**NDIS Consultation Paper: Interventions for Children on the autism spectrum**

**Submission by Royal Children’s Hospital Specialist Autism Team 13.5.21**

Thank you for the opportunity to respond to this consultation paper.

This submission is on behalf of the Specialist Autism Team at the Royal Children’s Hospital, Mental Health Service. We have been in operation for 30 years and perform multidisciplinary assessment for over 100 autistic children with complex presentations each year.

We applaud the review of NDIS funding program to ensure better integration with the needs of children and their families. We are also pleased to see the use of evidence to guide the process of selecting interventions to help families avoid services that would not be in the best interests of their child. Overall, the NDIS program has been a great improvement on previous methods of service provision.

We would however like to raise the following concerns:

* In the first 7 years of life, children on the spectrum rarely build sufficient capacity to have their funding decreased each year.  Their needs evolve, with therapy gains often laying the groundwork for further intervention.  For example, a child who has learnt to attend to others then needs further support to develop their communication and play skills.  Children with autism struggle with social communication and social demands increase markedly over this period, especially with the transition from kindergarten to school. These children are likely to require more support, not less, as the social demands increase across this time period, as their progress, even with intervention, is likely to be less than that of their peers.
* Many families struggle to access appropriate therapies due to long waiting lists. Not every therapist will be a good fit for a child, and the family may need to find a new practitioner. These issues are most likely to be encountered in the first year of NDIS support. A child may not be fully engaged in appropriate therapies until their second year of funding.

* The creation of a plan should be based on a holistic understanding of the child and an awareness of what is possible through therapy for a particular individual not just immediate needs. Professionals with a sound understanding of the scope of therapy and outcomes should be involved in the decision making.
* The research evidence to support the use of many intervention therapies is incomplete and some clinically useful services may not have a good evidence base (Wong, Odom et al 2015). A number of community services offer an eclectic mix of strategies that have not been evaluated.
* There is incomplete evidence for the additive effects of therapies. It is likely for instance that developing a communication system would improve a child’s ability to use behavioural scripts and cognitive behavior strategies. A good plan would make allowances for this
* While research might indicate the most reliable and efficacious practices, it often does not indicate which children may benefit from that particular service. Psychologists or paediatricians who understand the strengths and difficulties of a particular child may be able to advise about this.
* There is limited research about the long term outcomes of intervention (Matson and Konst 2013)
* Ideally NDIS plans should sit in a framework of longer term planning. Families may not be in a good position to make decision for the longer term development of their child. For instance, access to sports or toilet training may be very important to families, but developing a communication system that improves a child’s ability to engage with family, school may not be seen for its impact on social inclusion. Families may also not be aware of the natural evolution of some difficulties, eg toilet training, is often dependent on a child achieving a certain level of maturity and implementing strategies before the child is ready is a waste of effort.
* A significant contributor to poor quality of life and failure to engage in the community are the mental health conditions that often arise in ASD. Some therapies build resilience to prevent these conditions eg strategies and services that develop self-esteem, self-awareness and communication skills. These should be given priority in long term planning.

References

Wong C, Odom SL, Hume KA et al. J Autism Dev Disord (2015) 45:1951–1966 DOI 10.1007/s10803-014-2351-z

Matson JL, Konst JL, 2013 . <https://doi.org/10.1016/j.rasd.2012.11.005>