**Reasonable and necessary**

1. Building from the Autism CRC research the consultation paper outlines specific **principles** that the NDIS considers as early intervention best practice for young children on the autism spectrum (Section 6.1.) Is there anything you would like to add?

* The intervention is based on a good understanding of autism
* The people who deliver the intervention know the person well and respect their feelings and views. Comment: this is an excellent principle. The funding levels should take into account the time needed to develop this knowledge, to build trust and a good relationship.
* The intervention is adapted to the needs of the person receiving it. Comment: Also adapted to the capacity and ability of family to support the intervention.
* The intervention is based on a theory that is logical and scientifically plausible. Comment: this is a little vague and could be interpreted in many different ways. Suggest “based on best available evidence” which acknowledges the lack of good data for many interventions but also includes family and clinical feedback and aims towards evidence-based practice.
* The intervention works in the real world, not just in a research laboratory. Comment: the intent of this principle is good but it might be worth re-phrasing this to remove the word ‘laboratory’ e.g. ‘research setting’.
* Research evidence shows the intervention can work for people on the autism spectrum
* The intervention supports mainstream and community participation

1. Building from the Autism CRC research the consultation paper outlines specific **standards** that the NDIS considers as early intervention best practice for children on the autism spectrum (Section 6.2.) Is there anything you would like to add?

* The intervention is delivered by, or supported by, appropriately qualified and experienced professionals
* The people delivering the intervention follow established guidance
* The intervention provides significant and lasting benefits
* The intervention is carefully monitored and reviewed on a regular basis
* The intervention does not cause significant physical or emotional harm
* The benefits outweigh any costs (including risks)
* The intervention is good value for money and time invested

Comment: in identifying benefits (mentioned in standards 3 and 6) it would be good to clarify how these are identified and what data is considered. Family feedback especially on the effectiveness of interventions is an important and useful way to decide what is working, particularly in the absence of research data, and should be taken seriously.

1. Do you have any other feedback about how we explain the indicative levels of funded supports?

The levels could be improved by acknowledging the family’s capacity and setting. Given the focus on family involvement in interventions, the family’s capacity to do this should be recognised and considered in the funding levels.

1. There may be situations where families or carers need extra NDIS supports such as during first plans, or where plans reduce in value due to the impact of mainstream services. What do we need to consider in those situations?

We encourage the NDIA to think about their proposed funding levels as a starting point for children with autism who are in a stable environment. Other complexities should then be taken into account when considering additional funding and support requirements. Six of these factors include:

1. **Dual diagnosis**. In situations where a child has a second diagnosis in addition to autism.
2. **Major transitions**. The transition into school and from primary to secondary school are times of enormous change for the child and family. These times can be very challenging and stressful for the child and family and it is important to provide the right support and services at this time. These transition times are crucial; functioning in a school environment will set the child up for better outcomes later in life. However, other transitions are equally or even more stressful and we propose that change of circumstance reviews should take place immediately. Other important transition times include:
   * Switching between mainstream and specialist schools
   * Moving house, or changes to the home circumstance as siblings moving out of the family home
   * Parents separating or divorcing (especially if it is not amicable and services need to be provided in two homes)
   * Children moving in or out of out of home care
   * Puberty and associated hormone changes, and the impact on behaviour
   * Personal illness or medical procedure, or illness of a family member that disrupts the family balance
   * Death of a loved one.
3. **Age of diagnosis**. Some children with autism may not be diagnosed until they are 7 or 8 years old. These children have not received the early intervention services and support and may need ‘first plan’-like flexibility in funding in the first few years post-diagnosis.
4. **Behaviours of concern.** In line with the NDIA commitment to reducing restrictive practices, it would be prudent to fund families and services to allow for the time needed to write good behaviour support plans. This will lead to cost-savings in the long term but needs to be done thoroughly and correctly, and resourced properly. See Example 1 for more detail.
5. **Family situation**. If the child has a sibling with or without a disability; if the parents have disabilities or struggle with mental health; if the family is from culturally and linguistically diverse backgrounds; if the parents are separated and the child spends time with each parent; if the family has little to no support or have other complex family dynamics they are likely to require additional and tailored NDIS supports.
6. **Children living in rural or regional areas.** In areas where services are sparse and the market is thin, funding levels should allow flexibility for additional travel time and more individualised services. See example 2 for more detail.

## Example 1: Behaviour support plan

The time needed to develop a good behaviour support plan is variable and can be difficult to quantify. It varies depending on the number of behaviours of concern, number of restrictive practices and how many implementing providers are involved (registered and non-registered).

The stages of developing a good behaviour support plan are generally:

1. Develop interim behaviour support plan. Gather data to understand the baseline for that child and start to form hypothesis around the function of the behaviours of concern. Consider the relevant strategies and develop interim behaviour support plan. This interim plan is shared with all providers and lodged.
2. Implement interim behaviour support plan. Work closely with the child’s family and broader network including support workers, teachers, sport coaches or other people who interact with that child regularly. This involves modelling and hands on training. Initial training sessions can be recorded for future use, but the unique nature of each behaviour support plan requires tailored training for each child.
3. Monitor plan: collect data, hold meetings to discuss progress and test hypothesis. Adjust plan if necessary.
4. Write comprehensive behaviour support plan and lodge. Usually done at the 6-month mark.

The reason we write this, knowing this is not new information to the NDIA, is to explain why behaviour support plans need to be appropriately funded. It takes quite a few hours to do correctly and collaboratively. There are many people involved, the workers often change and new workers need to be trained. Sometimes local police need to be educated, sometimes the justice system is involved, sometimes family planning services are engaged. The family situation and support network can also heavily influence the time needed to develop a plan.

Funding for behaviour support plan and training in NDIS packages is often enough for the development of an interim plan but not sufficient for full implementation, monitoring and comprehensive behaviour support plan. We encourage the NDIS to take complexities and family situation into account when allocating funding for a behaviour support plan.

## Example 2: Services in rural and remote areas

Travel funding should be reviewed for all outer regional and remote NDIS participants. For example, while the Mansfield Autism Statewide Service offers a range of services, there are no local speech pathologists or occupational therapists in Mansfield in regional Victoria. This means families who live in Mansfield often have to either pay to travel several hours to access speech or occupational therapy or use a large portion of their capacity building budget on provider travel alone. Likewise our Mansfield Autism Practitioner service often provides in-home support for families who live several hours’ drive away.

The NDIS plan may provide sufficient funding for therapies but insufficient funding for travel; either for the therapist or the family. It is important to fund travel appropriately for regional and remote participants, and re-think travel caps for regional therapists and clinicians.

A second rural factor to consider is the scarcity of group sessions. Children who receive funding for group sessions but are unable to access these often have no choice but to access 1:1 services and support. This costs more and reduces the frequency of support they can receive. It is important to assess whether group sessions are available in the child’s area before allocating funding.

A third factor is the lack of school options in rural areas; children often attend mainstream school without sufficient support to truly participate in the education. This highlights the intersection between the education system and the NDIS and rural children especially often fall through this gap. If the child’s only choice is to attend mainstream school they are likely to require additional support.