



Syndromes Without A Name (SWAN) Australia

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Department of Social Services (DSS) National Disability Insurance Agency (NDIA)

29 June 2019

RE: NDIS Thin Markets Project

To whom it may concern,

Thank you for the opportunity to write a submission with regards to the NDIS Thin Markets Discussion Paper.

About Syndromes Without A Name (SWAN) Australia

SWAN Australia provides information and support to families caring 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 answers many questions on the NDIS particularly around seeking out service providers under the NDIS. One of the common themes of enquiry is around participants not being able to access the services they have funding for in their child's plan. SWAN itself is not a registered NDIS provider and offers information and support as a free service to its members.

Many SWAN families who live in rural areas have difficulty finding supports. Services are not available in their location and if they are, they have extensive waiting lists. We have outlined one SWAN family's experience of the NDIS in a case study on the next page. Their experience is not unique and we often hear similar stories from SWAN families living in rural areas.

Case Study:

Izzy is an 8-year-old SWAN child with a rare genetic condition and complex medical needs. She lives in rural Victoria in a town with a population of around 3500 people. For Izzy to attend her local special school, she needs to travel 42km one way. Izzy's mother does not drive, and her father works long hours so is not available to take her to school. The family have no informal supports that can assist them in caring for Izzy day to day. For Izzy to attend school, the family must pay a taxi \$56 (usually \$112 but Izzy qualifies for a taxi card) just to drive her 26km to the school bus stop. There is no funding for this daily taxi trip in Izzy's plan and Izzy lives outside the designated school transport zone so is not entitled to Department of Education school transport. This is despite the school being her local special school. A decision around how supported school transport in government schools will be delivered under the NDIS was expected to be made by 2020 but according to the Department of Education website the decision has now been postponed until 2023.

There are no support workers in her town who are willing to drive Izzy to school and even if there were, Izzy has no Core Support Funding in her plan as it is considered the "parents' responsibility" to care for their child. Izzy has complex health and disability needs and sometimes the family just needs a break to keep their informal supports going.

There is funding in Izzy's NDIS plan for therapy assistance, but there are no therapy assistances that live in their home town. The closest one would have to travel one hour each way and they don't get funded for travel so Izzy can't access their support despite having the funding to do so.

There are very few NDIS allied health providers in Izzy's home town and the ones that are there are at capacity and have huge waiting lists. So, the family pays for a 1 hour therapy session plus an hour for the therapist to travel to their home and another hour back. The family has tried to take Izzy to the therapist's rooms, but Izzy is a lot more engaged and comfortable in her home environment and the session is a lot more productive. Continuity of care is also very important for Izzy.

Izzy would like to access some programs in her local community but can't use her funding to do so because there are no classes she can attend. There is no music class and the local gymnastics centre said they couldn't take her because they needed to have a NDIA registered support worker attend with her and not a family member. There are no NDIA registered support workers that have the availability to work with Izzy as there are very few registered in her regional town.

There is a circus class an hour away, but the family have no way of taking Izzy there or picking her up as they cannot find a support worker to do so, nor do they have the funds in Izzy's plan to do so.

SWAN acknowledges the generous time spent talking to Izzy's family and their permission to tell their story for this case study.

Even in metro areas, SWAN families struggle to find supports such as support workers. Many support workers are only available within school hours. Therapists often only have availability during the day, where many families with school aged children want appointments after school. Afterschool appointments are in demand and often families are placed on long waiting lists to access these services. Psychologists often have at least a 6 month waiting list too.

It becomes harder for families to justify they need the same level of support in their plan when they have not spent their current 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.

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.

From interviewing SWAN families, there seems to be a shortage of therapists and NDIS support workers. Not every family we spoke to had 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 properly for people with disabilities and catch-up with the demand, we will continue to have this problem.

Obtaining disability support workers through Core Supports is also an issue for SWAN families with children in year 7 to year 12. Many are being denied Core Support funding as it 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. Many 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.

Many of our young SWAN children are being denied basic equipment such as safe seating and standing frames. The process to obtain equipment is long and time consuming, with many months passing by between when equipment is applied for and when it is eventually approved, and then again between approval and when it actually arrives at the participants house. SWAN would like the gap time decreased so there is a maximum of 2 months waiting time between the initial application and the outcome of the application, and only up to 2 weeks waiting time from when equipment is approved to when it is able to be used by the participant. This would avoid the added problem of the child growing out of their applied for equipment by the time it actually reaches them for use. It also avoids the inhumane situation of forcing a child to exist in a wheelchair that is far too small for them, or a child having to undergo orthopaedic surgery as they didn't receive their standing frame in time to prevent their hips from dislocating.

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 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 of the complexity of rare disease and the challenges a child faces with a rare condition or a lack of diagnosis.

We would be happy to discuss our submission further with you.

Kind regards

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