



**Association for
Children with a
Disability**

Submission

Association for Children with Disability

Supporting young children and families
to reach their potential

February 2021

ACD is the leading advocacy service for children with disability and their families in Victoria. We are a not-for-profit organisation led by, and for, families of children with disability.

Our vision is that children with disability and their families have the same rights and opportunities as all children and families.

Since the rollout of the NDIS we have supported more than a thousand Victorian families with young children to understand and access the NDIS with confidence. Their experiences inform this submission.

Not only was I struggling with having three young children, but also the medical maze, the Centrelink maze and the NDIS maze.

Children do best when families are supported

The ECEI Reset and the recommendations in the consultation paper have been long awaited. A distinct approach to Early Childhood is an integral part of the NDIS, but there is consensus that it needs significant changes to deliver best practice support to children and families.

We have responded to each of the recommendations. But first, we want to highlight four key areas:

1. Put family centred practice at the heart of the Early Childhood approach

Family centred practice is at the core of the National Guidelines for Best Practice in Early Intervention. Children do best when families have the capacity and confidence to support their child's development.

Early intervention doesn't happen in a once a week session between a child and a therapist, it happens at home every day with siblings and families.

A child's access to family centred practice cannot be dependent on their family knowing what best practice looks like, nor on assuming all service providers are offering best practice.

Recommendation

To ensure this reform delivers better outcomes for children with disability, family centred practice needs to be built into the DNA of the Early Childhood approach and be reflected across:

- NDIS rules
- Early Childhood operating guidelines
- Workforce
- Plan structures and the price guide
- Planning meetings
- Registration of service providers
- Providing families with information about best practice and quality service providers

2. Provide families with access to supports in the home and other forms of respite

The 2019 Tune Review made recommendations, which were accepted by the Australian Government, to amend the NDIS rules to recognise the additional informal supports provided by families. The Tune Review also recognised the need to provide families with access to supports in the home and other forms of respite.

The current recommendations do not mention supports in the home, respite care nor parental responsibility. This is a significant omission and a major concern for families.

The Early Childhood Approach must look at the family support needs as a whole. Families with young children with disability generally provide much great levels of care, supervision and support to their children compared with families of non-disabled children of the same age.

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The importance and benefit of families getting regular breaks, as well as support for families to participate in paid work, is widely accepted and has a positive impact on both child and family.

Recommendations

- Amend the NDIS rules to recognise the additional informal supports provided by families and provide families with access to supports in the home and other forms of respite.
- Embed support for families to have regular breaks, including support to care for all the children in the family and participate in paid work in the Early Childhood Operating Guidelines.
- Publish clear and publicly available guidelines in relation to Parental Responsibility. Parental responsibility is regularly used as a reason not to fund support, especially in the early years. There must be a consultation process as part of the development of these guidelines.

3. Need for independent information and advocacy

During the early years families with children with disability are navigating the complexity of the NDIS as well as medical services, early childhood education and Centrelink.

Independent information and access to support which builds the capacity of families to self-advocate for their child are critical.

This needs to be provided by child focus organisations that are separate from Early Childhood partners and service providers.

Recommendation

- Ensure child focused disability advocacy organisations are funded to help families navigate the NDIS, provide independent information and self-advocacy support to families.

4. Establish an Early Childhood Reference Group

Young children make up 16% of NDIS participants and will continue to be the biggest entry point into the future.

The ECEI reset is a major reform that needs ongoing consultation and oversight to ensure it delivers best practice support to children and families.

Currently there are no child focused reference group as part of the NDIA governance structure.

Recommendation

- Establish an Early Childhood Reference Group to ensure the ECEI reset is implemented in a way that delivers best practice support to children and families. This group should have representation from experts, service providers, families and advocates.

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#	Recommendation	ACD response
1	Explain, rename and promote the NDIS Early Childhood Approach.	<p>Having a clear brand for the Early Childhood approach is a good idea.</p> <p>We don't believe the NDIS Early Childhood Approach is the optimal brand.</p> <p>The branding and messaging of the Early Childhood Approach needs to incorporate the evidence from the Parenting Research Centre. While this research relates to how to talk about parenting, the principles are applicable.</p> <p>https://www.parentingrc.org.au/programs/reframing-parenting/</p>
2	Clearly and consistently, communicate the intent of the new Early Childhood approach and support for best practice.	<p>This recommendation needs to go further.</p> <p>The best outcomes for children result from family centred practice, building the capacity of families and supporting families and children to participate at home and in community settings.</p> <p>A child's access to family centred practice cannot be dependent on their family knowing what best practice looks like, nor on assuming all service providers are offering best practice.</p> <p>This recommendation needs to go beyond communicating best practice and instead build the principles of family centred practice into the Early Childhood Approach, including:</p> <ul style="list-style-type: none"> • NDIS rules • Early Childhood operating guidelines • Workforce • Plan structures and the price guide • Planning meetings • Registration of service providers • Providing families with information about best practice and quality service providers
3	Develop and publish new Early Childhood-specific Operating Guidelines.	<p>We have been calling for this for some time.</p> <p>Early Childhood Operating Guidelines are essential.</p> <p>We would expect to see the Operating Guidelines reflect the National Guidelines for Best Practice in Early Childhood Intervention as well as the National Early Years Learning Framework.</p>

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		<p>The Early Childhood Operating Guidelines also need to recognise the importance of providing families with access to supports in the home, other forms of respite and support to be able to participate in paid work.</p> <p>In addition, clear and publicly available guidelines are needed in relation to <i>Parental Responsibility</i>.</p> <p>Parental responsibility is regularly used as a reason not to fund support, especially in the early years.</p> <p>There must be a consultation process as part of the development of these guidelines.</p>
4	<p>Create a distinct delegate/planner workforce that is exclusively focused on young children and their families, to improve the way families are supported.</p>	<p>This is essential to good outcomes for children and families.</p> <p>The child focused workforce must have relevant child focused qualifications.</p>
5	<p>Continue to work with federal, state and territory governments to identify gaps and strengthen the role of mainstream services, so all young children receive support from the appropriate system when they need it.</p>	<p>This is an important recommendation and critical to children with disability being able to access mainstream services.</p> <p>Families regularly raise with us the lack of accessible and inclusive childcare. Child care services either don't know about the Australian Government Inclusion Support Program or tell families it is too time consuming to support children with disability.</p> <p>In addition, local government is a major provider of mainstream early childhood services. Most local governments have a long way to go to ensure their child and youth services are accessible and inclusive of children with disability.</p> <p>ACD have developed an Action Plan for Local Government https://www.acd.org.au/wp-content/uploads/2020/09/ACD-Local-Government-Action-Plan_accessible.pdf</p>

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6	Consider a range of mechanisms that will enhance compliance of providers with the NDIS Practice Standards on Early Childhood Supports and increase awareness by families of providers that adopt that best practice framework.	<p>We want to ensure children and families can access quality services that are delivering a family centred approach.</p> <p>We would like to see the NDIS Quality and Safeguarding Commission Early Childhood Supports Module to reflect more closely the National Guidelines for Best Practice in Early Childhood Intervention.</p> <p>We support the recommendation that families are required to use registered providers. However, we are concerned about the implications for thin markets and would want this to be a staged roll out with consideration of urban growth corridors, regional and remote areas.</p> <p>To increase the capacity of families to choose quality services, we recommend integrating this into existing Australian Government communication channels which empower families in their choices</p> <p>https://www.startingblocks.gov.au/</p> <p>Utilising the Starting Blocks communication channels as a platform to search for registered providers would demonstrate how the NDIS Early Childhood approach sits alongside mainstream early years services.</p> <p>It is also a much more accessible and user-friendly approach compared with the current list of registered service providers on the NDIS website.</p>
7	Improve sector wide understanding of how to identify families and young children experiencing disadvantage or vulnerability and tailor culturally appropriate services and resources so they can benefit from early interventions support.	<p>It is essential that universal services such as Early Parenting Centres, Child and Family services and Maternal Child Health Nurses have the knowledge, skills and confidence to support families to navigate the NDIS Early Childhood Approach.</p> <p>This is dependent upon ongoing professional development of the child and family sector.</p> <p>In Victoria over the past 18-months ACD in partnership with the Centre for Excellence in Child and Family Welfare has trained more than 1,700 child and family practitioners in how the NDIS can support families at risk.</p> <p>This has resulted in children and families in vulnerable situations being better supported as they navigate the NDIS.</p>

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8	Implement tailored methods of delivering supports for young children and their families living in remote and very remote areas to strengthen access to services.	<p>This is critical so children and families living in these communities can assess supports.</p> <p>Tailored approaches must be developed in a co-design approach that considers cultural safety, workforce availability and access to technology.</p>
9	Implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions.	<p>We support Independent Assessments being an option for accessing the Early Childhood approach.</p> <p>We agree this should sit with the Early Childhood partner.</p> <p>We support this option so that children can access support quicker. While NDIS timeframes for access and Plan approval are now quite quick, many children are on waiting lists to get reports and assessments to support their access request. For those who cannot afford private therapists this can be a long wait.</p> <p>For those who choose Independent Assessments we would want to see:</p> <ul style="list-style-type: none"> • Preparation and support for families. Assessments of young children often involved a long list of survey questions that families must answer. Many families focus on the positive and what their child can do, not knowing they need to highlight what the child can't do without support. • Independent Assessment outcomes should have the capacity to be reviewed and appealed. • The option to reapply even if an initial Independent Assessment does not meet the access requirements. This is critical as the developmental progress in young children can be unpredictable. If there is a change in how a child is tracking against developmental milestones they must be able to reapply. <p>While we support Independent Assessments as an option to meet access, we want to ensure there are no unnecessary steps for young children with an identified disability (even if there is no diagnosis due to it being a rare condition).</p>

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		<p>These children need access to the Early Childhood Approach on the basis of existing specialist medical reports. They also need confirmation as soon as possible that they will meet access to the NDIS at 9 years old and that no additional steps will be required.</p> <p>We do not support Independent Assessments to determine the scope of the Plan or to be a requirement of Plan Reviews.</p> <p>An Early Childhood Plan should be informed by:</p> <ul style="list-style-type: none"> • Information from assessments.* • Supplementary information from medical specialists or other therapists. • Goals of the child and family. • Context of the child and family. <p>*Assessments for Plan Reviews should be undertaken by service providers the child knows and trusts. Best practice is to incorporate assessments into capacity building therapy sessions.</p> <p>The Plan Review should accept assessments that are undertaken to support applications for school-based support to reduce duplication and over assessment of children.</p> <p>It is important that when service providers undertake assessments with children that the assessment accurately reflects the role of existing supports in enabling the child to meet their current developmental milestones.</p>
10	<p>Increase Early Childhood partner capacity to identify and help young children and families from hard-to-reach communities or those experiencing disadvantage or vulnerability, so they can connect to – and benefit from – early intervention supports.</p>	<p>This is essential to ensure the NDIS is accessible to all children who need it.</p> <p>Connecting with children from hard to reach communities is an ongoing process that needs to be funded and developed through a co-design approach.</p> <p>Fund child focused Aboriginal Controlled Organisations that have the relationships and knowledge to inform this work.</p> <p>To ensure children who are in contact with child and families services or child protection get the benefit of early intervention this workforce needs to understand and be confident about the NDIS Early Childhood Approach.</p>

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		<p>In Victoria over the past 18-months ACD in partnership with the Centre for Excellence in Child and Family Welfare have trained more than 1,700 Victorian child and family practitioners in how the NDIS can support families at risk.</p> <p>This has resulted in children and families in vulnerable situations being better supported as they navigate the NDIS.</p>
11	Increase Early Childhood partner capacity to connect families and young children to local support networks and services in their community.	<p>We support this as an important way to help families navigate the early years and find out what supports and services are available in their local community.</p> <p>Connecting to supports and services takes time. We would want to see Early Childhood partners connecting families with a range of services, including:</p> <ul style="list-style-type: none"> • Accessible and inclusive child care • Financial support for families with children with disability • Counselling and mental health support for families • Peer support networks for families • Advocacy for children with disability • Parenting programs such as Triple P • Playgroups and story time groups
12	Increase Early Childhood partner capacity to provide Short Term Early Intervention (STEI) support to eligible young children and families for longer.	<p>We support this as a way to help more children and families get support quicker. It can also give families time to understand what support can look like and to learn about best practice in action.</p> <p>However, there needs to be a transparent process to access a tailored individual plan if needed.</p> <p>This process needs to include the opportunity to reapply if there is a change in how a child is tracking against developmental milestones.</p>
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.	We will comment once we have the guidance.

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14	Increase the age limit for children supported under the Early Childhood Approach from 'under 7' to 'under 9' years of age, to help children and families receive family centred support throughout the transition to primary school.	<p>We absolutely agree with raising the age to under 9.</p> <p>We would like the language to reflect the early years sector and refer to children aged 0 to 8.</p> <p>Given one reason for lifting the age is to support transition to school it is important to look at other ways school transition can be improved.</p> <p>We would like to see dedicated support to assist families with the process and preparation to help their child start school. For example: a dedicated line item "Starting school support".</p> <p>This would help families to navigate the enrolment process, especially given the prevalence of gatekeeping, whereby mainstream schools inform families their child would do better at another school or in a special school setting.</p> <p>It would also help families to understand what support can be provided at school and how to work with the school to get the right support in place.</p>
15	Use the early intervention criteria, under Section 25 of the NDIS Act (2013) to make decisions around access to the NDIS for all young children.	<p>We want to see more information about what this would mean for children with an identified disability (even if there is no diagnosis due to it being a rare condition).</p> <p>Children with an identified disability need access to the Early Childhood Approach on the basis of existing specialist medical reports.</p> <p>Children with an identified disability must be able to access early intervention as infants, before developmental delays are apparent.</p>
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.	<p>We support this recommendation.</p> <p>Implementing a Plan takes considerable time and effort by families and is an enormous learning curve.</p> <p>Some families will need Support Coordination in the early years to get the supports in place. There needs to be the flexibility for Early Childhood partners to add Support Coordination if a family is struggling to implement a Plan.</p>

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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.	<p>We support this recommendation.</p> <p>But for it to be effective it needs to be implemented alongside recommendations that embed family centred practice into all aspects of the Early Childhood Approach, including:</p> <ul style="list-style-type: none"> • NDIS rules • Early Childhood operating guidelines • Workforce • Plan structures and the price guide • Planning meetings • Registration of service providers • Providing families with information about best practice and quality service providers
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.	We will comment once we have seen the guidelines.
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.	<p>We support this as an important way to help families navigate the early years and what supports and services are available in their local community.</p> <p>Including registered service providers on the Australian Government Starting Blocks communication channels would provide Early Childhood Partners with tools they can support families to use.</p> <p>https://www.startingblocks.gov.au/</p> <p>Advice and support on how to implement a Plan, use the portal and self-manage funds are also critical.</p> <p>There is information available but families need to know how to find it and to have someone to ask if they have questions.</p>

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#	Recommendation	ACD response
		<p>It is essential for families to have an independent source of information separate to the Early Childhood Partners and service providers. Advocates and information services such as ACD, Amaze and the Raising Children Network play a critical role.</p> <p>https://www.acd.org.au/</p> <p>https://www.amaze.org.au/autismconnect/</p> <p>https://raisingchildren.net.au/disability</p>
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.	<p>We fully support this recommendation.</p> <p>We want to highlight the specific need for ongoing research around how building the capacity of families supports outcomes for young children.</p>
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.	<p>Celebrating a child’s achievements at a Plan Review meeting and looking at how the whole family is going is an important part of the review process.</p> <p>For children who are part of the Early Childhood Approach there are broadly three groups:</p> <ul style="list-style-type: none"> • Children with identified disabilities who will receive NDIS support for life • Children whose support needs continue to evolve • Children who are likely not to meet the eligibility criteria for the NDIS once they are 9 years old <p>During the early years it can be difficult to predict a child’s developmental pathway. It is important to be open with families about how their child is progressing, understanding that during the early years it may not be clear what support will be needed in the future.</p>
22	Ensure providers are using the recently introduced ‘provider outcomes report’, as a mandatory measure to evaluate the effectiveness of their supports and services.	<p>We agree with requiring service providers to use a standardised Provider Outcomes Report.</p> <p>However, families who are using the current version have reported that they find it long and repetitive.</p>

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#	Recommendation	ACD response
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.	For children who are no long eligible for the NDIS this is an important step and needs to focus on linking children and families to mainstream services.

For more information contact:

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