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## **Written Submission to the Joint Standing Committee on the National Disability Insurance Scheme**

Thank you for the opportunity to provide a written submission in respect of the provision of services under the NDIS Early Childhood Early Childhood Early Intervention (ECEI) Approach.

Autism Spectrum Australia (Aspect) is Australia's largest not-for-profit provider of services and supports working with people with autism and their families. At Aspect, we believe that people on the autism spectrum are a different brilliant and this shines through in our work. We believe that every person, of any age, with a disability has the right to make age appropriate choices to have full participation and inclusion in society, to have respect for difference and acceptance as part of human diversity and to have equal opportunity. Our mission is to provide person centred solutions which are flexible, responsive and evidence informed. In our work we focus on the strengths and interests of people on the spectrum and we work in partnership with them, their families and their communities. We work to understand people on the spectrum from their perspective. Our approach is autism-specific. Our research focuses on best practice. We expect positive change and progress towards positive outcomes. Aspect Therapy provides Early Childhood Early Intervention services in NSW, ACT, SA and the ACT. We are an ECEI partner in all but 2 NDIS regions in NSW.

### The ECEI Pathway – Issues in NSW

While we acknowledge that there has been work done to help both families and providers understand eligibility requirements for NDIS, the introduction of the ECEI gateway in NSW has been confusing with continual changes to the process. The role of ECEI Transition Providers has changed over time, with a larger focus on supporting families through the access process with an additional step of completing an Access Request pre-approval process with the Transition Advisers. This additional administrative step is time-consuming. The actuary tool is inefficient to complete and very labour intensive for organisations. Aspect has over 1500 children who are requiring support to gain eligibility, with over 90% of these individuals having a confirmed diagnosis of Autism.

We expect there will be a backlog caused by the change to the process where Transition Advisers are approving who can have an Access Request Form (ARF) completed. We are concerned about the amount of therapist time being spent completing administrative processes when there is already a scarcity of early childhood intervention therapists providing therapy.

We have seen examples where proactive parents have been able to access the planning process more quickly than others and we are concerned about newly diagnosed children, those transitioning from federally funded programs and children from vulnerable families not being able to access supports in a timely way during their crucial early childhood intervention period.

We are currently receiving a high volume of families calling us to help them access the NDIS and we are working through each inquiry to support their access. One of the challenges is we may well be doing the same tasks for a child as another provider and we have no way of knowing if a family is working with several ECEI Transition Providers in their region to gain entry.

The guidelines indicate that families should receive a response with twenty one days from the National Access Team, however this time line is not being delivered.

The NDIS are passing on tasks to ECEI Transition Providers that should be addressed by the agency. Providers are being expected to manage very hard and often abusive phone calls from families who are waiting for NDIS planning. Families are distressed and concerned as their child has limited access to gateway services and feel organisations are not doing enough to get their child get a plan. This is a demoralising experience for staff as there is a sense that they are being caught between the NDIS and the family. This problem affects our reputation and reflects poorly on our organisation. It makes forward planning difficult as expectations keep changing.

We believe there should be priority of access for children who clearly meet eligibility requirements and that this could be determined at the time of diagnosis. Families are distressed and providers overwhelmed by the unclear messages. At times families are contacting providers directly and it is difficult to get an answer about what services can be provided and without clear information about funding levels and target numbers.

*Recommendations:*

- The provision of clearer information for families about the process, timelines and providers.
- Targeted supports to ensure vulnerable families are accessing the ECEI pathway.
- Access request processes differentiated.
- Clearer information about when planning processes can be completed for families which will prevent families contacting a number of providers.

The ECEI Pathway – Issues in VIC, ACT, SA

Our experience in the ACT, Victoria and SA is different. In these regions there has been a lag in plans being provided and timelines have not been met, but the process is much clearer to explain to families with a central contact point and the Access Planners in place. In areas where the Early Childhood Partners do not have local knowledge this delay has been exacerbated.

*Recommendations:*

- The provision of information about the Early Childhood Partners expected timelines and processes ahead of their start.
- A requirement of Early Childhood Partners who do not have local knowledge to prioritise developing an understanding of the local services.

Gateway Service

There is still ongoing confusion about eligibility and the level of developmental delay required to meet eligibility for the scheme, who is able to access the gateway services and how organisations can fund these gateway services. Some children on early phasing lists received funded packages but no longer meet the criteria. ECEI partners are also being placed in a difficult situation as we now have to work with families to access mainstream supports and explain why their child does not meet the NDIS eligibility criteria.

We are continuing to use a tool (PEDICAT) and we have concerns about the efficacy of this tool. It does not guide the development of planning in a meaningful and functional way. One of the flaws we have seen is that the tool does not identify the significant needs of many children with autism who score as having mild or moderate needs. We believe a 'stages and ages' model that clearly differentiates children from their neuro-typical peers would be a better approach. The results of the PEDICAT are often not a true indication of a child's functional needs e.g. many of our children have scored in the mild range, however still present with functional difficulties, which means we need to provide much more detailed rationales regarding why they require the supports as outlined in their planning tool.

Families of children receiving support under the ECEI pathway require a range of supports and services. While it is important to provide information about mainstream services and other supports we are finding that there are fewer universal supports that families can access. Many children who do not meet eligibility may still require ongoing therapy and monitoring which is beyond the scope of providers under the gateway model but is crucial if they are to successfully access education and develop to their potential. It is also very unclear how much service can be provided as funding levels are not clear and related to the number of

children seen.

*Recommendations:*

- The development of clearer guidelines regarding gateway services with clear funding models.
- Collection of data to identify gaps in universal service provision that might be most appropriate for some children.
- Research to identify a more appropriate tool to help guide and be embedded into the planning process.

Early Childhood Intervention Best Practice

Many families are still confused about early childhood intervention principles and there are many therapists providing services under NDIS funding who do not work in ways that support children in naturalistic settings and are not targeting the development of functional skills. Providers who see children in their home or community setting are able to see less children in a day – travel time is not fully funded. Not all providers are happy to collaborate with other providers, or even to include parents as key team members, but they are still able to provide services under this funding.

In terms of the objectives of the ECEI approach, it is based on strong evidence developed and well articulated in the ECIA National Guidelines for Best Practice Early Intervention (2016). Aspect strongly believes in these principles as leading to improved outcomes for children and their families. However not all providers have the necessary skills and willingness to provide services using this model. We see examples when providers are not willing to collaborate with other providers working with a family or do not support families to be key partners in developing plans and interventions.

The lack of guidelines around what is reasonable and necessary has led to very inconsistent packages for participants. There is anecdotal evidence that families who are best able to articulate what they want from an NDIS plan achieve packages that include more hours of therapy, support and funding for other services. While this should not be the case and ECEI Partners and Transition Providers should be able to develop plans that are based on the needs of the child and family this is a huge challenge.

*Recommendations:*

- Provide additional funding to services who work with children and families in natural settings and work in ways that support the development of all those working with the child.
- Provide clearer guidelines about what is reasonable and necessary.
- Establish processes to audit the plans that are provided to look for inconsistencies.

Timeframe in receiving services under the ECEI pathway:

As an ECEI Transition Provider in NSW, we are now expected to establish if a family should apply for the NDIS based on the child's needs, establish if the family has or has not completed an Access Request Form, complete pre ARF documentation and submit to our transition advisor, await the auto filled ARF and submit this paperwork and await confirmation of eligibility. If a family is deemed eligible we then have to talk to the family about phasing and explain the time line. If they are not eligible we need to connect them to appropriate services, some of whom will not see children as they claim they have a disability and should be seen by an NDIS provider, even though they are not eligible. We are expected to complete the PEDICAT on every client and complete a spreadsheet for the actuary tool that is labour intensive and needs to be completed for each individual. Once a child is ready for phasing, we complete the planning and submit to the NDIS. In some regions the turn around time for a plan is exceptional and children gain a plan within seven days, while in other regions we have submitted planning material and six months later the family receive a plan. This means the process from enquiry to entry to the scheme can take over eighteen months in the crucial early intervention time frame where we know if we provide intervention in these early years the best outcomes are achieved. In regard to interim support as an organisation, we are trying to help as many families as possible, but this is a significant cost to Aspect.

*Recommendations:*

- Rethink the access request form process to ensure that this is not as time-consuming for families and providers.

- Clearly articulate phasing arrangements (if they are in place) so that providers can clearly explain to a family when they will be able to have a plan developed. This will also help providers plan supports for children who are waiting for the planning process and those who will require an NDIS plan.

#### ECEI Pathway does not allow for flexible funding options:

Currently children can receive individual therapy or group programs but the group program rates do not support ratios that are required for young children with very complex needs. Aspect Therapy understands the value of providing therapy in social situations as children are supported to develop their communication and play skills in small and highly supported settings as a stepping stone to participation in more inclusive settings. A ratio of 1 therapist to 4 children is not appropriate.

Aspect Therapy was historically able to provide two highly valued services which are no longer funded. One was the Early Childhood Development Program (ECDP). This program was state funded and worked with Paediatricians, Allied Health Professionals and Early Education and Care settings to identify children at risk of not meeting their early milestones and also had a screening component for Autism and Developmental delay. The service worked with families and services to provide early intervention supports and also for individuals needing a diagnosis supported families through the challenging process. The other service - Early Intervention Readiness Program (EIRP) worked with families of newly diagnosed children to embed strong environmental supports and support families to understand the best practice principles of early intervention as well as provide information so families could make informed decisions. With the change in funding these two critical services are no longer available to families and whilst Aspect Therapy wants to support gateway services, there is not sufficient funding to maintain these outstanding models. One of the biggest risks is children and families are not receiving the intensive intervention and supports they need during the transitional period as organisations cannot sustain the cost which is not funded.

#### *Recommendations:*

- Flexible funding options to ensure that providers are able to create services that best meet the needs of the children and families.

#### Costs associated with ECEI services, including costs in relation to initial diagnosis and testing for potential ECEI participants:

Aspect Assessments provides comprehensive diagnosis, as do health services. The challenge is that many diagnostic processes need to be partially funded by families, which means that those families who can afford to pay receive a more timely diagnosis and therefore access to ongoing support. Whilst this does not impact on their ability to access the scheme under 7 years of age, a good diagnostic process does provide direction for intervention. Aspect is a firm advocate of early screening programs, however these programs are not funded under the NDIS.

#### *Recommendations:*

- Ensure that there is access to timely screening and diagnostic services for all children who require these services.
- Ensure that there are pathways so that vulnerable families are able to access the information they need including diagnostic services, so that they are able to fully benefit from the NDIS.

#### Accessibility of the ECEI Approach, including in rural and remote areas:

There are limited providers with expertise in rural and remote areas. Whilst we are exploring telehealth options and supporting professionals in these areas to increase their skills, it is also a transient workforce. Many professionals in regional and remote areas are still confused and by default, families are also confused about what they need to do to access a service in the 0-7 year space. Services in general are limited in many remote areas. There are limited incentives to provide services in regional and remote areas and the travel that can be billed cuts into the service/therapy time provided to a participant.

#### *Recommendations:*

- Create appropriately funded models that will encourage providers to be able to deliver high quality planning processes and therapy in regional and remote areas using both face-to-face, well

supported local providers and the use of new technology.

#### Principle of choice of ECEI providers:

While there are a number of ECEI providers in many areas in NSW, it is very unclear for families and providers about whether support and planning can be provided to a specific child and family. In many regional areas there are few choices and some providers have very limited funding and therefore are not able to provide services to all families. Again the situation benefits those with the time and resources to contact providers and providers are spending considerable time responding to enquiries which may be from families who are shopping around for the shortest wait time.

The other element is around transparency as planners need to give families the skills to make informed decisions. It is disappointing to hear reports of Early Childhood Transition Providers advising clients that if an organisation completes the ARF and plan, then the family must choose that same provider. This is against the principles of choice and control and at worst, an example of some providers taking advantage of vulnerable people. It is an approach that Aspect does not support.

The other consideration is that while there may be a choice in providers, not all providers are offering best practice early childhood intervention and may be delivering a clinical service with no collaboration or environmental supports. This is of particular concern for children with autism who strongly benefit from family centred, collaborative and environmental services to support generalisation of skills. In some cases families are opting to put their name on as many provider waitlists as possible and whoever can provide a service first is who they choose.

#### *Recommendations:*

- Provide clear information for families about the planning process

#### Application of current research and innovation in the identification of conditions covered by the ECEI Approach and in the delivery of ECEI services:

Aspect does not believe that we should be looking discretely at the identification of conditions covered by the ECEI approach but rather, there should be research done to help identify a range of tools that can best identify the children requiring additional support.

We need to balance strength-based approaches with information about functional skills that includes the challenges faced by young children on the autism spectrum (not well picked up by PEDICAT) and also helps highlight the need for support and capacity building for parents and carers. This would work best when embedded into high quality universal screening processes. This will ensure that children and families receive the most appropriate level of support at the earliest time, reducing the impact of disability.

#### *Recommendations:*

- The provision of high quality universal services including screening to identify children who would most benefit from early targeted support.

#### Any other related matters:

Some key issues that need to be addressed:

- Funding for interpreters and translators as part of NDIS packages (not just for the planning process) as this cost is not able to be met from NDIS funding.
- Ongoing portal issues – Providers spend significant amounts of time chasing issues in relation to plans. While the wait time for the 1800 number has improved, main issues that are not straight-forward are not being addressed. Service bookings and the loading of plans onto the portal are creating problems. There must be easier processes to edit service bookings if families are to be able to access choice and control over their plans. It is not appropriate to have providers unable to claim for services that they have delivered in good faith and for them to be told that it may take four to six weeks for an email sent to the finance team from the 1800 team to be acknowledged.
- Travel – while it has been helpful to have guidelines about claiming travel, the current situation does not support the key principle that services will be delivered in naturalistic settings. Families are forced to make a decision regarding the amount of therapy time they can receive and clinic-based

options can appear more cost-effective. This is not best practice in early childhood intervention.