



Syndromes Without A Name (SWAN) Australia

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Submissions

The National Disability Insurance Agency (NDIA)

22 February 2021

Re: - **Supporting young children and families early, to reach their full potential.**

To whom it may concern,

Thank for the opportunity to provide feedback into how the NDIS can supports young children and families early, to reach their full potential. SWAN Australia provides information, support and systemic advocacy for families caring for a child with an undiagnosed or rare genetic condition. About half of our families have children under the age of ten years old so this consultation paper is very relevant for our families.

SWAN is the peak not-for-profit organisation representing the estimated 2500 children born in Australia every year without a diagnosis and those children who have rare genetic conditions. Of the children who present to a geneticist with syndromic features, 40 to 60 per cent may never receive a diagnosis, which is heartbreaking, especially if the child has a regressive condition. Our mission is to increase community awareness and understanding about the impact and prevalence of rare and undiagnosed genetic conditions. We feel there is a distinct lack of understanding about the needs of our families from the NDIA.

SWAN helps reduce the isolation and emotional strain of raising a child with a chronic health condition or disability by helping parents connect with other SWAN families. We provide parent information seminars and workshops, peer support events and social networking opportunities where SWAN families can form lifelong bonds. SWAN also advocates for improved disability support services, free and equitable genetic and genomic testing, and increased research funding to ensure more children can obtain a diagnosis.

We provide a public voice for our families, campaigning for better community education and improved resources and pathways so that SWAN children can thrive. Many of our SWAN children are thriving thanks to the NDIS.

I have addressed the consultation questions on the following pages along with our key issues and recommendations and I would be happy to provide further feedback if required.

Kind regards

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

KEY ISSUES AND RECOMMENDATIONS

ECEI participants to increase to 0-9	SWAN supports extending the age range for ECEI participants from 0-7 to 0-9 to allow for more support to be given to our SWAN families.
Transition phase	SWAN supports a longer and smoother transition for ECEI families exiting the NDIS that is funded in participants plans.
Best practice	SWAN supports the best practice model of ECEI. The benefits of using the best practice model should be clearly explained to participants.
Registered NDIS providers	SWAN does not support the introduction of ECEI participants only using registered NDIS providers. This undermines the principles and vision of the NDIS around choice and control.
Independent Assessments	SWAN does not support the use of independent assessments. Reports provided to the NDIS written by clinicians and allied health professionals working with and supporting our SWAN families should be taken at face value and as real evidence, and these people should be considered the "experts" in their field. This is particularly important for SWAN children where independent assessors are unlikely to have knowledge of undiagnosed or rare genetic conditions, or their impacts on functional capacity. The NDIS should not rely on an independent assessment to determine plan budgets which may not be enough to support a participant's needs.
Resources	The NDIA should engage with and support a number of establishments and supports that are underutilised that actively work at connecting their members for peer support instead of replicating or duplicating these initiatives.

CONSULTATION QUESTIONS

General questions

- **Do you have any specific feedback in relation to:**

- **the increased focus on STEI outside of access to the Scheme**

SWAN agrees with Recommendation 12: *Increase Early Childhood partner capacity to provide Short Term Early Intervention (STEI) support to eligible young children and families for longer.* However, we are concerned that once the STEI supports are removed, education settings may not have the capacity or resources to support transition and the child in broad community settings. This may lead to the child regressing and the undoing of progress they have made by working with a STEI team. We fear that families will not receive the supports they need to ensure their child continues to develop their skills and may fall behind.

There needs to be dedicated support for transitions, either as a budget NDIS support item or for building the capacity of the child's family and mainstream supports.

- **the proposed increase in age range for the EC Approach from under 7 to under 9 years of age,**

SWAN agrees with Recommendation 14: *Increase the age limit for children supported under the Early Childhood Approach from 'under 7' to 'under 9' years of age to help children and families receive family centred support throughout the transition to primary school.*

Increasing the age limit of ECEI from under 7 to under 9 will ensure a smoother transition into mainstream services. Our SWAN community have told us that once an ECEI service no longer supports their child, they feel lost. They miss their ECEI key worker who can advocate for support on their behalf, assisting them with their NDIS plan and establishing mainstream supports.

This is particularly apparent in an education setting where a key support worker can add real value in supporting a child's integration into school, especially into a mainstream school as opposed to a specialist setting. They can ensure that supports such as continence needs and individual learning plans are set up in schools and assist the family with any NDIS portal concerns. A key support worker can ensure that therapists communicate with one another and the school, and they can advocate on behalf of families when required to do so.

An ECEI key worker can assist with ensuring there is a smooth transition into community supports and activities. Many families choose to let their child focus just on settling into school over the first few years rather than have them undergo extra curriculum activities in the community. Allowing the cut off for ECEI support to be extended to the age of 9 will allow more time for children to be supported and integrated smoothly into community and mainstream supports.

We estimate that around 30% of our SWAN members who have children under the age of 7 on the NDIS use individual therapists or therapists who act as individual contractors as part of a therapy centre or are self employed. SWAN members report that communication between their therapy teams can be limited in these types of settings. In the best practice ECEI model, the key support worker can coordinate team meetings,

providing therapists with an outline of the child and families changing needs on a regular basis. They can also work as part of a transdisciplinary team and provide practical support and strategies to families where necessary.

The need for coordinated and well-communicated care that the ECEI key worker model provides is even more critical when supporting families with multiple and complex needs and families from low socio-economic demographics. Very few of our SWAN ECEI families receive support coordination, which means that their ECEI key worker essentially becomes their families support coordinator as well.

There needs to be a clear distinction between the roles of key support worker and support coordination. This will ensure that families can get the targeted supports they need through their NDIS plans. Some of our SWAN families struggle to see the difference between the two roles.

➤ **the desire to see more successful transitions from the Scheme to the next state of life.**

Very few of our SWAN families have transitioned out of the scheme due to the complexities of their rare genetic condition and disability. Of the few that have transitioned out of the scheme, they have reported feeling like they were left to their own devices with little support.

They felt that the school did not understand their child's issues and the level of support they actually needed. Our parents felt that schools were under-resourced to provide the level of care and services and supports, such as speech therapy, that their child required. Families told us they felt like they were left to "sink or swim" with very little supports. Schools are big institutions and families felt they got lost in their system. They were often placed on long waitlists to see school allied health professionals, who often had to service several schools in one region. Unfortunately, schools just don't have the resources to support families as much as we would like them to.

SWAN feels transition is even more difficult for our SWAN children as there is little understanding of undiagnosed and rare genetic condition within the community. In many ways, not having a diagnosis for your child puts you at a disadvantage as you don't know how their rare genetic condition will progress and what supports your child will need. Even with a diagnosis, our SWAN children who have received a rare genetic diagnosis are often no better off in terms of knowing how their condition will progress because there are very few people in the world with the condition. Many rare genetic conditions have only been recently diagnosed due to the increased access and decreased cost of genomic sequencing tests. Genetic and genomic testing takes time and the average time to receive a diagnosis for a genetic condition is five years. SWAN estimates that 30% of our children under the age of 10 remain without a diagnosis for their genetic condition and genomic testing only provides a diagnosis yield in 40%-60% of cases¹.

SWAN would like to see a smoother transition phase which would slowly reduce funds as families move to community supports or provide dedicated funds to support transition and ensure families and the child's support network feel confident, skilled and supported in those settings.

¹ <https://www.nature.com/articles/s41431-018-0099-1>

The transition phase needs to be funded in NDIS plans otherwise, smooth transitions will be harder to achieve. The transition phase at the moment is, going from supports in your NDIS plan to no supports at all. Families can really struggle, particularly if they are vulnerable, from a CALD background or a low socio-economic background. Our SWAN families don't know what supports they can access, and that is where a smoother transition process, ideally with the support of a key support worker can be advantageous. A slower reduction in funds over a transition phase would make the process easier for everyone as we don't want situations like the illustrated case study below.

Case study – Transitioning out of the NDIS – Ava's story

Meet Ava, a SWAN eight-year-old who transitioned out of the NDIS. Prior to leaving the NDIS Ava received visits to her school on a fortnightly basis from her Occupational Therapist (OT) to assist her with developing her fine motor skills and regulating her behaviour. Ava's ECEI key support worker used to attend the Student Support Group meetings and ensure the Individual Learning Plan met her needs.

Suddenly when Ava was no longer supported by the NDIS, there was little support for her at school. There was no school OT and Ava's anxiety increased and she struggled to regulate her emotions and had frequent outbursts at school. The school contacted the parents several times to ask the family what to do or to come and pick Ava up from school as she was not coping (or the school was not coping). There were little resources put aside for an OT to work with Ava's new teacher and everyone's anxiety and stress levels increased; Ava's, her teacher, the school principal and her family's. The family was not in a financial position to continue to pay the OT and they felt let down by the NDIS as Ava no longer qualified for supports, yet the school was not adequately resourced to meet her needs. Ava's self-esteem declined along with her mental health.

- **How can we help families and carers better understand some of the terms the NDIA, and Early Childhood partners use such as:**

- **best practice**

The NDIS needs to provide families with examples of what the "best practice" model is. Best practice is evidence-based support, noting it may change as time goes by. The best practice ECEI model² is family centred, inclusive, collaborative and evidence and outcomes based.

There is a need to promote the ECEI best practice model under the NDIS. In our liaison with SWAN families, many of them don't understand the difference between the ECEI best practice model and using individual allied health workers not associated with an ECEI service. The best practice model can be extended to include additional therapists to best support the child's needs where necessary. It moves away from a medical model which amounts to a set amount of time on therapy. A skilled transdisciplinary person can meet a lot of the needs of a participant without having a large team involved. We need a flexible approach to supports to assist a child with meeting their goals at the level they require.

² Source: <https://www.eciavic.org.au/resources/eci-best-practice-guidelines>

An ECEI service utilises a key support worker to coordinate supports for a child and their family.

The allied health professionals are based at the service and can communicate with one another to ensure there is a continuity of supports and coordinated care, so everyone understands the families' needs. They can work on common goals and strategies to support the family's and the child's development and learnings. It is a holistic approach instead of the alternative, where families utilise independent allied health professionals or allied health professionals who work as contractors or employees at therapy centres. With that type of service delivery, there may be little communication between therapists, and they may even be working on different goals.

➤ **capacity building**

The NDIS needs to provide examples of what they mean by "capacity building". For example, a capacity building support is a support that can improve someone's ability or functional capacity to perform a task.

➤ **natural settings, and/or**

The NDIS needs to provide examples of what they mean by "a natural setting". For example, a natural setting is an environment that is comfortable for the child, such as in their home.

➤ **evidence**

The NDIS needs to provide examples of what they mean by "evidence based ". For example, evidence based suggests the matter has been researched and is credible.

Support with achieving goals

- **What is the best way for us to check in with families and carers on how their child is tracking to meet the goals for their child?**

SWAN suggests having a conversation to understand what communication method would work best for the family, e.g., telephone, email, and face-to-face visits. The NDIS will need to establish how frequently the family would like someone to check in with them and what days of the week and times would work best. Good communication will be vital in getting the best outcomes for families and ensure they feel supported.

- **Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goals?**

Yes, mandatory reporting would be a useful tool in tracking a child's progress against goals. However, it does come with some issues and would undoubtedly work better under the ECEI best practice model instead of employing individual allied health professionals. For example, if individual service providers are not communicating with one another, there is a lack of cohesion. Allied health professionals could be working on different goals or duplicating supports that is not cost effective. There is also the privacy factor to consider. Not everyone wants to share what they are doing with individual therapists or even disclose what allied health professionals they are working with. There needs to be a consistent approach, and some individuals will report on less than others. Then, there is a lot of time spent on reporting that could be spent working with families to support their child's goals.

- **How can we better support families to connect with services that are either funded or available to everyone in the community?**

Utilising an ECEI key support worker or support coordinator who understands a child's needs will better support families to connect with services, both funded and community supports. There may be cultural factors that impact how families support their child that need to be considered. It is important to connect families with the right supports to ascertain the best outcomes.

- **How can we make the process of transitioning out of the NDIS something to celebrate?**

Smooth transitions out of the NDIS where families feel comfortable to continue to support their child's capacity to learn should be recognised positively. Families should be praised as the child and their family achieve their goals. We don't want families to feel vulnerable and isolated once the NDIS supports are withdrawn, which is what our SWAN community fears might happen, particularly if there is not adequate transition funding allocated in participants plans.

Targeted support

- **If you live in a remote or very remote part of Australia, what are some ideas you have on how we can get early childhood supports to work in your community or communities like yours?**

Incentives are always a good motivator. There is the potential to make allied health student placements mandatory in the final year of the course in a remote area (unless there is a good reason not to undertake one, e.g., health or family commitments)

- **How can our Early Childhood partners and mainstream services best support peer-to-peer connections?**

They could link families in with genetic peer support groups such as SWAN so families can build connections. MyTime groups also offer support to parents. School parent groups may also be an option. Playgroups and mothers' groups also offer peer connections.

- **Are you interested in helping us co-design an approach that would make peer-to-peer networks easier to find and join for people?**

The NDIA should engage with and support a number of establishments and supports that are underutilised that actively work at connecting their members for peer support instead of replicating or duplicating these initiatives.

Groups such as SWAN, the Genetic Support Network Victoria, Genetic and Rare Disease Network WA, Genetic Alliance Australia (NSW), Mytime Groups around Australia and Playgroup networks in different states all provide peer support or connections to other groups that do. More referrals could be made to groups and organisations that already exist and funding them to grow rather than set up new ones that may not have sustainable funding.

- **How can we better reach and get support to young children and families who experience vulnerability and remove barriers so they can receive outcomes in line with other children and families?**

Vulnerable families should be given funding in their NDIS plan for an ECEI key support worker and a support coordinator to ensure they can access the supports to assist their child meet their NDIS goals.

Different cultural values and diversities need to be better understood. Many of our SWAN families from culturally diverse backgrounds feel more comfortable having a worker from their own cultural background than an Australian worker who does not understand their culture or rituals. Some NDIS participants prefer to only employ support workers from their own culture or religion so they don't feel embarrassed by carrying out rituals such as praying when their support worker is with them.

Tailored Independent Assessments (IAs) approach

- **Do you have any feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers?**

SWAN is strongly opposed to the introduction of independent assessments to assess eligibility and plan budgets. If the NDIA uses ECEI partners who employ allied health professionals for Independent Assessments, you are taking these valuable human resources away from an already in-demand workforce. There is already a shortage of allied health professionals, particularly in rural areas, so removing them from supporting families will cause longer waiting lists and delays with families accessing their capacity building supports in their child's plan. Currently, many of our SWAN families struggle to utilise their first choice allied health professional because of their lack of availability, e.g. for appointments after school.

Many of our SWAN families have difficulty concentrating and focusing for extended periods of time and cannot participate actively in assessments, and will score – "non-compliant". Why are we assessing our children on what they cannot achieve? Why do we make families feel bad when their kids don't score well in these assessments? These assessments will most likely be conducted by strangers who can cause huge anxiety for families.

Families should be empowered to lead their children's engagement with the NDIS. Most importantly, they should be empowered to lead the determination of goals and the development of plans and budgets. Goal setting should continue to be a key element of the current planning process, they should not be discussed only after the draft plan is completed.

Most independent assessors do not understand undiagnosed or rare genetic conditions, or the impacts of these conditions on functional capacity. Most undiagnosed or rare genetic conditions are complex and can be progressive or episodic. We cannot have a one size fits all approach when every child is different. There is still so much unknown about the impacts of rare genetic conditions that an assessment such as the ones proposed by the NDIS will not capture the needs of our SWAN children, and this is very concerning.

We are concerned that families will not know what discipline of an assessor to choose when their child has a complex disability. Families may not be able to choose an assessor that suits their needs. Some of these assessments are probably best performed by a psychologist or educator rather than an allied health professional who has little experience conducting such assessments. In most cases a multidisciplinary assessment will be required to fully understand the functional impact of complex genetic conditions.

There is also very little information about how these assessments will be administered if families have little grasp of English or require the assessments to be provided in Easy English or with visual supports. SWAN doesn't believe that the NDIA has put enough consideration into the needs and values of people with culturally diverse backgrounds prior to wanting to introduce independent assessments for everyone. From our conversations, we have heard, our families fear they will be sent back to their homeland by the government if their child does not perform well in these assessments, which adds to their anxiety and stress levels.

We need to rely on multidisciplinary reports from the child's experts, such as medical and allied health professionals. These professionals often have a long-standing relationship of supporting SWAN children from a very early age. Over that time, they build trust, gain expertise and develop a good understanding of children with undiagnosed and rare genetic conditions. Their reports identify multidisciplinary supports and goals for families, unlike assessments and they should be taken into consideration when determining eligibility and allocating plan budgets.

Assessors without experience, knowledge and expertise in undiagnosed or rare genetic condition will not be well placed to conduct these assessments. The NDIS should not rely on an independent assessment to determine plan budgets which may not be enough to support a participant's needs. There is still so much unknown about rare genetic conditions that an assessment such as the ones proposed by the NDIS will not capture our SWAN children and their families' needs.

Finally, we are particularly concerned that independent assessments will not be reviewable decisions. There is no avenue to request a review if you disagree with the independent assessment, which could impact eligibility or determine your plan budget. We believe this is wrong. The assigned budget aligned to your plan as a direct result of these independent assessments may not be enough to support a participant's needs. Furthermore, the NDIA is yet to share evidence that supports functional capacity assessments as proven tools for determining support needs and budgets, or how these assessments would be translated into budgets.

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

Greater transparency on providers of best practice

- **What mechanisms do you think could help achieve this?**

SWAN believes there needs to be greater accountability, perhaps through a yearly audit to ensure providers are delivering best practices standards.

- **Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?**

ECEI providers themselves would be best placed to lead the development of and manage any additional complementary mechanisms as they are the most experienced at what constitutes best practice in their field.

- **What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?**

- **Provide greater information to families about the benefits of using providers registered by the NDIS Commission.**

Benefit	Families may preference a registered provider over a non registered provider. We disagree with trying to influence a choice in the type of provider that a participant can choose. The benefits of both utilising a registered and non-registered provider need to be presented to families.
Concerns	Using registered NDIS providers does not offer choice and control to participants and is not flexible. You cannot choose to utilise a non registered provider that you may have a good working relationship with and one that understands your child's needs

- **Establish an industry-led 'best practice accreditation system'.**

Benefit	Providers will become more accountable for the service they deliver.
Concerns	Accreditation takes time, expertise, requires resources to set up and can be costly. Best practice standards may evolve with time, and accreditation may not keep up.

- **Establish a 'quality feedback / rating system'.**

Benefit	This will make organisations accountable and allows families to select highly rated services.
Concerns	High rated services may not have the capacity to take on new participants and may create a shortage of reputable allied health professionals.

- **Make registration with the NDIS Commission mandatory for all providers operating in the EC space.**

Benefit	This will aid accountability and confidence that best practice and ensure high quality services are being delivered. However, we disagree with making EC providers registered with the NDIS for the reasons below.
Concerns	<p>It costs time and money to be an established registered provider, it is complex to register to become an NDIS provider, and there is a lot of reporting to do, which take time away from working with families. These impacts are greater for small providers and sole traders, of which there are many in the allied health space.</p> <p>If families are locked into using only registered providers, this will take away choice and control for families, which was never the NDIS intention. Participants may be forced to move to providers who don't understand their family's or child's needs.</p> <p>There are already thin markets with regards to allied health providers in regional areas. Enforcing restrictions could prevent people from accessing any local services.</p>

- **Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.**

Benefit	Families may preference a registered provider over a non registered provider. We disagree with trying to take away choice and control as this goes against the principles of the NDIS Act 2013, so we cannot support the benefits of this statement.
Concerns	<p>It costs a lot of money to be a registered provider, it is complex to register, and there is a lot of reporting to do, which take time away from working with families.</p> <p>There will be no choice and control for families, and people may have to move to providers who don't understand their families or child's needs.</p> <p>Families may want to work with a therapist experienced with complex care children, but unless they are a NDIS registered provider, families won't be able to use them, which may mean children may miss out on targeted therapy for their child with complex needs. The best therapists for your child may not be registered NDIS providers. There are already extensive waiting lists for accessing allied health services, time spent on these waiting lists would only increase.</p>