Syndromes Without A Name (SWAN) Australia

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Productivity Commission
Review of NDIS Costs
GPO Box 1428
CANBERRA CITY ACT 2600

www.pc.gov.au/inquiries/current/ndis-costs

RE: SWAN Australia submission to NDIS Costs - Position Paper

To whom it may concern,

Syndromes Without A Name (SWAN) Australia thanks you for the opportunity to write a response to the Productivity Commission Position Paper - NDIS Costs.

About Syndromes Without A Name (SWAN) Australia

SWAN Australia is the Australian peak body representing families caring for a child with an undiagnosed or rare genetic condition, many of whom have at least one disability. The majority of our members would be eligible for the NDIS but not having a genetic diagnosis or being diagnosed with a rare genetic disorder can mean our families can still fall through the gaps.

We strongly believe in the NDIS as a social reform for Australia but recognise there is still more work to be done to ensure the scheme is successful. We urge the government to continue with the rollout as planned to avoid disappointment amongst our members eager to enter scheme. The NDIS Costs – Position Paper recommends a number of improvements to the scheme but also raises some concerns, which we have addressed below:

Operational Guidelines Lists

Life is difficult enough when you care for a child with an undiagnosed or rare genetic condition but when nobody can give you an answer for your child’s syndrome, life is that much harder. Medical experts and SWAN parents don’t know the extent of their child’s condition, which can makes it even harder to advocate for your SWAN child to become a NDIS participant. Educating planners around a SWAN child’s needs can be difficult, especially when little is known about the child’s condition. SWAN parents might not know whether their child’s development is likely to progress or regress. This is why it is important that SWAN children with disabilities be given the opportunity to enter the NDIS scheme as easily as possible.

Recommendation:
That “Undiagnosed Genetic Disorder” or “Syndrome Without A Name”, and “Rare Genetic Disorder” be added to List, A, List B or List D in the NDIS Operational Guidelines.

Planners

There seems to be an inconstancy with the quality and competency of planners. Some planners have offered to ring a participant with their plan prior to submitting the plan to NDIA and others have submitted it almost straight away. The length of time it takes to issue plans varies considerably from 3 days to over 6 weeks. The planning meeting is a time for transparency and clear communication.

Recommendation:
Planners and LAC's to give a clear estimate as to when participants will receive their plan.

A consistent approach to planning meetings, which will require further training for planners and LAC's

Further education and training be given to planners and LACs about undiagnosed and rare genetic conditions and around the types of supports that can assist SWAN children. We have come across people who have thought that all disabilities must have a name.

Service Providers

Through engagement with our community, it is apparent that service providers are not keeping up to speed with the roll out of the NDIS. For example in North East Victoria, day services are still operating 9am – 3pm and closed in the school holidays. There is still a big gap in the availability of school holiday programs for children with disabilities. Mainstream programs offer excursions to activities not always suitable for SWAN children, often to movies or sensory stimulating indoor play centres. Many SWAN children simply cannot cope due to their sensory issues with those mainstream environments. The programs and services are not always available for SWAN children, particularly in rural areas.

Recommendation:
There is much needed work to be done in the ILC space with educating and training mainstream services around the needs of people with disabilities. The workforce needs to expand in the disability sector for the NDIS to fully succeed.

Reviews

Further information needs to be given to NDIS participants about the review process. It is unfair that people risk losing items out of their plan when they go through an internal review. We believe this should not happen as it makes the internal review process seem like a lottery. People will not want to risk launching a review if there is the chance they will be worse off.

There is also lack of distinction between what is regarded as "education" and "NDIS". A recent SWAN participant was asked to get a speech assessment done as part of their internal review. The assessment illustrated that the participant required intensive speech therapy as they had a severe language delay. The request for further allied health was denied because the NDIS review team said the participant was accessing speech through the education department. There was no guarantees by the school that the client would continue to access speech therapy from the school for the remainder of the year.

Recommendation
More information needs to be provided at the planning meeting about the review process. Often it will be participants who are confident to advocate for themselves or have knowledge of advocacy agencies who will ask for an internal review of their plan.

Participants should be given a list of advocates in their area who can assist them with an internal review if they are unhappy with their plan. Advocacy for NDIS participants needs to be easily accessible, available and continue to be funded by Government.

Further education needs to be provided to planners and review teams about what constitutes an “education support” and a “NDIS” support.

NDIS Preplanning Workshops

Service providers giving NDIS preplanning readiness workshops are not always giving potential participants the correct information particularly when it comes to self-managing their plan and the review process. There is a lack of consistency and knowledge from the disability support organisations and the NDIA who provide information to participants.

Recommendation
Education and training needs to be given to disability support organisations giving NDIS preplanning workshops to ensure the same information is given to NDIS potential participants.

People presenting NDIA planning workshop, disability support educators/trainers, planners and LAC’s require a better understanding of what is involved in self-managing a NDIS plan and the time required to self-manage a plan. With an estimated 5% of NDIS participant selecting to self-manage their plan, improvements in this area can be made.

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

Yours sincerely

Heather Renton
President
Syndromes Without A Name (SWAN) Australia