot wait for essential equipment as it can be detrimental to their health and disability long term.

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- g) The reassessment process, including the incidence and impact of funding changes;**
 - Limit unnecessary reassessments when little has changed with the participant.
- h) The review process and means to streamline it;**
 - More planners dedicated to the review process to shorten the wait times.
 - 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.
 - Clear communication given to participants and transparency of the review process, including where reviews are at in the review process, including an online tracking capability through MyGov.
 - Wording to be changed in section 48 (3) of the NDIS Act 2013 to replace “as soon as reasonably practicable” to “within a 4 week period” with regards to the NDIA responding to review requests.
 - A triage process to be applied for plan reviews to identify and prioritise the most urgent cases.
- i) The incidence of appeals to the AAT and possible measures to reduce the number;**
 - Clearer communication and transparency of the progress when an AAT has been lodged.
 - Transparency about KPI on the cases settled prior to reaching the AAT.
 - More funding for advocacy agencies and clear pathways for participants to access advocates.
- j) The circumstances in which plans could be automatically rolled-over;**
 - A flexible approach to the plan lengths (including roll-overs) should be considered by the NDIS and the participant.
 - Clear consistent language should be used for to identify the difference between plan roll-overs, plan extensions and plans issued for longer than 24 months.
 - Age should not be a barrier to a plan roll-over being considered.
- k) The circumstances in which longer plans could be introduced;**
 - A more flexible approach to plan lengths needs to be introduced.
 - Longer plans should be offered at the time of participants NDIS plan review meeting and introduced at the participants request.
- l) The adequacy of the planning process for rural and regional participants;**
 - Match NDIS participants living in rural and regional areas with planners who understand some of the limitations that come with living in a rural area including limited services and distances spent travelling.
 - Provide NDIS rural and regional participants with the option to support participants in a virtual manner.
- m) Any other related matters.**
 - NDIS Planners to replace LAC’s to build and implement to ensure better communication is received between participants and Planners.

a) The experience, expertise and qualifications of planners;

The expertise and qualifications of Local Area Coordinators (LAC's) and NDIS Planners vary considerably. There are no formal qualifications required to do their job and the industry is not regulated.

Our members have reported a huge variance in the knowledge and expertise between LAC's that work for different organisations as well as Planners. Many, had no life experience of disability, qualifications or even experience with working with people with disabilities. The lack of experience and qualifications of LAC's and Planners, is clearly reflected in the number of plans which 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 the much needed supports, therapy and equipment in their plan, particularly for equipment for those children under five years old.

We do not expect every LAC or 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 that a particular undiagnosed or rare genetic condition has on a participant.

b) The ability of planners to understand and address complex needs;

Direct experience with disability and complex special needs in children should be required in order for LAC's and 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 Planners around the complexities of rare diseases and complex issues.

Evidence letters and reports written by clinicians and allied health workers (who are experts in their field) need be valued and considered by LAC's and Planners when approving requests for funding supports in plans. A number of SWAN families have reported to us that don't feel that their evidence letters are taken into consideration when Planners determine what supports to include in their child's plan.

Damian's case study on the next page illustrates an example of this where letters from experts were ignored and insufficient funding was available to support him under section 3 of the NDIS Act – (d) *"provide reasonable and necessary supports, including early intervention supports, for participants in the National Disability Insurance Scheme launch;"* and (ga) *"protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the National Disability Insurance Scheme"*. Objects of the Act - section 4 (3) of the NDIS ACT *"people with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime"* were also over looked.

Case Study One: Damian's Story

For Damian's first plan, we were as organised as two new parents could possibly be. We attended NDIS information sessions, we educated ourselves around the process, we got quality advice from reputable sources, we submitted an entire folder of every professional report, allied health report, equipment quote and recommendation we could obtain - each spelling out the details of Damian's disabilities, the supports he requires and the reasons why he requires those supports in order to meet his goals.

However, Damian's approved NDIS plan fell drastically short of meeting his needs and goals.

- *Damian's specialised seating system, required to provide head, and lateral trunk support, to help minimise the risk of aspiration and skeletal issues and to enable him to safely attend appointments and take part in community activities, was declined.*
- *Damian received minimal required funding for his improved daily living requirements. Even with extended hospitalisations in December, January, March & April, Damian only has enough funding to cover the cost of one in-home therapy session each week- in order to meet his goals, Damian requires weekly physiotherapy; speech & occupational therapy so he is already missing out on vital therapies as his budget is so limited. Due to Damian's low immunity and extreme sensitivities to light and sound, these therapy sessions need to be home-based, which leads to additional costs.*
- *Home modification assessments in order for Damian to be cared for long term at home by myself and my husband were declined.*
- *In home assistance as we are not able to rely on any other family members for support due to Damian's high care requirements, was declined.*
- *A request for increased incidental funding to help finance specialised educational equipment required to assist Damian's development due to his low tone, hearing and visual deficits was declined.*

Without the combination of these important supports, Damian has zero chance of meeting his NDIS goals.

SWAN Australia supports a number of families who have children with life limiting conditions. These children cannot wait for a 12 month plan review when they need essential pieces of equipment now to assist their child and provide them with a better quality of life. A more flexible approach to plan reviews is required for NDIS participants who have undiagnosed or rare genetic syndromes. Families who have children with life limiting conditions should be able to request a plan review when their circumstances change, without having to endure long waiting times.

c) The ongoing training and professional development of planners;

The rare disease space is constantly changing with advances in genetic and genomic testing and 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.

There is a need for a rare disease reference group consisting of experts in the field with knowledge of current published research into rare genetic conditions. These could be listed on the Proda Portal and could include reference groups such as the Genetic and Rare Diseases Network (GaRDN), Australian Genetics Alliance (AGA), Genetic Support Network Victoria, Syndromes Without A Name (SWAN) Australia and Rare Voices Australia (RVA) and the National Organisation for Rare Disorders.

The LAC or Planner could seek these experts out for ongoing support and guidance after meeting with a participant who has a rare genetic condition. Rare disease experts are critical for educating planners about the latest treatments, therapies and supports for rare disease. Research can also improve knowledge of complex genetic conditions and highlight the need for *no waiting times* for crucial equipment for SWAN families to improve their children's quality of life.

d) The overall number of planners relative to the demand for plans;

The experience of SWAN families indicates there are not enough Planners to consider plans and respond to any correspondence from participants about their plan in a timely manner. There are very long access waiting times for some SWAN families to initially be accepted onto the NDIS and SWAN families have reported waiting around 6-9 months for their first planning meeting. SWAN families who lodged a review of reviewable decisions and urgent reviews have reported waiting up to 12 months before being offered a plan review meeting, despite their original request for a review meeting being accepted within 14 days of being lodged.

Section 48 (3) of the NDIS Act states that the NDIA needs to respond to reviews "as soon as reasonably practicable" but doesn't qualify what time frame constitutes "reasonably practicable". Many families are waiting months for a plan review, often resulting in a plan review of the plan they were appealing being superseded by a new plan. This alone highlights there are not enough planners in the review team to cope with the number of requests for plan reviews.

Many SWAN families were never offered the option of a follow up meeting with their LAC after they received their child's plan. The idea of offering these meetings are to ensure that participants understand what supports they can utilise and guide them on how to spend their funding.

SWAN families have reported leaving multiple messages for LAC's to return their calls only to discover weeks later that their LAC had left. The high staff turnover of LAC's and Planners makes it difficult to have the same LAC or Planner for each planning meeting, even if you were allowed to choose your LAC or Planner. This makes it difficult to receive comparable plans year to year, and also results in unnecessary repetition of background information about your circumstances to multiple individuals.

There not only needs to be more planners, but the need for continuity of LAC's and Planners delivering plan reviews. This will ensure appropriate, coherent and timely funding decisions are made from plan to plan. Currently participants' successive plans appear to be allocated to different planners, which erode any consistency of decision making and intimate understanding of the participants' situations. This is particularly problematic in the rare or undiagnosed disease space as these participants often have complex needs and disabilities and require a LAC or Planner to have a coherent understanding of how these needs will change over time.

e) Participant involvement in planning processes and the efficacy of introducing draft plans;

No plan should be submitted to a Planner without first being reviewed by a participant. Draft plans are crucial and imperative to decrease the number of review of reviewable decisions being requested. A draft plan could identify where participant's needs were not met, often due to a communication breakdown between the participant's LAC and Planner.

A draft plan that allows for participant feedback that can be addressed in a timely manner and would improve the current disconnect in the system between the participant needs and planner funding decisions. Ideally participants should be sent a summary of their meeting discussion points, goals and recommended therapies for review before plans are submitted to the NDIS. This would reduce the number of reviews and appeals that occur after a plan is already approved. Allowing participants to review their plans prior to the NDIS approving them would allow participants have a second chance to justify their “reasonable and necessary” supports if they failed to be funded in the draft plan.

It would be a chance for participants to ask why supports were not funded and it would also identify if evidence were not taken into consideration. Parents need to be provided with opportunity to correct misunderstandings and incorrect information submitted for approval.

Along with the funding requests, the opportunity to review participant’s goals also needs to be provided. Too often SWAN families have read goals in their child’s plan that was not what they agreed on with their LAC or Planner. If the goals are incorrect, it leads to problems when it comes to a plan review as goals might not have been addressed because they were not reasonable or not what the participant wanted to work on.

The frequency of therapy requested are often not discussed and if they are, letters from therapists who are experts in their fields are often disregarded and what seems to be the unwritten “standard” of 10 sessions of therapy per allied health professional are approved.

Currently there are no safeguards for participants to ensure letters of supporting evidence for funding requests are even read or taken into consideration by either LAC’s or Planners. This is evident by from the case study below:

Case Study Two: SWAN Parent Story

I provided my usual pre-plan document, which included my daughter’s individual participant statement, my carers statement, my daughters weekly schedule and the requested supports needed to implement her NDIS goal. Letters of evidence accompanied all our requested supports from her therapists and support team. When the plan was approved it did not include nearly enough funding for my daughter to achieve her NDIS goals. The reasoning the LAC told for therapy not being adequately funded was because my daughter attended a special school. There seems to be a misconception amongst planners that children attending specials schools get access to 1:1 therapy which is not the case.

My daughters plan said that my daughter participated in activities she didn't, including taking supported student transport to school provided in-kind by the Department of Education.

The individual participant statement mentioned my daughter had changed schools and was no longer in the designated school student transport zone. In fact a supporting document giving the reason we changed school was totalling ignored along with the request for funding to provide a support worker to transport my 13-year-old daughter, who has a moderate intellectual disability. Without out these support in place and appropriate funding it is very difficult for me to remain in full time work.

Had I had the opportunity to review my daughters plan prior to it being approved I could have questioned why the evidence was not considered and why her supports were not likely to be approved. Now I need to lodge yet another appeal which is time consuming and a further cost to the NDIA and myself.

Parents are often their child's best expert when it comes to rare diseases, and are often more knowledgeable about the disease than their child's clinicians or therapists and certainly more knowledgeable than any LAC or Planner. So why do we hear repeatedly that SWAN parents are dismissed as experts in their NDIS planning meetings and their request for supports including essential equipment declined?

f) The incidence, severity and impact of plan gaps;

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 losing the benefits gained from the therapy, support workers are not able to work losing their income and reducing socialisation and community participation for the participant, 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.

If essential physical equipment was approved in a participants plan when first requested it would be cost saving to the health and disability sectors in the long term. This also has a flow on affect on the stress and mental health of the carer. An example of this is for a standing frame, which has the potential to limit the risk of a child with complex disabilities requiring hip surgery for hip dysplasia in the future. Not only can it save the child a stressful and painful operation, it also will limit the number of hours of intensive physiotherapy the child will require post operation.

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.

g) The reassessment process, including the incidence and impact of funding changes;

It is fundamentally unfair to ask participants to fund reassessments when inadequate funds have been provided for in the plan. Participants can perform better on any given day and risk losing the funded supports they need to assist them in achieving their NDIS goals. Assessments are stressful for participants and put a strain on already stretched resources.

h) The review process and means to streamline it;

The terminology around the review process is very confusing. We hear terms 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

Clear guidelines and transparency is 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 participants 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.

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 Administrative Appeals Tribunal. This means the true indicators of how many people are not happy with their plans are not reflected in the NDIS reported key performances indicators. It also means that fewer precedents are set to guide future decisions on.

We have heard from a number of SWAN families who have 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.

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

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.

Participants have 3 months from their plan start date to lodge a review. If a participant request 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 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 4 week period”* in Section 48 (3) of the NDIS Act 2013.

Long waiting times to have a review meeting is evident that more planners dedicated to review processes are required. 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 Intervention category have experienced a long drawn out process to receive their requested changes to their equipment needs.

i) The incidence of appeals to the AAT and possible measures to reduce the number;

Participants are not made aware of how many cases are settled prior to reaching the AAT, which can set a precedent for subsequent cases coming before it. Only 3.5% of cases reach the AAT and only 56 decisions have been published as a result. KPI’s need to be reported on, and transparency needs to be improved. Too frequently, planners discourage participants from lodging an appeal.

Allowing direct communication between the participant and planner from their initial plan to urgent reviews 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. Providing participants with a clear decision-making framework around their plans and reviews and involving participants as active participants in this 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.

j) The circumstances in which plans could be automatically rolled-over;

Participants or their representatives and support team should have the option to guide LAC's and Planners as to the length of their NDIS plan. In situations that include individuals who are medically stable year on year and who are not undergoing rapid development, a plan roll-over may be appropriate but for other children in the Early Intervention category or who have degenerative conditions, it may not. Participants should be given the option each year as to whether they want their plan reviewed or just rolled over prior to their scheduled review meeting.

There is no age limit defined in the NDIS Act 2013, operational guidelines or rules about the age requirements for plans to be rolled-over, plan lengths or reference as to when plans expire or any reference for 2 year plans to be granted. This means there is inconsistency with some NDIS Planners refusing to give 2 year plans to children under the age of 14, whilst other are granting them to 9 year olds.

The language used for plan roll-overs is confusing. Does a roll-over mean a plan extension, a roll over for another 12 months or plans issued for a longer than 12 month period prior to being reviewed. Clear consistent language needs to be used.

The option of a light touch review, which could be implemented, by the LAC or Planner should also be considered at a 12 month period. Having a review every 12 months puts a considerable strain on resources both within the NDIS but also for participants and their representatives requesting letters of evidence from therapists and their support team. SWAN families have told us that the average preparation for a plan review meeting takes 6 hours, which is difficult to find if you work full time plus care for a child with a disability.

k) The circumstances in which longer plans could be introduced;

Longer plans should be offered if a person's circumstance has a limited chance of changing much over the coming years. Longer plans should be offered to participants at the time of their NDIS plan review meeting and introduced at the participant's request.

Shorter plans should be considered for children with complex needs who are undergoing rapid development in the Early Intervention category. This will eliminate the need for most urgent reviews being lodged by these participants and their carers.

l) The adequacy of the planning process for rural and regional participants;

The needs of rural and regional participants can differ from metropolitan NDIS participants due to the distance spent travelling to services and the limited number of services available to them. It is important that regional participants are matched with planners who understand some of the limitations that come with living in a rural area and that sufficient funding (including appropriately funded travel) is allocated to these participants to ensure they can meet their NDIS goals. The option to support participants in a virtual manner and care should be considered and not disregarded.

m) Any other related matters.

SWAN would like to see NDIS Planners replace LAC's to build and implement plans to ensure better communication is received between participants and Planners. Too many times we hear that LAC's are not conveying correctly the participants wishes to the Planner. LAC's take it upon themselves to make decisions as to what funding they request from the NDIS Planner on behalf of the participants. The double handling of information requests makes the communication of the participants funding request open to misinterpretation and vulnerable to errors.

SWAN Australia acknowledges the generosity and support of the SWAN parents who kindly shared their stories with us for this submission.