

# **Improving the NDIS for children with disability**

## **CYDA Submission to the *Supporting young children and their families early, to reach their full potential* consultation paper**

**Children and Young People with Disability Australia**

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Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

**This submission has been endorsed by:**



Australian Federation of  
Disability Organisations



**Inclusion Australia**



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## Recommendations

### **Recommendations to ensure Short Term Early Intervention (STEI) approaches are guided by need, not as a measure to drive down participant numbers**

- Do not limit the length of STEI duration and the transition to the mainstream supports, this should be determined on individual need
- Further consult on which organisations are best qualified to deliver STEI so more children are receiving quality and timely support when needed
- Develop a service model for STEI
- Ensure procedures and practice are based on children's needs and not actuarial estimates

### **Recommendations to improve the governance and contracting for better outcomes for children with disability**

- Improve the oversight and operation of Early Childhood Partners contractual obligations and KPIs to reflect the importance of capacity building, service navigation and community linkages work
- Provide transparent information on participants (and their families/caregivers) experiences of Early Childhood Partners for service improvement

### **Recommendations to get the interfaces between the NDIS and mainstream services and other systems right**

- Ensure the Early Childhood Approach has a specific focus on promoting inclusive education
- The National Disability Strategy, develop a clear strategy that outlines actions and responsibilities between the NDIA and other services systems and jurisdictions
- The strategy should include clear responsibilities of the NDIA and Partners in the Community to build the capacity of mainstream services across regions

### **Recommendations to include disability representative organisations, children and young people and their families in redeveloping the NDIS**

- Ensure families and caregivers are meaningfully included in the development and implementation strategies of the Early Childhood-specific Operating Guidelines
- Ensure families and caregivers are meaningfully included in the development of information provision, sector awareness and outreach activities.
- Engage with representative organisations and community leaders to ensure the inclusion of families and caregivers in service improvement and development activities is done in a safe, genuine and appropriate manner

## **Recommendations to consider the appropriateness of Independent Assessments for young children**

- Commission an independent and rigorous research and evaluation into independent assessments of children, including any possible risks or unintended consequences. Publish and listen to the findings.
- Consider and respond to the serious concerns being raised by families and caregivers of children and representative organisations about the proposed changes.
- Provide genuine consultation and engagement mechanisms for families and caregivers, to learn about the Agency's proposed changes and provide feedback.
- Plan and implement any large changes to ECEI and the NDIS through a meaningful co-design process with family and caregivers of children with disability.
- Work with families and caregivers and representative organisations to design and trial evidence-informed approaches to addressing existing inequities.

## Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

- Driving inclusion
- Creating equitable life pathways and opportunities
- Leading change in community attitudes and aspirations
- Supporting young people to take control
- Calling out discrimination, abuse, and neglect.

This submission is in response to the proposed changes as outlined in the *Supporting young children and their families early, to reach their full potential*<sup>1</sup> consultation paper. CYDA has worked closely with the National Disability Insurance Agency (NDIA) in identifying areas for improvement in the Early Childhood Early Intervention (ECEI) Implementation Reset Project<sup>2</sup>, and welcomes the opportunity to continue to contribute and collaborate. We have provided a separate submission in response to the *Access and eligibility policy with independent assessments* and *Planning policy for personalised budgets and plan flexibility* consultation papers.

The early years of a child's development can impact their entire lives. This is why it is so important that they receive the supports they need, when they need them, so they have every opportunity to thrive now and as they transition into middle childhood and beyond.

Some of the changes proposed in the ECEI consultation paper are welcome initiatives that, if implemented with appropriate consultation, should improve the NDIS and assist young children with disability to receive appropriate and timely support and their families and caregivers experience family-centred practice. However, many areas outlined in the consultation paper lack clarity and depth about what the changes would entail in practice. In other instances, the paper outlines recommendations that risk being too rigid, such as the short and limited timeframe children have to 'transition out' of receiving supports through the NDIS and need to be expanded to ensure all children are supported both in the ECEI service and beyond.

CYDA's submission provides general feedback on the ECEI consultation paper as a whole – as well as targeted feedback on how some of the recommendations could be expanded, clearer or best implemented.

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<sup>1</sup> Referred to as the ECEI consultation paper in the submission

<sup>2</sup> NDIA. (2020) Early Childhood Early Intervention (ECEI) Implementation Reset: Project Consultation Report. Available at <https://www.ndis.gov.au/media/2892/download>

## Improve the NDIS for children with disability so they have a great start in life

Children and young people aged up to 25 make up the largest proportion of all NDIS participants (57 per cent). However, the NDIS was borne out of a movement which had a focus on adults with disability, and hence other than the Early Childhood Early Intervention (ECEI) 'pathway' there has not been a focus on what supports children and young people as they grow and develop.

We welcome the attention, consultation and work that has gone into the ECEI reset project and the subsequent consultation report *Supporting young children and their families early, to reach their full potential*.

In our submission to the Tune Review<sup>3</sup>, we noted the NDIS was not designed for children and there is a lack of family-centred practice. We noted the NDIS considers children and young people in isolation from their families despite extensive research which shows the development and wellbeing of children and young people is facilitated through supportive home learning and support environments. We noted the push to medicalise the supports rather than consider the natural environments and supports in the community which promote the wellbeing and development of children and young people.

We recognise the particular intersectional discrimination and barriers to access that many First Nations children with disability face. Additionally children from culturally and linguistically diverse families and those from low socio-economic backgrounds face particular challenges with the NDIS. The consultation paper does not sufficiently address these challenges with the new Early Childhood Approach and more must be done in consultation with disability representative/persons organisations for these cohorts.

There are many elements stated in the consultation paper including in the future state of the Early Childhood approach<sup>4</sup> that align with CYDA recommendations for the future state of the NDIS for young children. However, like all overarching principles, in moving from current state to future state, the 'devil is in the detail'.

Therefore, in this submission we highlight areas where there is further consultation and work needed to improve the NDIS for children with disability.

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<sup>3</sup> Children and Young People with Disability Australia. (2019). Improving the NDIS for children and young people with disability and their families, Submission to the Tune Review <https://www.cyda.org.au/resources/details/66/improving-the-ndis-for-children-and-young-people-with-disability-and-their-families>

<sup>4</sup> NDIA (2020) Supporting young children and their families early, to reach their full potential Consultation Paper, p.10.

## Ensure Short Term Early Intervention (STEI) approaches are guided by need, not as a measure to drive down participant numbers

### Recommendations

- Do not limit the length of STEI duration and the transition to the mainstream supports, this should be determined on individual need
- Further consult on which organisations are best qualified to deliver STEI so more children are receiving quality and timely support when needed
- Develop a service model for STEI
- Ensure procedures and practice are based on children's needs and not actuarial estimates

Delivering early support to children and their families to support their development, without having to jump through hoops, can only be a good thing. We often hear from families and caregivers in the community about the difficulties they face in accessing appropriate supports for their child in a timely manner. STEI interventions may help address this. CYDA also endorses the shift toward the NDIS building on the strengths of the child and their family, and the prioritisation of supporting children in their natural environments, such as in their home, early-education setting and in school.

Should the Early Childhood approach age be moved to up to 9 years of age, it should also be acknowledged that children may need to access STEI at various times during this period of development and growth. Therefore, STEI may not be a one off, but may be needed at various transition points.

Who delivers STEI should also be considered. CYDA members report variable experiences with Early Childhood Partners in the Community. For example, in our recent 2021 NDIS survey, 85 per cent of respondents (n=63) who had accessed the ECEI said they had experienced challenges with the planning process (delivered by ECEI partners). Common comments were that planners lacked knowledge about disability or were not sufficiently qualified to work with children with disability and their families and caregivers.

Comments from parents and caregivers with disability on barriers experienced in the planning process.

*'Felt like as a parent was expected to know and understand my son's recently diagnosed rare genetic condition and to know and understand what supports he needs. There was little support in helping us understand his needs to identify what support he should receive. The medical team just handballed us to NDIS and then in that system we are assumed to be the expert, when we are really just learning ourselves how it all works and should work.'*

*"It can be difficult for some planners to understand the complex challenges our son lives with and the unique needs that he has in his everyday life."*

*"The questions seem to be more related to mobility rather than autism or mental health. Can my child dress himself? Yes, BUT he may have had a meltdown because he didn't like the texture of the t shirt he was wearing or didn't want to wear anything at all. So the 30 min[ute] conversation before and meltdown after is not discussed or considered. It is not strengths based. It's hard to discuss your children in the negative. Once the plan is*



*received, there is no support to gets supports in place. No one explained [the] price guide [and] we didn't qualify for a support coordinator. It broke me."*

*"ECEI partners don't understand enough about the condition or impact on our family."*

*"Planners don't listen. Don't read reports. Don't believe specialists. Don't help us, they work against us. It's stressful and harmful to us and our [person with disability]."*

The consultation paper provides insufficient detail about the funding and operation of STEI, and there needs to be greater consultation and consideration of who is best placed to deliver STEI. This support could be invested in local community agencies to assist families on the ground to navigate and access complex service systems and to work with mainstream and community services to ensure they are fully inclusive.

Additionally, a service model for STEI, including a program logic and workforce capabilities is required, in consultation with disability representative organisations, academics and families. This service model would describe evidence informed approaches and help inform families understand the benefits of full inclusion in mainstream and community services.

It is also critical not to assume that STEIs will always be enough for many children before transitioning to the mainstream service system. While fundamentally mainstream services should be able to offer universal services and appropriate supports for all children – disability or not – the reality is they don't. First Nations children and their families, those from culturally and linguistically diverse background and those from low socio economic backgrounds face particular challenges in accessing mainstream services. This is not because of their backgrounds, but because that mainstream services tend not to struggle with engaging and being fully inclusive of diversity.

A recent report released by the Productivity Commission<sup>5</sup> reviewing government services found that more than one in four (27.7 per cent) people with disability avoid using mainstream services because of their disability. Similarly, data indicates that health services – which are assumed to play a large role in the ECEI reset – are not fully accessible or appropriate for diverse needs, with 12 per cent of people with disability avoiding medical facilities<sup>6</sup> because of their disability.<sup>7</sup>

CYDA's own research has demonstrated how mainstream education settings are not appropriately supporting the learning and social needs of students with disability. The results from our 2019 National Education Survey, *Time for change: The state of play for inclusion of students with disability*<sup>8</sup>, found that nearly half (48.7 per cent) of respondents believe that students with disability do not receive adequate support in their education. The survey also found that more than half of families (57.2 per cent) had paid personally for specific supports or equipment to enable access to, and participation in, education for their child. This includes purchasing of specific aids and equipment and accessing allied health supports.

While in theory some children should only need disability-related supports early in life, because of the inadequacies of the mainstream service systems, families may realistically need to rely on

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<sup>5</sup> Productivity Commission. (2021). *Report on Government Services 2021: Disability Services*. Available at [Section 15 Services for people with disability \(pc.gov.au\)](#)

<sup>6</sup> At least once in a 12 month period

<sup>7</sup> AIHW. (2020). *Health of people with disability*. Available at [Health of people with disability - Australian Institute of Health and Welfare \(aihw.gov.au\)](#)

<sup>8</sup> Children and Young People with Disability Australia. (2019). *Time for change: The state of play for inclusion of students with disability*. Available at [time for change 2019 education survey results.pdf \(cyda.org.au\)](#)

disability-related services, such as the NDIS, for longer to ensure their child is getting the support they need and have a right to. Similarly, if a child were to transition out of the NDIS to mainstream supports, the length of time that it takes should be based on individual and family need, rather than arbitrary time limits.<sup>9</sup>

CYDA also cautions against the overuse or rigidity around of estimates and projection of who 'should' and 'shouldn't be' receiving NDIS funded supports beyond the initial STEIs, as these figures likely do not factor in the complexities and barriers that children and their families and caregivers face in mainstream settings. This is of particular concern when families do not have the means or safety net to personally purchase their own supports when government systems are failing them.

Channelling children into STEI's to reduce the number of funded participants is a risk that should be avoided, as many children needing STEI, will also require additional disability supports. This would also undermine the insurance principle of investing early to enhance lifelong outcomes, which is particularly important for children, based on this unique window of time development which is well articulated in child development research.

## **Improve the governance and contracting for better outcomes for children with disability**

### **Recommendations**

- Improve the oversight and operation of Early Childhood Partners contractual obligations and KPIs to reflect the importance of capacity building, service navigation and community linkages work
- Provide transparent information on participants (and their families/caregivers) experiences of Early Childhood Partners for service improvement

The recommendations proposed in the ECEI consultation paper will bring about some welcome change and help address existing inequities, particularly the change in Early Childhood Partner functions and the increased focus on outreach, information provision, service navigation work and community linkages. These service offerings have long been advocated for by CYDA, the disability sector, and the community and will help see the NDIS live up to its potential.

However, good intentions will not result in actual change unless the governance and contracting of Early Childhood services prioritise these service offerings. This has been demonstrated in the Local Area Coordinator service model, where community capacity building functions largely remain unrealised. The emphasis on planning outputs as Key Performance Indicators has likely contributed to this shift in service provision away from the original design.

Contracting obligations of Early Childhood Partners must reflect the importance of personalised supports, otherwise organisations may be disincentivised to do this type of work, and instead focus on work that is formally recognised. It must also be acknowledged in governance structures and reflected in caseloads that the type of work and supports as outlined in the ECEI consultation paper can be more time intensive for EC Coordinators.

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<sup>9</sup> Such as the 'up to 3 month transition' period outlined in the ECEI consultation paper

## Get the interfaces between the NDIS and mainstream services and other systems right

### Recommendations

- Ensure the Early Childhood Approach has a specific focus on promoting inclusive education
- The National Disability Strategy, develop a clear strategy that outlines actions and responsibilities between the NDIA and other services systems and jurisdictions
- The strategy should include clear responsibilities of the NDIA and Partners in the Community to build the capacity of mainstream services across regions

Many mainstream services are currently not providing safe and inclusive services for children with disability. CYDA rejects the ECEI consultation paper's recommendation to merely *continue* to work with federal, state and territory governments to identify gaps and strengthen the role of mainstream services – but rather recommends the development a clear strategy that outlines objectives, actional plans and activities, clear accountabilities, and mechanisms to measure and report on outcomes.

This includes early childhood education and schools, that continue to provide non-inclusive environments for children with disability and child protection systems, where there is a paucity of data on the outcomes for the NDIS in improving the lives of children who have been harmed or at risk of harm. It needs to go beyond delineating responsibilities or which system funds what.

The overarching goal of the NDIS for young children must be full inclusion in the community and mainstream services, yet accountability and monitoring for this is essential. The opportunity of raising the age of the Early Childhood Approach to nine years, covering the important transition to school period, is substantial. But the consultation paper is largely silent on this.

As outlined in the Australian Coalition for Inclusive Education's 2020 paper,<sup>10</sup> *Driving change: A roadmap for achieving inclusive education in Australia*,<sup>11</sup> we note a transformation in education is needed to ensure Australia complies with the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

All Australian children must be welcomed and supported at their local school and provided with a high-quality inclusive education. Sadly, for too many children and young people with disability, this is not the case. They are segregated in special schools and special classrooms, not included with their peers, but decades of research tell us inclusive education will lead to better outcomes<sup>12</sup>. Therefore, the NDIS needs to be a vehicle for ensuring inclusive education.

The NDIA must work closely with the Department of Social Services and the National Disability Strategy to strengthen and improve the interfaces between the NDIS and different service systems and jurisdictions. This includes a clear and measurable activities of the NDIA and Partners in the Community to build the capacity of mainstream services in communities.

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<sup>10</sup> CYDA is the chair and co-founder of the Australian Coalition for Inclusive Education.

<sup>11</sup> Australian Coalition for Inclusive Education (2021) *Driving change: A roadmap for achieving inclusive education in Australia* available at <https://acie105204494.files.wordpress.com/2021/02/acie-roadmap-final-11-feb-2021.pdf>

<sup>12</sup> Cologon, K. (2019) *Towards inclusive education: A necessary process of transformation*. Report written by Dr Kathy Cologon, Macquarie University for Children and Young People with Disability Australia (CYDA) available at [https://www.cyda.org.au/images/pdf/towards\\_inclusive\\_education\\_a\\_necessary\\_transformation.pdf](https://www.cyda.org.au/images/pdf/towards_inclusive_education_a_necessary_transformation.pdf)

A clear strategy and accountability are also required as an issue of safety. At a governance level, research has identified that there is a lack of clarity around the boundaries of the NDIS and how it interfaces with different services and systems, including education, health, justice, and child protection.<sup>13</sup> This results in systems ‘passing the buck’ on who is most responsible for providing supports and care. This not only creates increased stress and added time and administrative burden for children, their families and caregivers, but it also risks individuals falling through the gaps between systems.

## **Include disability representative organisations, children and young people and their families in redeveloping the NDIS**

### **Recommendations**

- Ensure families and caregivers are meaningfully included in the development and implementation strategies of the Early Childhood-specific Operating Guidelines
- Ensure families and caregivers are meaningfully included in the development of information provision, sector awareness and outreach activities.
- Engage with representative organisations and community leaders to ensure the inclusion of families and caregivers in service improvement and development activities is done in a safe, genuine and appropriate manner

The recommendation to develop and publish new Early Childhood-specific Operating Guidelines is strongly supported by CYDA. Because of the outsourcing nature of ECEI services, we hear from our community that the types of supports they receive differs between organisations, regions, and individual practitioners. The development of operating guidelines can help ensure that all children are receiving quality and consistent support, irrespective of where they live or which planner they happen to be delegated.

To ensure the guidelines reflect diverse strengths and needs of children; families and caregivers should be meaningfully included in the design process. Their input will be vital in ensuring that the evidence-based approaches are grounded in practical application. As families and caregivers are also an intended audience<sup>14</sup>, their insights are essential to ensure the guidelines are relevant and useable.

Other recommended strategies and plans outlined in the consultation paper, such as the communication of the early childhood approach, efforts to increase sector awareness and ensure materials are accessible to all diverse communities, and improvement of outreach activities, will also greatly benefit from being designed with safe and genuine inclusion families and caregivers – particular from communities the strategies intend to target.

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<sup>13</sup> Dickinson, H., & Carey, G. (2017). Managing care integration during the implementation of large-scale reforms: The case of the Australian National Disability Insurance Scheme. *Journal of Integrated Care*, 25(1), 6–16. <https://doi.org/10.1108/JICA-07-2016-0026>

<sup>14</sup> NDIA. (2020). *Early Childhood Early Intervention (ECEI) Implementation Reset: Project Consultation Report*. Available at <https://www.ndis.gov.au/media/2892/download>

## Ensure the NDIS has a developmental focus for children and young people with disability (up to 25 years) including young children

### Recommendations

- Develop a distinct delegate and planner workforce for young children up to age 9
- Extend the ECEI supports program to up to the age of 9
- Develop an operating framework for working with children and young people up to age 25 to ensure consistency of practice and that children and young people's social and developmental needs are appropriately considered and supported. This framework should be developed with families and carers, young people and Disability Representative Organisations to ensure it suitability.
- Accompany the NDIS framework for children and young people with workforce training and clear accountabilities

Along with these individual changes, children and young people also rapidly transition through different life stages and encounter new systems. How they experience these life transitions – and whether there are safeguards in place – then have flow-on impacts on the trajectory of their lives and the opportunities they can access.

Factoring how important and influential these early years are, services and systems must have the capacity to understand and support the distinct needs of children and young people. As such, the introduction of a distinct delegate/planner workforce for young children and the extension of the ECEI for children up to nine years old are welcomed changes. Too often we hear from our membership that despite the lived expertise of families and supportive evidence provided by experts in the field, planners have denied access or planning requests because of their ill-informed understanding of children's developmental and social needs.

Increasing the age limit for children supported by the Early Childhood approach up to age of nine will also help ensure that children are adequately supported as they transition into school – a large and critical milestone for anyone.

While positive, the proposed recommendations are only a partial solution. Children's specific developmental and social needs do end at the age of nine. Extending the ECEI age limit and only having a specialist delegate workforce for this period during a participant's NDIS journey only delays the inevitable – that children will transition into a service system that is designed for adults.

Having a one-size-fits all approach for all participants once they transition out of the ECEI program is not supported by neurodevelopmental theory and does not acknowledge the importance of middle childhood and the life transitions that occur for children and teens. The shift in the types of supports offered by the ECEI program in comparison to the adult NDIS service system can also be a harsh transition for many families.

CYDA urges the NDIA develop an operating framework for working with participants up to the age of 25. Building on the proposed Early Childhood-specific Operating Guidelines, the framework should detail best practice approaches and engagement strategies for children and young people. In line with the NDIS' intent to help promote independence, the framework should also promote capacity building in children and young people, so participants can gradually obtain new skills,

confidence and knowledge that will support them to have agency over decisions about their NDIS plan and supports.

This framework should be accompanied by workforce training for staff in the NDIS ecosystem – including Local Area Coordinators and NDIS delegates – and outline mandatory child safety obligations and clear accountabilities to ensure continuity of support across systems such as education, health and child protection. To ensure its suitability, it should be developed with young people, families, caregivers and their disability representative organisations.

## Consider the appropriateness of Independent Assessments for young children

### Recommendations

- Commission independent and rigorous research and evaluation into independent assessments of children, including any possible risks or unintended consequences. Publish and listen to the findings.
- Consider and respond to the serious concerns being raised by families and caregivers of children and representative organisations about the proposed changes.
- Provide genuine consultation and engagement mechanisms for families and caregivers, to learn about the Agency's proposed changes and provide feedback.
- Plan and implement any large changes to ECEI and the NDIS through a meaningful co-design process with family and caregivers of children with disability.
- Work with families and caregivers and representative organisations to design and trial evidence-informed approaches to addressing existing inequities.

In CYDA's submission to the proposed changes to the NDIS' access, eligibility and planning processes, we outlined deep concerns held by us and our community for introducing independent assessments for children and young people. This includes the:

- Limited and unjust powers a person has to appeal their independent assessment results
- (In)appropriateness of a person not known to you assessing your functional capacity in a short period of time
- Use of assessment tools which are designed or not-fit-for-purpose for determining support needs and plan budgets
- Lack of transparent research, consultation, and evaluation processes
- Lack of activities and time to genuinely inform the community of the proposed changes
- Workforce issues in allied health professionals delivering independent assessments in already thin markets
- Failure to address existing inequity issues in NDIS access and planning
- Risk of producing new inequities through self-reporting approaches
- Undermining of people with disability's lived-expertise, goals and aspirations.

While it is encouraging to see that the ECEI consultation paper has proposed a tailored approach to independent assessments for children, many questions and concerns for our community remain. For instance, how will individual recent reports and assessments be included, if at all, for children? Also, what rights will children and their families and caregivers have to appeal the results of independent assessments and under what circumstances will children be exempt?

Comments from parents and caregivers of children in our recent survey show the level of concern in the community about the proposed introduction of independent assessments:

*"Independent assessments make the personal care and reports my child gets from his therapists worth nothing to the NDIS, and risk that his funding won't be tailored to him. This either means we (his parents) have more work to do to advocate for him, or that there's no point in advocating to the NDIS at all. The NDIS was meant to be*

*individualised solutions for disabled Australians. Independent assessments take away that individuality.”*

*“The independent assessors are not experts in my child’s disability, her therapist and I are and they should lead her NDIS funding not a pen pusher or the wrong allied health professional.”*

*Some people may find them positive, but I worry about another business being involved in decision making, where their priority might be on numbers or outputs rather than individuals and their families. My child has been regularly assessed and reviewed since he was born, he doesn’t like assessments and often refuses to participate meaning the process needs to be broken down over a number of sessions, often taking weeks (or sometimes months) to complete.”*

*“My son has multiple and significant disabilities, including severe anxiety. He will be completely unable to participate in a functional assessment with a stranger. Even in our own home, he hides or becomes aggressive if someone he doesn’t know enters our home or tries to approach him.”*

*“An [independent assessor] cannot understand the functioning capacity of our participant in one meeting, it takes months of sessions with allied professionals to gain trust and insight to their capacity. We also don’t want to speak negatively about shortfalls of our participant in front of our participant which we would need to do, to answer the barrage of questions that will be asked by the [independent assessment] because they don’t know our participant, not to mention the anxiety levels brought on by having an [independent assessor] (stranger) in our home and the repercussions of that anxiety on our participant after they leaves.”*

*“It is stress and anxiety provoking for both the child and the parent and probably not very accurate either as this snapshot assessment will not be representative of this person’s disability and the impact this has on his/her daily life at all. Ignoring reports from allied health professionals and medical professionals who have either known your child for a long time, or who are actually experts in their medical field, sounds absolutely ridiculous to me and will only set the [person with disability] up for failure.”*

While it is not fully explored how assessment of functional capacity of a child can translate to allocation of funding, there is a strong body of work that details what best practice for assessing children entails. The Division for Early Childhood, an international membership organisation that promotes policies and advances evidence-based practices, has developed a resource highlighting the practices that have been shown to result in better outcomes for young children with disability, their families, and the people who work with them – including in assessment.



The following are recommended best-practices to guide practitioners:

1. “Practitioners work with the family to identify family preferences for assessment processes.
2. Practitioners work as a team with the family and other professionals to gather assessment information.
3. Practitioners use assessment materials and strategies that are appropriate for the child’s age and level of development and accommodate the child’s sensory, physical, communication, cultural, linguistic, social, and emotional characteristics.
4. Practitioners conduct assessments that include all areas of development and behaviour to learn about the child’s strengths, needs, preferences, and interests.
5. Practitioners conduct assessments in the child’s dominant language and in additional languages if the child is learning more than one language.
6. Practitioners use a variety of methods, including observation and interviews, to gather assessment information from multiple sources, including the child’s family and other significant individuals in the child’s life.
7. Practitioners obtain information about the child’s skills in daily activities, routines, and environments such as home, centre, and community.
8. Practitioners use clinical reasoning in addition to assessment results to identify the child’s current levels of functioning and to determine the child’s eligibility and plan for instruction.
9. Practitioners implement systematic ongoing assessment to identify learning targets, plan activities, and monitor the child’s progress to revise instruction as needed.
10. Practitioners use assessment tools with sufficient sensitivity to detect child progress, especially for the child with significant support needs.
11. Practitioners report assessment results so that they are understandable and useful to families.”

Division for Early Childhood (2014)<sup>15</sup>

As outlined above, accurate assessment is complex – with the use of assessment tools only being a small component. Further information is required to clarify whether those in the current EC workforce are qualified to do the independent assessments, or if one professional is able to do an accurate assessment alone. Then the question is – if the EC workforce is to grow so there are enough trained professionals hired by the NDIA to be able do assessments (and deliver STEIs and other supports), what impact will this have on the already thin market of allied health professionals that have the skillset to work with children and young people?

Literature also emphasises the importance of ‘authentic assessment’ of children – whereby assessment is most accurate when children’s natural behaviours are observed in their natural settings, such as their home or kindergarten.<sup>16</sup> What is essential in this type of assessment is that the child feels comfortable and is acting naturally, as they would any other day. While the proposal

<sup>15</sup> Division for Early Childhood (2014). *DEC recommended practices in early intervention/early childhood special education*. Los Angeles, California: Division for Early Childhood, Council for Exceptional Children, p.14.

<sup>16</sup> Neisworth, J.T. and Bagnato, S.J. (2004). The mismeasure of young children: the authentic assessment alternative. *Infants & Young Children*, 17(3), 198-211; Bagnato, S. J. (2005). The authentic alternative for assessment in early intervention: An emerging evidence-based practice. *Journal of Early Intervention*, 28(1), 17-22.

of Early Childhood Partners undertaking the assessment is a preferred method than a person entirely not known to the child being the assessor<sup>17</sup>, CYDA questions if all Early Childhood Partners will have established a rapport enough with each child that the child will feel comfortable in their presence to behave naturally.

Acknowledging the complexities of assessment and ensuring there is a qualified workforce to run a national assessment program to a consistent level, CYDA recommends that a rigorous research and evaluation process is conducted before any decisions or changes are made to ECEI service and access eligibility. As part of this research and evaluation, parents, caregivers and disability representative organisations and early-childhood researchers and experts must be meaningfully genuinely included. So that the community have every chance to be consulted and included in an informed manner, the NDIA must first proactively engage with the community to provide information in accessible and diverse ways.

In developing an assessment framework for all children, with all needs and strengths, across all of Australia – one approach will never work for all individuals. To ensure that assessments are equitable and appropriate, the NDIA must consider alternative options to assessment, such allowing a person’s existing health professionals to complete assessments using the same tools. These alternative options should then be guided by the child’s needs and family preferences.

### **Embed evidence-based practice for supporting children with disability and ensure the NDIS is promoting full inclusion**

#### **Recommendation**

- Develop a holistic response to pivot the NDIS to promoting full inclusion of children
- Conduct deep consultation about the development of a national quality framework for ECEI and subsequent accreditation, monitoring and reporting
- Provide clear responsibilities and guidance for Early Childhood Partners when supporting families in areas where there are thin markets

We welcome the emphasis of the consultation paper on support in ‘natural settings’ like the home, community and mainstream services like early childhood education and care and mainstream schools. This is consistent with best-practice.

However, much work will be required to ensure families and Early Childhood Partners understand the benefits of full inclusion, as opposed to medicalised, therapy models that don’t build the capacity of families to work with the child in their everyday environment and to promote full inclusion in other settings.

Additionally, there needs to be concurrent data and reporting on children’s participation in mainstream services, and accountability for systems that are non-inclusive. For example, a goal should be that more NDIS participants and those experiencing STEI are participating in early childhood education and care, and mainstream education. This requires holistic actions that go

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<sup>17</sup> As proposed for individuals aged 7 and older in *Access and eligibility policy with independent assessments* consultation paper

beyond one part of the ECEI eco-system. It requires a whole of government response supported by other players in the disability advocacy and early childhood and school eco-systems.

CYDA supports Early Childhood Partners to provide advice on best practice services, and guidance on where children, families and caregivers can engage with a service that will meet their needs and is right for them. Families who have access to support, and as such, higher capacity for system navigation, are more likely to experience positive outcomes in using the NDIS.<sup>18</sup>

However, a key consideration is how Early Childhood Partners understand best/evidence informed practice or services without a quality framework that articulates best practice. While the NDIS Quality and Safeguards Commission could be an organisation that articulates and accredits best/evidence-based services, this function is currently not part of its mandate, nor has the expertise or funding yet to undertake. A similar parallel might be drawn from the National Quality Framework for Early Childhood Education where reforms have been made for many years and which is overseen by the Australian Children's Education and Care Quality Authority to improve quality.

The consultation paper references an 'industry led' best practice accreditation system, however it is not clear who the industry is, and if it is providers there is an inherent conflict of interest. While CYDA is supportive of articulating best practice, accreditation and quality improvement, this is an area that requires substantial consultation and work.

The scope of the Early Childhood Partners' roles when there are no appropriate services available in the child's community is also unclear and unaddressed in the ECEI consultation paper. CYDA recently ran a survey asking our community if they faced any barriers in using their plan. Roughly 87 per cent of respondents had experiences at least one barrier (see Table 1). Most commonly (67 per cent), parents and caregivers struggled to find suitable services in their area. Approximately half of respondents had difficulties finding workers that are understanding and empowering, and an additional 45 per cent struggled to get supports that were appropriate for children and young people.

While advice and service navigation support are critical (as also highlighted in our survey findings, with approximately 45 per cent of respondents experiencing difficulties in finding what services and supports are available and how to access them), this does not address how children will be supported when services are not available to them. The framework for EC Coordinators that the ECEI Implementation Reset Project report suggested will be developed<sup>19</sup>, should also make clear the responsibilities of EC Coordinators to support families and caregivers to explore and implement innovative solutions in areas where there are thin markets.

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<sup>18</sup> Boaden, N., Purcal, C., Fisher, K., & Meltzer, A. (2020). Transition experience of families with young children in the Australian National Disability Insurance Scheme (NDIS), *Australian Social Work*, DOI: [10.1080/0312407X.2020.1832549](https://doi.org/10.1080/0312407X.2020.1832549)

<sup>19</sup> "Conflict of interest and other risks would be mitigated by developing a framework to provide objective and evidence based advice and to reduce claims of bias"; NDIA. (2020) *Early Childhood Early Intervention (ECEI): Implementation Reset Project Consultation Report*. Available at <https://www.ndis.gov.au/media/2892/download>

Survey comments from parents and caregivers show the significant barriers many experience implementing their child’s NDIS plan:

*“It is very challenging to find service providers in the ‘thin market’ here in Tasmania, but almost impossible to find service providers that have specialist skills and expertise.”*

*“Finding supports that are available outside of school hours. and both his parents work full time so outside of hours for us is almost impossible to find also.”*

*“Relatively few supports in our rural area, very little choice, some of them are not safe in my experience.”*

**Table 1: Respondents’ reported barriers to using their child or young person’s NDIS plan (n=183)**

<b>Barriers</b>	<b>Number</b>	<b>Percentage</b>
Finding suitable services and supports in my area	122	66.67%
Finding workers that are understanding and empowering	90	49.18%
Getting supports appropriate for children and young people	83	45.36%
Finding out what services and supports are available and how to access them	83	45.36%
Feeling safe and comfortable accessing the available supports	56	30.60%
Other	35	19.13%
Accessibility barriers	32	17.49%
I don't experience barriers to using my NDIS plan	24	13.11%
Accessing supports that are culturally appropriate	8	4.37%