



Children and Young People
with Disability Australia

Response to NDIS Support Coordination Discussion Paper

**Children and Young People with Disability Australia
September 2020**

Table of Contents

Introduction	0
Our recommendations	1
Key concerns and areas for action	2
High quality support coordination must be available when and where needed	2
Support coordination is vital for participants facing barriers to services	3
Greater clarity and better data will improve effectiveness	4
Plan flexibility must not undermine the inclusion of funded support coordination	4

Authorised by:

Mary Sayers, Chief Executive Officer

Contact details:

Children and Young People with Disability Australia

E. marysayers@cyda.org.au

P. 03 9417 1025

W. www.cyda.org.au

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0-25 years. CYDA has an extensive national membership of over 5,000 young people with disability, families and caregivers of children with disability, with the majority of our members being families.

CYDA's purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia. To do this, we focus on the following:

- Listening and responding to the voices and experiences of children and young people with disability
- Advocating for children and young people with disability for equal opportunities, participation and inclusion in the Australian community
- Educating national public policy-makers and the broader community about the experiences of children and young people with disability
- Informing children and young people with disability, their families and caregivers about their citizenship rights and entitlements
- Celebrating the successes and achievements of children and young people with disability.

CYDA appreciates the opportunity to help shape the future of support coordination services by providing this submission to the National Disability Insurance Agency (NDIA).

Our recommendations

We make several recommendations regarding the provision of support coordination services for children and young people with disability.

- Fund support coordination when it is needed, regardless of age
- Ensure children and young people who live in circumstances where there are barriers to accessing services are well supported by the NDIS through support coordination
- Provide support coordinators working with children and young people with best practice training, including inclusion models and developmental theory
- Take a family-centred approach when deciding to fund support coordination in a child or young person's plan
- Introduce a whole-of-childhood NDIS framework aligned with developmental theory for ages 0-25 – including for support coordination
- Adopt a reasonable framework around the concept of “parental responsibility”, including addressing “reasonable and necessary” specifically for children and young people
- Deliver greater clarity for advocates and community members to understand how and when support coordination is provided
- Improve data gathering to better understand the impact support coordination has on participants and families
- Ensure the move to plan flexibility does not lead to support coordination being underfunded

Key concerns and areas for action

CYDA consistently hears that support coordination provides invaluable support to children, young people with disability and families, particularly those accessing the NDIS for the first time. For it to be most effective, support coordination for children and young people must be funded at an appropriate level and quality, and it should be delivered by professionals with appropriate understanding of disability, inclusion best practice, and general childhood development. In CYDA's previous submission to the NDIS Participant Service Guarantee and Legislative Review, we recommended that support coordination be provided for all children and young people during the implementation of their NDIS plan.¹

This submission is informed by our members and results from a national survey conducted by CYDA in July 2019 of 189 young people with disability and families and caregivers of children with disability about their NDIS experience. Almost half of survey respondents (47%) were Victorian. Respondents from all states completed the survey. Most respondents lived in metropolitan areas (64%), followed by regional (28%), rural (8%) and remote areas (1%).

High quality support coordination must be available when and where needed

There are serious concerns around the implementation of support coordination for children and young people regarding allocation of funding and the quality of support provided. Respondents to CYDA's national survey expressed several frustrations in attempting to access and utilise their NDIS plans. When children and young people are accepted onto the NDIS, the complexity of the system often leaves families struggling to make sense of the systems, language and processes. Families frequently report finding the NDIS "cumbersome" and "bureaucratic", and that navigating the scheme effectively adds additional pressure and constraint into already busy lives.

Families also repeatedly mention the significant extra work that is required to transition to and use the NDIS effectively. The administrative burden placed on carers and families can be significant and overwhelming. Stressors include the need for multiple service agreements and service providers ("fragmentation of services"), finding and understanding the supports that are available, increased time investments, and managing staff.

The rigidity of the NDIS system also causes frustration and distress. Alongside significant administrative burden, there is no acknowledgement of the impact on young people managing their own plans, or on families and carers. We often hear of supports and services being denied to children and young people due to "parental responsibility", and this is reflected in the support coordination data. Only 7% of children aged 0-6 have support coordination funded in their plan in comparison to an all-ages average of 40%. Children and young people aged 7-14 receive only half

¹ CYDA (2019) *Improving the NDIS for children and young people with disability and their families: NDIS participant service guarantee and removing legislative red tape review*. Available: <https://www.cyda.org.au/resources/details/66/improving-the-ndis-for-children-and-young-people-with-disability-and-their-families>

of the average funding for all age groups at 20%. By age 15-18, funding increases to 37%, close to the average for all age groups².

Additionally, the NDIS lacks a broader understanding of childhood and the developmental processes that occur until individuals are in their twenties, including the family or home environment that children live in. The current NDIS process does not often consider the whole family's role in supporting the development of children and young people, and their inclusion in community and mainstream services. The Tune Review also highlights this issue, stating that "rigid adherence to individualisation can have a negative effect, particularly when it is clear that some participants cannot access the supports they need, even when a robust market has been established."³

If a child still requires supports after exiting the ECEI pathway, they move onto the full NDIS along with every person from seven to 65 years of age. This approach 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.

According to the Tune Review, people who have support to navigate the NDIS from initial entry tend to achieve better outcomes than those without. For many children and young people accessing the NDIS for the first time, support coordination is not funded. While the NDIA makes note of other services that people can access for support, including Local Area Coordination, the Tune Review findings suggest that Partners in the Community do not have the capacity to fulfill their service navigation and capacity building functions. This means that children and young people are entering the Scheme without additional supports that are regarded as 'critical' in enabling participants to maximise the benefits of their funding.⁴

While support coordination can provide the additional support participants need to navigate the NDIS, it is vital that support coordinators working with children and young people are appropriately skilled for the position. Families speak of the benefits of support coordinators who have lived or appropriate professional experience and can recommend services and work with families in a respectful and inclusive way. There is a need for wider understanding of best practice in support coordination specifically relating to children and young people, including childhood development and inclusive practice. It is hoped that this will then pave the way for a workforce that can best support children and young people to fully utilise their plans and to lead inclusive lives.

Support coordination is vital for participants facing barriers to services

Support coordination is also crucial for participants facing additional complexity and/or barriers to accessing services. This includes people living in low socio-economic circumstances or with cognitive impairments, and people from First Nations or culturally and linguistically diverse communities.

² National Disability Insurance Agency (2020). *Support Coordination Discussion Paper, Table 2: Support coordination by age group, as at 30 June 2020*. Available: <https://www.ndis.gov.au/community/have-your-say/support-coordination>

³ Tune, D. (2019) *Review of the National Disability Insurance Act 2013*. Available: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

⁴ Tune, D. (2019) *Review of the National Disability Insurance Act 2013*. Available: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

There is also a lack of transparency about the NDIS experiences of children and young people with disability who are involved in child protection and out-of-home care systems, including their experiences of support coordination. Although there are significant data limitations, we know that children and young people with disability experience higher rates of maltreatment and abuse⁵ and are over-represented in child protection systems.⁶

Children in these cases, where the state acts as the parent, are already living in precarious circumstances and need extra care from systems – and the introduction of the NDIS brings opportunities as well as added complexity for these children’s lives. Improved data collection, support provision and service integration for this cohort requires significant work from the Agency and other stakeholders.

Given these challenges, support coordination needs to be provided for all participants who face additional barriers to accessing services.

Greater clarity and better data will improve effectiveness

CYDA’s survey respondents expressed significant confusion around eligibility and support coordination requirements, with participants and their families unsure of who is eligible for support coordination, how to access it, or how much would be appropriate. One respondent reported having “no funding to support us as a family because there is no support coordination under 7”. There is a strong need for clarity for participants, families, advocates and the wider disability sector regarding support coordination funding and eligibility requirements.

Plan utilisation rates do not differ significantly for participants who had support coordination funded in their plans and participants who did not across the spectrum⁷. However, CYDA consistently hears reports from families who say they “could not have done it” without support coordination. This points to a need for more specific data gathering around individual successes and failures with support coordination, and more investment in exploring what best practice support coordination looks like for participants of all ages and backgrounds.

Plan flexibility must not undermine the inclusion of funded support coordination

While the NDIS is making positive moves towards increased flexibility in plans, support coordination should not be made an optional inclusion in a funding package, which could result in less funding overall for purchasing services. If children and young people with disability and their families are forced to choose between funding for services or service coordination as part of a total package, there is the risk that support coordination does not get prioritised, leading to many participants missing out on vital support. The NDIS needs to guard against the value of plans being eroded because support coordination is not funded and absorbed into packages.

⁵ Maclean, M.J, Sims, S., Bower, C., Leonard, H., Stanley, F.J., & O’Donnell, D. (2017) Maltreatment Risk Among Children With Disabilities, *Pediatrics*, e20161817; DOI: 10.1542/peds.2016-1817.

⁶ Kelly, B., Dowling, S. & Winter, K. (2016) *Disabled children and young people in out-of-home care: summary report*. Belfast: QUB & OFMDFM.

⁷ National Disability Insurance Agency (2020). *Support Coordination Discussion Paper, Table 4: Plan utilisation by age for participants not in SIL, as at 30 June 2020*. Available: <https://www.ndis.gov.au/community/have-your-say/support-coordination>