



**Carers Australia submission to the
National Disability Insurance Agency
consultation paper:
*Interventions for children on the autism
spectrum***

14 May 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 *Interventions for children on the autism spectrum*. The submission has been informed by the National Carer Network. Carers Australia welcomes the opportunity to engage and provide comments on this paper, and wants to work with the new Minister and Australian Government, people with disability, disability representative organisations and advocates to improve the National Disability Insurance Scheme (NDIS).

Carers Australia notes that the Joint Standing Committee on the NDIS is conducting a dedicated inquiry into independent assessment, and that Minister Reynolds has indicated she will 'pause' the rollout of independent assessment for the time being. Further detail is needed about the Minister's intentions for NDIS reform.

Who is a carer?

Carers are people who provide unpaid personal care, support and assistance to family members and friends or other individuals who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. There are over 2.65 million carers in Australia, and more than 860,000 of those are primary carers, who provide the most informal support to a family member or friend. Around 1 in 11 carers (235,300 people) are under the age of 25.

Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems.

The Carer Recognition Act 2010

It is important that carers are supported to participate in economic, social and community life, as recognised by the *Statement for Australia's Carers* under the *Carer Recognition Act 2010* (the Act). The Act aims to increase recognition and awareness of carers and acknowledge the valuable social and economic contribution they make to society. The *Statement for Australia's Carers* states that all carers should have the same rights, choices and opportunities as other Australians, and that carers should be acknowledged as individuals with their own needs within and beyond the caring role.

Discussion: general comments

Critical role of caregivers demonstrates need for sufficient supports

In summarising the research findings of the Autism Cooperative Research Centre (CRC), the consultation paper reflects the CRC's emphasis on the important positive effects that parents' and carers' involvement in delivery of interventions can have on child outcomes, and sometimes to greater effect compared with interventions delivered by clinical practitioners alone (p. 9). It also pointed to evidence that either parent or caregiver-mediated and peer-mediated interventions had a positive effect on a range of child and family outcomes (p. 9). This demonstrates need for sufficient supports, and for parents and carers to be part of holistic assessment – not only in terms of the individual needs of the child, but the needs of parents and carers to support that child – both in delivering and supporting interventions, and in terms of maintenance of the caring role.

Parent and carer preferences, priorities – inclusion in processes and decision-making

The paper also highlights – following findings from the Autism CRC – that child and family preferences and priorities should be part of the basis on which individual interventions are selected within an evidence-based practice framework, together with evidence from clinical practice (p. 9). The question is whether, and if so how, these views and preferences are

formalised within NDIA processes. The same issue has been identified by Carers Australia in previous submissions in relation to independent assessment, where there is no formal, standardised process for carers to contribute to the process if appropriate, and no clear requirement for NDIA planners and delegates to consider this as part of their decision-making (discussed further below).¹

Similarly, the consultation paper posits that interventions should “have the child and family at the centre as equal partners” with practitioners (as well as being based around the core characteristics of autism, be related to skills and development, and build capacity) (p. 15). Yet at points (e.g. in the case of weighted blankets on p. 15) the paper implies that although parents and carers may hold the view that certain interventions benefit their individual child, such a view may be discounted if that benefit is not demonstrated a general level in research or if the NDIA thinks the parents or carers imagined a positive benefit. As the paper does not describe who or how such an assessment would be made – who has the authority to assess whether a parent or carer is imagining a benefit – it is difficult to see how parents and carers would be equal partners. We are not suggesting that evidence-based interventions shouldn't be key: the issue is the unresolved tension between need for tested-evidenced based interventions, the fact that children on the autism spectrum respond differently and there is no one-size-fits-all-approach, the views and experience of parents and carers who are experts on their children, and the role of the NDIA in weighing up these three factors.

Skill and capability of NDIA staff to assess the evidence and relative balance of cost and benefit

The paper does not articulate the skill and capability required of NDIA planners and delegates to be reviewing and assessing the latest research and evidence, or to the ability of staff to assess for an individual child the relative benefit and cost of interventions and outcomes.

Standards 6 and 7 (p. 16) respectively discuss the challenges in assessing the potential costs and benefits of different interventions, and whether interventions are good value for money and time invested. These are complex assessments and as the paper acknowledges there will be differing views and levels of evidence. The NDIA needs to set out who will be responsible for making these sorts of assessments, and the skills and experience needed for such a role. Operational documents setting out guidance and decision-making considerations should be publicly available.

Differing funding levels across different socio-economic areas

This and previous consultation papers point to differences in funding levels across different socio-economic areas as evidence and justification for independent assessment and other changes. However, the paper does not flesh out the different factors that might contribute to different funding levels across different socio-economic areas. For example, rather than implicitly assuming that funding levels in higher socio-economic areas are too high, it may be that parents and carers in lower socio-economic area need individual advocacy and greater support to navigate different parts of the system. Another factor may be thin markets in lower socio-economic urban areas and regional and remote areas; that is, services and supports are not included in plans because services and health professionals are not available to deliver them. Similarly, there are likely additional challenges in getting health professionals to visit families at home to help integrate interventions and strategies into the child's natural setting. The paper does not present any data or evidence or interrogate potential factors contributing to different funding levels. If the NDIA has such data then this should be made publicly available.

¹ See also Carers Australia's "Submission to the National Disability Insurance Agency – Consultation papers *Access and Eligibility Policy with independent assessments and Planning Policy for Personalised Budgets and Plan Flexibility*" available on the Carers Australia website at <https://www.carersaustralia.com.au/submissions-reports/submissions/>.

Early intervention and NDIS funding and supports need to properly support parents and carers

The NDIA acknowledges that parents and carers are critical to successful outcomes for children with autism. For this reason they need to be properly supported and enabled to support delivery of those interventions and them in their caring role. But they also need to be supported to participate in education, economic and community life. The paper (p. 21) notes that Autism Specific Early Learning and Care Centres (ASELCC) with its long day care model allowed parents to participate in education and employment, and that children attending an ASELCC are transitioning to the NDIS. It is critical that the NDIS continue to fund such supports which benefit children and parents and carers.

The level of supports – especially in terms of respite care – parents and carers receive, whether directly or indirectly, will differ depending on whether a child is accessing services through the ECEI pathway or as a participant. ECEI funding is focused on capacity building with limited core supports. As such, there are often minimal if not entirely non-existent respite options available to carers engaged in the pathway, which needs to be addressed.

Holistic planning and assessment

The consultation discusses holistic planning, but does not fully consider a holistic approach to assessment. Notwithstanding the ‘pause’ on the rollout of independent assessment by Minister Reynolds, Carers Australia refers to its previous submission on independent assessment and comments about the need to properly and formally consider carer perspectives and needs.

There is little across the consultation papers about the role of carers in relation to assessment and planning. Under current arrangements carers are able to complete a carer statement (or Impact Statement) outlining their role and how that role impacts them, as well as how the NDIS Plan can ‘sustain capacity to care’. Noting that there is currently no requirement for these statements to be considered in NDIS access, budget and planning decisions (and carers may not be aware of them in the first place), it is also unclear from the consultation papers released whether or how such statements would be considered as part of assessment, budget and planning decisions.

A standard-form Carer Statement or Impact Statement should be used as a formal and compulsory part of assessment to provide a more accurate picture of the everyday barriers experienced by children, their parents and carers, and to verify how much care and support an individual may need. This would support the NDIA’s policy intention to improve consistency of information and decision-making, and if collected appropriately contribute to better data about the informal care provided to people with disability (and carer policy in general). This should then be integrated into the referral pathway for Carer Gateway services.

Proposed funding levels

The consultation paper sets out the proposed indicative funding levels for autism early intervention. Indicative funding levels, according to the paper, are based on “a holistic approach that also considers community inclusion, participation, non-funded and funded interventions” (p. 25).

The paper also describes at a general level some of the factors that may contribute to an individual child’s funding level; according to the paper “considerations include family wellbeing including supporting the development of caregivers and interaction strategies and social and environmental needs” (p. 25). There is little further explanation or detail, nor is there any account of the formulation or methodology through which the funding levels were determined. It would be helpful if the NDIA released more information about its assumptions and

methodology in arriving at these indicative funding levels in order for stakeholders to provide further feedback.

In relation to the 'development of caregivers' and consideration of 'social and environmental needs', Carers Australia would welcome further detail about how such needs would be assessed and how parents and carers would be part of assessment and planning.

Implementation considerations

Participant choice and control

The move toward more flexible use of plan funding is positive, and is consistent with seeing parents and carers as partners in care. It is also positive that the paper recognises that children, parents and carers will need better information and support to understand these changes and to enable them to make informed decisions, without being directed or needing to seek approval from the NDIA for all decisions made when implementing a child's plan. Carers Australia would welcome further detail about the proposed approach to improving information and support, and would welcome engagement from the NDIA to comment on or otherwise assist the agency from the carer perspective.

Responses to specific consultation questions

Questions 1 and 2

The NDIS website and NDIS Operational Guidelines are currently not useful sources of information about choosing and accessing best practice interventions (nor is it helpful to find information about NDIS service providers). Participant decision making guides could be a helpful source of information if developed in consultation and tested with children, parents and carers.

Parents and carers likely seek information from a range of sources, including NDIS partner contacts, Autism organisations and peak bodies, and may seek information other sources (e.g. Carer Gateway, Disability Gateway, the National Carer Network, GPs). Carers also seek information from their own networks and support groups, which in some cases will be the first or only source of information.

Consideration needs to be given to the role of the Carer Gateway and Disability Gateway in providing information and educative resources in relation to choosing and accessing best-practice interventions for children on the autism spectrum, and the NDIS more broadly.

Question 3

Further to the comments above, the first step in holistic planning – in the sense of considering and incorporating the full range of services and supports that may be available to a child with autism and their family – is helping families to understand the scope and interface of the health, disability, education and other systems that operate at different levels of government. This is not easy, as demonstrated by the difficulty the Disability Gateway has had in providing information and education resources on navigating these different systems and their interfaces. This needs considerable thought and work.

It should also be noted that many state-based mainstream services are not suitable for and do not adequately meet the needs of children on the autism spectrum.

Questions 4 and 5

At a general level, the paper contains tensions in relation to both proposed principles for decision-making and standards for delivery of autism delivery, which are not clearly resolved. First, it is not clear where the paper sits on interventions that either don't have sufficient research evidence to support or disprove the efficacy of supports either way, or, interventions for which there is no general evidence, but where it reportedly works for individual children. By the paper's own admission, many evidence-based supports may not work or be effective for all children on the autism spectrum; and interventions that may work for individuals are not necessarily generalisable or applicable to all children on the autism spectrum.

It is positive that the paper acknowledges the diverse range of needs of children on the autism spectrum and that there is no one-size-fits-all approach to early interventions and supports. We hope this indicates an open-mindedness and flexible approach to interventions suitable to the individual child and family as opposed to all children with autism.

Questions 6 and 7

As the consultation paper acknowledges, parents and carers need more clarity about how the NDIA makes decisions about 'reasonable and necessary' early intervention supports for children on the autism spectrum. More and better information, advice and supports are needed to help parents and carers make informed decisions and to find services for their children, and these must be consistent and accessible.

As discussed in Carers Australia's previous submissions, what constitutes 'reasonable and necessary' turns in part on what parents and carers are 'reasonably' expected to provide. The line between what is 'normal' or 'reasonable' parenting support and what parents of autistic children provide is not necessarily distinct, and may differ between individual families depending on family structure, background and personal factors. The approach to assessing 'reasonable' or 'normal' informal supports needs further consideration.²

While they provide individual examples of the application of 'reasonable and necessary', the case studies at Appendix one are not particularly helpful in understanding the NDIA's decision making processes.

Question 8

While the tables set out the indicative funding levels there is no detail about the methodology used to determine them. Further information about how the levels are determined would be welcomed.

Question 10

As indicated above, the interfaces between the different disability, health and education systems are complex and can be very confusing for families. The NDIA needs to consider how it can address interface issues, e.g. the parameters of the NDIS and how these may change at different life stages and support families to navigate them. The NDIA needs to consider the range of interactions or contact points participants and their families may be having with different systems, and then also educate those different organisations and agencies about the parameters of the NDIS and points at which mainstream or other disability services come into play.

Question 11

The questions are helpful, but there are limitations. Some parents and carers might not know they can or feel comfortable asking such questions. Parents and carers need to know they

² While the Government supported Recommendation 12 of the Tune review, further work needs to be done on how the NDIS will support families and carers. See "Australian Government response to the 2019 Review of the *National Disability Insurance Scheme Act 2013* report", p. 9. <https://www.dss.gov.au/sites/default/files/documents/08_2020/australian-government-response-tune-review-28-august-2020-release.pdf>

have autonomy within the system. The questions may be less useful if parents and carers don't already have a certain level of knowledge about best practice approaches. Further consideration should be given to other forms of information, support and upskilling.

Question 12

Other guidance or tools could include:

- greater support (e.g. more hours) from ECEI partners to help families to implement plans, assuming ECEI workforce is sufficiently skilled and qualified; and
- greater availability of in-reach support by practitioners delivered in the child's home.

Further consideration should be given to the different support needs of and alternative approaches for diverse families and communities, for example, people with varying levels of literacy, Culturally and Linguistically Diverse and migrant communities, Aboriginal and Torres Strait Islander communities, and LGBTIQ+ communities. The NDIA should consult directly with these groups to understand the guidance and tools best suited to their individual needs.

The NDIA should also consider other levers that may support best practice approaches and choice and control for participants and their families. The obvious one which is barely explored in the paper is what could be achieved by provider oversight and transparency. Much of the NDIA's public consultation to date has focused on changes for participants and their families, and has not considered what providers could and should do differently, or what the NDIA or NDIS Quality and Safeguards Commission could do. For example, as Carers Australia has previously suggested, consideration could be given to 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.³

³ See Carers Australia, "Submission to the National Disability Insurance Agency – Consultation paper *Supporting young children and their families early, to reach their full potential*", pp. 9-10.