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Supporting Young Children and Families Early, To Reach Their Full Potential

Response to request for comment on a Consultation Paper

23 February 2021

**Aruma is an NDIS registered provider of Early Childhood
Early Intervention supports.**

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Recommendation 1. Explain, rename and promote the NDIS Early Childhood Approach

The NDIS Early Childhood Approach is unclear in terminology, particularly for families from non-English speaking backgrounds.

We would support using the word "Pathways" rather than using the word "Approach" which conveys that there are many ways in which a child could first enter the NDIS and many ways in which support could be provided by EC Partners and NDIS ECEI providers.

We support the Re-Imagine Australia submission which states "Access to services must be built around the assumption that there are multiple pathways rather than a lineal one".

Recommendation 2. Communicate the intent of Early Childhood approach and best practice

Effective and easily understood information about the Early Childhood approach is needed as we experience many families and Early Education & Care services staff contacting us for guidance about the approach.

We then refer to the local EC partner, however unfortunately, there can be significant delays with the local EC partner returning calls made to their 1800 number and some families are left unsure as to what is available.

Children need to receive support as early as possible, but there is a gap from when children are discharged from Child & Family Health services, as they become eligible for NDIS ECEI support, until receiving an ECEI plan up to 6 to 12 months later.

Families are often then unsure of how to implement the plan which can lead to further delays. This is particularly true for families with complex needs, from Non-English-speaking backgrounds or experience other barriers such as sourcing providers, getting on waitlists, etc.

Additional resourcing for EC partners would be welcome to assist them to provide information and support to families on an ongoing basis throughout their ECEI journey.

Recommendation 3. Develop and publish new Early Childhood Operating Guidelines

Aruma supports the development of Early Childhood Operating Guidelines, so that all ECEI providers have clarity about what is required for each child's delivery of supports based on best practice, minimum qualifications of staff and requirements for maintenance of professional registration.

It would be helpful if these guidelines could be linked to the EC module of the NDIS Practice Standards.

Recommendation 4. Create a distinct delegate/planner workforce for young children

We support this recommendation in principle.

It is important for NDIS delegates to have the training and expertise to understand ECEI and the needs of children and families when making access decisions and approving ECEI plans.

The current shortage of qualified staff in the Early Childhood sector may make this challenging, however without having this understanding, professional decisions relating to the needs of children may be affected.

Current EC partners should continue in their current role of developing NDIS plans and conducting plan reviews but should not be expected to also deliver Short Term Early Intervention (STEI) supports.

Further comment will be made on this under recommendation 12.

Recommendation 5. Work with governments to identify gaps and strengthen role of mainstream services

As identified in our response to Recommendation 2, there are clear gaps occurring with children being discharged from Child & Family Health services because they are eligible for NDIS ECEI support, but then experience delays, and may not receive an ECEI plan until 6 to 12 months later.

In other cases, children may have not had any contact with Child & Family Health or with the local EC Partner until they are 4 or 5 years old.

Currently Aruma ECI is principally receiving new referrals for children already in their transition year or their first year of school, which is not considered best practice. Under these circumstances building a relationship with a child and a family to provide support to prepare them adequately for starting school is challenging.

Kindergarten teachers from local schools are calling Aruma ECI services because they have children with developmental delays or disabilities who have not received any early intervention prior to starting school. For example, the child may be exhibiting unacceptable behaviours in the classroom due to sensory or communication issues that have not been-supported in a timely way. These can result in the child being excluded from others or suspended from school and increased pressure on families. In addition, this may have long term consequences which not only impacts on the child's lifelong trajectory but also has implications on the future cost effectiveness of the NDIS due to future support needs of the child in adulthood that may require funding.

Timely and accurate service provision ideally from 3 years of age on, ensuring strategies and recommendations are implemented in schools and other environments create successful outcomes for all concerned.

Aruma ECI staff are increasingly being limited by schools in terms of the times and frequency that they can see the child at school to provide Key Worker or therapy support in their "natural environments".

While we can understand the complexities for the school with a variety of NDIS providers visiting, the logistics of providing adequate support to school-aged children is becoming increasingly difficult as many families are working and do not have the time for after-school appointments.

Aruma supports the suggestion in the Re-Imagine Australia submission of a shared plan across Health, Education and the development of strategies where the NDIS could assist in bridging these gaps.

Recommendation 6. Enhance compliance of providers with NDIS Practice Standards EC module and increase awareness by families of providers that adopt the best practice framework.

Aruma supports a plan where all NDIS registered ECEI providers can be audited under the NDIS Practice Standards Early Childhood module to ensure compliance. However smaller providers may find this process too costly and not viable.

An alternate solution may be a similar accreditation system as with Early Education & Care services, where a national ECEI Best Practice body is established and funded to provide this oversight with all ECEI providers undergoing accreditation every 3 years.

In the Early Education & Care accreditation system, providers may receive "Working Towards", "Meeting the Standards" or "Exceeding the Standards" ratings and these ratings would be available to be accessed online by families when choosing providers, in a similar way as to when they are choosing childcare providers. Smaller ECEI providers who receive a "Working Towards" rating would have a certain time period to meet the Standards or they would not be allowed to claim under ECEI NDIS plans.

Recommendation 7. Improve sector-wide understanding of disadvantaged or vulnerable families and tailor culturally appropriate services

Families with vulnerabilities or from disadvantaged groups within our community respond more positively to familiar services rather than having to navigate yet another service. For example, in our areas, the EC partner and Aruma as ECEI providers work with the local Aboriginal Medical Services who provide referrals and support for families to access the NDIS initially and then to access supports once the child has a plan.

It is suggested that NDIS ECEI Coordinators be embedded in these types of services so that they can provide advice and support in a culturally safe way.

Recommendation 8. Implement tailored methods of delivering supports in remote and very remote areas to strengthen access to services

Methods of delivery need to be delivered collaboratively with existing services in remote and very remote areas.

Delivering supports through online platforms only, does not adequately meet the needs of children in remote and very remote areas.

Sufficient funding should be included in ECEI plans for these children to ensure they have the same opportunities for best therapeutic outcomes by covering the travel costs of providers to those areas, or to cover the transport costs of families who travel long distances to access programs.

“Seed” funding and professional support could be provided to existing community organisations in remote and very remote areas to provide ECEI supports.

Increasing the remote area loading in the NDIS price guide would also support ECEI organizations to attract and retain suitably qualified staff with competitive remuneration packages.

Recommendation 9. Implement a tailored Independent Assessments (IAs) approach

The proposal of moving towards Independent Assessments is concerning. This is not aligned with best practice principles for children requiring ECEI supports, where assessments of children's developmental needs are done over time, in their natural environments, with people with whom they know and have an established relationship and are conducted in a family-centred way.

ECEI providers who have been working with the child and family in their natural environment and who are experienced in working with young children are best positioned to offer this service to attain the most accurate results

Recommendation 10. Increase EC Partner capacity to help families in hard-to-reach communities, those experiencing disadvantage or vulnerability to connect to early intervention supports.

EC Partners need time to establish relationships and trust with hard-to-reach communities.

Funding and other support to locally trusted existing community services to provide the information and warm referrals to encourage families to access-early intervention supports would increase and support engagement with families and their children

A community approach where “no door is the wrong door” should be implemented to avoid delays and allow ECEI providers increased opportunity to fulfill their role in remote areas sooner.

Recommendation 11. Increase EC Partner capacity to connect family and young children to local support networks and services

Aruma understands that this was intended to be part of the EC Partner role.

Our experience is that ECEI Coordinators are extremely busy with assisting with ECEI access and writing ECEI plans, and may not have enough time to get out into the community and foster those vital connections.

Alternatively, the provision of STEI packages to ECEI Providers could outsource this role to the services who already have close connections with support networks. For example, they could establish playgroups in remote locations or attend playgroup with family to build confidence.

Recommendation 12. Increase EC Partner capacity to provide Short Term Early Intervention (STEI) support

Aruma supports Re-Imagine Australia's submission that STEI support should be provided by quality ECEI providers under "STEI packages".

Quality ECEI providers have the expertise, local connections, and existing infrastructure to provide this short-term early intervention support.

Recommendation 13. Clarify the interpretation of the developmental delay criteria under Section 25 of the NDIS Act (2013) to improve the consistency and equity of Agency decision-making.

The developmental delay criteria should be referenced in all areas of a child's development. Currently, the criteria refer to "mental or physical impairment or a combination" and does not include delays in social and emotional development.

The other component of the criteria: "substantial reduction in functional capacity..... in one or more of the relevant areas of major life activity (i.e. self-care, receptive and expressive language, cognitive development or motor development)" again does not include social and emotional development which is fundamental to a child's functioning in their daily lives and to their functioning as an adult later in life.

The term "substantial reduction" could be clarified as this is open to interpretation. Clarifying what is a substantial reduction (for example, a delay of 6-12 months or more behind normal developmental milestones) could assist with improving the consistency of determining access to the scheme and reasonable and necessary supports needed.

Recommendation 14. Increase the age limit for children from ‘under seven’ to ‘under nine’ years of age

Aruma supports the increase in age limit as this is consistent with a smoother transition to the full NDIS scheme if needed, and increased opportunity for better therapeutic outcomes and lifelong trajectories for children.

Recommendation 15. Use Section 25 to make decisions around access to the NDIS for all young children

Aruma supports the use of Section 25 with the addition of the inclusion of social and emotional development and the removal of the need for a formal diagnosis at the age of 7 years.

Recommendation 16: Increase Early Childhood partner capacity and flexibility to tailor the level of support provided to families to implement a child’s plan and more quickly connect to the right supports and services.

Aruma supports this recommendation as we have seen delays in families understanding how to implement their child's plan.

Increased flexibility around “conflict of interest” guidelines for EC partners, so that they can more actively assist families to connect initially with ECEI providers who have a Key Worker model, would also bring benefits to the child accessing additional community and other local support services in a more timely way.

Recommendation 17: Introduce a ‘capacity building support in natural settings’ item in the NDIS Price Guide to encourage families and early childhood providers to prioritise supports delivered at home or other natural settings.

Aruma agrees that this supports best practice in the delivery of ECEI supports.

Funding for Key Worker and Therapist travel will need to be included in children's ECEI plans to ensure that the good intent of this recommendation is able to be operationalized.

Recommendation 18: Publish new guidance about what is considered ‘reasonable and necessary’ when making decisions around support for children on the autism spectrum, based on evidence found in the Autism Cooperative Research Centre (CRC) 2020 report.

Evidence based practice should always underpin decision making for children with a disability.

This should not only include decisions for children on the autism spectrum but should also utilise research for children with other disabilities wherever possible; for example, Cerebral Palsy or Foetal Alcohol Syndrome Disorder (FASD).

Recommendation 19: Empower Early Childhood partners to provide families with clear advice about the best providers for their child and situation so families can make more informed choices.

Increased flexibility around "conflict of interest" guidelines for EC partners, so that they can more actively assist families to connect initially with ECEI providers who have a Key Worker model would bring efficiencies and better outcomes for children

A form of accreditation for ECEI Providers would also assist EC Partners to be able to advise on the quality of providers in the area.

Recommendation 20: Undertake further ongoing research and study on the outcomes of young children after receiving early intervention support, to inform future policy and operational changes.

Further research is always welcome on the benefits of early childhood early intervention support. This is vital to inform the work of ECEI Providers and to inform governments in their development of policy and operational changes

Recommendation 21: Improve the existing annual progress review process for young children, to support families to celebrate the achievement of reaching their goals and outcomes and transition out of NDIS supports to the next stage of their lives.

The plan review process can be stressful for families, particularly families with vulnerabilities.

Reviews should be a celebration of achievement of children achieving goals. Goals need to be achievable for the time frame to set the child up for success.

It is our experience that the goals originally set are too broad and often unachievable for just a 12-month period.

Plan reviews happen frequently at the 9 or 10 month point as EC partners try to balance their workload.

It is suggested that goals be modified for review after the 9-month period, so successes can be celebrated.

Recommendations to extend adult NDIS plans to five years with check-ins during that time, could also be reflected in an extension of the timeframe for children's ECEI plans to two years. This will increase stability and flexibility for families to achieve goals.

An annual check-in by the EC partner to celebrate achievements and ensure progress and then the more formal plan review at the end of 24 months is another suggested option.

Recommendation 22: Ensure providers are using the recently introduced 'provider outcomes report', as a mandatory measure to evaluate the effectiveness of their supports and services.

The ECEI provider outcomes report is one of many tools in measuring effectiveness of supports and services and should remain voluntary.

The report is a collaboration between providers of supports which can lead to delays in responses for report provision based on each service providers responsiveness and capacity.

A holistic approach with multiple measures is suggested to inform progress.

Recommendation 23: Offer families of young children a 'transition out' plan for up to 3 months' duration, to support them to transition to the next stage of their lives, if they are no longer eligible for the NDIS.

Aruma ECEI Providers supports the concept of a 'transition out' plan.

It is suggested that the timeframe should be 6 months for providers to support the transition process adequately and for families to have the time to navigate to mainstream services for their child if required.