

Carers NSW Questions on Notice

Implementation of the NDIS and provision of disability services in NSW

The question taken on notice by Sarah Judd-Lam, Manager, Policy and Research, Carers NSW was asked by the Hon. Shayne Mallard:

“On the same theme, you said that once people got used to the NDIS you might see a reduction in the transition role because we are focused on problems with the transition. Carers that are providing a coordination role are not being supported and that is a transition issue. I would like to focus on that. How big a problem is that? You did say it may well reduce once people get their systems set up, which might be the experience you are seeing already. Do you have some numbers around that?”

- Report on proceedings before Portfolio Committee No. 2 – Health and Community Services, 2 October 2019 (Uncorrected Proof)

Mr Mallard’s question seeks evidence on the extent to which carers are providing an unsupported coordination role during the NDIS transition, and whether this issue is likely to be resolved with time.

In order to provide data addressing Mr Mallard’s request for “numbers”, Carers NSW examined:

- Data from the Carers NSW 2018 Carer Survey (both unpublished and published in the recently released *Carers NSW 2018 Carer Survey: Summary report*)
- Data from the ABS 2015 Survey of Disability, Ageing and Carers
- Client data from our delivery of the Older Parent Carer Support Coordination, Mental Health Respite: Carer Support and NDIS Coordination of Support programs
- Published data regarding carers’ experiences of the NDIS

Unfortunately we were unable to find specific numbers or proportions of carers (whether in our survey sample, client group(s) or statewide) that might demonstrate a change over time in the categories addressed by Mr Mallard. However we have included further evidence on these matters below.

Context

Many carers are experiencing a significant increase in the administrative responsibilities of their caring role as a result of the NDIS transition. This is because ongoing, intensive case management no longer exists as a support type for people with disability under the age of 65 in NSW, and funding for Coordination of Supports under NDIS plans:

- does not appear to be allocated on a basis that adequately takes into account a carer’s situation and capacity to help a participant coordinate their supports
- assumes that the majority of participants receive a lower level of support with plan implementation from local area coordinators (but we have heard consistently that this often does not occur or is inadequate)
- is intended to be a time limited support, assuming that capacity will increase over time, and
- is often not adequately funded to meet the perceived needs of participants and their carers

Carers are doing more support coordination than they have before as a result of the NDIS, and this contribution goes largely unsupported

Carers NSW conducted a statewide survey of 1,830 carers in May to July 2018. Of the 63% of respondents who were caring for someone under the age of 65 years, the majority (61%) reported that the amount of time they spend each week organising support for the person they care for had *increased* in the past two years (i.e. since the full rollout of the NDIS in NSW commenced in July 2016) (see Figure 1). This majority was even more pronounced among the 713 carers who were caring for an NDIS participant, at 68% (see Figure 2).

Figure 1: Change in amount of time spent organising support in the past two years (all carers of under 65s)

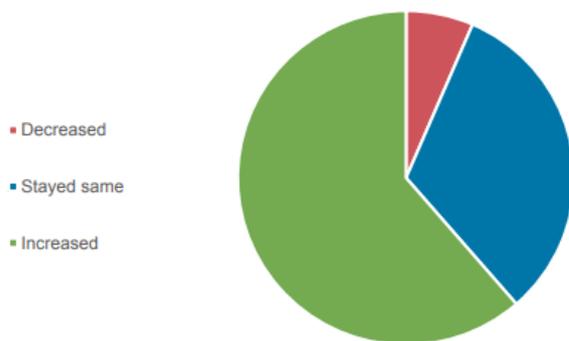
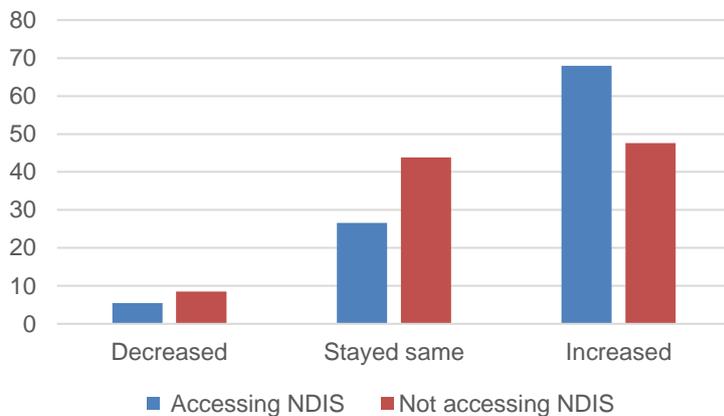


Figure 2: Change in amount of time spent organising support in the past two years (carers of NDIS participants compared to carers of under 65s not accessing the NDIS)



While 40% of carers of people under the age of 65 years said that the support the person they care for accesses had increased, this was much less often true of the support accessed by carers themselves (see Figure 3). Indeed, nearly one third of carers of people under the age of 65 years had experienced a reduction in support during this period (see Figure 3).

The survey did not specifically ask about the allocation of coordination of support funding, however, it did ask to what extent carers had been asked about their own needs in the planning process (see Figure 4). While the majority (72%) of respondents to this section agreed that they had been included in the planning process, just over one third (38%) indicated that they had been asked about their own needs.

Figure 3: Change in access to support over the past two years (care recipient vs. carer)

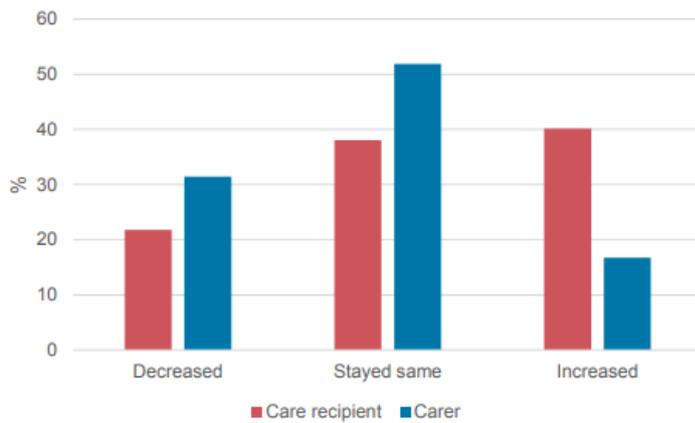
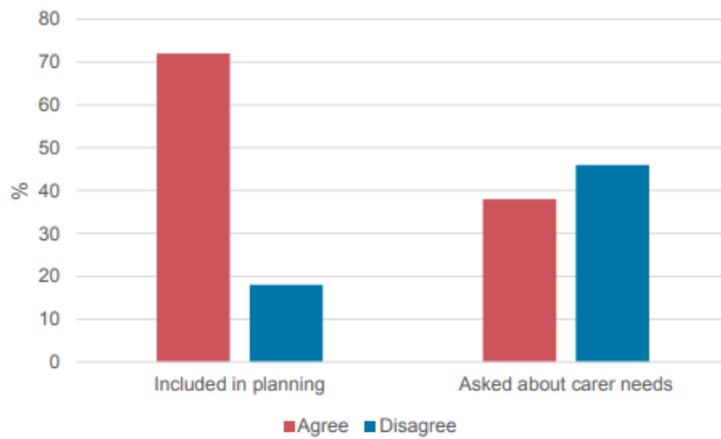


Figure 4: Carer inclusion in NDIS planning



These findings are supported by other publications, including the National Institute of Labour Studies evaluation report on the NDIS¹, which found that access to supports for family members and carers to directly assist them in their caring role was limited under the NDIS and many carers of NDIS participants reported that their own needs and those of the family more broadly were not addressed in the planning process.

A Carers Australia survey and focus groups undertaken in 2015 also found that many carers reported the plan did not meet the needs of the participant, were confused about how to implement NDIS plans and were not given direction or support about their next steps. On the whole, respondents did not believe NDIS supports reduced the hours of care they were required to provide.²

¹ Mavromaras, K. et al (2018) *Evaluation of the NDIS: Final Report*, available online at: <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/national-disability-insurance-scheme/ndis-evaluation-consolidated-report>, last accessed 18 October 2018.

² Carers Australia (2015) *NDIS Carer Capacity Building Project: Survey findings*, available online at: <http://carersaustralia.com.au/storage/carers-australia-report-on-ndis-survey-findings.pdf>, last accessed 18 October 2018.

This appears to be a particular feature of the transition period, but may or may not continue to be a problem for carers

The Carers NSW 2018 Carer Survey also asked carers of under 65s whether they had had any difficulty accessing the NDIS, and if so to describe their experience. Carers NSW is still in the process of analysing this large, qualitative dataset so cannot provide decisive numbers on the carers who raised this specific issue, however it is of interest to note that, according to early analysis it appears that:

- Approximately 22 respondents cited that the NDIS process as a whole was long, time consuming and difficult to navigate, with a further 16 highlighting its stressful nature and another 8 describing it as confusing.
- Approximately 46 respondents reporting long waiting times, 14 described too much paperwork, 16 cited a lack of service availability and a further 16 indicated difficulties using funds.
- Approximately 44 respondents reported that the support funded in the participant's plan was inadequate in relation to their needs
- Approximately 41 referred to long waiting times for plan reviews, and 8 specifically to inadequate funded supports following plan review.

These findings support carer case studies collected by the Carers NSW Policy Team since 2013, and the findings from three focus groups conducted with carers of NDIS participants in 2016 and 2017. They also indicate that complexity and waiting times appear to apply to both the planning process and to subsequent plan reviews, suggesting that regardless of what stage of the process carers are in, they may still be undertaking considerable support coordination responsibilities.

Three de-identified case studies featuring clients of Carers NSW programs are included below to demonstrate the significant impact a lack of funded support coordination can have on carers:

Amy cares for her 8 year old daughter Jessica who lives with physical and psychosocial disability. Amy was happy to self-manage Jessica's plan in order to have flexibility to engage with providers for Jessica, but wanted funded coordination of supports to provide continuity while she was learning to navigate the NDIS and engage with providers. This was not included in the plan, and the plan implementation support that was meant to be provided by the LAC was inadequate. As a result, Amy was unable to return to work.

Pamela cares for her adult son James who lives with intellectual and psychosocial disability. Pamela also supports her daughter who experiences substance abuse and lives with a mental illness, and Pamela has her own health issues that limit her mobility. While coordination of supports was included in James' first plan, this was not the case with later plans and Pamela struggled to manage her caring responsibilities, her own health and the many service bookings and payments she had to juggle in implementing James' plan.

Elizabeth cares for three sons, two of whom have NDIS plans. Initially Elizabeth's youngest son had no coordination of supports funding in his plan. Elizabeth was distressed as she didn't understand the new system, had limited supports herself, and was also caring for her elderly parents.

Carers NSW anticipates that once the NDIS settles in, and once carers and participants are onto their third and fourth plans, the organisation carers are required to undertake may reduce in many cases. However, while the eligibility criteria and duration of funded coordination of supports remain limited, the administrative burden experienced by many other carers is likely to continue.