

National Disability Insurance Agency

13 May 2021

Re: Consultation paper: Interventions for children on the autism spectrum

Autism Awareness Australia welcomes the opportunity to lodge a submission to address the consultation paper: *Interventions for children on the autism spectrum*.

Founded in 2007, [Autism Awareness Australia](#) (AAA) is a not-for-profit autism education and awareness organisation. Our goal is simple: To improve the lives of all Australians on the autism spectrum and the families who love them.

As one of the country's leading voices for autism families, Autism Awareness Australia aims to spark positive change by increasing education and understanding of autism in Australia.

Autism Awareness Australia has long been led by parents of children with autism. Our CEO has a child with autism, as does 75% of our Board and 50% of our staff.

Many contributors and volunteers over the years have either had autism or were the parents of children with autism. Our CEO Nicole Rogerson has also had 14yrs experience in the Early Intervention field and was one of the original advisors on the Federal Government's Autism Advisory Board which looked into the original Best Practice Guidelines and the introduction of the HCWA funding scheme for young children.

In addition to this personal experience, Autism Awareness Australia has sought input from our extensive community of over 130,000 members. This submission incorporates their feedback.

Consultation Questions

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**

It is critical that families are given quality, accurate and clear information about early intervention, following their child's diagnosis. Families need to be empowered with evidence-based information about best practice interventions. Families often describe this period as being 'overwhelming' and with a lack of clear guidance, they often resort to Google and can lose months of time trying to ascertain what their child's options are.

In no other area of paediatric healthcare would we allow such an ‘open market’. As it stands, there is no agreed national standard between evidence-based and non-evidence-based interventions. This lack of guidance and regulation often sees families enrolling (and spending their NDIS funds) in non-evidence-based interventions. Some interventions, with little or no support to show efficacy in young children with autism, may indeed attract a significant clientele with the use of marketing alone.

That Australian Federal and State Governments (NDIS) now fund children's early intervention, has been a great step forward for the autism community, however, funding without guidelines to ensure these funds are being guided towards interventions that are actually going to help children with autism is a significant misstep.

Autism Awareness Australia would support the development of a **National Early Intervention Guideline**, which, like the **‘Guidelines for Good Practice’ 2012 (Margot Prior and Jacqueline Roberts)** before them, would provide families with the confidence that, they still had the right to choose the early intervention that they believed suited their family, but that they were choosing from a list of interventions that had research to show efficacy for their children. For far too long parents have been at the mercy of certain autism therapies and services that lack supporting research to show efficacy.

If a **National Early Intervention Guideline** was developed it should be hosted on numerous reputable platforms for families to source the information. It should have the endorsement of the NDIS and be supported by the major autism organisations and peak bodies (who are not service providers). It is critical that the information is seen as scientific and independent. A guideline does not reduce a family’s access to choice, it merely ensures they’re choosing from a list of interventions that are more likely to help their child. We have regulations and guidelines around all sorts of areas for Australian children, a guide to quality early intervention for children with autism should be no different and is of critical need.

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

I believe we have answered this in our response to question one. If there was a recognised **National Early Intervention Guideline** then it could be accessed from multiple reputable sources, ensuring as many families see this as possible.

Autism Awareness Australia (AAA), with a grant from DSS, has produced the **‘Autism: What Next?’** digital toolkit to assist parents at the time of their child's diagnosis. AAA will ensure that quality information about best practice interventions is included in that resource. We have a Clinical Advisory Board, including Professor Andrew Whitehouse (who is also on our Board of Directors), who worked on the recent early intervention research at the Autism CRC which should inform the new Guideline.

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 is critical that in addition to NDIS funding and early intervention, families are connected to supports and resources in their local community. Of course, no two autism families are the same and as such the level of support they need will be determined by the size of their family, where they live and what other things are going on in their life. When choosing early intervention, families need to take into consideration both what is best practice and what they can reasonably undertake as a family.

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?

The key principles in section 6.1 are a good overview of what existing good early intervention service providers already practice. Additions could include a checklist for families on what makes a good early intervention service provider. That may include information about communication between parents and providers, data taking, accountability and regular ‘team meetings’ to gauge progress and modify the child’s program if gains aren’t being made and skills development could be improved.

Families are a critical part of their child’s early intervention program, so services must have mechanisms in place to ensure families are part of the learning ‘team’, communication is free-flowing and the skills being taught in therapy settings are being generalised to the home and community environments.

Families also have to be given the confidence to walk away from a service that they feel isn’t right for their child.

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?

We agree that these are very good standards. It is, however, critical for the NDIA to articulate how these standards will be implemented and regulated. Without transparency around a regulatory framework, these standards are in danger of simply being ‘aspirational’. Future workforce considerations must also be factored in.

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

AAA has no objection to providing clear resources to families as to what is reasonable and necessary; however in the list of things that ‘would not get funded it’ there needs to be a much clearer message regarding reporting and contributing to the planning process. Appendix One is not clear.

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?

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

We are at a loss as to how these levels of funding were determined. All young children deserve the best quality early intervention in the early years to kick start their development and embed a love of learning. No child has “x” levels of autism. You cannot neatly put children into one of three categories, particularly when they are very young and we may not know a lot about their learning style. These funding levels will deliver very low-intensity interventions which will see us miss the critical window for early intervention to make its greatest gains. Good levels of funding support are not wasted on children with lower levels of disability with their autism (typically described as level 1). In fact, those children might go on to make great gains and need a lot less from the NDIS in future years. We should be backing all children with autism to reach their best potential with funding packages that match the individual needs.

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?

Extra NDIS supports during the development of first plans is critical. Developing a strong foundation for the family at the outset will be beneficial for all future plans.

If funding is 'reduced in value due to the impact of mainstream services', then NDIS staff need to have a smooth and ongoing communication with those services. For too long, families have fallen through the cracks of Federal funding (NDIS) and State-funded services (education and health).

Any reduction in funding needs can only occur in the presence of certainty that the other services are providing adequate levels of support. In the absence of this, it is not acceptable nor ethical to reduce support. To achieve this smooth transition and communication requires Federal and State Government leadership, along with engagement with the disability and education sectors. This is a big task, but it is critical to providing best-practice support to individuals on the autism spectrum across their life span.

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?

These types of questions are very good guides for families and will help them compare different service providers. Some families however may need additional support with this as the concept of 'early intervention' itself can be very overwhelming and families may not have a clear understanding of both what it is and why their child needs it. With the ***National Early Intervention Guideline*** along with checklists like this and support from NDIS staff, families are better placed to choose the right service provider.

Important to consider though, the lack of quality early intervention providers in many parts of Australia have left families with little or no choice as to who they enrol with. The NDIA should ensure that service providers in thin markets are still adhering to best practice.

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?

There seems to be a significant misunderstanding as to what the Autism CRC report concluded. The report is not a guide to early intervention. It was merely a review of existing research into early intervention for children with autism. The report itself would not be a good guide for families and indeed would be quite confusing to those outside of early intervention therapies and the research field. However, we do feel that the information in that report might be the basis to build a National Early Intervention Guideline.

One of the biggest barriers to families feeling confident about engaging in best practice early intervention is that the NDIS has allowed funding to flow to non-evidence-based interventions for far too long. If Child A is enrolled in a non-evidence-based intervention using their NDIS funds, then it is feasible that Child B's family might consider that a worthwhile intervention.

The NDIS's desire to give families 'choice and control' leads to an environment with little regulation over who and where funded supports go. If the NDIS only allowed families to spend money on therapies that are recognised as effective for children with autism, we believe this would go a long way to cleaning out non-effective therapies in autism service providers whose business model dominates their clinical model.



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?

We believe the lack of a National Guideline allows for the ‘market’ to ‘inform’ families about their options. This situation benefits large Service Providers who spend significant marketing dollars to attract their customers. This is particularly true in autism with some of the largest service providers presenting themselves as credible sources of information.

Having a national, independent, respected and authoritative guideline will remedy this situation.

Autism Awareness Australia would be happy to discuss these issues with the NDIS at any time.

Kind Regards

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CEO Autism Awareness Australia