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Syndrome Without A Name (SWAN) Australia's submission to:

Joint Standing Committee on the NDIS's inquiry into the provision of services under the NDIS Early Childhood Early Intervention Approach.

Syndromes Without A Name (SWAN) Australia thanks you for the opportunity to make a submission to the Joint Standing Committee on the NDIS's inquiry into the provision of services under the NDIS Early Childhood Early Intervention Approach.

SWAN is a peak body in Australia representing and supporting families caring for a child with an undiagnosed or rare genetic condition, many who have at least one disability as part of their genetic condition. Many of our families first come to us for support when their children are aged between 0-6. They are in a fog of confusion as they try and negotiate the systems that can hopefully support them. Our families are dealing with the fact their child may not ever receive a diagnosis. They have to learn to accept that their child may require many medical interventions just to keep them healthy. And then there is the puzzle of the disability maze and learning what supports are available to them at any given point in time, and then try and access them. Thankfully the NDIS has made it easier for some of our families but others are still very challenged by the system that has the potential to support them.

We have addressed the terms of reference that are of most concern for our members:

a) The eligibility criteria for determining access to the ECEI pathway;

Unfortunately, not being able to "tick a box" with a name of a genetic condition is still an issue for many SWAN families. The NDIS is designed as a needs-based system as opposed to a diagnosis-based system. However many planners do not understand that there is even further uncertainty about a child's development when you cannot put a name to their genetic condition. Even when SWAN children are diagnosed, the majority of them are diagnosed with incredibly rare genetic conditions which no medical professional can tell them much about. So we ask that planners be sympathetic to our families' needs and support them the best they can.

We don't believe you can use a "one size fits all" approach to access ECEI and NDIS services as every child will tell their own story.

Recommendation:

- ECEI pathways should be fair and children living without a diagnosis or with a rare genetic condition should not be disadvantaged by not having a diagnosis
- Include undiagnosed and rare genetic conditions to lists A, B and D of the NDIS operational guidelines
- ECEI eligibility should be guided by recommendations from experts; paediatricians, geneticists, maternal health workers, allied health workers and early childhood educators

b) The service needs of NDIS participants receiving support under the ECEI pathway;

Access to a range of services needs to be offered to NDIS participants under the ECEI model. Often a family does not know what they want or require for their child when entering ECEI. Once familiar with ECEI, families can develop an understanding of what supports are required for their child. Families can be guided by service providers and learn what therapies and programs will support their child best to reach their full potential.

Location should not be a limiting factor of support. Travel needs to be factored into plans particularly for those ECEI families living in rural areas.

ECEI should be as much about supporting the family, as it is the child. If you don't support the family, they are at risk of breakdown, which will leave the child with limited support. As one SWAN family told us –

“When I first attended ECIS, I thought we didn't really need to be here. Little did I know we would be still there 5 years later, and have formed a family of friends and support for life” – SWAN Parent

You cannot underestimate the value of peer-to-peer support from families travelling a similar journey.

A high level of support around the NDIS preplanning stage needs to be given to families new to disability and ECEI. ECEI families should also be matched with NDIS planners experienced with ECEI services for their initial NDIS planning meeting. NDIS participants should be allowed to review their plans prior to them being submitted to the NDIA. This will decrease the need for an internal review which are requested when there is not enough funding in their child's NDIS plan to meet a participant's needs.

Choice and control need to be exercised. Families should be able to select between ECIE providers and use different ECIE providers to need their child's needs e.g. attend a hydrotherapy session on one day at one ECIE provider and a music therapy session at another ECIE provider another day. There needs to be flexibility as to where the service will be provided e.g. in home, at a centre or in the community.

Recommendation:

- Funding allocated to support preplanning NDIS meetings for ECEI participants to ensure they don't miss out on essential services to support their child
- Better access for rural families
- Families (including siblings) need to be supported
- Funding to support parents of children entering the NDIS and ECEI needs to be considered e.g. continue to fund Mytime groups and peer-to-peer support groups
- Choice and control between ECEI providers and flexibility as to where the service will be provided.
- Provide NDIS planners for ECEI families who are experienced with services or have been given training about the supports that ECEI families require and their needs
- Training for ECEI service providers and NDIS planners to have a better understanding of the impact of caring for a child with an undiagnosed or rare genetic condition
- Participants need to be able to review their plan prior to NDIA approval to lessen the need for internal reviews because support needs are not met

c) The timeframe in receiving services under the ECEI pathway;

After consultation with a number of our members, it appears there are inconsistencies with access to services. Some families get their plans within 1 week of the planning meeting whilst others can wait up to 6 weeks. For families who don't live in a NDIS roll out areas, there may be long wait to access ECEI and access to therapists and supports maybe limited. SWAN children fall through the gaps and are not eligible for Better Start Funding because they don't have a diagnosis or a diagnosed with a rare genetic condition. ECEI services should be offered immediately for those families not in NDIS roll out areas.

0-6 is crucial for a child's development and children with global development delay should not have to wait. Waiting times and uncertainty cause huge anxiety for our members. Parents' dreams are shattered as they deal with the ambiguous loss of not have a "typical child". With ECEI pathways comes support not only to the child but the whole family when they have a family-centered approach.

Recommendation:

- Children 0-6 wait no longer than 2 weeks to receive their NDIS plan
- Access to services to ECEI services should be a priority under the NDIS and for those awaiting entry into the scheme

d) The adequacy of funding for services under the ECEI pathway;

Funding needs to be allocated to services that first identify global development delay such as GP's, maternal health nurses, allied health professionals and paediatricians. Support needs to be offered to parents and carers at this time as their child's world as they know it is shattered. The impact can be devastating to families as they hear the words:

"your child has global development delay and is behind in all areas of development" – SWAN Parent

Funding needs to be directed into supporting families when they are first told there is an issue with their child's development. Clear pathways need to be set out for them, because they are not always in the right headspace to be empowered to find the best supports for their child. It can appear to be a foreign world to them. For SWAN families it is worse, as they find themselves in "*Limbo Land*" with no answers for why they are there. Families need to be well informed and educated about services and supports they can access.

Funding for advocacy should be supported to ensure ECEI children's needs are met.

Recommendation:

- Funding for counselling for families/carers who care for a child newly diagnosed with global development delay
- Training for maternal health nurses and health practitioners around negotiating ECEI and the NDIS
- Information about accessing and planning for the NDIS provided to ECEI families
- Educate ECEI families about service and supports available to them
- Funding for peer support groups to support ECEI families
- Advocacy to be funded for ECEI families

e) The costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants

The cost of raising a child with a disability is considerably higher than a “typical” child. Many parents are no longer able to sustainably work due to the large number of appointments and therapy required for their child.

The cost of additional therapy whilst families waiting to enter the NDIS can be a burden on families, particularly for those living in rural areas who have to travel long distances to access services.

Diagnosis testing for SWAN children is expensive. Currently the advances in genomic medicine with whole exome sequencing (WES) tests and whole genome sequencing (WGS) tests are not covered by Medicare. So if a family wants to try and seek a diagnosis for an undiagnosed genetic condition, they must either apply for a research project which will fund a WES or WGS, or pay for that themselves at the approximate cost of \$2500 for a singleton WES, \$5000 for a trio WES or \$4350 for a singleton WGS or \$8450 for a trio WGS.

“Children have access to better treatment plans and outcomes if an early diagnosis can be made” – Dr Sue White, Clinical Geneticist

Recommendation:

- NDIS cover the cost of genetic testing where a disability is present
- The cost of carers allowance be increased
- 20 mental health care sessions be funded per year for parents/carers who have children eligible to access and already accessing the ECEI services
- Support travel costs for rural families traveling significant distances to access ECEI services

f) The evidence of the effectiveness of the ECEI Approach;

It is evident that model of ECEI works with a family-centered practice and key worker model approach. I think as a parent of a child newly diagnosed with a disability, you are in a vulnerable position. You are naïve about services and supports and need to be guided by experts working in the ECEI field.

“My child didn’t walk until they were 3 and talk until they were 4, we did hours and hours of therapy. Without the guidance and support of allied health professionals working in ECEI, we would have been lost and I am sure it would have taken my child even longer to reach their milestones” – SWAN Parent

Recommendation:

- Continue to support the ECEI family-centred practice and key worker model

g) The robustness of the data required to identify and deliver services to participants under the ECEI;

Children develop at different rates so there needs to be a consistent approach to measuring the data collected. Services should be offered on a needs basis which are “reasonable and necessary” for child to reach their full potential. Regular assessments should be made and programs modified as required and have flexibility to best meet a child’s needs.

Recommendation:

- A consistent approach taken to identifying a child’s needs and for delivering services around them to best support their needs.

h) The adequacy of information for potential ECEI participants and other stakeholders;

Potential ECEI families should be given a range of resources in which they can make a decision about the services they want to access. These resources should be offered in a range of mediums including brochures, websites and “Easy English” formats. They should be readily accessible. Guidelines around “best practice” for ECEI providers should also be developed.

Fact sheets around accessing and planning for the NDIS need to be provided to potential ECEI families. This includes giving them choice and control about what they want included in their NDIS plan. Clear and non-judgmental information should be given to families about their options on how they can manage their plan; NDIS, Plan Managed, Self Managed or a combination of the management options.

Recommendation:

- Make information around decision making for potential ECEI participants accessible to all who might benefit from their services
- Guidelines around ECEI “best practice” for ECEI providers should also be developed through consultation with the sector and the community who access their services
- Provision of fact sheets around accessing and planning for the NDIS need to be provided to potential ECEI families

i) The accessibility of the ECEI Approach, including in rural and remote areas;

Access and choice remains a limiting factor for many SWAN families living in rural and remote areas. There are limited number of service providers and some have chosen not become registered NDIS providers due to the high level of complexity of the NDIS provider registration process. This means that families that live in rural and remote areas will have even less choice when choosing providers to support their child’s needs.

Recommendation:

- Make the registration process for NDIS providers less complicated
- Allow additional funding for travel for families living in rural and remote areas
- Provide face to face planning meetings if that is what rural and remote participants desire
- Provisions for improved internet access for rural and remote families to allow for on-line video links “face to face” meetings, with clear guidelines

j) The principle of choice of ECEI providers;

Families should have the right to choose their ECEI providers, and to mix and match to suit their child’s needs and their time constraints. A variety of services should be offered on any given day. It should be an open market to support “choice and control”, which aligns with the philosophy of the NDIS.

Different service providers offer different support services e.g. hydrotherapy, physiotherapy. It is about choosing and having access to services that support your child’s needs at any given point in time. We need to be adaptable to change.

Recommendation:

- It should be about choice and control
- Flexibility should be built into NDIS plans and changing service providers or support services should not be difficult

k) Any other related matters.

Further support needs to be given to understanding NDIS plans, particularly when families are new to disability. Services are difficult to negotiate and the ability and knowledge of support coordinators varies considerably, with many SWAN families not having a lot of confidence in the support coordinator they have chosen. Further training to assist service providers help families interpret their plans and find services is something that needs to be addressed.

Recommendation:

- Further support be provided for families so they can interpret and access their NDIS plan

We would welcome the opportunity to discuss this submission further with you or require further information.

Yours sincerely

Heather Renton
President
Syndromes Without A Name (SWAN) Australia