

31 October 2019

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Carers NSW wishes to thank the Department of Social Services (DSS) for the opportunity to provide a submission in response to the discussion paper, *Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape*. This submission is informed by the experiences of carers of people with disability receiving support through the National Disability Insurance Scheme (NDIS) in New South Wales (NSW), as relayed to Carers NSW staff.

A carer is any individual who provides care and support to a family member or friend with a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). 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.

This submission focuses on the challenges experienced by NDIS participants, their families and carers at various points of engagement with the NDIS, especially the access, planning and review stages.

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

Yours sincerely,



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**Carers NSW submission:**

***Improving the NDIS Experience: Establishing  
a Participant Service Guarantee and removing  
legislative red tape discussion paper***

31 October 2019

**AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS**

## Introduction

The National Disability Insurance Scheme (NDIS) holds great potential to improve the lives of people with disability, their families and carers living in New South Wales (NSW). However, since its launch in NSW in July 2013, the implementation of the NDIS has resulted in a number of key concerns for Carers NSW. We have raised these concerns continually through papers, submissions and contact with Ministers and Shadow Ministers, at both State and Commonwealth levels and have seen some improvement over time. However, there are a number of key issues that remain present for many carers, especially throughout the planning cycle.

Carers NSW commends the Department on their review of the *National Disability Insurance Scheme Act 2013* (NDIS Act) and associated NDIS Rules and welcomes the introduction of any solution that seeks to improve the experience of NDIS participants, their families and carers, including the proposed Participant Service Guarantee.

Drawing on two state-wide surveys of carers in 2018, ongoing consultation with carers and service providers via focus groups and working groups, multiple carer case studies and our experience working with people with disability, their families and carers through government funded programs, this submission discusses the service standards of the proposed Participant Service Guarantee; the challenges participants and their carers face at various stages of the NDIS planning process, including eligibility and application, using and reviewing plans and appealing decisions made by the NDIA; and the legislative framework that underpins these processes. This submission also provides recommendations on how to overcome these challenges and provide better support for participants, their families and carers.

## NDIA Service Standards

Carers NSW commends the Department on seeking to embed service standard principles that aim to ensure participants, their families and carers receive responsive and quality service at all stages of their interaction with the NDIS. However, Carers NSW has noticed that many of the proposed principles already exist in the current legislation. While Carers NSW understands that this Guarantee aims to act as a mechanism which improves participant experience with the NDIS, there are concerns about how this Guarantee will be implemented and upheld, particularly as the current legislation has not succeeded in ensuring consistently positive experiences for participants, their families and carers. It is unclear what mechanism would enable complaints and appeals should the Guarantee not be upheld or appropriately implemented. As such, Carers NSW recommends that a mechanism be clearly identified.

The 2015 review of the *NDIS Act 2013* made similar amendments seeking to improve participant, family and carer experiences, amending principles that directly referenced carers, ensuring that they aligned with the 'recognise and respect' terminology of the *Carer Recognition Act 2010*.<sup>1</sup> Despite this, carers have continued to report to Carers NSW that there is a lack of consistency in how they are treated within the NDIS, especially with regard to their opinion or feedback being valued and recognised.

### **Recommendation 1:**

A clear complaints and appeals mechanism be identified within the proposed Participant Service Guarantee.

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<sup>1</sup> Department of Social Services (2019), Improving the NDIS Experience: Establishing a Participant Service Guarantee and removing legislative red tape Discussion Paper, attachment C.

## Eligibility barriers

In several prior submissions on the NDIS, Carers NSW has raised concerns about the process of accessing the NDIS, particularly in regards to participant eligibility and its implications for families and carers. In a submission responding to the implementation of the NDIS and the provision of disability services in NSW, Carers NSW reported that a large number of people with disability, their families and carers were found to be ineligible for the NDIS or were otherwise prevented from testing their eligibility in order to qualify for a package.<sup>2</sup>

In some cases this has been a result of eligibility criteria being unclear or being applied inconsistently. The application of eligibility criteria in relation to certain conditions, such as cystic fibrosis, mild to moderate disability, episodic mental illness and degenerative and terminal illnesses continues to be contested and unclear. While some individual decisions have been subsequently appealed and overturned, these have not always resulted in precedent or policy change, maintaining uncertainty and inequity for other families in similar circumstances.

Evidence also suggests that for those denied access to the NDIS on an eligibility basis it is easier to prepare and submit a new application rather than filing for an appeal. Feedback to Carers NSW has indicated that a new application can be processed within three months, while due to a backlog of reviews pending an outcome, a review can take up to nine months. This raises concerns about the accuracy of data being captured about decisions being made by the NDIA that may have been otherwise overturned.

Carers and other stakeholders continue to report to Carers NSW that local area coordinators (LACs) and planners are not always equipped with adequate skills and experience to make sound and fair judgements as to a person's eligibility and support needs. In some cases, people with disability, their families and carers have not been able to acquire and submit adequate documentation and 'proof of disability' due to a lack of awareness of what is required among health professionals and the costs associated with obtaining some evidence.

Further, carers are not always provided with the opportunity to provide input or express their own needs, or if they are, this information is not necessarily captured or reflected in the participant's plan. This can be a particular problem for participants who require support with communication, including those with cognitive impairment and those from culturally and linguistically diverse (CALD) backgrounds.

Key groups that Carers NSW has identified as missing out on the NDIS due to eligibility barriers include:

- People with a condition that the NDIS would deem is health related rather than a disability, including people with degenerative diseases such as dementia, Parkinson's and Huntington's
- People with mild to moderate or episodic disability or mental illness which is just under the NDIS threshold or difficult to demonstrate
- People who do not meet the residency criteria for the NDIS
- People over the age of 65 who have a congenital, pre-existing or acquired disability (e.g. quadriplegia) that is not well accommodated by the aged care system

In many cases, individuals from these cohorts previously received support through a State or Commonwealth government funded program has transitioned, or is in scope to transition to, the NDIS - for example, the ADHC funded Community Care Supports Program (CCSP) or the DSS Personal Helpers and Mentors Program (PHaMs) - yet have not been able to move across. For example, a

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<sup>2</sup> Carers NSW (2018), submission to inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales (NSW).

recent report on the transition of people from Partners in Recovery (PIR), PHaMs and Day to Day Living (D2DL) identified that over a quarter of people who had applied were assessed as ineligible for the NDIS.<sup>3</sup> If these former recipients of government funded disability support, who often belong to vulnerable population groups and have complex needs associated with episodic or chronic health conditions, are not adequately supported, they risk ending up in inappropriate care situations, such as lengthy hospital stays or within unsustainable informal care arrangements, affecting carer health and wellbeing.

**Recommendation 2:**

- Policy changes be applied to clarify recurring eligibility barriers.
- Additional support be provided to people with disability, their families and carers to prepare evidence of disability.

### Other access barriers

Carers NSW has found via our research and consultation that considerable access barriers are preventing many people with disability who would likely meet the eligibility criteria from testing their eligibility and therefore from accessing the NDIS. These access barriers include negative past experiences leading to mistrust of government services, language barriers, cognitive impairment and/or reluctance to identify as having a disability, as well as system barriers such as digital literacy and financial resources.

Furthermore, many other carers are supporting someone who is eligible, or likely to be eligible, for the NDIS but are temporarily unable to access a package due to delays. Commonly identified causes of delays include system errors such as lost paperwork, incorrect advice or non-response, as well as misinformation and administrative waiting periods. Delays have been particularly problematic for the early childhood early intervention (ECEI) cohort, which has recently been addressed with the introduction of an interim \$10,000 plan if they are required to wait more than 50 days. Carers NSW recommends that interim packages be provided more broadly to ensure those facing delays are adequately supported.

**Recommendation 3:**

- Additional pre-planning support be provided to vulnerable groups.
- Interim supports be provided to eligible participants where processes are delayed.

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<sup>3</sup> Hancock, N., Gye, B., Digolis, C., Smith-Merry, J., Borilovic, J. & De Vries, J. (2019). *Commonwealth Mental Health Programs Monitoring Project: Tracking transitions of people from PIR, PHaMs and D2DL into the NDIS. Final report*. The University of Sydney & Community Mental Health Australia, Sydney.

## Planning

Since the commencement of the NDIS in NSW in 2013, carers have consistently reported to Carers NSW significant challenges at every stage of the planning cycle. Carers have identified difficulties with pre-planning relating to insufficient information. Many have reported unsatisfactory planning meetings due to a limited understanding of disability among LACs and planners. Carers have also identified limited consideration of carer input, needs and goals in the planning process, resulting in inadequate or insufficiently funded plans. Unexplained significant reductions in funding following plan reviews and excessive delays in accessing both scheduled and unscheduled plan reviews have also been raised frequently. Many carers have reported that their NDIS planning experiences have caused significant distress and resulted in increases in the direct care and support coordination they provide to the person they care for.

It is therefore unsurprising that the *NDIS Family and Carer Outcomes 30 June 2018*<sup>4</sup> report indicated that the self-reported health of family and carers of NDIS participants under 25 years of age declined after one year under the NDIS. The Carers NSW 2018 Carer Survey found that 61% of respondents caring for an NDIS participant (n=713) were spending more time organising supports for the person they care for since the full roll out of the NDIS across NSW in 2016.<sup>5</sup> Respondents further reported that although they appreciated the increased opportunities and supports that the NDIS provided for participants, the arduous administrative load associated with implementing the NDIS had been detrimental to their health, wellbeing and social and economic participation.

Carers NSW recognises the ongoing work done by the NDIA to improve NDIS planning, including the increase in specialist staff, introduction of participant pathways and ongoing simplification of processes. However, we also wish to highlight that further review and improvement of the planning cycle will be required if informal caring roles are to be strengthened and sustained.

Some carers have reported to Carers NSW that during planning meetings, NDIA representatives have asked inappropriate or condescending questions, causing distress and raising concerns about the limited awareness and understanding of NDIA representatives. Other carers have reported that costly assessments and subsequent recommendations from medical or allied health professionals have not been considered or included in the participant's NDIS plan. In many cases, carers have reported that no feedback was provided in regards to why recommendations were not implemented.

Additionally, the NDIS requires participants, their families and carers to actively request the supports and services that they need during the planning meeting. However, participants, their families and carers are not always aware of the supports needed by the participant to maximise their abilities or enable them to meet their goals. Carers may also not be aware of, or be able to articulate, the supports that they need to sustain their caring relationships and improve their own wellbeing or participation. Further, in many occasions, practitioners have recommended a certain number of support hours on assessment, and yet the NDIS plan has come back with fewer hours than identified, negating the role of experts in determining required support.

The *NDIS Family and Carer Outcomes 30 June 2018*<sup>6</sup> report indicated that following one year under the NDIS, there was an increase in the number of family members or carers of participants aged 0-14 years who knew what they could do to support their child's learning and development, and knew what specialist services were needed. However, approximately half reported that they do not know what they could do to support their child's learning and development and over half reported that they did

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<sup>4</sup> National Disability Insurance Agency (NDIA) (2019), *NDIS Family and Carer Outcomes 30 June 2018*. Available online at: <https://www.ndis.gov.au/media/1548/download>, last accessed 10 September 2019.

<sup>5</sup> Carers NSW (2018), *Carers NSW 2018 Carer Survey: Summary report*. Available online at: <http://www.carersnsw.org.au/research/survey>, last accessed 12 September 2019.

<sup>6</sup> National Disability Insurance Agency (NDIA) (2019), *NDIS Family and Carer Outcomes 30 June 2018*. Available online at: <https://www.ndis.gov.au/media/1548/download>, last accessed 10 September 2019.

not know what specialist services were needed to support development.<sup>7</sup> Similarly, more than half of families and carers for participants aged 15-24 were not able to identify the needs of the participant and how to access available supports and services to meet those needs, with lower rates for family and carers of participants with autism and intellectual disability.<sup>8</sup>

Many carers may therefore need the assistance of appropriately skilled NDIA representatives who are able to, through pre-planning and planning conversations, actively identify support needs or innovative ways to enable increased participation of both the participant and carer. If NDIA representatives do not have a thorough understanding of disability and the available interventions or supports to facilitate participants to meet their goals, or cannot appropriately defer to practitioner assessments and recommendations, they may not be able to effectively assist participants, families and carers to develop a thorough and holistic support plan that optimises the capability of the participant while ensuring the sustainability of informal supports.

**Recommendation 4:**

- LACs and planners receive more comprehensive training in specific disabilities and related needs.
- Practitioner assessments and recommendations be more closely reflected in the plan, or a written reason be provided.
- LACs and planners be trained and provided guidelines on consistent carer inclusion in the planning process.

## Thin markets

Carers NSW has previously raised concerns about thin NDIS markets and the implications this has for participants, their families and carers being able to use the supports that have been allocated in their plans. In response to the 2019 NDIS Thin Markets Project, Carers NSW drew on direct feedback from carers, particularly those based regionally and rurally, to highlight the difficulty participants, their families and carers were experiencing as they tried to access funded supports. This is and was largely due to the fact that services providers are experiencing significant challenges in maintaining their financial viability while providing services. Pricing and workforce limitations under the NDIS model, coupled with minimal service coverage in many large geographical areas have affected the sustainability of service provision in regional and remote areas. As a result, this threatens to reduce rather than increase choice and control of people living with disability in some parts of NSW, resulting in pressure on carers to fill service gaps.

Further, a 2016 study<sup>9</sup> of carers in regional NSW reported on their frustration with a lack of choice and availability of disability services in their community. This lack of choice and availability has resulted, in part, from existing service shortages and ongoing sector changes. The NDS *State of the Disability Sector*<sup>10</sup> report found that 13% of NDIS providers consulted had discussed closing in the past 12 months. Additionally, for some service providers, inadequate pricing has not only affected service quality, but has also resulted in them discontinuing services to some participants. Providers that continue to operate have reported that recruitment and retention difficulties are exacerbated in

<sup>7</sup> Ibid

<sup>8</sup> Ibid

<sup>9</sup> Galego, G., Dew, A., Lincoln, M., Bundy, A., Chedid, R. J., Bulkeley, K., Brentnall, J. and Veitch, C. (2017), 'Access to therapy services for people with disability in rural Australia: a carers' perspective', *Health and Social Care in the Community*, vol. 25, issue 3, pp. 1000-1010. <https://doi.org/10.1111/hsc.12399>.

<sup>10</sup> National Disability Services (2018), *State of the Disability Sector Report 2018*. Available online at: <https://www.nds.org.au/pdf-file/d3f2aa1f-52e9-e811-80cf-005056ac7853>.

regional and remote areas, with one provider reporting that they simply cannot meet the workforce demands.<sup>11</sup>

This pressure has been felt more acutely in recent times in NSW with a number of large, reputable and long-standing service providers withdrawing all or some of their services that were being provided through the NDIS. The cessation of these services, many of which cover large service areas and a range of service types, have contributed to even thinner markets nationally. In NSW, the recently announced withdrawal of Australian Unity from NDIS service provision in some areas of NSW, combined with ongoing regional and remote service shortages is placing additional strain on carers who, as a result, are required to provide additional direct care and spend additional time sourcing alternative, high quality services.

**Recommendation 5:**

- Consultation with providers withdrawing from the NDIS market to gain further insight into how to develop sustainable markets in regional and remote areas.
- Further clarification regarding how provider of last resort provisions may be implemented in the absence of ongoing state funded disability supports.

## Conclusion

Carers NSW commends the Department and the NDIA as they work to improve the experiences of participants, their families and carers at various stages of engagement with the NDIS. The review of the *NDIS Act* and its rules along with the proposed Participant Service Guarantee presents a valuable opportunity for the NDIA to improve the quality and consistency of access and eligibility, the creation and utilisation of plans and the administration of reviews. However, to ensure that the Participant Service Guarantee is truly effective, Carers NSW urges the Department and the NDIA to amend the current legislation to accurately mirror the Guarantee as well as clearly identify a redress mechanism participants and carers can easily access.

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<sup>11</sup> National Disability Services (2018), *State of the Disability Sector Report 2018*. Available online at: <https://www.nds.org.au/pdf-file/d3f2aa1f-52e9-e811-80cf-005056ac7853>.