

Feedback for PB Autism Consultation Paper

Consolidated Report:

Feedback From:

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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	Rarely
NDIS Operational guidelines	Never
Participant decision making guides (not yet developed)	It would be best if clinicians and participants used the same guide
My usual NDIS or NDIS partner contact	Rarely
Autism organisations or peak bodies	Autism CRC – Regularly
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?

- Peak professional bodies such as Occupational Therapy Australia
- Speech Pathology evidence review sites (e.g. SPA Speech Bytes, The Informed SLP)
- Autism Cooperative Research Centre (Autism CRC)
- Regular updates – case studies etc.; research
- Webinars etc.
- Through further research – it was clear from the Autism CRC review that good quality evidence is lacking – and through being guided by the lived experience of autistic advocates as some evidence-based practices included in the Autism CRC report have been highlighted by this community as causing harm.

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?

- Families find it frustrating when they call a generic number and speak to numerous different people who often cannot answer their questions.
 - Advocate for Key worker allocation that family can contact and seek advice from – consistent person with wealth of knowledge around Evidence Based Practice etc.
 - Local Area Co-ordinators were previously used to assist families to identify mainstream community supports. However this can also be the responsibility of the child health nurses, school nurses, local GP, local councils advertising what is available to families in the local area.
 - A small amount of NDIS funding for a Social Worker to undertake this role would be appropriate. Alternatively, a Service Coordinator could undertake this role if they were adequately trained

- For families to find the supports they need, they should have access to centralised databases, with greater co-ordination, user friendly, updated websites, and access to other resources including health and educational / day care supports for families, which advertises inclusive recreational activities, day cares who have additional training and experience in autism, school holiday programs that accommodate children with communicative or behavioural challenges, parent support groups for parents of children with autism.

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?

- Point 2 – “should know the person they are working with well”
 - This terminology should be changed as it is both vague and assumes that there is a pre-existing long-term relationship with the provider and participant.
 - It is also slightly contradictory to the section in the paper that refers to conflict of interest. Having established relationships may increase the risk of bias, consumers could be unduly influenced by a provider that they already have a relationship with, as it can lead to the provider recommending intervention to benefit their own business. The established relationship could affect the measure of influence on recommendations made.
- Mealtimes
- For point 1 – The intervention needs to be based on a good understanding of autism. This also needs to take into account information from the lived experience of autistic adults. For example, many adults have reported post-traumatic stress disorder resulting from applied behaviour analysis (ABA) interventions.

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?

- There is reference to providers having “appropriate level of experience” when working with people with autism. Reference is made to have “actually worked successfully with children”. This definition appears to preclude new graduates working in the autism space, and if this is the case, how then do we build and grow experience within our workforce?
 - Experience can only be gained by working with people with autism. We need to future plan by rewording this statement to include suitably qualified therapists, expanding their level of experience by working with children on the autism spectrum and being supervised and supported by professionals with an appropriate level of experience.
 - Example: Consideration should be made to re-word this section to state “people who are qualified, with new clinicians with less than 3 years’ experience supervised by an experienced mentor or supervisor.
- Some interventions that are listed as ‘no effect’ do have positive impacts for some of our clients (but not all of them). There has to be the capacity for experienced clinicians to use their clinical judgement to use interventions that have lower quality/less evidence in order for the evidence to emerge.
 - Many of the interventions that are listed as low quality evidence etc. are used with clients and significant gains are made. Using a blanket approach may not suit all clientele.
 - Allowing experienced clinicians to use various interventions in intervention sessions will allow for more evidence to be gathered. Each client and circumstances is so different.
- Families and clinicians are able to work together and discuss benefits of certain interventions and whether these may be suitable.
- Point 3 – how will the NDIS define ‘significant benefits’ when few of the interventions in the CRC report showed high effectiveness? Will we have a set amount of time to trial an intervention? What about when the guidelines have been followed and interventions have not been found to be significant? Who defines what is significant? We may not see significant improvements in the individual but family well-being could be impacted (this is difficult to quantify and would best be measured through parent report – is that problematic?).

- Point 5 – This may seem to be just semantics, but it's very important to point out that the example given of 'holding therapy' is NOT attachment therapy. Attachment theory, developed by Bowlby and Ainsworth, involves attunement and emotional co-regulation between a child and their caregiver. So, the caregiver notices and responds appropriately to the emotional state of the child. The therapy described in this point is a behavioural therapy because the child is held until they perform the expected behaviour (looking at the carer's eyes). It is important to point out the difference because the Autism CRC report details results on both behavioural therapies and developmental therapies. The developmental therapies are guided by a range of principles, one of these being attachment theory. The wording of this example shows a lack of understanding about these two very different approaches.

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”?

- Whilst the case studies help to understand what is a typical family cost compared to an NDIA funded support I think NDIA need to create an easy to understand imprest list (similar to what was used in the Community Aids and Equipment Scheme). This listed all items that could be funded under the scheme and had very clear guidelines on what was not included in the scheme.
- There seemed to be much less confusion, “hear say” and appeals to decisions under this scheme as providers and consumers were very clear on what could and couldn’t be funded.
- For example the table could include Items not included in the scheme
 - Fees for recreational activities
 - Weighted blankets
 - Therapy items such as “move n sit” cushions etc
 - High chairs

This would provide transparency to decision making and clarity for all.

- There should be greater flexibility to offer support in what can be considered more traditionally ‘academic’ skills – it may look like an intervention replicates something that should be covered by CAPE/Education, but is not being addressed in that setting to a level that that student w ASD can benefit from (e.g. literacy support from SPs). We know the nature of ASD is complex and the way it impacts on academic learning can be supported by Allied Health in therapy settings.
- There is often inconsistency in information families are given. They often don’t understand why a requested service is not deemed reasonable and necessary. It is often left up to therapists to navigate and explain to clients which I feel can affect relationships. NDIS needs to make guidelines clearer and families need to be able to access someone who can explain things accurately and in a manner which is easy to understand. Often families are given conflicting information and this causes a great deal of frustration.

- It is mostly clear, except for the last example giving a mix of funded and non-funded supports. Child care educators seem to providing non-funded support for language and fine motor development without any input from therapists to individualise the recommendations for this child.
- It seems that the examples are proposing a drastic reduction in funding for therapy services of autistic children in early intervention. The examples don't seem to take into account the training required to build parents, child care educators and educators understanding of autism in general and of the individual needs of the child in particular. This can be a period of rapid change in development, meaning that goals and strategies need to be revised frequently and there appears to be no allowance for therapists to support significant others more than one or two appointments per month from 5 years of age. That is a completely unreasonable amount of support for children in their formative years who are having multiple developmental challenges, as we would expect with autism. Funding needs to include development of individual resources and direct training and support of significant others. The body of the report talks about AT being funded separately, but does not mention funding supports for a therapist to assess, trial, apply for AT and support implementation of AT (e.g. AAC), which would come from the capacity building funding.

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

- As mentioned previously, create a very clear imprest list that is made available to participants and providers.
- Consistency is key. Families are often part of support groups etc. and will hear that something has been funded for someone else but rejected for them.
- From Section 7.1, bullet point 5:

“There is no evidence that the support will increase the child’s participation in mainstream and community settings or the child is being withdrawn from educational settings to receive supports”

While it is ideal that services are provided within the child’s natural settings, I just wanted to highlight that sometimes we don’t have control over whether a child is withdrawn from educational settings to receive supports, usually because the teacher or school have requested that the child be withdrawn or because having a therapist in the classroom is disruptive to other students or the child is too distracted in the class to benefit from therapy. Also, some interventions are best done in a quiet environment (e.g. articulation/motor speech/phonological awareness) or where other students won’t hear the therapist and start to give the child feedback at other times (e.g. articulation/motor speech/stuttering). A student wanting privacy might be another reason for withdrawal from class. Therapists can’t always provide services out of school hours (this would not be economically viable nor practical as we could only do one or two sessions before dinnertime), nor would this be appropriate for students (especially in EI) who may be tired and overwhelmed by the end of a school day. Also, often the choice to provide therapy at school rather than at home is made by the parents, i.e. it is their preference or there are other factors that impact whether parents have the capacity to have therapists come to the home.

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?

- The tables do clearly indicate the level of funded supports.
- Yes, as long as it takes into account the impact on the family when it discusses high-medium-low levels of need.
- Will there be room for clinicians to alter the supports plan?
- Generally clients need ongoing support of the same level despite starting school. Goals change as they get older etc.
- Where it states Supports it would be reassuring to know that the NDIS are taking into account how many professions are likely to be involved as this is not clear.
- How is the functional impact measured to be low, medium or high need?

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

- The tiered system is very linear and assumes there will be a decline in the need for supports as the child enters formal schooling as costs are then shifted to the Education Department. This does not recognise that there are very often comorbidities that exist with autism such as a high prevalence of ADHD and anxiety which is exacerbated when a child enters a busy classroom environment and transitions into school.

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?

- Please don't assume that mainstream supports can be used for all children with autism. In a lot of cases, these programs are not adequately staffed or trained to accommodate children with a severe communication impairment or with challenging behaviours regardless of an Occupational Therapist or Speech Pathologist providing them with support.
- Consider therapy summary reports and why plan usage may be low etc. – consider recommendations from clinicians
- That the family around the child are a holistic unit. If a parent is ill or also has a disability, this will impact on development of the child. The child should not be considered for funding in isolation from their family unit.

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 are good questions. It would be beneficial to have more families asking questions like these.
 - Providers should be transparent and accountable for the services they deliver and the outcomes they are achieving.
- As the research has indicated outcomes are improved by parent engagement and a holistic approach
 - The best outcomes are achieved when there is parent engagement and a willingness to carry out recommendations at home. Unfortunately there are times where outcomes are not achieved due to a lack of engagement by families and a reliance to complete therapy in school environments in the absence of a caregiver.
- Additional questions:
 - What will the intervention look like?
 - Why are you recommending this intervention over other interventions?
 - Where will the intervention occur?

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?

- If fixed line items are going to be included in plans then it means this practice has been mandated by NDIA as an evidence based practice, which will give customers some surety.
- Strong understanding of ASD + Strength based/independence based goals for the child's lifetime.
- Clearer understanding of NDIS
- Clear, concise and consistent information
- Having a regular contact person
- Many families would benefit from high quality (i.e. appropriately trained) support coordinators to assist them in navigating the NDIS and finding and choosing providers.
- Families should be provided with a separate document that just identifies the interventions in the Autism CRC report that had positive findings so they are not overloaded with unnecessary information. They can then refer to the other reports if they would like further information.

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?

- Perhaps having a brochure that indicates the evidence and using Support Coordinators during the first few plans so families have support to navigate through potential services.
- If families have a greater understanding of Evidence Based Practice in Autism Spectrum Disorder interventions in different phases of a person’s life, they can have greater control of the goals that are set and the interventions that are implemented.
- The NDIS could mandate and fund a one hour meeting for the therapist/s and family to discuss the findings and recommendations, including a discussion of all therapies identified and why they have not been recommended. This meeting could have a recommended agenda and documentation template (including interventions discussed but not recommended) for all attendees to sign if in agreement. Alternatively, professionals could be required to write an assessment report detailing rationale for recommending one intervention over others (keep in mind though, this adds administrative time which will be taken from time spent with the child and family in intervention. The one hour meeting may be more efficient.

Other Feedback

The consultation paper didn't express an understanding that evidence-based practice has three components. The research evidence is one component. Participant preference and clinical expertise are the other two components, and these must be considered in order to be truly using evidence-based practice.