



Carers Australia submission to the National Disability Insurance Agency – Consultation paper *Supporting young children and their families early, to reach their full potential*

23 February 2021

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged

Our vision is an Australia that values and supports the contribution that carers make both to the people they care for and to the community as a whole.

We believe all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Introduction

This submission is made in response to the consultation paper [Supporting young children and their families early, to reach their full potential](#). Carers Australia has responded separately to the [Access and eligibility policy with independent assessments](#) and [Planning policy for personalised budgets and plan flexibility](#) papers.

This submission has been informed by consultation with the state and territory Carer Network. Carers Australia welcomes the opportunity to engage and provide comments on these papers, and wants to work with the Australian Government, people with disability, disability representative organisations and advocates to improve the National Disability Insurance Scheme (NDIS).

This submission has also been informed by the Better Start Registration and Information Service (RIS) Network, where Carers Australia and the Carer Network have been involved in implementing the *Better Start for Children with Disability Initiative* since 2011. Better Start provided funding for early intervention services for eligible children aged between 4 and 7 years, prior to full implementation of the NDIS, with the RIS function to cease on 31 March 2021. Better Start also included delivery of 'Moving Forward' workshops for parents and guardians to learn about early childhood early intervention and options available for accessing funded ECEI supports.

Carers Australia notes these consultation papers have been developed by the National Disability Insurance Agency (NDIA) following the 2019 Independent Review of the NDIS Act 2013. DSS describes the reforms as seeking to "improve the NDIS" and "make the NDIS fairer, with better information for decision making, at less cost for participants and those applying to become participants"¹. The Australian Government has indicated it expects to release draft legislation for consultation in the first half of 2021.

Discussion

Carers Australia acknowledges the stated intention of the Early Childhood Early Intervention (ECEI) reset to deliver the "original strategic intention [...] of ensuring children and families can identify and receive best practice supports, and in particular that young children can benefit early from intervention supports"². Carers Australia also welcomes the recognition of the need to focus on the family as a whole and to support parents and carers.

Carers Australia, like other stakeholders, is concerned that the potential effects of Independent Assessments on participants' budgets (at an individual level) and funding (at a scheme level) are not transparent. Government and the NDIA need to be transparent about the modelling and parameters it is proposing to accept around potential reductions in funding that might result from the Independent Assessments.

In terms of Early Childhood, the NDIA needs to be transparent about the modelling around the number of children who might not be eligible for the NDIS following transition out of the EC approach. The NDIA needs to be transparent to the community that there are indeed sufficient mainstream supports for children (and their parents and carers) who do not graduate to the full scheme.

General questions

In response to the general questions (page 16 of the consultation paper), Carers Australia supports the increased focus on Short Term Early Intervention (STEI), and supports the proposed increase in age range for early childhood from under 7 to under 9 years of age.

¹ DSS website, accessed 5 January 2021.

² NDIA, *Supporting young children and their families early, to reach their full potential*, p. 4.
<<https://www.ndis.gov.au/community/have-your-say/supporting-young-children-and-their-families-early-reach-their-full-potential>>

However, Carers Australia emphasises the importance of a planned, well-communicated transition for children, parents and carers from ECEI to the NDIS or other mainstream and community supports. There needs to be greater clarity for Early Childhood partners about when to start talking with parents and carers about transitioning their child out of ECEI and the next steps (e.g. assessments for NDIS eligibility).

Communication and planning for transition should start at least six months before the expected end of the child's eligibility for ECEI, with consideration of:

- Connecting early with coordinators for the next stage, whether for mainstream services or Local Area Coordinators if NDIS;
- Clarifying for parents and carers the timeframes and process for supplying further information and evidence to transition to the NDIS;
- Information about whether ECEI funds can be used to pay for costs associated with obtaining that supplementary information for NDIS access and eligibility;
- Ensuring that parents and carers understand that eligibility for ECEI does not automatically make the child eligible for the NDIS, and that the NDIS is not the sole option for disability supports and services.

To help parents and carers better understand terms used by the NDIA and Early Childhood partners, the NDIA should consider how to ensure that such terms are used and explained consistently across the NDIA and NDIS workforces, including planners, delegates and Early Childhood partners. Well-trained Early Childhood partners could have an educative role, but this needs to be reinforced by consistent usage within the NDIA (noting the apparent inconsistency that can occur between 'plain English' resources and the more formal, legalistic letters issued by the NDIA).

The NDIA should work closely with parents and carers and relevant organisations, such as Carers Australia, to develop resources for promotion by organisations and on the Carer Gateway and Disability Gateway.

Government intervention, market forces and choice and control

There is a tension underlying the ECEI Reset recommendations between the objects of enabling people with disability – in this case, parents and carers – to exercise choice and control in the pursuit of their goals and planning and delivery of their supports, with the emphasis or drive toward 'best-practice' approaches. While parents and carers, and NDIS providers, should certainly be provided with information about and options for best-practice approaches, it is important that government ensure it provides options, but does not dictate, the choices and decisions of parents and carers. It should be more about empowering parents and carers with the information about safe and effective interventions than steering them to certain providers or controlling what they choose to spend funding on.

The NDIA needs to engage with providers and think about incentives for best-practice in service delivery, particularly in thin markets. If government intends to rely on market responses to deliver on choice and control, it needs to think about how in the short term at least it can steward the market/s to provide best-practice approaches, but also how it can support parents and carers to be able to exercise choice and control in that environment.

Empowering parents and carers (and participants in general)

If government intends to rely on market responses to demand from parents, carers and participants, the NDIA needs to consider how it can better support the provision of public information about NDIS providers, in addition to the use of Early Childhood partners (and Local Area Coordinators) as a conduit. The current arrangements – where anyone without access to the *myplace* portal is limited to downloading long lists of providers – is completely unusable and unsuited to driving market-based responses to demand. Parents, carers, family and friends and members of the public should be able to access information about NDIS providers, which receive significant government funding, easily. The My Aged Care website,

for example, allows prospective care recipients and members of the public to research aged care providers by suburb or postcode, care and service types, languages and more. Carers Australia therefore recommends the NDIA develop a similar website and service finder for people with disability, parents and carers to be able to more easily find information about NDIS and Early Childhood providers.

Responses to specific recommendations

Recommendation 1: *Explain, rename and promote the NDIS Early Childhood Approach – and stop using the term “gateway” – so families understand and follow a clear pathway with a mix of early childhood support options available.*

Carers Australia supports this change, noting that it will need to be supported by better articulation and communication of the potential pathways and mix of early childhood support options available. For example, simple flowcharts and other resources that can be translated into Easy Read, Auslan and other languages other than English.

Recommendation 2: *Clearly and consistently, communicate the intent of the new Early Childhood approach and the Agency’s support for best practice, so families understand how the approach informs positive outcomes for young children.*

Carers Australia agrees that any change needs to be clearly and consistently communicated to parents and carers. Any resources or training for parents and carers needs to be accessible and available in Easy Read, Auslan and languages other than English, with consideration of parents and carers who may themselves have a disability.

The NDIA workforce needs to be better trained in communicating with parents and carers, and better able to work through questions or issues outside standard scripts. The NDIA could consider hiring more experienced staff, including those with lived experience of disability and caring roles^{3,4}. The NDIA could also consider alternative approaches to training its workforce, including communities of practice-type models.

Recommendation 3: *Develop and publish new Early Childhood-specific Operating Guidelines – so our decision-making processes and best practice evidence are transparent and implemented consistently by partners and NDIS planners.*

Carers Australia supports the development and publication of Early Childhood-specific Operating Guidelines so decision-making processes and evidence are transparent and implemented consistently. These need to be available in accessible formats, including Easy Read, Auslan and languages other than English.

Recommendation 4: *Create a distinct delegate/planner workforce that is exclusively focused on young children and their families, to improve the way families are supported.*

Carers Australia supports this proposal, noting that nationally consistent training, underpinned by transparent Operating Guidelines, will be essential to ensuring consistent approaches to planning and decision-making. The dedicated delegate/planner workforce for young children and their families should have appropriate levels and mix of qualifications and experience for their roles. For example, at minimum diploma-level qualifications in early childhood education, social work, or allied health or suitable professional experience and/or lived experience of disability.

³ According to the *NDIA Annual Report 2019-20* (p. 105), the NDIA has a target of 15% employment of people with disability, sitting at 11.1% at the time of the report. The report does not provide a detailed breakdown of other aspects of diversity within its workforce, nor within those with disability.

<https://www.ndis.gov.au/about-us/publications/annual-report> [accessed 19 February 2021]

⁴ The Australian Public Service Disability Employment Strategy 2020-2025 has an overall target of 7% (10,500 employees) people with disability employed by 2025.

<https://www.apsc.gov.au/australian-public-service-disability-employment-strategy-2020-25> [accessed 19 February 2021]

Recommendation 5: *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.*

It is important that the Australian Government and NDIA continue to work with state and territory governments to address any interface issues, identify gaps and strengthen the role of mainstream services, so all young children receive support from the appropriate system when they need it.

Many people do not understand that the NDIS is not intended to cover all disability supports and services for all people and children living with disability. The role and availability of mainstream and community supports needs to be better communicated to the community, including how to access mainstream supports, and the different approaches taken in different jurisdictions.

Recommendation 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.*

Accessible and engaging information and resources for parents and carers will help raise awareness of providers that adopt best practice approaches and empower parents and carers to exercise choice and control. Carers Australia would welcome the opportunity to work with the NDIA, providers and parents and carers to develop appropriate resources. Of course, the ability of parents and carers to seek services from providers that adopt best practice will be influenced by their location and the supply of different providers in their area, as well as their literacy and communication skills. The NDIA should consider how to encourage best practice approaches in thin markets, where competition will have less impact.

It is clear from Carers Australia's experience in the Better Start program that families and carers would benefit from further collaboration between Carers Australia and Early Childhood partners to bridge a gap that exists in some cases between parents and carers and the NDIS Early Childhood partners. Families and carers in the early intervention space often assume the Early Childhood partners to be part of the broader scheme. It is not clear for many vulnerable families and carers that while the EC partners represent and deliver the NDIS, part of their purpose is to be approachable and knowledgeable about community services and to link families with them.

Recommendation 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.*

A more diverse workforce across the NDIA, Early Childhood partners and NDIS providers that includes more people with lived experience of disability, of disadvantage, from First Nations communities and culturally and linguistically diverse communities, will improve sector wide understanding, empathy and expertise. The NDIA and government needs to include and consult these communities early in policy and service co-design.

Recommendation 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.*

The NDIA does need to consider different models – e.g. pooled funding across different social service systems, community run services – for delivering supports for young children, parents and carers living in remote and very remote areas, particularly where there are limited numbers of providers operating in those areas. The NDIA could consider evidence heard by and recommendations from the Royal Commission into Aged Care Quality and Safety about challenges and approaches to delivering aged care services in outer regional, remote and

very remote areas, as there would be some similar issues and there may be opportunity to harmonise/link government responses.

The NDIA needs to work closely with families and communities in remote and very remote areas to co-design and implement tailored methods of delivering supports for young children in these areas.

Recommendation 9: *Implement a tailored Independent Assessments (IAs) approach for young children to support consistent access and planning decisions [including] commissioning Early Childhood partners to administer Independent Assessments for young children rather than use a separate IA Assessor workforce, using IAs for young children above one years of age and using the tools described on p. 13 of the paper.*

Carers Australia and its member organisations have heard that parents are confused about independent assessments. It may be some parents are confused about the different consultation processes underway, and it may not be clear enough that the independent assessments the government has indicated it will push to commence in 2021 do not relate to early childhood. The NDIA needs to clarify the proposed timetable for consultation and implementation of independent assessments as they relate to the ECEI approach.

As stated in Carers Australia's response to the [Access and Eligibility Policy with independent assessments](#) paper, Carers Australia supports in-principle the policy aims of independent assessments; that is, the use of government-funded functional capacity assessments using evidence-based, standardised tools to improve consistency of information and decision-making.

Carers Australia supports the proposed use of the existing Early Childhood partner workforce to conduct functional assessments. This recognises that Early Childhood partners will in many cases have existing relationships with young children and their parents and children. It is important that Early Childhood partners have the appropriate qualifications and training to administer the tools: the NDIA needs to release more information about how it proposes to ensure the Early Childhood partner workforce is appropriately trained and equipped, and what the review arrangements will be for decisions based on these functional assessments.

Consistent with Carers Australia's submission in response to the [Access and Eligibility Policy with independent assessments](#) paper, it should be an option for parents and carers to use Early Childhood partners to conduct the functional assessments, and not mandatory.

Recommendation 10: *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.*

Consistent with Carers Australia's response to Recommendation 7, a more diverse Early Childhood partner workforce (including people with lived experience of disability, of disadvantage, from First Nations communities and culturally and linguistically diverse communities), will improve capacity to identify and help young children, parents and carers from hard-to-reach communities or those experiencing disadvantage or vulnerability.

It is essential that Early Childhood partners are connected to and have relationships with local communities and service hubs (e.g. social housing services), and that frontline points in the community (e.g. GPs, social workers) are aware of ECEI and the role of Early Childhood partners.

Recommendation 11: *Increase Early Childhood partner capacity to connect families and young children to local support networks and services in their community.*

Building on the response to Recommendation 10 above, Carers Australia contends that the NDIA needs to examine existing barriers to Early Childhood partner capacity to connect

parents, carers and young children to local supports and services. For example, impact of workloads on Early Childhood partner capacity, and the Key Performance Indicators (KPIs) used to measure performance. In many cases these focus on administrative milestones rather than measuring the quality and frequency of services or degree of connection to local networks and services.

Recommendation 12: *Increase Early Childhood partner capacity to provide Short Term Early Intervention (STEI) support to eligible young children and families for longer.*

Carers Australia supports this recommendation, noting this is largely a workforce planning issue for the NDIA and contracted Early Childhood partners. As noted above, a diverse and skilled workforce is critical.

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. Establish thresholds for key criteria using Independent Assessments.*

Any changes to criteria under the NDIS Act need to be clearly explained and communicated, with the opportunity for consultation.

Recommendation 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.*

Carers Australia supports this recommendation, noting the need for early communication and planning for transition at least six months before the expected end of the child's eligibility for ECEI, as noted above. Parents and carers need to understand possible pathways following the end of ECEI, including the different supports and services available through mainstream and community services as well as under the NDIS.

In recognition of the need to focus on the family as a whole and to support parents and carers, the NDIA should introduce a new item under ECEI/STEI for family – parents and carers – capacity building through mentoring, upskilling or education. This could be used to support the transition period and/or to build parents' and carers' understanding of best-practice approaches, differences between medical and social models of disability and human rights approaches.

Recommendation 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.*

The scope and intention of this change needs to be clarified. For example, is "all young children" intended to mean all children up to the age of 9, or include children over the age of 9 for the purpose of access to the NDIS? What is the objective of the change? Any change to access criteria needs to be clearly communicated.

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.*

Carers Australia supports this recommendation, and notes the important intersection with family capacity building. Greater 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 is needed. There should also be flexibility in the number of hours Early Childhood partners can spend assisting families; there should not be a 'one-size-fits-all' approach.

The fact of the additional flexibility and potential benefits for parents and carers needs to be clearly and proactively communicated by the NDIA and Early Childhood partners. Parents and carers need to be assisted to better understand how to make best use of flexible plans.

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.*

Carers Australia supports this recommendation. It must be associated with additional funding to reflect travel costs and time so the time spent on direct care and services is not affected.

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.*

Carers Australia cannot comment on this without seeing the consultation paper foreshadowed on page 5 of the paper. Consultation must include parents and carers of young children with autism, and Carers Australia would welcome inclusion in this consultation.

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.*

Carers Australia supports this recommendation, although the scope of 'advice' an Early Childhood partner can provide depending on their qualifications and experience needs to be clarified.

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.*

Carers Australia supports this recommendation, noting the importance of both process and outcome evaluations of government policies and programs. Research and outcomes for young children from early intervention support should be published and translated into meaningful and practical resources for providers, parents and carers.

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.*

Carers Australia supports this recommendation, noting that goal-setting should be in line with best-practice case management. Goals need to be framed in ways that are meaningful to the child and parents and carers, and be measurable (not necessarily quantitatively) and achievable. There should be a distinction between short- and long-term goals, correlating to practical milestones or goals that work towards aspirational goals. Not-meeting goals should not be viewed as failure. Progress reviews should reconsider or add new goals as appropriate, and should take into account other events or circumstances impacting the child and family (for example, the COVID-19 pandemic, caring needs of other family members, or family violence).

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.*

Carers Australia supports this recommendation, noting that 'provider outcomes reports' should be provided to parents and families. The NDIA and NDIS Quality and Safeguards Commission need to consider compliance and reporting mechanisms to ensure there is transparency around effectiveness of NDIS supports and services, but also to provide

information to parents and carers to inform decisions when choosing providers, supports and services for young children, as discussed above.

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.*

Transition plans are needed, but must be of six months' duration at minimum, noting the comments made above under General questions and in response to Recommendation 14.