



Promoting best practice

1. Which of these would you use to find information about choosing and accessing best practice interventions (or services) for children on the autism spectrum?

NDIS website

NDIS Operational guidelines

Participant decision making guides (not yet developed) My usual NDIS or NDIS partner contact

Autism organisations or peak bodies

None of these

2. Where else would you like to find information about accessing best practice interventions (or services) for children on the autism spectrum?

It would be very helpful if NDIA resources provided access to comprehensive information relating to all possible therapies and their related evidence.

Almost every family we work with advises that NDIS staff and LAC's do not provide detailed information about service options. Many families also advised that NDIS staff actively advise against Early Intensive Behavioural Intervention. This seems to be in conflict with the NDIA's desire for families to have access to evidenced based information and impedes their ability to exercise the choice and control afforded by the Act and so often referred to.

3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. A description of "holistic planning" is included in [Section 7.4](#). How can we help families to find and connect with other supports outside of NDIS?

It would be helpful for families to have access to a NDIA funded service that has a particular focus on connecting families to community services. Families may be seeking community based services (eg swimming classes, dance classes, holiday programs) but need support to connect to such services. This may be the intention of the LAC role for older children but we do not see this service provided to families of younger children. Given that families are unique in their needs this should be someone the family can work with over the course of their plan and be funded in a way that is similar to support coordination.



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While it is important to connect families to support outside of NDIS, it is just as important to not assume disability support is the responsibility of other services or systems, and let the child's disability needs fall through the gaps. For example in education, the NDIS *Planning Operational Guideline Appendix 1 - Table of guidance on whether a support is most appropriately funded by the NDIS*, under 'School Education' - it outlines that disability support that addresses a child's functional skills, supports activities of daily living and specialised behaviour intervention at school, as well as school transition is indeed listed as support funded by the NDIS. However from our experience NDIS staff almost always advise they do not provide funding for children in school.

While the start of the consultation paper notes some promising principles for best practice, and highlights the need for a life cycle approach to supporting children with ASD through NDIS funding, the funding levels outlined in the paper are contradictory to all the NDIA are suggesting. Without access to evidenced based services children with autism will continue to experience insurmountable barriers to inclusion in mainstream services and the value holistic planning is diminished.



Reasonable and necessary

4. 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?

We agree that these principles are present in quality service provision, the clarification of some terms would be helpful. For example, principal 6 states that 'research evidence shows the intervention can work for people on the autism spectrum'. It would be helpful to define what 'work' means and what level of research evidence should be considered.

It is hard to understand how the limited funding described in this table could allow for the true implementation of these principals. What is lacking is an explanation of the funding levels proposed, the services each level intends to support and how this level of funding allows for the implementation of these principles as the needs of children increase across the levels.

For example Principle 2 states that "The people who deliver the intervention know the person well and respect their feelings and views". How much time does the NDIA expect it would take a provider to know a child well and to maintain this knowledge of a child as they grown and learn as a child learns? Given the complexity of behaviour



and learning common to children with autism an explanation of how the proposed level if funding levels allow for a service provider to “know the person well” is required.

Principle 5 states “Evidence-based interventions are important as the evidence provides assurances that they have been tested similar to health and medical practice, and that they have been assessed for risks”. An explanation of how the proposed funding levels allow for the implementation of evidenced based intervention must be provided. From our clinical experience with hundreds of Australian children over more than 20 years, it is hard to imagine what evidenced base services have formed the basis of the funding levels proposed. It is also hard to imagine intervention falling within these limited brackets truly impacting a child's development in a manner that will result in a reduction in the need for services in the future.

It appears that a large underestimation of funding required to adequately support a large number of children with autism is evidenced in the proposed funding levels. An urgent review of the proposed funding levels is required to ensure that they allow for the delivery of early intervention in line with the proposed principles. A failure to do this will not only result in poorer outcomes for children and families but also puts at risk the apparent financial modelling of the scheme. With the proposed funding levels, a large number of children with autism will not see an increase in capacity that leads to a reduction in supports in the future.

5. 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?

Whilst the standards themselves seem very reasonable the examples given ignore much of the national and interventional evidence that is available. The statement *‘There was insufficient evidence in the Autism CRC research to determine whether particular delivery characteristics (e.g. individual or group delivery; clinic, home or school setting, face to face or tele practice) may maximise the effects of an intervention and, if so, for which children’* grossly over generalises the literature that exists and completely ignores the detail of what is widely accepted as evidence based intervention.

The standard 7 relating to ‘value for money’ also seems to take a shallow view of value for money, risking the opportunity to genuinely reduce the support needs of individuals in the future. It seems the entire focus on this augment is on higher intensity interventions instead of considering the lack of value for money in continuing to fund low intensity interventions for a large number of children with autism.



Some explanation of how much progress a child needs to make and over what time frame for the NDIA to consider an intervention value for money is required. This needs to be clearly defined to prevent the subjective and inconsistent assessment of this that currently exists through the planning and review processes.

6. “Reasonable and necessary” is a term from our legislation. [Appendix one](#) of the consultation paper includes case studies which might be used to explain reasonable and necessary. Do these case studies help you to understand what we mean by “reasonable and necessary”?

No, these are not helpful

7. Do you have any other feedback about how we explain “reasonable and necessary?”

These examples are not representative of a large number of children with autism, grossly underestimate the support needs of children with autism and are in no way helpful.

An explanation of the evidence base that supports these examples is plainly lacking.

It is concerning to see the last example showing what early intensive intervention might look like through NDIS, with only 1 hour a hour delivered by a therapist and the majority allocated to parents to provide. The evidence used to support this claim must be provided if we are to trust that this recommendation is in fact evidence based.

The provision of more realistic examples to accurately reflect the support needs of a larger number of children with autism and the evidenced based interventions that have shown to reduce support needs in the future. NDIA should consult with families who have participated in both low intensity and high intensity evidenced based interventions and document their experiences.

8. Table 2 (0-6 years) and Table 3 (7-12 years) are an example of how we might explain Indicative level of funded support for children on the autism spectrum ([Section 7.5.](#)) Do these table/s clearly explain the indicative levels of funded supports?

No, this is not explained clearly





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

The tables do not clearly explain the indicative levels of funding. Whilst they do provide proposed amounts of funding it is unclear what constitutes high, medium or low need and what assessments will be used, and by whom, to assess high medium and low needs. It is also unclear on what basis these funding levels have been determined. How have they been calculated? What evidenced based interventions are these funding levels providing for? How do these funding levels support the implementation of the proposed Principles of Early intervention.

The paper lacks informed discussion and clarity around adequately funding evidenced based intensive intervention programs for autistic children with a high level of need in multiple domains, reflecting the majority of children we see.

There is a concerning theme throughout the paper that intensive interventions for children with autism will be short term with plans reducing each year. Our experience of building functional capacity and multiple foundational skills (communication, behaviour/emotional regulation, socialisation, motor, cognition, safety, daily living) shows that it does not happen in a short term or over the course of just 2-12 months. It is imperative that any consideration of reducing support or funding is based on the child's individual progress and ongoing/long term needs, rather than focussing on set rules about reducing costs each year.

Further, the consultation paper underestimates the needs of school aged children and assumes their capacity will be built to a level whereby they no longer need ongoing support. However we know, a portion of school aged children will continue to have a high level of support needs and the proposed funding tables and the concerning theme of reduced plan funding over time does not account for these older children.

It would be helpful to have a definition of High, Medium and Low needs and to also define the 'areas' you will be considering, some examples are given but there is no clear list of 'areas'.

10. 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?

Correctly identifying the level of support required per individual child will reduce the number of families who find themselves in the position of needing additional support.



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Having realistic expectations of the level of support required will help ensure that there are fewer families needing an early plan review or needing to go through an s100 internal review or appeal. One thematic concern with the paper is that the needs of children with autism and their families have been grossly underestimated. These funding levels proposed on the table do not allow for the implementation of therapies with a strong evidence base. Our concern is that very many families who are given a package size reflected in the table, will find that the afforded supports will not assist their child to become more independent or reduce their support needs in the future.

Further, it is concerning that there is a theme around intensive interventions being short term and an assumption that plans will reduce each year. As noted previously, our experience of building functional capacity and multiple foundational skills (e.g. communication, behaviour/emotional regulation, socialisation, motor, cognition, safety, daily living) is that it does not happen in a short term. While short term early intervention may be appropriate in some circumstances, it is important that NDIA staff do not misinterpret an increased focus on short term to mean that most children will require only short term intrusive support to reduce support needs in the future. Many children with ASD, and their families, will require disability support longer term or for their lifetime. The families we work with continue to experience planners saying some version of “don't expect to get as much funding this year as you did last year” almost always before they have even enquired about a child's progress across the previous plan period. An incessant focus on reducing support through the period of early intervention will only lead to missed opportunities in genuinely reducing support needs in the future. It is imperative that any consideration of reducing support or funding is because of a child's individual progress and ongoing/long term needs, rather than focussing on set rules about reducing costs each year.

Supporting parents and carers to exercise choice and control

11. We want to support children and parents with implementing plans using the Autism CRC research and best practice. In [Section 8.2](#) there is a suggested list of questions for parents and carers. These can be used to understand the best intervention for a child and their family and how a provider is delivering an intervention. Are these questions helpful for parents and carers when selecting providers?

Yes, these questions are helpful



12. What other guidance or tools do families need to feel confident to implement plans in line with the Autism CRC research and best practice?

These questions are useful though it would be helpful for parents to also consider the evidence base of interventions and have access to a easy to use table that clearly defines the level of evidence available to support specific types of therapy.

It seems as though the summary of the CRC review left out key literature related to early intensive behaviour intervention for children with autism.

Without a comprehensive understanding of all therapies and the related research no family will ever have true choice and control. The reliance on brief summary statements of research in the paper and the complete lack of intention to help families understand the current evidence base does not support true choice and control and also does not assist the NDIS to reach its aim of reducing future support needs.

Further information related to evidence based therapies and what the current international evidence base suggests is likely to improve the outcomes of children with autism is required. This information should be accessible and easy to understand, it must however also provide more detail of what research has shown. Providing only general, summary statements is misleading and does not assist families to make informed choices.

Conflicts of interest

13. This question relates to Section 8.3 of this paper: “Addressing conflicts of interest.” How can we support families and carers to feel confident to make decisions about what is in the best interest of the child and family?

It is concerning that NDIA are suggesting that professions are only interested in financial gain. This does not align with the ethical standards in which health and allied health professionals work within. Further, a provider is the professional in the field, often with many years experience, and their professional recommendations are based on their expertise and qualifications.

You can support families by providing them with current and comprehensive information relating to the evidence base of various therapies. Families are then able to make informed choices and are less reliant on the individual opinions of providers.



14. Other Feedback

The NDIS legislation supports access to evidence based practices, plans being based on individual needs and participants having choice and control of their support needs. Families must be given accurate information relating to the evidence base of all therapies and NDIA plans must support the delivery of such therapies for children for whom such services are recommended.

Aside from individual lived experiences of the benefits of intensive ABA, there is a large volume of evidence to support ABA (Cohen et al., 2006; Eikeseth et al., 2007; Hayward et al., 2009; Howard et al., 2005; Lovaas, 1987; Remington et al., 2007; Sallows & Graupner, 2005; Smith et al., 2000; Wood et al., 2017).

In particular, the Australian *“Early Intervention for Children with Autism Spectrum Disorders: Guidelines for Good Practice”* (Prior & Roberts, 2012) note the following about ABA:

a) *“High intensity interventions which address the child and family’s clearly documented needs, using behavioural, educational or developmental approaches have been shown to be the best of currently available early interventions. Research has consistently shown good outcomes for intensive ABA programs”* (p.4) b) *“15-25 hours per week is generally recommended for autism early intervention”* (p.5).

An overarching goal of ABA/early intensive behaviour intervention is to reduce my/our child’s/children’s support needs over time and prevent their reliance on more costly supports in the future.

Cost-benefit analyses consistently demonstrate the return on investment when children participate in EIBI programs. Given the possibility of a greatly reduced need for funding in later life, EIBI is considered value for money. See Jacobson, Mulick & Green (1998) and the Synergies report (2013) for relevant cost-benefit analyses.

Reference list

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