



## Syndromes Without A Name (SWAN) Australia

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### **Organisation Submission - Draft Service Concept**

Thank you for the opportunity to provide feedback on the draft Service Concept. I appreciate the detail and effort undertaken to present the information in draft format for community consultation. Of the eight draft Service Concepts proposed, the two areas I would like to provide feedback on are Peer Support and Needs Identification and Planning.

#### **Peer Support**

I manage Syndromes Without A Name (SWAN) Australia, a peak advocacy body which provides information and support to families caring for a child/children with an undiagnosed or rare genetic condition.

We advocate for further funding into genetic research, genome sequencing to move into clinical practice, faster turnaround times for genetic tests, better resources and pathways for our children, increased availability of information for our families, and awareness of undiagnosed conditions within the wider community.

We are a not-for-profit group staffed by volunteers, the majority of whom care for their own children with disabilities and medical conditions. We offer peer support for our members/carers and encourage families to build their own peer-to-peer support networks within the SWAN community. There is no charge for our members to join our group because many of them are full time carers and therefore cannot work. We offer a parent support phone line and run information sessions for carers which are beneficial for both carers of children with chronic illness & high medical needs, and for carers of children with disabilities. We offer support and guidance in the hope of limiting isolation and the feeling of hopelessness amongst our carers. Utilising social media allows us to distribute information to our members with minimal effort and expenditure.

Through social media and peer support meetings, SWAN carers have opportunities to share ideas, and although our journeys are individual we can learn and gain knowledge from sharing our stories, strategies and experiences with our SWAN peers. I cannot stress enough the value and benefit of peer-to-peer support for our group. This provides opportunities and resources for carers to support each other in a safe nurturing environment, making the carers' role less isolating.

SWAN carers experience frustration, isolation, uncertainty and anxiety. Life is difficult enough when you care for someone with a chronic illness or disability, but without a diagnosis it is that much harder. Grief, depression, helplessness, guilt, emotional vulnerability and denial are just some of the emotions experienced by SWAN carers. As stated in your draft Service Concept, peer support should be included in the future support model. I believe funding should be allocated to more Genetic Support Groups who provide support to carers of people with chronic illness, complex medical needs and disabilities. This support needs to be both emotionally and in a scientific capacity to aid in understanding of the individual's illness or disability, both present and in the future. It is wonderful that the importance of Mytime groups has been acknowledged, but peer support needs to be expanded to include Genetic Support Groups that provide invaluable support for families who have children with similar conditions. Often parents look for a specific group relating to their child's diagnosis or lack there of.

Support groups offer value for money for their service and understand and identify with many of the issues carers face. It is important to support the carers themselves, and also the networks that support the carers. I believe that including Genetic Support Groups under Peer Support would provide cost saving benefits to the Government in the long term, and assist with achieving the key objectives of the plan, leading to better outcomes for all.

### **Needs Identification and Planning**

I appreciate the provision in the plan for assisting carers' return to work. However, the majority of special schools and special developmental schools do not provide afterschool care or school holiday programs, making it extremely difficult for carers to participate in paid employment.

Another area of concern is that many work places still do not offer a flexible work environment for carers. Because of this, carers often have to cease employment and become full-time carers, as opposed to combining a carer role with part- time employment. If I am a carer, who pays my superannuation? Who makes up the difference for the lost years not climbing the corporate ladder? The \$123.50 per fortnight Carer Allowance does not compensate for the inability to contribute to the workforce.

Caring for a loved one is not valued as a profession. If the Government does value carers so much, maybe they should pay them the equivalent of the minimum wage? Whilst I recognise that this is not feasible, at the very least, make the process for receiving Carer Allowance for families caring for an undiagnosed child easier. Many SWAN families get rejected by Centrelink for Carer Allowance because they care for a child who doesn't have a diagnosis.

It is estimated that 60% of children with syndromic features never receive a diagnosis. The provision of the Carer Allowance should depend not on the name of a syndrome or condition, but instead be determined by the nature of the caring role provided to the child. Carers want to put their energy into caring for their loved ones, not fighting a bureaucratic system.

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

**Heather Renton**  
**President**  
**Syndromes Without A Name**