



## **Position paper: NDIS Reasonable and Necessary Supports – the Case for Respite**

**October 2018**

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

## **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

Carers Australia believes 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.

### **For information contact:**

Ms Ara Cresswell  
Chief Executive Officer  
Carers Australia  
Unit 1, 16 Napier Close  
DEAKIN ACT 2600  
Telephone: 02 6122 9900  
Facsimile: 02 6122 9999  
Email: [acresswell@carersaustralia.com.au](mailto:acresswell@carersaustralia.com.au)  
Website: [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

## WHAT DO WE MEAN BY RESPITE?

Fundamentally respite provides an opportunity for carers and those they care for to take a break from each other.

Respite services can include:

- alternative supported accommodation for the person being cared for in an emergency when the carer is not in a position to provide care
- paid replacement care being offered in the home
- community based day centre activities for the person being cared for
- the opportunity to take a break overnight, over a weekend or even a number of weeks when alternative supported accommodation is available for the person being cared for
- the ability to take a break or holiday with the person being cared for accompanied by a paid carer.

## WHY DO CARERS NEED RESPITE?

Carers often put in years of constant care, especially if they are primary carers (those who provide the most substantial amount of care).

According to the 2015 Australian Bureau of Statistics Survey on Disability, Ageing and Carers (SDAC), 26 percent of primary carers had been caring for between 5 and 9 years and 28 percent had been caring for between 10 and 24 years. In terms of hours of care provided, 33 percent were providing care for 40 hours or more per week and 19 percent for between 20 and 39 hours. Parents of the person being cared for (including parents of adult children) were most likely to provide the most substantial amount of care (47 percent caring for 40 or more hours per week).<sup>1</sup>

Carers report that the provision of care can be very stressful. Australian Bureau of Statistics (ABS) 2012 data reveals that 50 percent of primary carers identified that caring has one or more negative impacts on their physical or emotional wellbeing. Thirty-six percent indicated they were weary and lacked energy. Twelve percent said they frequently felt angry and resentful. Forty-eight percent reported having interrupted sleep. Twelve percent had been diagnosed with a stress related illness.<sup>2</sup>

The capacity to take some time off can provide carers with a period of relief from such stressors and an opportunity to re-charge their batteries. Replacement care in the home can provide opportunities to catch up on much needed sleep. It can also contribute to their capacity to provide quality care.

As the Productivity Commission noted in its report on NDIS costs:

---

<sup>1</sup> Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers (SDAC), 2015, Table\_40.3  
<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>

<sup>2</sup> Australian Bureau of Statistics (ABS), Caring in the Community, 2102, Table 27  
<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4436.0>

“Internationally, respite services are recognised as both improving the wellbeing of carers, improving the quality of care to people with disability, and reducing costs to governments (OECD 2011, pp. 127–129).”<sup>3</sup>

From the perspective of the person being cared for, a short period in respite care can provide them with the opportunity to experience a new environment, to make new social connections and, in some cases, develop new skills. It can also provide them with a break from their families and carers. People living in a close proximity day-in and day-out can benefit from some periods of absence and interaction with other people. Carers and people with disability are no exception.

## A SHORT HISTORY OF RESPITE IN THE NDIS

While respite was not a service mentioned under the NDIS legislation, the Act does acknowledge that the provision of support needs to take into account what it is reasonable to expect families, carers and informal networks to provide.”<sup>4</sup> The Act also refers to building and strengthening the capacity of families and carers to support participants.<sup>5</sup>

These provisions invite the question: Is it reasonable and necessary for carers to provide very high levels of care over an extensive period of time without being supported to take a break from caring?

As the NDIS has evolved, the answer to these questions has waxed and waned.

For example, in 2014 the NDIA developed a guideline entitled ‘Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Sustaining Informal Support’. This Guideline identified that carers could access three levels of “respite-like” supports for funding as part of a participant’s plans:

- Level 1: 7 to 14 days per year to allow the carer to attend key activities
- Level 2: 14 to 28 days per year and includes a strategy to build capabilities for future independence
- Level 3: Equivalent of 28 days per year, when the carer provides support most days and informal support is at risk of not continuing due to the intensity of the support required or severe behavioural issues.

At some time, we are not sure exactly when, this guideline suddenly disappeared from the NDIS website without notice.

Subsequently, the NDIA issued the ‘Plain English Guide to Supports for Families and Carers under the NDIS’. This guide made it clear that: “if carers and families have need of supports and services in their own right they are directed to find them through other government programs”. This guideline has also disappeared from the NDIA website.

---

<sup>3</sup> Productivity Commission, National Disability Insurance Scheme (NDIS) Costs, October 2017, p.355

<https://www.pc.gov.au/inquiries/completed/ndis-costs/report>

<sup>4</sup> National Disability Insurance Scheme Act 2013, Number 20, 2013, Section 34 (e)  
<https://www.legislation.gov.au/Details/C2013A00020>

<sup>5</sup> National Disability Insurance Scheme Act 2013, Number 20, 2013, Part 2, Division 2, Section 31 (d) and (da)  
<https://www.legislation.gov.au/Details/C2013A00020>

The current position is that respite is not identified as a support anywhere in the NDIS, but there is a somewhat oblique reference to something that can constitute respite in the Price Guide:

“Short Term Accommodation and Assistance: From time to time, participants may require temporary supports that are different from their usual arrangements. These are nontypical days and may include short stays in a group-based facility (short term accommodation), or the purchase of additional in home support.”<sup>6</sup>

(Note that the 2017 version of this guideline actually included the word “respite”<sup>7</sup>, but it has subsequently been deleted.)

We note that currently approximately 1.3 per cent of NDIS participants access short term accommodation supports.<sup>8</sup>

## **WHY IS RESPITE NOT ACKNOWLEDGED AS A SERVICE IN THE NDIS?**

We believe this comes down to three major causes:

- The belief that NDIA packages will provide so much support for people with a disability that carers won't need access to formal respite. They will get sufficient rest periods as a by-product of the services to the people they are caring for.
- The belief that carers of NDIS participants can get access to planned respite in their own right through carer services such as those brokered by the Commonwealth Respite and Carelink Services (CRCC) or through state-based services.
- The view that respite from caring can be regarded as a pejorative term which is insulting and hurtful to people with disability. Therefore, it must not be used.

These views are explored below.

## **DOES THE NDIS REMOVE THE NEED FOR REGULAR BREAKS OR RESPITE?**

We can find no evidence to support this as a general proposition.

In May 2013 the Australian Government Department of Social Services (DSS) commissioned a consortium led by the National Institute of Labour Studies (NILS) at Flinders University to conduct the evaluation of the trial of the NDIS, which it did over four years. In its Final Report, it concluded that:

“In the quantitative survey, carers reported high levels of dissatisfaction with family support to relieve stress, the availability of outside help to take care of all family

---

<sup>6</sup> National Disability Insurance Agency (NDIA), 2018-19 Price Guide for NDIS service providers – Beginning 1 July 2018, <https://www.ndis.gov.au/providers/pricing-and-payment>

<sup>7</sup> National Disability Insurance Agency (NDIA), NDIS Price Guidelines: Victoria, NSW, Queensland, Tasmania, Valid from 1 July 2017 <https://www.ndis.gov.au/medias/documents/h0b/h20/8802195243038/201718-VIC-NSW-QLD-TAS-Price-Guide.pdf>

<sup>8</sup> NDIA spokesman quoted in Probono news September 2018 [https://probonoaustralia.com.au/news/2018/09/family-faces-devastating-loss-support-son-disability/?utm\\_source=Pro+Bono+Australia+-+email+updates&utm\\_campaign=b4f3e9159a-EMAIL\\_CAMPAIGN\\_2017\\_08\\_18\\_COPY\\_01&utm\\_medium=email&utm\\_term=0\\_5ee68172fb-b4f3e9159a-147226889&mc\\_cid=b4f3e9159a&mc\\_eid=9d9cbeed9d](https://probonoaustralia.com.au/news/2018/09/family-faces-devastating-loss-support-son-disability/?utm_source=Pro+Bono+Australia+-+email+updates&utm_campaign=b4f3e9159a-EMAIL_CAMPAIGN_2017_08_18_COPY_01&utm_medium=email&utm_term=0_5ee68172fb-b4f3e9159a-147226889&mc_cid=b4f3e9159a&mc_eid=9d9cbeed9d)

members, opportunities to pursue their own interests, and the availability of friends or other people to provide support.”<sup>9</sup>

The other major source of statistical data we have available to us on the impact of the NDIS on carers is through the NDIS Quarterly Reports to the Council of Australian Governments (COAG).

The Agency uses an outcomes framework questionnaire as one of the key tools to assess the medium and long-term benefits of the Scheme. This survey provides a small number of questions relating to the circumstances of families and carers of NDIS participants, including their capacity to work and their wellbeing.

For example, the June 2018 Quarterly report<sup>10</sup> identifies the percentage of families/carers who rate their health as good, very good or excellent as follows:

- family/carers of participants aged 0-14 = 73%
- family/carers of participants aged 15 to 24 = 62%
- family/carers of participants aged 25 and over = 60%

However, health is not the only indicator of well-being and the data above suggests that about a third of carers across these groups do not enjoy good health.

Similarly, the percentages of families/carers who say they (and their partner) are able to work as much as they want are:

- family/carers of participants aged 0-14 = 47%
- family/carers of participants aged 15-24 = 42%
- family/carers of participants aged 25 and over = 67%

But over 80 percent of the large number of carers who say they can't work as much as they want identify that “the situation of their child/family member with disability is a barrier to working more”.<sup>11</sup>

While this is very partial data, it does suggest that a very large number of carers of NDIS participants are likely to be in situations where they could benefit from a break.

## **CAN CARERS OF NDIS PARTICIPANTS GET RESPITE FROM CARER SERVICES OR OTHER DISABILITY SERVICES?**

Frequently they can't.

Before the NDIS was introduced carers were able to access planned respite through a number of national and state programs. These are often no longer available to them. In some cases, the funding for these programs is being or will be transferred to the NDIS as part of state or national

---

<sup>9</sup> National Institute of Labour Studies (NILS), Evaluation of the NDIS; Final Report, February 2018, p.147

[https://www.dss.gov.au/sites/default/files/documents/04\\_2018/ndis\\_evaluation\\_consolidated\\_report\\_april\\_2018.pdf](https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf)

<sup>10</sup> NDIS, COAG Disability Reform Council Quarterly Report 30 June 2018, p.37 <https://www.ndis.gov.au/medias/documents/coag-report-q4-y5-full/2018-Q4-June-COAG-report-Full.pdf>

<sup>11</sup> NDIS, COAG Disability Reform Council Quarterly Report 30 June 2018, p.37 <https://www.ndis.gov.au/medias/documents/coag-report-q4-y5-full/2018-Q4-June-COAG-report-Full.pdf>

contributions to the Scheme. In other cases, where programs are continued, carers lose access to them if they are caring for someone in the NDIS.

## **OBJECTION TO THE TERM “RESPIRE”**

It is the view of the Independent Advisory Council on the NDIS, as expressed in its advice on reasonable and necessary supports, that the word respite is insulting or hurtful to people with disability.<sup>12</sup> They refer to the Oxford Dictionary definition of respite as “a short period of relief from something difficult or unpleasant”.<sup>13</sup> (We note that the Oxford Living Dictionary Thesaurus synonyms for ‘respite’ have less negative connotations: “a rest, break, breathing space, interval, intermission, interlude, recess, lull, pause, time out, hiatus, halt, stop, stoppage, cessation, discontinuation, standstill, relief, relaxation, repose”.)<sup>14</sup>

The NDIA has noted the advice of the Independent Advisory Council. As they explained in their submission to the Productivity Commission’s Inquiry into NDIS costs: “On the advice of the Independent Advisory Council (IAC) ‘respite’ is not a distinct service listed in participant plans.”<sup>15</sup>

## **WHAT ARE THE PRACTICAL IMPLICATIONS FOR CARERS OF AVOIDING THE WORD ‘RESPIRE’?**

Prior to their engagement with the NDIS, a great many carers have been accessing a service called respite for many years.

They do not use it in any pejorative sense.

It is the word they are familiar with. It is the word used in aged care. It is the word used in the Department of Social Services guidelines identifying the number of days someone on the Carer Payment is entitled to take a break from providing constant care. It is the word used when carers access supports from Commonwealth Respite and Carelink Centres (CRCCs) and other national and state programs which give them the opportunity to take a break. It is the word that will continue to be used when the new Integrated Carer Support Services initiative, which will offer emergency respite, is rolled out. It is the word used by a great many service providers. It is a word carers who have engaged in the carer support system understand.

So when carers and those they care for come to the NDIS requesting that they would like respite support to be included in the package of supports, they tend to be surprised and distressed to be told by planners that this form of support is not available – especially when it was before they entered into the world of the NDIS.

Carers Australia has been approached by many older parent carers, in particular, who tell us they have only been able to continue providing care over decades because they have had access to respite services and that, now they are older, they need them more than ever

---

<sup>12</sup> Independent Advisory Council to the NDIS (IAC), Reasonable and Necessary Supports for Families (Advice), October 2014, <https://static1.squarespace.com/static/5898f042a5790ab2e0e2056c/t/5b1a02b62b6a286703f766f6/1528431291173/Reasonable+and+Necessary+Support+for+Families.pdf>

<sup>13</sup> <https://en.oxforddictionaries.com/definition/respite>

<sup>14</sup> <https://en.oxforddictionaries.com/thesaurus/respite>

<sup>15</sup> Productivity Commission, National Disability Insurance Scheme (NDIS) Costs, October 2017, p.355  
<https://www.pc.gov.au/inquiries/completed/ndis-costs/report>

before. They are totally nonplussed when we tell them that “respite” is considered a bad word in the NDIS.

Other carers who have a deeper knowledge of the NDIS and its language can, in a roundabout way, get the outcome they are seeking. In the words of one carer who had been denied respite:

*What I've learnt over the last year rather than pushing, this sounds terrible, rather than pushing a point I'll just change it. I'll just change it so it fits...What I did was then ask for a support worker to help build his independence skills, teaching life skills, catching a bus, working out change, telling the time and that got approved.<sup>16</sup>*

Recognising that people with disability may be offended by its use, the term could be discouraged over time as NDIS planners work with participants and carers.

In the meantime, avoidance of the term within the NDIS is producing inequitable outcomes for carers based on their knowledge of NDIS language and processes.

## RECOMMENDATION

Carers Australia supports the recommendations of the Productivity Commission in relation to respite. These are:

“The National Disability Insurance Agency should:

- ensure planners take into account the amount of respite care that is reasonable and necessary under an individualised support package, based on the amount of informal care that is expected to be provided by informal carers
- label short-term accommodation supports provided in participants’ plans in a way that makes it clear that these supports can be used for respite
- better inform participants and their informal carers that core supports provided in individualised support packages can be used to fund additional in-home care or support in shared facilities to provide respite
- include specific measures to ensure a supply of respite services in its provider of last resort policies.”<sup>17</sup>

However, if the NDIA continues to resile from the word “respite”, then the only resolution which does not arbitrarily disadvantage carers who do not ‘speak NDIS’ is to send clear and explicit instructions to planners that the use of the word must not result in a refusal to consider this kind of support. Instead planners should be specifically instructed to explain to those carers and participants that respite is not in the NDIS lexicon, but that their requests may be operationalised if they ask instead for short-term accommodation for the participant or additional paid care replacement in the home.

---

<sup>16</sup> National Institute of Labour Studies (NILS), Evaluation of the NDIS; Final Report, February 2018, p.139

[https://www.dss.gov.au/sites/default/files/documents/04\\_2018/ndis\\_evaluation\\_consolidated\\_report\\_april\\_2018.pdf](https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf)

<sup>17</sup> Productivity Commission, National Disability Insurance Scheme (NDIS) Costs, October 2017, p.58

<https://www.pc.gov.au/inquiries/completed/ndis-costs/report>