

Written Submission to the National Disability Insurance Scheme

- Interventions for children on the autism spectrum

Autism Spectrum Australia (Aspect)

Autism Spectrum Australia (Aspect) welcomes the opportunity to provide written feedback to the National Disability Insurance Scheme (NDIS) on the consultation paper – *Interventions for children on the autism spectrum*.

Aspect is Australia's leading national autism service provider and knowledge leader. Using the expertise within our own research unit, Aspect Research Centre for Autism Practice (ARCAP), to identify evidence-informed practices, Aspect provides a broad range of services to support individuals and their families across their life span to achieve outcomes that are important to them, by engaging with them in their communities.

These include:

- Regular services provided in all states and territories (except WA).
- A national program of workshops and consultancies known as Aspect Practice, based on the organisation's distinctive capabilities.
- Diagnosis and assessment.
- Direct services (both fee-for-service and NDIS funded) for children including:
 - Early childhood supports.
 - Behaviour support.
 - Schooling and education - incorporating nine autism specific schools with over 100 satellite classes.
 - Family and carer support.
 - Therapy.
 - Transition support and educational outreach services.
 - Tele practice and innovative models of service delivery.
- Supports for regional and remote participants and their families through including regional and remote Allied Health Assistants, services supported by Aspect Allied Health Professionals.
- Direct services for adults (Aspect Adult Community Services, Aspect Employment) in the form of community-based services and preparation for employment.
- A national resource for families and services seeking information and advice about people on the autism spectrum.

The organisation employs more than 1000 staff, many of whom are highly skilled professionals and experts in the field of autism, including clinical psychologists, psychologists, specialist teachers, speech pathologists, occupational therapists, social worker, allied health assistants and adult services staff.

The following feedback is based on our expertise, work and services.

Promoting best practice

1. Which of these would you use to make decisions about accessing best practice interventions (or services) for children on the Autism Spectrum?

Autism organisations and peak bodies are often the providers of best practice information for families and carers of children on the autism spectrum. These websites contain valuable information on current research, best practice guidelines and seek to link families to the most accurate and up to date information to allow them to remain well-informed.

Until recently, the Autism Advisor Programs (state based) provided information to families to help them navigate and connect with support services within their local region. *Autism Connect* will become the National autism helpline providing free and independent information and should become the “go-to” service to provide information for families and will be able to provide advice about evidence-informed practice.

All information available to families must be presented in easy to read language, and be supported with links in various languages.

The other sources of information listed by the NDIS have limitations and are not the most suitable options for families. Some limitations include:

- NDIS website – difficult to navigate, with most information to be found within the site relating to funding. There are excessive amounts of information, lack of archiving making it challenging to find the latest information and many documents are not easy to understand.
- NDIS Operational Guidelines – the new guidelines may be better, but still a lot of information that may not be relevant for a family wanting guidance on how to access best practice supports.
- Participant decision making guides (not yet developed so unable to comment).
- My usual NDIS or NDIS partner contact – previously have not supported families to connect with services or provide any in-depth support around decision-making. NDIS ECEI partners will provide general information to families relating to service options. There is no information being provided consistently around current best practice and evidence informed practice. Information provided is often dependent on the relationship the family has with their planner, the planners level of experience in the early childhood space, the region or location of the family and what services are available to access.

2. Where else would you like to be able to find the information you need to make decisions about accessing best practice interventions (or services) for children on the Autism Spectrum?

- Research, including from the Autism CRC.
- Professional Bodies.
- Internal organisation research such as Aspect’s ARCAP.
- National Autism Help Line – Autism Connect.
- Organisations offering supports to families – can provide information to a wider audience including those who may also be supporting the child outside of the home environment but can also tailor advice to the family or filter information and provide what is most relevant.
- Parents sharing with each other through a variety of mediums including the use of social media.
- Workshops/webinars including the National Early Days Workshops/Webinars which provide pathways for families of young children to learn information to be able to make informed decisions.
- Support Coordinators when these are funded and when individuals in these positions have lived experience, wide knowledge of the sector and understanding of the family.

3. Holistic planning is a part of the proposed funding framework for early intervention for children on the autism spectrum. How can we help families to find and connect with other supports outside of NDIS?

- “Holistic planning” must be fully implemented and not side-tracked by a focus on finding non-NDIS supports.
- We must move away from binary systems whereby families receiving NDIS funding are not eligible for any additional state-based service. There is currently no universally accessible service. At present,

participants are excluded from service if they are deemed eligible to access NDIS support. This makes it very difficult for families to transition from NDIS-funded supports as they are then not able to receive state-based supports. An example of this is when children are receiving quality early childhood supports such as speech or occupational therapy from their local Community Health Centre, the family and therapist have built up a relationship, and then this is discontinued as soon as the child is approved under the NDIS. This child, despite receiving funding, then sits on NDIS providers waitlists to access therapy for the next 12 months with their family wishing they could go back and continue with Community Health. Some schooling systems also rely on NDIS eligibility to determine if a student receives additional funding at school – so again, a student may miss out on support in this system if they are not deemed eligible for NDIS funding. Currently there are many ways that children (and families) can fall through the cracks in various systems. There needs to be the continued and consistent access of supports for the child and their family whether eligible for the NDIS or not, and not discounting state based funded services should a child be deemed eligible for the NDIS. There need to be clear and transparent guidelines relating to eligibility for state, territory and federally funded programs that allow for easy transitions between systems or for children to be supported by multiple avenues of funding if holistic planning is not possible.

- NDIS plans must be built flexibly to support families and services to work together to best meet the needs of the child and family at any given time. NDIS funding has not supported collaboration and holistic service delivery models with some planners discussing x amount of funding for Speech Pathology and x amount of funding for Occupational Therapy. This type of discussion does not lead to families taking up options of group-based supports, parent training and capacity building supports which is often one of the best early supports for children. As available on the NDIS website 'The evidence reinforces the important role of parents. There is evidence that both parent-led (also called caregiver-mediated intervention) and peer-led interventions have a positive effect on children and their families. The outcomes when parents were involved in the intervention were sometimes greater than interventions delivered by clinical practitioners or educators alone.'
- Holistic planning and holistic supports are extremely difficult to coordinate when there is not sufficient focus on the need for services to collaborate and plan together. Again, a strong focus on a particular amount of therapy hours in plans, makes it difficult for families to understand the time needed for collaboration and other capacity-building supports. There needs to be attitudinal change starting with health professionals and diagnosing clinicians, running right through the NDIS planning process on the importance of a collaborative model with the child and family as a member of that support team. Delivering services in silos is not beneficial to anyone.
- Short Term Early Intervention support is not best practice for children on the autism spectrum. Autism is a lifelong disability that starts when a person is born and stays with them into old age.
- It is unclear how extended short-term interventions and other proposed changes may impact on the current funding environment and changes may be more confusing, with additional gate-keeping by EC Partners. Transition into, and sustained access within mainstream systems for children with a disability requires ongoing support for the child and their family. Short Term Early Intervention would only briefly touch on this process before exiting the family and may lead to unsuccessful placements and likely to lead to need for more intensive supports. Let's not wait until they fail to provide more support!
- Holistic planning relies on having a seamless and integrated system of universal and specialist funding sources which would allow for movement and trust. Funding of plans need not be wasteful, but the system needs to allow for flexibility, responsive to changes and transitions and changing circumstances in a timely way and be consistent so that families feel that they will be able to gain the support they need when they need it. Families should not feel that sense of "use it or lose it" when it comes to disability funding, especially when their child is functioning well within a mainstream setting outside of the NDIS. Families should be allowed to celebrate their success however still have access to the funding required should the placement break down or further support be required at any given time.
- Most services are willing to and able to work together in a harmonious way to provide evidence informed supports for children and their families. A knowledge of local services is key and continued collaboration between services working with children is vital in supporting our next generation of children.

Reasonable and Necessary

4. The consultation paper outlines specific principles that the NDIS considers for young children with autism as early intervention best practice for young children on the autism spectrum. Is there anything you would like to add?

Aspect supports the key principles for autism intervention as outlined in the Autism CRC Research Paper, but we believed that the principles need unpacking to ensure that the intended meaning is well understood. We have provided some prompts/concerns regarding each principle.

4.1. The intervention is based on a good understanding of autism:

- What does “good understanding” actually look like in relation to models of support? Autism is complex and we are continuously learning about how it impacts on an individual and what approaches are best. Providers need to be constantly updating their understanding and adjusting approaches – as the paper points out, there have been interventions designed on “flawed” understanding. More than a good understanding is needed – we need models of support that provide the best support for the individual and their family. There is a need to ensure that families also have access to information about autism so that they can be informed consumers and ensure that supports are working towards the best outcomes for their child and family.

4.2. The people who deliver the intervention know the person well and respect their feelings and views:

- This is a key principal and central to success of supports but there is a need to do more than respect feelings and views – we need to work to understand the child and family, their other supports, their culture and beliefs and provide a tailored service to meet their individual needs

4.3. The intervention is based on a theory that is logical and scientifically plausible:

- While there is a need to ensure that providers are able to innovate and develop new models of service, there needs to be rigorous processes to support new ways of working and providers should be able to support their approaches with logical and strong evidence. There are questions around why the homeopathy example was chosen as it does not seem relevant if other principles were being followed.

4.4. The intervention is adapted to the needs of the person receiving it:

- An individualised, family centred approach is vital but could also be at odds with indicative funding levels that are based purely on level of functioning rather than on the individual needs of the child and his/her family. NDIS plans need to be individualised.

4.5. Research evidence shows the intervention can work for people on the autism spectrum:

- This principle links strongly with Principles 1 and 3. There should be solid evidence to support any approach used and providers should be closely monitoring progress and outcomes for the particular child and family they are supporting.
- Aspect defines 'Evidence-Based Practice' as strategies that:
 - have the highest quality available research showing positive impacts for Autistic people and their families in real-world settings
 - meet the aspirations, preferences and values of people on the autism spectrum
 - fit with Aspect’s 50 years of expertise in autism practice and assists the work of our educators, therapists and support staff
 - are positive and not painful or distressing, respect the full diversity of Autistic people and can contribute towards an Autistic person’s satisfaction with their quality of life and their inclusion in society

4.6. The intervention works in the real world, not just in a research laboratory:

- There is ongoing work to ensure that research is linked to practice and practice is linked to research. There is continuing research being carried out by ARCAP to ensure that research links with the real world. There needs to be ongoing collaboration between practitioners, researchers and between providers. Current funding models need to prioritise evidence in

practice research. Families need to see the value in collaboration and data gathering to help monitor the impact of support.

4.7. The intervention supports mainstream and community participation:

- This is an important principle but current planning processes do not support families choosing community-based rather than clinic-based options. There are extra costs associated with a community based support such as travel time and travel costs. Waiting lists are often shorter for families to access a clinic-based support as the clinician is not having to travel to support the child within their natural environment. However provision of all services within a clinical setting is not best practice.
- The intervention provided must support a successful engagement and transition into mainstream and community settings.
- There are challenges and barriers for families to access mainstream supports and to participate in community-based activities. There is a need for more support for mainstream providers/groups to understand how to provide inclusive opportunities for everyone. While there has been piecemeal funding to support individual providers or some organisations, there is still a lot that needs to be done to ensure that all children and all families are welcomed and feel a sense of belonging across mainstream and community based activities.

5. The consultation paper outlines specific standards that the NDIS considers for young children with autism as early intervention best practice for children on the autism spectrum. Is there anything you would like to add?

It is again important to point out that these standards need clarification and will mean different things to different people. We have added comments below.

5.1. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals:

- There needs to be clearer information about what “appropriately qualified means. Many allied health professionals are already registered with AHPRA or need to be eligible for membership with their association.
- Aspect believes that it is important to ensure that all practitioners are adequately supported through a robust support and supervision process, good induction and ongoing learning and development frameworks. We believe that new graduate therapists can provide support when appropriately supported. We cannot expect everyone to be experienced in working with children with autism – as they need to start somewhere – they just need to have the right supports in place. By ensuring that staff are receiving the supports they need, they will be able to provide the best possible service to the child and their family.
- While attitudes are extremely important – the idea that they need to “get autism” and “get children on the autism spectrum”, is not helpful as it is not possible to quantify what this means. Having a good understanding and being intuitive is not enough, practitioners need to implement evidence-informed practices, receive support and supervision and be following models with clear clinical reasoning as a starting point. Aspect invests heavily its staff and provide a 12-week induction program for all new starters to ensure that they are able to work competently – this is required as university training does not adequately prepare many therapists for work in the disability sector and particularly with people on the spectrum.
- The NDIS Quality and Safeguards Commission have just regulated the registration of PBS Practitioners. Practitioners needed to provide evidence of practice in line with the PBS Capability Framework process and practices. A similar process should happen for early childhood supports where individual NDIS staff should be able to register as an Early Childhood Practitioner based on evidence of their practice, skills, training and support and supervision structures.

5.2. The intervention provides significant and lasting benefits:

- While it is important to measure outcomes, it is unclear what “significant” means in this context – we need to ensure that there are meaningful and positive outcomes for the child and the family based on their individual needs and goals.

- Interventions and outcomes need to be important for the stage of the child and also take a life-long approach to improving quality of life and meaningful participation.
- Overtime, interventions should also lead to a positive impact for communities and our society.

5.3. The intervention is carefully monitored and reviewed on a regular basis:

- Practitioners should be monitoring and reviewing their support and its impact on a regular basis and then reporting on it as required.
- It can be challenging to report on progress when some families can feel that this will impact on their funding package. We have had a recent request to write a report to be less positive as the parent was concerned that her child's plan would be reduced if his progress was documented. We explained that we needed to provide clear and honest information but in doing so, this would highlight the areas where support was still required. Information shared by a therapist needs to be an honest reflection of how far a child has come with their goals, however still highlighting the often significant need for support.
- Progress needs to be reported against NDIS goals but there are still issues when the planner and family have determined goals that are not the most relevant for the participant. It would be better for therapy goals to be collaboratively developed by the family and the team of therapists and shared with the NDIS planner.
- NDIS plans also rarely include family goals which can be most appropriate for young children.

5.4. The intervention does not cause significant physical or emotional harm:

- Interventions should not cause any physical or emotional harm.

5.5. The benefits outweigh any costs (including risks):

- This point is unclear as there will be cost associated with funding - if it is to do with value for money then it is covered with the point below.
- To prove that benefits outweigh costs you would need a control to be able to identify the cost of not providing the service.
- Social benefits are often difficult to measure, how do we measure quality of life in dollar amounts.

5.6. The intervention is good value for money and time invested:

- Again, this is a difficult point to prove as there is a risk of not providing the intervention. It is unclear who is measuring this value – is it the participant/family/planner. There are multiple ways of measuring value for money and this is a complex area.
- Outcomes can be short or long term and not all supports lead to immediate outcomes.
- The same intervention for two different children can progress at vastly different rates and therefore while one may require more hours of implementation, another may make progress quickly and need less hours of implementation. There may be many and often complex reasons for this including family capability, language and cultural barriers, the child's autism profile and suitability of the approach, and/or the experience of the NDIS provider.

5.7. The people delivering the intervention follow established guidance:

- There is a range of established guidance that can inform supports – therapists need to be able to access the established evidence and incorporate it with their knowledge of the child and family and their clinical experience. A national accreditation system would provide more structure and community of practice around this.

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 cases help you to understand what we mean by “reasonable and necessary”?

The case studies are not helpful. There is so much complexity involved when considering the unique strengths, needs, challenges and priorities of children and families that cannot be captured in case studies like these. It is better to be clear about what can be funded and what cannot be funded – it

does not need to be illustrated by a case study. If supports are at the discretion of planners then this should be clearly stated.

The case study of Jackie, the 3-year-old, highlights the challenges when parents are wanting a particular model of funding, in this case intensive support – they may not be open to a capacity-building model. In this case study, it appears that the family were happy to accept a much more limited funding package than they had anticipated but often it can take time for a family of a young child to understand the benefits of capacity building supports in natural environments. The description of Jackie, while very brief, would not warrant 20 hours per week of intervention. Most 3 years olds would need support to express their feelings and can be challenged to use cutlery and pencils. These descriptors were not helpful and also not typical of the needs of young children with an autism diagnosis, where needs can be complex and there is a need for more intensive support to help families understand and support their child through modelling, coaching and regular consistent direct therapy.

The example of reducing funding over subsequent plans is also very simplistic. There is not sufficient information to understand this child's needs and therefore understand why there can be such a reduction of funding. It is difficult to think that a child would move so quickly from Level 3 to Level 2 supports. It is unclear how short bursts of intervention can be effective if there is a need for ongoing rapport building and contact with the family and other supports. There are often many challenges that arise within early childhood, including many transitions that children may require additional support with. There is not a clear-cut reduction in funding requirements per year.

Case Study One makes a sweeping statement that private swimming lessons do not promote inclusion or create opportunities for social participation, but some private lessons which allow very targeted and individualised support to a young child, can definitely support progression to mainstream or group lessons once confidence has been developed. In the same way that a child may see a speech therapist 1:1 to develop their language and play skills to then use these to participate in their social environment at preschool or out in the community, some children need individualised swimming lessons to transfer or generalise to the mainstream community.

It is also important to note that fair and reasonable relates to what is fair and reasonable for an individual participant at a particular stage of their life. Case studies cannot illustrate all the elements that need to be considered.

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

While it is important that there is a level of transparency and consistency in decision-making, it also needs to be very clear that “reasonable and necessary” relates to a unique individual and the process for determining appropriate levels of support are complex. We cannot just consider the individual child's needs but must look much more holistically to determine what is reasonable and necessary for this child, this family and their support system.

It is better to be clear about what is not able to be considered.

8. Table 2 (0-6 years) and Table 3 (7-13 years) explain Indicative level of funded support for children on the Autism Spectrum. Do these table/s clearly explain the indicative levels of funded?

Aspect does not agree with the concept of indicative levels of funding based on functional levels. There are clearly other factors that need to be considered including issues impacting on the family. There is no direct link between functional levels and the need for supports and therefore funding.

The tables and the examples chosen are confusing. Children with issues relating to rhythm and pitch of speech in isolation from other communication challenges are not good examples. For children on the spectrum, they are much more likely to have complex receptive and expressive communication difficulties, social communication difficulties rather than have challenges with their speech in isolation.

There is no evidence that very low levels of funding can lead to positive outcomes – the lowest levels in the tables would equate to very limited number of therapy hours (especially when travel, collaboration, report writing and any indirect hours are considered).

The tables seem to be designed to explain reduction in funding over time and this also seems to be based on flawed logic. Autism is lifelong and while autistic people develop new skills throughout their lives, they are not cured. Periods of transition in particular, are times when more intensive supports will be required and where there is a great need for collaborative support across different environments. These could be planned or unplanned transitions such as starting schooling (planned), or the sudden

need to move house (not planned). This cannot be account for within a 12month period as things will occur throughout the year that require additional supports.

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

Autism presents differently in each individual and needs can vary over an individuals life. Considering expected and unexpected changes the indicative levels of funded support do not explore issues *around* the child such as family, supports, access to mainstream supports, travel or remoteness which can all impact on the levels of support required.

There are also factors such as age of diagnosis that impacts on how intensive services need to be and we know that there are challenges in getting diagnoses and therefore delays in getting autism-specific services and supports.

We need to move beyond thinking that there is one intervention that will be effective for every child and family and that there is one framework that will be able to identify the correct level of funding and therefore the intensity of the intervention a child will receive. The complexities of the interaction between the child's strengths and challenges across domains, the unique circumstances of the family and their supports (or lack of them) and the environments in which the child and family participate all need to be considered.

There is no evidence that level of functional need equates to level of funding or intensity of therapy, just as diagnostic levels do not identify support needs. We know that children who have higher functional skills may require as intensive, or more intensive supports to address these challenges.

Supporting parents and carers to exercise choice and control

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

- Planning dialogues need to ensure that all of these potential impacts are discussed as all are likely to play a role in leading to the need for additional support.
- NDIS review reports written by therapists who know the child and family well can also identify factors that should be considered. It seems that often these reports are only given a cursory glance by planners and yet they contain important information,
- In some situations, families are not able to articulate clearly the additional impacting conditions and they may not even be aware of them.
- The NDIS need to consider when plans have been significantly reduced at Plan Review time, the time and strain it takes for families to gather supporting documents to justify a review to regain the amount of funding lost. Losing funding is extremely stressful and families report often having to provide the same paper work to different planners over and over each time reviews occur. It would be great to have a central file where diagnoses and medical documents could be stored so each new planner can reference relevant paper work. Families also put in much time and effort and feedback indicates planners dont even read the extensive information families compile.

11. We want to support children and parents with implementing plans in line with the Autism CRC research and best practice. In Section 8.2 of the Consultation Paper there is a suggested list of questions for parents and carers. These can be used to understand different interventions and whether and how a provider is applying best practice. Are these questions helpful for parents and carers when selecting providers?

These prompts may be helpful but they could also be overwhelming. Families also need support to understand the responses that they might receive. They need to be encouraged to look more widely for evidence about a service – talk to others, look at websites.

It can be difficult for a provider to answer these questions when they have not met the child – e.g. “what improvements have you seen in children you're working with” is very general and the provider may not have worked with a child with similar strengths and challenges.

It will be important for a family to know if the provider is open to collaborating with other providers or mainstream supports and what this will look like.

Yes, these questions are a useful way to empower families to make informed choices, but how informed are they if the provider offering services is answering them? There needs to be a separate accreditation system where providers provide evidence to all these questions where families can go to make an informed choice. This would incentivise providers to register with the NDIS to provide early childhood supports and allow them to prove their status as an approved and accredited provider of best practice supports.

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?

It will be good to see national guidelines – written in easy to understand language that could be made available to families based on the Autism CRC research. The large research paper was not written for this purpose.

The paper outlined that there was no consistent evidence as to whether the amount of intervention influenced child and family outcomes, variable evidence with regards to the impacts and outcomes related to the range of reviewed interventions, and not enough evidence 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. Therefore, it will be very important to remind families that there is not one best practice or one model that is best for every child.

We need to ensure that families are supported to understand that they know their child best and they can exercise choice and control to make decisions about their child.

It will be important that there is not conflicting information circulated by NDIA – at the moment there is uncertainty about the Early Childhood Support framework and the document currently under consideration.

A key factor relating to whether plans are implemented currently is workforce issues with extremely long wait times for services and lack of providers with autism-specific understanding. While families may have guidance and tools if there are not services available then funding will not be able to be utilised.

Conflicts of Interest

13. How can we support families or carers and providers to feel confident to make decisions about what is in the best interest of the child?

Providers need to ensure they:

- Make recommendations about the types of supports that could assist rather than name individual services that provide them.
- Provide a number of options when recommending specific service providers.
- Make sure that any recommendations are able to be justified and based on information about the service and the child or family's needs and priorities.
- Make sure families feel comfortable to discontinue supports if they do not feel they are in the best interest of their child.

If services are providing assessments and therapy supports there need to be clearly defined and differentiated referral pathways, with no obligation or pressure to use both services offered.

We welcome the opportunity to provide input into this consultation and welcome ongoing discussion.