



Please find below our submission to the following NDIS consultation paper:

Consultation paper: Supporting young children and their families early, to reach their full potential

1.1 General questions

● **Do you have any specific feedback in relation to:**

- **the increased focus on Short Term Early Intervention (STEI) outside of access to the Scheme**

While STEI may be appropriate in some circumstances, it is important that NDIS planners and staff do not misinterpret an *increased focus* on STEI to mean that disability can be “fixed” or “reduced” with short term intervention. Many children with a disability, and their families, will require disability support longer term or for their lifetime

- **the proposed increase in age range for the EC Approach from under 7 to under 9 years of age**

The increase in age range is a great step forward in acknowledging that many young children with a disability and their families still require support to build key foundational/functional skills and develop strategies to help manage and navigate their disability for a longer period than the first 6 years of life. In particular, it's vital to take into account the key milestone of when children transition to school and acknowledge that children with a disability will continue to need assistance to transition to, navigate and the build skills needed to participate meaningfully (both academically and socially) in large group learning environments.

- **the desire to see more successful transitions from the Scheme to the next state of life.**

This desire and focus is somewhat suggesting that disability needs are short term. While some people with a disability may only require short term or minimal support, many children with a disability, and their families, will require disability support longer term or for their lifetime. The emphasis in the consultation paper (including case studies used) on short term support or transitioning people out of the scheme is concerning. It is imperative that any consideration of transitioning people out of the Scheme is because of their individual progress and ongoing/long term needs, rather than focussing on the cost of continuing to participate in the scheme.



- **How can we help families and carers better understand some of the terms the NDIA, and Early Childhood partners use such as:**
 - **best practice**
 - **capacity building**
 - **natural settings, and/or**
 - **Evidence**

Experience from working with many families starting in the NDIS scheme is that they get information overload and find it hard to remember or take everything in. A mix of verbal and written material outlining key terms, as well as consistently applying the key terms will assist families to understand these key terms.

1.2 Support with achieving goals

- **What is the best way for us to check in with families and carers on how their child is tracking to meet the goals for their child?**

At present, families advise they only hear from their Early Childhood Planner when an end plan review is due and there is little follow up during the year. Families appreciate being given the opportunity to be heard and in our experience, they appreciate this to be in person/verbal communication, rather than an email check in. Scheduling a regular check in (if the families desire one) quarterly may help families.

- **Would a mandatory early childhood provider report developed between families and their provider be useful for tracking against their goals?**

A mandatory report in a particular format may not always apply or be best suited to all participants and the services they receive. However requiring that a report (in any format) be developed between the family and the provider, and submitted to NDIS, is definitely beneficial for all parties that are supporting a child with a disability (family, providers, NDIS, other institutions (i.e school)). The report should cover at a minimum, progress against NDIS goals, outline support provided to families and identify goals for the next period.

- **How can we better support families to connect with services that are either funded or available to everyone in the community?**

Providing advice to families about other forms of support is important, but again we must be mindful of information overload. Families may benefit from 'warm referrals' to other services (ie the NDIS planner calls to connect the family and the provider, or attend the meeting with them).

It is also imperative that encouraging connections with other services does not suggest that other supports replace the disability support that should be funded by NDIS.



- **How can we make the process of transitioning out of the NDIS something to celebrate?**

Celebrating all progress, milestones and successes is important for the child and their family, so they feel a sense of achievement. It is imperative that we do not only celebrate a transition out of the scheme, it suggests that this is the ultimate goal or what is defined as success by the NDIA, and many children with a disability, and their families, will require disability support longer term or for their lifetime. Perhaps what is more appropriate would be an ongoing celebration of progress toward goals.

1.3 Targeted support

- **If you live in a remote or very remote part of Australia, what are some ideas you have on how we can get early childhood supports to work in your community or communities like yours?**

The increased uptake of telehealth is beneficial for those that live in remote parts of Australia, however many families report that children, particularly those very young do not respond or cannot work in this format. Possible strategies to reach those in remote areas may be:

- incentives for providers to travel remotely to deliver services
- NDIS adequately funding provider travel
- Increased collaboration and secondary consultation with providers in the area

- **How can our Early Childhood partners and mainstream services best support peer-to-peer connections?**

At a macro level, Government Departments that oversee NDIS and other mainstream services (i.e education, early childhood learning, medical field etc.) should continuously and collaboratively be reviewing services to find any gaps, to ensure that NDIS and mainstream services do not avoid or shift responsibility for who should be providing the critical services and supports needed for children with a disability.

At a micro level, increase networking opportunities so that Early Childhood partners are aware of and can make connections with other providers.

- **Are you interested in helping us co-design an approach that would make peer-to-peer networks easier to find and join for people?**

Yes

- **How can we better reach and get support to young children and families who experience vulnerability and remove barriers so they can receive outcomes in line with other children and families?**



Vulnerability spans many areas, no one approach will fit all. The best way to work out what will support vulnerable children and their families is to consult those different cohorts and encourage them to identify what would work best for them.

1.4 Tailored Independent Assessments (IAs) approach

- **It is recommended that the Agency implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions. Specifically, we are planning to:**
 - **Commission Early Childhood partners to administer Independent Assessments for young children rather than use a separate IA Assessor workforce**
 - **Use IAs for young children above 1 years of age**
 - **Use the following tools (as outlined in an appendix to the previously published [Independent Assessment Tools Paper](#)):**
 - **Ages and Stages Questionnaire (ASQ-3) OR Ages and Stages Questionnaire -Talking About Raising Aboriginal Kids (ASQ-TRAK)**
 - **PEDI-CAT (Speedy) OR PEDI-CAT ASD (Speedy)**
 - **Vineland-3 Comprehensive (Interview Form)**
 - **Young Children's Participation and Environment Measure (YC-PEM) for children under 6 years**
 - **Participation and Environment Measure - Children and Youth (PEM-CY) for children 5+ years**

Do you have any feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers?

It is acknowledged that a lot of work has been done to develop a range of assessment tools for the independent assessors to use to determine a person's functional capacity and eligibility for access to the NDIS scheme. It is likely these tools and the independent assessment process may benefit those with a disability who do not have diagnostic or health information readily available that describes the disability and its functional impact.

However, for those who already have diagnostic information or health / clinical information about their disability and functional capacity, the independent assessment process will likely be more timely and onerous for the participant. They may duplicate assessments and information gathering already undertaken and will require people with a disability to repeatedly tell their story/provide information to multiple people. A professional who has diagnosed a person or has already been working with the person with a disability is likely to have already completed assessments and have information readily available to describe function capacity.



Standardisation should not replace specialisation and expertise. The introduction of independent assessments is likely to take away the voice of those professionals who work with children with a disability (and in fact anyone with a disability given this is being rolled out to all participants). Disabilities are not all the same, they are vastly different and therefore there is a long list of professionals that provide support to people with different types of disabilities. It seems counterproductive, and likely dangerous, to suggest that an Independent Assessor from a particular field will know all the clinical needs of every disability. In regards to the Early Childhood Stream, Early Childhood partners are not the experts in all fields of disability, without in depth professional understanding on an individual type of disability, Early Childhood Partners could not make reliable planning decisions. Even if Early Childhood Partners are experts in a particular diagnosis, without knowing the child and family, it will be impossible to make reliable recommendations. This approach would likely lead to the development of plans that respond to a general understanding of a condition and its likely impact on a child's life, rather than an accurate assessment of the individual. Standardised testing is often not sensitive enough to capture the true essence of services a participant may require.

Further to this, if the NDIA is proposing that the Independent Assessment won't replace the recommendations made by professionals and experts in the field, then it would seem a duplication of roles. The money would be better spent if given to participants to access the actual amount of services they need rather than investing in a standardised approach that is unlikely to lead to recommendations specific enough to each individual participant's circumstances.

1.5 Greater transparency on providers of best practice

It is recommended, from the previous consultation leading to this paper, that a range of mechanisms be considered to enhance providers' compliance with best practice standards and to provide greater transparency on which providers, both registered and unregistered, are following Early Childhood Intervention best practice.

- **What mechanisms do you think could help achieve this?**
- **Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?**
- **What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?**
 - **Provide greater information to families about the benefits of using providers registered by the NDIS Commission.**
 - **Establish an industry-led 'best practice accreditation system'.**
 - **Establish a 'quality feedback / rating system'.**



- **Make registration with the NDIS Commission mandatory for all providers operating in the EC space.**
- **Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.**

We fully support efforts to enhance providers compliance with best practice standards. Given the potential impacts of early intervention it is critical that services adhere to the best practice guidelines. It is also important that families maintain their choice and control. Requiring any participant, whether they are a child or adult, to only use a registered provider takes away their choice and control and limits their ability to determine what is in their best interest, this is in direct conflict with the NDIS legislation. Ensuring providers are delivering services that will support participants to reach their goals and manage their disability can be achieved without mandating that all the many professionals that provide support to people with a disability must be a registered provider. Providing guidance on best practice and requiring that providers report on the work they do with participants, in particular outlining the progress of participants and detailing how the best practice principles have been applied, allows providers the opportunity to reflect on their practices and ensure they are continuously meeting the needs of each individual and provides the NDIA with insights into the practices of individual providers.

Given the need to maintain participants' choice and control, perhaps one of the most powerful things the NDIA can do is increase its education aimed at participants' families, to help them to understand best practice guidelines and what they should expect from their provider. Given the volume of information families receive around the time of their first planning meeting, it would be worthwhile revisiting this information with families on a regular basis. This education could be supported by increased contact with planners throughout a plan period to ensure that families continue to assess the impact of the services they are receiving and also to think carefully about their provider and the degree to which they are implementing best practice guidelines. Simple reminders of what they should be expecting via social media, the portal and email may complement this. Family and participant experience of the implementation of best practice guidelines may give the NDIA the most accurate information of what is really happening in practice. Individual providers can report on anything, how families and participants experience this is far more important.