



Submission

Productivity Commission Position Paper National Disability Insurance Scheme Costs

12 July 2017

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.

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Submission on the Productivity Commission Position Paper: National Disability Insurance Scheme Costs, June 2017

Introduction

Carers Australia and the Network of State and Territory Carer Associations broadly support the recommendations of the Productivity Commission's Position Paper on National Disability Insurance Scheme (NDIS) Costs.

We are particularly gratified that the Position Paper has incorporated many of the comments and concerns that were raised in relation to family and friend carers in our submissions to the Discussion Paper.

These include:

- ageing parent carers are a vulnerable cohort
- not all carers will be able to provide ongoing care
- respite may be critical in sustaining care arrangements
- there is inadequate respite
- forgone wages can be a barrier to sustainable caring arrangements
- carers are finding the NDIS difficult to understand, which will compromise its effectiveness
- concerned providers are having to provide hours of unpaid preplanning and support coordination due to inadequate funding of these supports in plans
- gaps are falling to carers to fill, contrary to the scheme's objective
- continuity of support is not being consistently applied
- there has been a perceived reluctance from the Agency to address service gaps
- the reiteration of the Commission's 2011 *Disability Care and Support Inquiry Report* recommendation that carer support needs be assessed as part of the planning process
- long-term costs (e.g. costs to carer wellbeing) should be considered above and beyond short term costs.

At a more general level, especially welcome are recommendations for:

- further clarity around what constitutes 'reasonable and necessary' supports
- improving the transparency and quality of planning processes to become more participant/carers friendly and responsive (including more face-to-face communication)
- greater use of specialised planning teams
- simplifying review processes
- ensuring that LAC workforces are established prior to NDIA roll-out

- funding for ILC be increased until full scheme rollout
- states and territories to make public, and fully transparent, their commitment to continuity of support beyond the support provided by the NDIS and bear the cost of participants who were intended to be covered by the National Injury Insurance Scheme (NIIS)
- introduction of an independent price monitor and price regulator
- implementation of an E-Market place
- phasing out of in-kind funding beyond transition.

In this submission, we have focused on recommendations and questions posed in the Position Paper on two areas of fundamental significance to carers:

1. The impact of the NDIS on access to respite services and policy changes required to improve such access, both for carers of NDIS participants and carers of people with a disability who are not NDIS participants.
2. The payment of family and friend carers in thin markets where replacement care (or appropriate replacement care) is not available.

1. Respite

INFORMATION REQUEST 7.2

How has the introduction of the National Disability Insurance Scheme affected the supply and demand for respite services? Are there policy changes that should be made to allow for more effective provision of respite services, and how would these affect the net costs of the scheme and net costs to the community?

The Commission's concerns in relation to the impact of the NDIS on the availability of respite is most welcome. Carers Australia has been advocating in relation to this issue ever since we became aware of the initial bilateral agreements which soak up existing carer funding for respite and other carer services and which subsequently have led to access constraints on existing carer support programs.

From the very beginning, we were told that respite was not a service available under the NDIS and the term has been avoided within the NDIS lexicon (with the exception of one operational guideline which was released early in 2014 on **Planning and Assessment – Supports in the Plan – Supports for Sustaining Informal Support (v 1.0)** which is discussed below).

The NDIS position has been that carers get a respite-like benefit to the extent that replacement care and activities for the person being cared for mean that the carer is no longer responsible for providing care for set periods and that this is sufficient to meet the carer's need for a break. This simplistic presumption has been hotly contested by both carers and carer support organisations. In some cases it may be that packages do provide a significant break from caring. However, the National Institute of Labour Studies' (NILS) evaluation of the NDIS found that family and friend carers at the time of their surveys were still providing the most substantial amount of care.

"The quantitative data indicates that the overwhelming majority of NDIS participants need assistance on a daily basis. The most frequently mentioned person that assists NDIS participants was their own mother or father."¹

"The family members and carers data paints a picture of support provided primarily by close family members to NDIS participants. Support is intense in that it often involves long periods of uninterrupted support activity, with long hours every day, involving many different types of supports."²

One factor which is likely to be contributing to this trend is that initial plans under NDIS are developed to simply continue to provide current levels of care that the recipient requires. 'Reasonable and necessary' has been interpreted as retention of the status quo in many cases.

¹ National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page XIV

² National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page 57.

Moreover, the provision of short breaks from the weekly schedule of caring does not mean that carers do not need longer breaks from time to time, as is recognised in conditions relating to respite in the *Guide to Social Security Law*, which does not count short periods of care (of less than 24 hours) provided by another person or organisation against the respite entitlements of people in receipt of the Carer Payment or Carer Allowance.³

So, to what extent are carers getting respite through the packages of those they care for under the NDIS? The answer is that this is not shown in NDIS service data (as opposed to surveys inclusive of carers), partly because the NDIS avoids the term “respite”. When Carers Australia has sought information on the degree to which respite for carers has been provided through packages, we have been presented with charts which identify at a totally undifferentiated level the usage of paid care in packages. There has been no breakdown of whether package recipients using paid care actually have carers, which makes the data unusable for determining the extent to which carers have benefited from a respite-like effect through replacement care.

What we do know from the National Institute of Labour Studies', *Evaluation of the NDIS, Intermediate Report* is that:

“both the quantitative and qualitative data indicate that many family members and/or carers of NDIS participants are unable to take adequate breaks from providing support and they cannot access carer support in a consistent manner.”⁴

This finding is consistent with feedback from carers from across our Network of Carer Associations.

The impact of the NDIS on carers accessing respite in their own right outside the NDIS

The Plain English Guide to Supports for Families and Carers under the NDIS makes it very 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” (<https://www.ndis.gov.au/families-carers/information-families-and-carers.html>).

The problem is that, as part of the initial bilateral agreements, the Commonwealth Government committed funding from three dedicated carer support programs - which include the provision of respite, information and referral, and counselling - for transition into the NDIS

³ Australian Government, *Guide to Social Security Law*, version 1.234 – released 3 July 2017, 3.6.4.40 Qualification for CP during Temporary Cessation of Care and 3.6.7.50 Qualification for CA during Temporary Cessation of Care

⁴ National Institute of Labour Studies, *Evaluation of the NDIS, Intermediate Report*, 2016, page 19

funding pool.⁵ In 2015-16, the funding for these programs was \$78.628m and constituted about 46 per cent of total Department of Social Services carer support funding in 2015-16.⁶

The approach under the new operational guidelines pertaining to these programs has been to progressively transition this funding to the NDIS over the three years to full roll-out, commencing 1 July 2016. This means that block funding for providers of services to certain carers will reduce in line with the transition schedule for the area their services cover. This, in turn, means that carers of package recipients will not get access to this funding. A carer who supports someone who is not, and will not be, NDIS eligible or who is testing eligibility or waiting for plans, will be able to access these services under Continuity of Support (CoS) arrangements up until full roll-out (when all the funding will have transitioned). New clients will not.

It should also be noted that carers are also losing access to respite services funded by state governments. For example, Carers NSW reports that Ageing, Disability and Home Care (ADHC), part of the NSW Department of Family and Community Services, is completely transitioning to the NDIS and will no longer exist from July 2018. ADHC currently funds a range of respite service types, including: own home respite, host family respite, peer support activities, flexible respite, Aboriginal flexible respite, after school and vacation care, respite camps, centre-based respite, specialised centre-based respite and emergency respite. In addition, ADHC funds the Together Program for disability carer support groups, which offers peer support and recreation to carers that can have a respite effect. The Older Parent Carer Support Coordination program, delivered by Carers NSW and nine other NGOs, also offered some flexibility for peer support and recreational activities to be funded, including retreats in some areas, which a number of carers reported were a critical form of respite for them.

Carers ACT also reports the loss of territory funded respite. Carers ACT was funded through the ACT Government to provide respite care through two properties, particularly 24-hour and overnight respite care. Under the NDIS transition funding for this was ceased. A viability study by Carers ACT found that the services were not sustainable under NDIS plans, particularly given that users of the service for many years were not receiving funding supports for respite in their NDIS plan. Carers ACT has subsequently closed the respite houses. This has left the Territory with very limited options for overnight respite for both carers and care recipients. The main cohort of carers affected by this decision are those who are over 65 years of age and are providing care for adult children who still reside in the family home.

What to do?

Option 1

The simplest solution would be for respite care to be made available to carers outside the NDIS, regardless of who they care for, including whether or not they care for a package recipient. Over the past two years, the Department of Social Services has been co-designing

⁵ These programs are Mental Health Respite; Carer Support (MHR:CS), Respite Support for Carers of Young People with Severe or Profound Disability (RSCYP) and 18 per cent of Young Carers Respite and Information Services (YCRIS)

⁶ Calculated on the basis of Carer Support Programs funded by the Department of Social Services identified in Department of Social Services, *Designing the new integrated carer support service, Discussion Paper 1, Appendix B, May 2016*

a new Integrated Carer Support Service (ICSS) system to address some of the fragmentation of nationally funded carer services. This fragmentation resulted partly from the aged care and disability care reforms and also as a result of the establishment of special programs for different categories of carers that have evolved over time.

It is expected that the ICSS program will be block funded. However, ICSS does not yet have Government endorsement and it can be expected that, if it does get that endorsement, it will be some years until it is fully implemented. In the meantime, transition arrangements which keep current funding to providers going will need to continue.

A central concern is that it is not expected that the ICSS will attract much additional funding beyond that which is currently available to carers in their own right, and a very substantial proportion of that funding is being transferred to the NDIS. Its capacity to meet the needs of a growing body of carers of people both over and under the age of 65 years will be severely compromised with the loss of that funding. Under these circumstances, it seems appropriate that the funding for carer support programs transitioning to the NDIS be reinvested in the ICSS program. Alternatively it needs to be compensated for through the provision of matched funding.

Option 2

An alternative is to make respite and other supports for carers of NDIS participants available to carers in their own right. This could be through the participant's package on the basis of their own assessed needs (and not just also on the basis of whether it serves the interests of the person with disability). Indeed, the Commission's 2011 *Disability Care and Support Inquiry* recommended that the needs of carers be considered as part of a participant's individualised supports.⁷ However, such funding must also be available outside plans, particularly for carers of people not receiving package supports under the NDIS.

As with Option 1, the quantum of carer program funding being transferred into NDIS funding would need to be restored to meet the needs of carers. How that funding would be divided between NDIS funded services and general carer funded services is not clear to us at this stage.

An additional issue which would need to be resolved where carers are supported through the NDIS (and which is raised in the Commission's Position Paper) is whether the current caps on respite access under the 2014 **Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Sustaining Informal Support (v 1.0)** are appropriate. Under this Guideline, it is stated that support arrangements on non-typical days may include funding to provide replacement support, or respite, in group based facility or in-home support. Three levels of such support arrangements are identified:

- Level 1 – between the equivalent of 7 and 14 days per year where the family otherwise provides support most days. This support is provided to the participant so that the family or informal carers can attend key activities relevant to other members of the family, or
- Level 2 – between the equivalent of 14 and 28 days per year where respite includes a strategy to build capabilities for future independence, or

⁷ Productivity Commission Inquiry Report, *Disability Care and Support, Overview and Recommendations*, No. 54, 31 July 2011, page 11

- Level 3 - the equivalent of 28 days per year where the family provides support most days and informal support is at risk of not being able to be sustained because of severe behavioural issues or where the person requires intensive support.

It is also advised that some levels of additional support may be justified in circumstances where: the participant has unstable sleep patterns, suction or invasive medical supports are required, the participant needs extensive behavioural management, where there are multiple children with a disability in the household, or where assistance activity is needed overnight. This very attenuated and prescriptive list of special circumstances, which is all about the condition of the person being cared for and makes no reference to carers' needs, is something of a puzzle to us.

Moreover, carer associations report that they have seen very few cases where the levels of respite which are technically available under the NDIS guidelines are actually included in plans. Generally any 'respite' entitlements are included in the support cluster for assistance with daily living and are not clearly identified as respite support.

Whether respite entitlements under the Guideline are used or not, the caps on respite are certainly ungenerous compared to respite entitlements in aged care and days of care required to receive the Carer Payment and/or Carer Allowance, both of which allow for 63 days of respite per year without restrictive pre-conditions. Indeed, it introduces conflicting entitlements for someone who cares for an aged person *and* an NDIS eligible person with disability under the age of 65 years. As can easily be imagined, a carer in this situation would have a particularly high need for respite, as would be the case for any carer who cares for multiple people with disability in the house *whether or not* they happen to be children. Similarly, the NDIS rules introduce a conflict of entitlements for a carer who is receiving Carer Payment and is caring for someone who is an NDIS participant.

Summary

Limitations on access to flexible respite to assist carers to meet their own needs under the NDIS must be resolved. The fiction that the NDIS effectively serves all the legitimate needs of carers through services to those they care for must be abandoned, especially given that package funding constraints and service gaps clearly are not meeting the needs of many participants and it is unclear how and when they might do so in the future.

Both options to address the situation identified above are likely to impact on Scheme funding (unless, in the case of Option 1, the Government is prepared to commit significant funding additional funding to the Integrated Carer Support Service Program to compensate for the loss of carer support funding diverted to the NDIS.)

However the extent to which the diversion of funding for support to carers in their own right would drive up NDIS costs as opposed to the current funding pool would need to be calculated against the risk that under-supported family and friend carers would no longer be able to provide current levels of care and would need to be replaced by paid carers.

2. Paying co-resident family and friend carers

DRAFT RECOMMENDATION 7.3

The National Disability Insurance Agency's (NDIA) guidelines on paying informal carers who live at the same residence as a participant should be relaxed for core supports for the period of the National Disability Insurance Scheme (NDIS) transition. Such payments should be:

- accessible under clearly defined and public guidelines, which make reference to worker shortages in the relevant market using the NDIA's information about providers and supports in the participant's region
- set at a single rate determined by the NDIS price regulator in a transparent manner
- reviewed by the NDIA as part of plan reviews.

The issue of paying co-resident informal carers to provide care to family members or friends is the subject of some controversy across the carer, disability and aged care sectors.

Many family and friend carers would regard being paid to care for a loved one as anathema and possibly an extra source of relationship strain within the family. Among those who are anxious about the consequences of family carer employment, the possibility that carers will become even more entrenched in their caring role is often raised. As noted in a cross-national study of 'cash for care' schemes:

“[I]n this type of 'job' it is particularly difficult to exit – should these care-givers or care-users decide that they would prefer an alternative form of care (e.g. residential care or a different care-giver), then these relationships are now even more difficult to leave, since to do so would incur direct economic costs as well as emotional costs.”⁸

Further, paying informal carers can create extra burdens, particularly if it assumes that it will be in addition to the care already provided, or carers feel that receiving payment means they should be doing more than they are already.

However, we know from consultations around the NDIS, that other carers and those they care for regard the option to choose to pay family or friend carers, in preference to a worker who they believe would not provide the same standard and quality of highly personal holistic care, is a key element of choice and control.

Having noted the lack of consensus around the merits of paying family and friend carers, we are of the view that the recommendations of the Commission do bear consideration, especially in cases where replacement care is not readily available and where, as a consequence, carers are not benefiting from NDIS supports in the way intended.

A number of questions, concerns and suggestions for additional supports for carers are raised under the proposal.

⁸ Clare Ungerson, *Whose empowerment and independence? A cross-national perspective on 'cash for care' schemes*, Ageing & Society 24, 2004, 189-212

Questions

- Who would be the employer of the carer? Would it be the participant? If so, would the participant become responsible for superannuation, occupational health and safety, industrial relations and workers compensation insurance which, the Commission has noted, would require to be covered in a pay for care context?. We note that in some other countries which offer cash for care, the carer would register with a provider who provides administrative support and oversight or a local government takes on these administrative requirements.
- Which markets are covered by the proposal? On page 36 of the Position Paper (and indeed in other sections of the Paper) thin markets as described as:
 - outer regional or very remote areas
 - where participants have complex, specialised or high intensity needs, or very challenging behaviours
 - participants are from culturally and linguistically diverse backgrounds
 - participants are Aboriginal and Torres Strait Islanders
 - participants have an acute and immediate need (crisis care and accommodation).⁹

However on page 39, where recommendations for mitigating workforce shortages are discussed, only regional and remote areas are mentioned. No doubt carers of participants in the other categories would also want to make a case that they too should be offered paid care opportunities.

- Given that many carers are available to provide care and need to be in attendance on a 24/7 basis, how would the hours of care for which they should be paid be calculated? Would it be on the basis of the care needs identified in the participant's plans which cannot be operationalised because of the absence of services?

Concerns to be addressed

- **Continuing Access to Carer Support Services**

Access to family and friend carer support services provided by the Department of Social Services such as respite, peer support, counselling and education, are only available to unpaid carers. Being paid for a proportion of care provided doesn't remove the need for these supports. The operational guidelines relating to these programs would need to be adjusted to allow for paid family and friend carers.

- **Some carers in receipt of Social Security payments may be worse off**

Depending on the number of care hours approved for payment, carers may be at risk of being financially worse off if they lose their entitlements to Social Security payments such as the Carer Payment, the Carer Allowance and the Carer Supplement – all of which are untaxed and may, when combined, amount to more than the remuneration they receive as paid carers. Carers and participants or both must also be able to cover the administrative fees relating to their employment as paid carers if a third party is involved.

⁹ Productivity Commission, Position Paper: *National Disability Insurance Scheme (NDIS) Costs*, June 2017, p.39

We believe many carers would need some assistance in calculating the financial risks associated with accepting payment for care.

In addition, to the extent that their eligibility to be paid under the NDIS may be removed when it is assessed that a workforce shortage no longer exists, they may have to go through the intensive and time-consuming process of reapplying for Social Security payments. We would recommend that, even if they receive no benefits during the period for which they are employed, they should remain eligible for these benefits which can be quickly restored if they cease to be employed. In addition, they should continue to receive the Carer Allowance which assists to cover the additional costs of care and the annual Carer Supplement. Neither of these benefits are income or activity tested, but they are not currently available to paid carers.

- **No clear rationale for carers to be paid under award rates**

It is the Productivity Commission's view that informal carers should be paid less than the award rate. The rationale for a lower rate of payment is not clear and, from our perspective, devalues the care provided by family and friends. Why should a carer get paid less than a care worker, and at a flat rate, if they are performing the same tasks? Why should they be paid less than market or award rate for their work?

We suggest that carers should be paid the award rate for casual paid care workers. We have opted for the casual rate partly because it has a loading to compensate for the fact that casual workers get no sick or holiday pay. It goes without saying that family and friend carers who are to be paid because of shortages of replacement care in thin markets are unlikely to be able to take the holiday and sick leave available to permanent paid care workers.

To the extent that qualifications impact on the rates for paid care workers, we would suggest that family and friend carers be assisted to obtain relevant qualifications at the Certificate 3 level and that Recognition of Prior Learning (RPL) be accessible to these carers on the basis of their caring experience. Course requirements would have to be adjusted to take into account the capacity of carers to complete these requirements while continuing in their caring role. Carers Queensland currently provides such a model. Carers Queensland is a registered RTO which delivers a carer-friendly course in [CHC33015 Certificate III in Individual Support](#). Email, phone and Skype support is incorporated into the course and, where necessary, the delivery strategy includes home visits if students' caring role means they are unable to attend class for a couple of weeks, or they get behind in their course work, due to caring responsibilities.

Such training can also provide additional advantages to carers who wish to seek employment in the sector, subject to improvements in the availability of supports under the NDIS which would enable them to undertake other employment - if that is their wish. It would also contribute to building the disability workforce in the areas in which they live.

- **Impact on the development of paid care workforces in thin markets**

Paying informal carers (whether at the award or discounted rate) may also make it more difficult to alleviate thin markets, as it may hide, or artificially reduce, demand for recruiting and training paid workers.

- **Carers must have a choice**

No pressure should be brought to bear on family and friend carers who do not want to enter into employment on a fee-for-service basis– whether this is for personal, family, financial or any other reason.

Alternatives to moving directly to the payment of carers in thin markets

1. Given the uncertainties and complexities highlighted in relation to this proposal, it might be advisable for the initiative to be piloted with a small number of carers in limited locations. This would enable positive and negative outcomes to be identified and assessed, particularly in relation to complex issues of interaction with other programs and payments, satisfaction with the arrangement by family and friend carers and those they care for, and impacts on providers and the paid workforce in thin markets.

Trialling the scheme would be consistent with previous recommendations by the Productivity Commission¹⁰.

2. If the unintended consequences and complexities of employing family and friend carers in thin markets constitute major barriers to the proposal, an alternative approach might be to offer a taxable reimbursement or compensation payment to carers who have lost opportunities to lighten their care load as expected under the NDIS, rather than through wages or salary.

Among the advantages are:

- it would avoid the potential strains of an employment relationship between family and friend carers and those the care for
- it would enable carers, who would continue to provide informal care beyond the hours for which they are being reimbursed, to remain carers under the definition of the *Carer Recognition Act 2010*, and remain eligible for the supports and services they need to maintain their own health and wellbeing
- while it would be means tested against Social Security payments, it would not disqualify carers from receiving a Carer Payment based on hours of paid employment
- it would avoid the need for carers to undertake onerous administration, including registering as businesses and meeting regulatory and other requirements or additional costs.

Summary

While the merit of paying family and friend carers where there is a lack of support services in thin markets certainly bears consideration, given the complexity of the issue and the diversity of views within the sector, we believe that further work needs to be undertaken to determine the feasibility and impacts of the proposal. We would urge that this work includes hearing directly from carers and people with disability and the organisations which support them.

¹⁰ Productivity Commission Inquiry Report, *Disability Care and Support, Overview and Recommendations*, No. 54, 31 July 2011, p32