**Ashton’s Place – Supporting - The Autism Connect Early (ACE) Programme.**

**Thank you for the opportunity to make this submission from Ashton’s Place.**

**I am only too happy to provide further feedback or information on request.**

**I would be happy to provide our Programme rationale and delivery guide if required.**

## Consultation questions

The NDIA is working to finalise the design of the new Early Childhood approach. We are committed to working with families, carers, people with disability, the disability community and other stakeholders to get these changes right.

We would value your feedback on the proposed improvements to the NDIS Early Childhood approach. You can provide general comments on the paper, or answer the following questions. Feel free to respond to all of them or just a few.

### General questions

* Do you have any specific feedback in relation to:
  + the increased focus on STEI outside of access to the Scheme

Short-term early intervention needs to be clarified before it could be recommended. What parameters? How is it defined when doing a plan review for example, if the child has been in an early intervention programme for three months and has not achieved the goals set, do they become ineligible to receive further funding? What does short term mean? To some it may mean two months three months and to an Autistic child level three in my experience and from the research, it could mean years. There needs to be a clear understanding of Autism, as goals are not usually achieved in one to three months.

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

Increasing the age from under seven to under nine would be recommended. If having an Autism diagnosis means that you are developmentally behind your peers in social – emotional and cognitive skills for example then by the time you are seven you could still require early intervention as you may be seven or eight in years but developmentally you are functioning at a four or five year old level.

School entry should also be delayed.

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

This would be recommended. It will require a measurement system in place that could guide decision makers

* 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.

The terms need to be clear, as this is something foreign to families in the early stages of diagnosis. Facts sheets with examples in relation to child profile to ensure relevance to the families would be the simplest and most effective approach.

### 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?

Feedback on goals that have been set. A generic report would make it easier to be able to provide the necessary feedback. It will allow for consistency across the sector and provide transparency. There could be a continuum for goals set and a scale would allow for progression to be evident therefore giving the NDIS representatives a clear understanding of the progress or the early intervention that has been done with the child. There would need to be a section on supporting ties to family and services or communities or “Natural settings” to ensure that there is evidence that support has been offered to families. Often support is offered outside the service but family participation is poor due to lack of time.

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

The report would need to be consistent across early childhood providers and families as described in the point above. It would be unable to be measured if everyone used a different way of reporting.

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

There should be a register for providers that offer early childhood intervention. Providers should be able to submit their information etc. and identify what it is that they offer and families would be able to choose. There could be an accreditation process as in early childhood education and care services that have clear guidelines that need to be met.

Providers should not have to pay to be on the list or register.

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

A transition support package could be in place so that people are not supported one day and then nothing the next, as the point states a “transition” that is skill based not time based.

It is important people feel that they are not alone and unsupported.

1.2 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?
* How can our Early Childhood partners and mainstream services best support peer-to-peer connections?

Ashton ‘s Place in partnership with University of New England is developing an early intervention programme. It has been in operation since 14th July 2019, it is based on inclusive practices that build functional skills for children and offer gradual inclusion as we build capacity.

We are situated in Early Childhood education and care services.

Ashton’s Place funds the programme.

Children are encouraged and supported to participate with their peers in play situations both structured and unstructured. This intentional teaching is supported by an adult educator who gradually withdraws support but is on hand to offer suggestions etc. to the child/children as required, with the aim to withdraw as the child’s capacity and functional skills are established, this supports peer interaction at a play level.

Autism Connect Early (ACE) Programme

Our partnership with UNE is one that will have a practical implication for early intervention programmes and will bring about societal change.

These findings come from my thoughts, my research, and my experience as I reflect and continue on this autism journey.

**Inclusive programme an ACE objective**

It has been my observation that, whilst inclusion of all children is a valued goal and one we are dedicated to, it is not always achievable for Autism Spectrum Disorder (ASD) children in general mainstream settings. Therefore the underpinning ethos of the ACE programme is to provide meaningful inclusion tailored to the needs of these children.

The programme is focused on using the research evidence to develop innovative educational approaches for children with autism. To achieve this, we have partnered with the University of New England (UNE) to embed continued review and evaluation across ACE activities so that we obtain an objective measure of how children are developing and growing.

When developing lifelong learning skills, we believe that it is important to introduce all children to the world holistically. Along with the typical developmental skills that are learnt, neurotypical and neurodiverse children who immerse themselves in the ACE Programme will learn empathy, social connectedness, sharing and understanding, and a way to develop awareness of and support for their peers. This learning will help create lifelong positive social connections. Our hope is that these skills will support children through their school life, on to college and the wider community. Our inclusive programming allows neurodiverse and neurotypical children to develop with an awareness of diversity, thus enabling them to be positive contributing members in our social world. Meaningful inclusion ensures that we promote a healthy mental lifestyle by bringing awareness to the needs of others by modelling how we can support each other and connect in an ever-changing world.

*ACE aims:*

a. Meaningful inclusion based on ASD childrens’ competencies, interests, and tolerances with a focus on ‘whole child’ and ‘whole world’ learning experiences;

b. Skill-building across key domains such as physical, sensory, social by exposing children to a range of age-level and developmental-level experiences involving play, movement, pre-academics; and

c. Learning via social connection and relationships with educators and peers.

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

Ashton’s Place would have the capacity to assist with this initiative.

* 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?

We need to provide more opportunities to ensure greater inclusion in mainstream Early Childhood Education and Care Services. These Services need to be supported financially by funding, available to them from Government funded programmes, e.g Inclusion Support and NDIS. Early Childhood services are often a parent’s first port of call. Educators need to be recognised as key workers within the NDIS. There needs to be training in the areas that are essential to understanding parent’s needs and children’s needs. There needs to be an understanding of how autism effects children but is not limited to, the social, emotional, cognitive and self help domains. ACE Programme provides an environment that meets the child’s needs while allowing opportunities to be continually connected to their peers, as they feel comfortable and their functional skills are built along with their capacity to have meaningful peer relationships.

As I have stated previously inclusion is not possible for all children but if we make reasonable and necessary adjustments in line with the child’s diagnosis then we can meet the child’s needs in a meaningful way with supportive adults who have built relationships with the children but not to the point of reliance on one person. We provide a holistic approach to early intervention and work with a transdiciplinary team that supports children, educators and family.

We have had children transition from the ACE Programme to Pre-Kindy and Kindergarten and then onto mainstream school. We have allowed them time to transition to these new environments while we build on their functional skills by providing environments where they feel safe and secure and can deal with their regulatory issues and sensory issues. This can’t be achieved if children are placed in mainstream with no plan.

We have trained our educators and continue to build their skills. We have adapted our environments and we have provided reasonable and necessary adjustments.

This had all been implemented with no funding or support from any government department. It took over 12 month months to get any NDIS funding for our families and we are still having discussions with Inclusion support after two years. If you are to truly make a difference to these children and their families and are to “ build a world leading model that delivers evidenced based, high quality and timely supports to children and families,” then you need to be open to suggests that are put forward by people working at the cold face.

### 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](https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-toolkit)):
    - 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?

I would not recommend this approach.

From personal experience my son who has Autism would not have been represented accurately by information from these tools. It has taken many months and years of relationship building with his Speech therapist and Occupational therapist to take part in formal assessments and it is only through their guidance because of their understanding of my son that assessment have been achieved at all.

This assessment method, especially minimal interaction between assessor and child, is likely to show greater severity of symptoms and therefore greater needs that will require increased funding. Careful assessment by professionals who are familiar with the child is crucial for accurate measurement and funding decision.

A relationship would have to be built over time and that is too long to wait for funding if your aim is to support the needs of families with timely early intervention.

My Psychologist took six months to make a formal assessment of my son. If I had waited for this before I started Early Intervention valuable time would have been lost.

Yes, part of these assessment tools may be quick parent questionnaires with rating scales so your argument may be that they could be done by independent assessment partners, but why not have the known qualified clinical therapists to the child and family complete these.?

### 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.

Providers compliance with best practice standards and transparent demonstration of that compliance is crucial and non negotiable.

Early childhood educators must be included as key workers. The guidelines should be mindful of Early childhood education and care services that provide early intervention and acknowledge the professionals in the early childhood space as Key workers.

Please note there have been research papers and reports funded by the NDIA that have been guided by the “Guidelines for good practice” 2012 (Margot Prior and Jacqueline Roberts.) These reports are:

National Guidelines Best practice in early intervention – ECIA (not sure of date as it is not evident in the report).

Autism Spectrum Disorder: Evidence- based/evidence-informed good practice for supports provided to pre-school children, their families and carers. (Jacqueline Roberts, Katrina Williams with assistance from Kate Smith & Lanie Campbell Feb 2016.)

There was no transparency from NDIS representatives that they existed and I only came across them through thorough research and investigation.

* What mechanisms do you think could help achieve this?

Current clear, applicable best practice guidelines for service delivery. Those guidelines could include specific criteria to reflect on and evaluate performance and outcomes.

- Guideline: Provider to collect objective and concrete measures of child skills in specific domains of performance.

* + - * Key terms: Measurement, skills, domains
      * Progress: Child specific goals.
      * Criteria: (examples) For instance Goal
        + Strong………………….
        + To be improved…………
        + Weak………………..
* Who would be best placed to lead the development of, and manage, any additional complementary mechanisms? NDIS representatives; key accrediting bodies (Department of education), researches, specialist practitioners, families, early childhood Educators , specialEdteachers. Composition of the working party to vary depending on the service providers service focus (e.g Early childhood education.)
* 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.

This would be determined on the registration process – I would not recommend this in its current state.

* + Establish an industry-led 'best practice accreditation system'.

I would recommend this.

* + Establish a 'quality feedback / rating system'.

I would recommend this.

* + Make registration with the NDIS Commission mandatory for all providers operating in the EC space.

NO! As it currently stands, the costs are prohibitive. This is a deterrent to capturing highly trained professionals and service organisations who cannot dedicate funds for registration further and most importantly, this registration process is not capable of excluding practitioners and services with questionable practices.

* + Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.

NO! Not in it’s current process. This takes away family choices.

Thankyou for providing the platform for open discussion on these very important points within NDIS It is important that the ability to included children in services that provide Early Intervention is made easy for families to navigate. At present we assist our parents through the NDIS process because it is actually causing anxiety for parents and they end up giving up. This is not going to benefit children or families get the care they need.

Realistic fees need to be established for Early Childhood Intervention – it has been estimated that “best practice” approach would cost up to $80 000.00 per child per year. This is currently is not happening.

Kind regards

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