

6 October 2021

NDIS Act Review Consultations  
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Carers NSW welcomes the opportunity to provide a submission to the Department of Social Services (the Department) on the proposed National Disability Insurance Scheme (NDIS) legislative improvements and the Participant Service Guarantee. This submission will focus on opportunities to increase carer inclusion and support through proposed legislative changes and concerns regarding the limited consultation period and agreed reforms that are not addressed in the proposed changes.

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation

Thank you for accepting our submission. For further information, please contact Madeleine Gearside, Policy and Development Officer at [madeleineg@carersnsw.org.au](mailto:madeleineg@carersnsw.org.au) or on (02) 9280 4744.

Yours sincerely,



Elena Katrakis  
CEO  
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## Introduction

Carers NSW thanks the Department of Social Services (the Department) for the opportunity to provide feedback on the proposed NDIS legislative improvements and the Participant Service Guarantee. The current legislative review provides an opportunity to improve the implementation of the NDIS for people with disability, their families and carers.

Carers NSW believes in the importance of autonomy and self-determination for people with disability and is supportive of policy and practice that facilitates their independence and meaningful participation in community life. Additionally, Carers NSW recognises that not all people with disability receive informal support or would identify as having a 'carer'. However, family members and friends are important in the lives of all Australians, and the Australian Bureau of Statistics (ABS) reports that the majority of Australians with a reported disability who need assistance receive at least some of that assistance from a family member or friend; in many cases, on a daily basis.<sup>1</sup>

While Carers NSW supports a number of the proposed amendments to the *NDIS Act 2013* in the *National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Bill 2021* (the Bill), Carers NSW believes that these reforms could be further strengthened to ensure greater carer inclusion and support for carers and the people they care for.

Additionally, Carers NSW has concerns that the limited consultation period for the proposed legislative changes - which are likely to have long lasting effects - may not adequately capture the interests of all stakeholder groups, limiting the appropriateness and effectiveness of services for people with disability, their families and carers. Carers NSW also has concerns that some elements of legislative reform previously agreed to by Government have not been actioned in the proposed Bill, likely resulting in ongoing challenges and confusion for participants and their carers navigating the NDIS.

## Strengthening carer inclusion and support through reforms

### The role of carers and families in decision-making

Schedule 2 of the revised Bill includes several changes which aim to place participants more firmly at the centre of decision making, adjusting the role of carers and families in decision-making processes. Carers NSW views decision making as a fundamental human right, and fully supports maximising opportunities for enabling all NDIS participants to have decision making autonomy. Autonomous decision making is underpinned by the concept of self-determination, which seeks to overcome a default position that carers and others may take in 'speaking for' people with disability, which can result in disempowerment and indignity for the person involved, and can in some cases contribute to the risk of abuse and neglect.

In the context of decision making, current policy and practice generally involves the presumption of capacity without substantial documentation to the contrary. Governments and service providers are intentionally moving away from traditional substitute decision making models such as guardianship, in favour of supported decision making approaches, which prioritise enabling people living with cognitive impairment to express their needs and preferences. Carers are expected to play a supportive role in this process, however, little guidance tends to be provided to carers on exactly how to ensure that a person's preferences are adequately captured and conveyed in decision making processes.

Carers NSW supports the increased agency of people with disability in making choices that affect them, provided that the carers who are expected to support this process are provided adequate information and support and treated with respect and dignity. Clarity and consistency with regard to

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<sup>1</sup> Australian Bureau of Statistics (2019) *Survey of Ageing, Disability and Carers 2018*, TableBuilder Dataset, available online at: [www.abs.gov.au](http://www.abs.gov.au)

the implementation of decision making support is also paramount, not only for the benefit of carers, but also to ensure effective support of people with disability. The Commonwealth Statement for Australia's Carers<sup>2</sup> states that the valuable contribution of carers should be recognised and supported. It also stipulates that the relationship between carers and the people they care for should be respected, and carers should be considered partners in care, with Government departments and agencies and service providers acknowledging carer knowledge and experience.

Data from Carers NSW 2020 National Carer Survey<sup>3</sup> found that, of the respondents providing support to a person with disability, over 80% provided support with cognitive and emotional tasks (including decision making) and nearly three quarters provided assistance with communication (including reading and writing tasks). Additionally, nearly 65% were involved in supporting the person they care for with finances, and the same percentage were involved in handling the person's finances directly. Over 70% were involved in advocating for the needs of the person they care for and providing support with behaviour. It is also important to note that around 10% provided support with language interpreting, another key consideration in relation to capacity and decision making.

Whilst Carers NSW fully supports ethical and genuine maximisation of autonomous decision making capacity for participants, we also strongly advocate that this action should not compromise the rights of participants to nominate one or more carers or other persons to formally support decision making. The proposed actions must also be carried out in a way that supports the participant's outcomes without having adverse implications for their carer or carers.

With 60% of participants requiring support with decision making,<sup>4</sup> Carers NSW is concerned for the outcomes of these participants in circumstances where their carers and families may be excluded from decision-making processes, or inadequately prepared to support the person. Carers NSW advocates that the revised Bill be reflective of common law, within which formal support roles are legislated and recognised as imperative to the safety and wellbeing of people who require such support.

### **Interim supports for children awaiting Early Childhood Early Intervention (ECEI)**

Schedule 2 of the revised Bill also includes proposed changes to help children with disability access support earlier. Carers NSW commends the Department for their commitment to this change, recognising that this will have a number of positive impacts for parent carers of children living with disability.

Since the commencement of the NDIS, carers and service providers have reported indefinite and lengthening waiting times, administrative errors, incorrect and inconsistent information provided to them by the NDIA, as well as the inappropriate withdrawal of state-funded early intervention services. With limited free state-funded services available while families wait for NDIS funded services, this scenario has placed families who cannot afford private services at risk of being without *any* early intervention support for extended periods.

Families and carers have understandably reported to Carers NSW distress and frustration when they experience uncertainty around services for their child. Furthermore, an absence of services can hold serious implications for the safety and wellbeing of an entire family, impacting parent carers and siblings who may also be providing care – otherwise referred to as young carers.

Carers NSW believes the proposed changes to enable the NDIA to provide funding for interim supports while a child's plan comes into effect will ensure timely intervention for children with

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<sup>2</sup> Carer Recognition Act 2010, Schedule 1 The Statement for Australia's Carers

<sup>3</sup> Carers NSW (2020). *2020 National Carer Survey: Summary report*. Available online at: <http://www.carersnsw.org.au/research/survey>

<sup>4</sup> National Disability Insurance Agency (2021). Consultation Paper: Supporting you to make your own decisions. Accessed online at: <https://www.ndis.gov.au/media/3230/download?attachment>

disability. This is critical to positive long-term outcomes, and reflects the foundational 'no disadvantage' principle of the NDIS and bilateral commitment to continuity of support. Carers NSW advocates that these interim supports should not however, affect the commitment to continue to reduce wait times for early intervention services.

### **Inclusive approaches to understanding psychosocial disability**

It is widely recognised that people with psychosocial disability face additional challenges when accessing support from the NDIS. Narrow eligibility criteria can complicate the application process and make providing appropriate evidence challenging. NDIA staff often have a poor understanding of psychosocial disability, leading to reduced applications, application rejections, and NDIS plans being inappropriate for a person's needs.<sup>5</sup> Carers and those they support living with psychosocial disability, often report that ineligibility has been determined on the basis of fluctuating or "episodic" impairment.

Carers NSW is pleased to see that Schedule 2 of the revised Bill includes proposed changes intended to make eligibility clearer for people living with psychosocial disability. This involves steering away from psychiatric conditions, and a more inclusive approach to understanding psychosocial disability, including recognition of fluctuating and episodic impairments. We are supportive of this change and hope that it results in positive impacts for mental health carers.

Carers often play a significant role in the support and recovery of people living with mental illness. The issues surrounding eligibility for people with psychosocial disability has left mental health carers filling service gaps and incurring social and financial costs. Findings from the Productivity Commission's Inquiry into Mental Health have shown that consumers and their families pay approximately \$700 million annually in costs associated with mental health supports.<sup>6</sup>

The financial costs incurred where supports must be privately funded can create hesitancy with regards to long-term engagement in support or treatment, ultimately impacting on the mental health of the care recipient and resulting in higher intensity caring responsibilities for carers, particularly if they are unable to privately fund these supports. Carers are often required to cover other hidden costs associated with the care of their family member or friend, including reducing work hours to provide care while also supporting the care recipient financially if they are unable to participate in paid employment.

### **Reducing administrative burden for participants and carers**

In the Carers NSW 2020 National Carer Survey, carers who supported an NDIS participant reported that they provided, on average, nearly 60 hours of informal care per week. Around 85% of carers of people with disability also regularly invested time in administration and organising supports and services for the person they care for, and a similar percentage reported spending time on coordinating support services and formal care workers.<sup>7</sup>

Many carers have administrative responsibilities, including management and coordination of services and finances on behalf of the person they care for. In many cases, there is a clear expectation that the carer – who is often ageing, experiencing their own health or mental health issues, may be from a culturally and linguistically diverse (CALD) background and/or lacking skills and confidence with dealing with service providers and using the internet – would take responsibility for coordination of supports and finances on behalf of the person they care for.

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<sup>5</sup> St Claire, R (2020). *People with severe mental illness face difficulties accessing NDIS*. Accessed online at: <https://www.disabilitysupportguide.com.au/talking-disability/people-with-severe-mental-illness-face-difficulties-accessing-ndis>

<sup>6</sup> Australian Government Productivity Commission (2020). *Mental health: Productivity Commission Inquiry Report*. Accessed online at: <https://www.pc.gov.au/inquiries/completed/mental-health/report>

<sup>7</sup> Carers NSW (2020).

Some carers are willing and able to perform this role, but many others communicate to Carers NSW that they feel overwhelmed and under-supported in doing so. Many carers indicate that this high level of administrative responsibility is often not undertaken as a choice, but rather occurs because either the person they care for is ineligible for support coordination, or because there is simply not enough funding or time allocated to this in their NDIS plan - most plans receive 5 hours of support coordination services per month.

Carers NSW is pleased to see that Schedule 2 of the revised Bill includes proposed changes to reduce the administrative burden on participants. Carers NSW wishes to emphasise that there should also be a focus on the administrative burden experienced by carers when they provide administrative support. The increased provision of formal support provided by the NDIA will reduce strain on carers and improve long-term outcomes as plans are implemented and managed effectively.

## Addressing gaps within proposed reforms

### Clarifying the scope and role of the NDIS

Carers NSW commends the Department on actioning a number of proposed improvements based on the 2019 review of the NDIS Act 2013 conducted by David Tune.<sup>8</sup> However, Carers NSW has concerns that a number of key recommendations, supported by the Government in their response to the review<sup>9</sup> aimed at clarifying the role and scope of the NDIS, have not been actioned in the proposed legislative amendments.

While Carers NSW understands that the NDIA has released a number of new guidelines to address some of the confusion around reasonable and necessary supports and boundaries between service systems, there has been no proposed changes to the Act that will look to clarify this on a legislative level, as recommended in the Tune Review. This is likely to result in ongoing confusion and differences in interpretation of reasonable and necessary. Furthermore, Carers NSW has concerns that recent efforts by the NDIA to clarify the scope and role of the NDIS have in fact narrowed its scope, as opposed to simply clarify boundaries and responsibilities as cautioned against in the Tune Review.<sup>10</sup>

Carers NSW has heard from carers that, as opposed to the integration of support across service systems over time since the rollout of the NDIS, the gaps between the NDIS and the health, education, transport and housing systems have only continued to widen and solidify. Many carers have reported to Carers NSW participants have been unable to access the services or supports that they require as a result of their disability to enable optimal outcomes due to gaps between services, requiring carers to not only fill gaps, but also to engage in advocacy across a

*Paula provides care to her daughter 9 year old daughter Nina, who is an NDIS Participant living with autism. Due to ongoing disagreements between the NDIS and NSW Education System about whose responsibility it is to fund supports for Nina within public education settings, Paula has resigned from her employment to home school Nina, as this is the only way to facilitate the appropriate level of support from paid workers during 'school time'.*

<sup>8</sup> Tune, D. (2019) *Review of the National Disability Insurance Scheme Act 2013, Removing red tape and implementing the NDIS Participant Service Guarantee*. Accessed online at: [https://www.dss.gov.au/sites/default/files/documents/01\\_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf](https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf)

<sup>9</sup> Australian Government (2020) *Australian Government response to the 2019 Review of the National Disability Insurance Scheme Act 2013 report*. Accessed online at: [https://www.dss.gov.au/sites/default/files/documents/08\\_2020/australian-government-response-tune-review-28-august-2020-release.pdf](https://www.dss.gov.au/sites/default/files/documents/08_2020/australian-government-response-tune-review-28-august-2020-release.pdf)

<sup>10</sup> Tune (2019).

range of state and federal service systems concurrently, which can be very psychologically demanding and take considerable resources.

Carers NSW recommends that the Department further consider the clarification of reasonable and necessary provisions, as well as the clarification of boundaries between service systems within the proposed legislative reform to enable participants and their carers to more easily navigate and access supports they need, when they need them.

### **Overcoming barriers to consultation with people with disability and their carers**

Carers NSW is also concerned that the Department has provided people with disability, their family and carers, as well as community organisations representing these groups only four weeks to respond to the proposed legislative changes. With people with disability and their carers already disproportionately affected by COVID-19 and barriers to accessing COVID-19 vaccines, Carers NSW believes that now, more than ever, NDIS participants and their supporters should be provided with adequate time to understand and respond to the proposed changes.

Furthermore, while Carers NSW understands the importance of progressing these legislative reforms, due to complex, legalistic nature of the proposed amendments and ongoing delays within the legislative reform process, we believe that community members require more time to fully consider these legislative changes, their potential implications and provide feedback.

Carers NSW has previously raised similar concerns about the consultation process undertaken by the NDIA, both in regards to consultation timelines and volume and complexity of content. Carers NSW acknowledges that the Department has provided easy read versions of the proposed legislative changes. However, given the extensive length of the *NDIS Act 2013*, and proposed changes to many sections, resulting in a number of complex and extensive consultation papers, Carers NSW believes that the Department should extend or re-open the consultation period to enable genuine consultation with participants, their families and carers.

### **Conclusion**

Carers NSW commends the Department for continuing to progress reforms that aim to improve the NDIS for participants, their families and carers. The current review of the *NDIS Act 2013* presents a valuable opportunity for significant and meaningful reform in the context of disability support for people with disability, their families and carers. However Carers NSW has concerns that without thorough consultation and further clarification of the roles and responsibilities of the NDIS, NDIS participants and their carers will continue to experience challenges and confusion when navigating the NDIS.