

Submission: Interventions for children on the autism spectrum

People on the autism spectrum form the largest group being supported through the NDIS. For children, it is the diagnostic category that has generated the most discussion, and controversy, about how eligibility for support should be determined and the quantum of support that should be provided.

NDS acknowledges the work of many stakeholders—parents, providers, researchers and academics, and the NDIA—in contributing to the analysis and understanding of how young children with autism should best be supported. This recent consultation paper focuses on some important decision points which will hopefully further develop the thinking on how best to assist young children with autism. We acknowledge upfront there will not be a consensus on much of the paper but hope the discussion on these important issues takes us a step in the right direction.

The consultation paper draws on information from the research undertaken by the Autism Cooperative Research Centre. One of the disappointing things apparent from that research is there is a need to build knowledge about the efficacy of interventions and the intensity of their use. We don't yet have a solid base of evidence that can inform funding and support decisions. The NDIS is well-placed to support the research that is needed in this area, research that should be a priority.

While this paper is not consulting on access to the NDIS, NDS wishes to put on the record our concerns about some children with disability who are found not eligible to be a participant and who are not receiving the level of support required to fulfil their potential. This group includes some children on the autism spectrum who require a greater level of specialist interventions than is available to them currently. Addressing this failing must be prioritised and include broad consultation with the sector on Early Intervention requirements as outlined in the NDIS legislation and operational guidelines.

Specialist interventions are needed for Indigenous children and families. Work on this issue is urgently needed as is consideration of how any child living in a remote or very remote area and needing early intervention supports can receive them (and receive them at an appropriate intensity). Similarly, additional work is required on how best to engage with culturally and linguistically diverse communities to support their children who have a disability.

Special mention needs to be made of families where a parent/carer may be living with a disability. Decisions on appropriate early intervention supports for their child with a disability need to take this into account.

Final comments before NDS addresses elements of the consultation paper are: the critical importance for funding and supports for a child to be made in the context of their family circumstances (the importance of taking a holistic approach to how best support a child to reach their full potential); and on the need to ensure NDIS structures do not discourage the provision of childhood supports in the most appropriate setting.

The allocation of funds in a separate travel budget for early practitioners would encourage more families to have supports delivered in natural settings or in groups. This is critically important for children living outside major metropolitan areas.

Early childhood intervention is an investment in the future and is actually critical to the future sustainability of the scheme. Children need to be given the opportunity to reach their potential which in turn will decrease the scheme's lifelong support costs for them. High quality and timely specialist interventions for children must not be compromised by the current focus on scheme sustainability.

Framework and funding levels

Extensive consultation with providers of early childhood services raise so many concerns that NDS does not support the adoption of the proposed funding framework nor the funding levels.

This decision was taken after consideration of the following unresolved questions and comments on both the framework and proposed funding levels:

- The individuality of the child (within their family context) would easily be lost as they are slotted into the framework rather than being carefully assessed to determine what funding they require to support their development
- It gives inadequate attention to the needs of children who have other conditions (i.e. have a dual or multiple diagnosis) which impact on their support needs
- The statement that most children will sit in the middle of the bands is inappropriate in an individualised scheme
- The proposed lowest funding levels are totally inadequate for a child on the autism spectrum
- The consultation paper is silent on how quickly and easily funding could be altered when the plan is found to be inadequate for what the child needs
- Some of the highest cost participants in the scheme are young adults with severe autism, intellectual disability and challenging behaviours; the framework does not give confidence that children who may grow to be part of this group will be identified as early as possible and adequate investment be made in supporting their development
- While it is noted that some children with more complex needs will fall outside the framework, the sector does not have confidence they will be identified and appropriately funded

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- The framework and funding levels are silent on the additional resources required to support children in remote and very remote areas, particularly Aboriginal children
- Some children will be over six years of age when they are initially deemed eligible for support; they are very likely to benefit from levels of support higher than suggested by the framework for a participant in that age category
- The interfaces between mainstreams services (particularly education and early childhood education and care) and the NDIS are often difficult, impacting on being able to maximise the impact of available funding
- State and territory governments are not adequately funding supports for children not deemed eligible for the NDIS; they need to be held accountable for supporting these children
- More information is required on those children in the ECEI Gateway not likely to become NDIS participants but need to have access to the supports they need
- The family environment, and the informal supports available to maximise the impact of interventions varies greatly; how well would the framework accommodate the family context when funding decisions are made
- How would funding for other supports, such as those available under core, be made for those children who require that assistance

NDS urges the NDIA undertake more work with the sector to discuss these issues and how best to address them.

Key principles for autism interventions

The principles are broadly supported providing they are explained to families and other stakeholders as a general guide to expectations rather than being measurable. For example, “the intervention is based on a good understanding of autism” is what families should be able to expect of a therapist working with their child but it does not necessarily help a family to determine whether a therapist actually has a good understanding.

The principles would be strengthened by the inclusion of a statement on the importance of a holistic, family-centred approach to decisions on interventions and to a commitment to including families in the delivery of interventions.

The principles that the ‘intervention is logical and scientifically plausible’, and that ‘the intervention works in the real world’, are appropriate but require a caveat. Over time, it is very likely that the understanding of ‘best practice’ interventions will change; innovation in approaches will drive those changes. Perhaps the inclusion of a principle that commits parties—such as the NDIA; the Autism CRC; researchers; and practitioners—to continually build knowledge that improves the interventions available to young children on the autism spectrum.

The NDIS has created a tension for families as to whether interventions should be provided in natural settings, small groups or with individual children. Families should be given the best available information on the options available and an assessment of what is recommended for a particular child. Providing a fixed line item for therapy

travel would be one way of limiting concern about the cost of therapy travel on the decisions of families about how and where interventions are delivered.

Standards for the delivery of autism interventions

NDS recommends more work be done on improving the standards before they are finalised.

While the standard, “the intervention is delivered by, or supported by, appropriately qualified and experienced professionals”, seems simple, it is anything but. Within the sector there has been prolonged debate as to whether all early childhood professionals should be required to be registered—and thereby meet the requirements of the NDIS Commission’s Early Childhood Supports module. As a step towards promoting the importance of using ‘qualified and experienced professionals’, consideration should be given to how the merits of registration can be promoted among early childhood professionals.

The standard on interventions following established guidance needs nuancing. The Autism CRC’s research paper clearly shows there is a need for stronger evidence on the best approaches to working with young children on the autism spectrum; a commitment needs to be made by governments on funding the work needed to improve the evidence. In the meantime, clinicians need to balance evidence-based practice with practice-based evidence and consider them together with the family context in order to implement the most appropriate interventions for any particular child.

That “the intervention provides significant and lasting benefits” seems to be common sense but similar to the above, we need a commitment to build the evidence on interventions (and the dissemination of evidence).

One standard that stands out as concerning is that “the intervention does not cause significant physical or emotional harm”. The word ‘significant’ must be removed.

Given the other standards, the standard that “the benefits outweigh any costs (including risks)” is confusing and could be removed.

The inclusion of a standard on “good value for money and time invested” is to be expected but is again dependent of improving the evidence on the impact of interventions.

Consideration should be given to including a standard that links the intervention to the child’s family environment and to any mainstream services used by the child.

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National Disability Services is the peak industry body for non-government disability services. It represents service providers across Australia in their work to deliver high-quality supports and life opportunities for people with disability. Its Australia-wide membership includes more than 1150 non-government organisations which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to State, Territory and Federal governments.