



**Submission to the Joint Standing Committee into
NDIS Transitional Arrangements**

August 2017

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.

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Introduction

Carers Australia thanks the Committee for this opportunity to contribute to its Inquiry.

The main focus of this submission is the transition issues arising from national and state/territory government contributions to the NDIS which are leading to the diminution of supports for carers of people who are eligible for NDIS packages and those who are not. We note that transition issues in relation to the provision of services for people with psychosocial disability and their carers and to the implementation of Early Childhood Early Intervention under the NDIS have been the subject of other submissions to the Committee.

However, in this submission we have also included commentary on the roll out of the Information, Linkages and Capacity (ILC) Building Program.

Transition issues relating to carer supports

Transition of national carer support funding to the NDIS

Carers Australia has been advocating in relation to this issue ever since we became aware of the initial bilateral agreements which are soaking 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. One 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)**. This is very restrictive with respect to the amount of respite available, the conditions under which it is provided. 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.

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’ support has been interpreted as retention of the status quo in many cases.

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 funding pool. 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 2015-16.³ The programs in question were the:

- Mental Health Respite: Carer Support (MHR:CS) Program (MHR:CS)
- The respite component of the Young Carer Respite and Information Services (YCRIS) Program
- Respite Support for Carers of Young People with Severe or Profound Disability (RSCYP)

Ironically, the area of the NDIS which is most underdeveloped and problematic in terms of eligibility and access to services is support for people with psychosocial disability related to a mental health condition. And the cohort of carers who are particularly unlikely to have any engagement in NDIA planning processes which may impact on access to respite are young carers under the age of 18. The diversion of funding from these two programs among the suite of Commonwealth funded carer support programs couldn’t have been more badly targeted.

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.

³ 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*

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 has begun to 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.

While the projected Integrated Carer Support Services (ICSS) being developed by the Department of Social Services may address gaps in carer supports arising from NDIS design and implementation, this outcome will be highly dependent on the adequacy of funding for the new program. If funding for the new carer service model is largely restricted to the funds currently available (and bearing in mind the substantial loss to that funding with NDIS roll out) then the level of carer support will continue to be substantially reduced.

Loss of state/territory carer and disability supports in the transition to NDIS

It should also be noted that carers are also losing access to respite and other support services funded by some state and territory governments.

The NSW position is particularly bleak. Nearly all direct services targeted at carers that have been funded by the NSW Government are in scope for transition to the NDIS, despite carers not being the focus of NDIS plans. While many carers stand to benefit indirectly from the supports provided to those they care for, many carers will not due to the fact that the person they care for is not eligible for the NDIS, or because there is realistically very little direct support available to them under NDIS plans and ILC.

Carers NSW has identified the following existing carer support types funded by the NSW Government through the Department of Ageing, Disability and Home Care (ADHC) that are in scope for the NDIS, but are not being replicated in NDIS plans or ILC. . The ADHC will close down from mid-2018. These support types include:

- Seed funding, training and support for carer support groups
- Support coordination working with the carer as client and prioritising their own needs
- Tailored support for ageing parent carers
- Funding packages that carers can use to meet their own needs
- One-off purchases to benefit the carer and their household that are not disability specific

- Recreational and educational opportunities integrating peer support and respite components (including events, retreats)
- Respite supports that focus on the carer's need for a break
- Case management that provides ongoing individual support to a person with disability and their family and carers.

The only remaining direct services available to carers as clients under NSW Government funding are broad information, training and emotional support opportunities (mainly group based) for carers of people in the health and mental health systems.

Carers NSW notes that it is not only carer supports that are disappearing with NDIS transition and the abolition of the Department of Ageing, Disability and Home Care. While continuity of support arrangements are being put in place for both aged and disability care for the over-65s and under 65s respectively, the sector has identified a number of gaps, including for a range of cohorts under the age of 65 using HACC-type services who will not, for various reasons, be eligible for the NDIS. If these support needs are not met into the future with government funding, carers will likely take them on, in some cases unsustainably.

Another key gap is the loss of all state funded information, referral and advocacy, currently delivered by a range of cohort-specific NGOs. Carers tell us that they rely on these services to navigate the service system, especially as the NDIS rolls out. A final gap of key concern to Carers NSW is the ineligibility of ageing parent carers for support in their own right. A targeted NSW Government funded program has provided a case management service to these carers, but the client group will not be eligible for continuity of support channels.

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.

In other states the situation is less clear at this point because governments are still assessing their options in terms of what will be included as part of their co-contribution to the NDIS.

Recommendation 1:

Carers Australia strongly supports Draft Recommendation 5.2 in the Productivity Commission's recently released Position Paper on NDIS Costs. That is:

“The Australian, State and Territory Governments should make public their approach to providing continuity of support and the services they intend to provide to people (including the value of supports and number of people covered), beyond supports provided through the National Disability Insurance Scheme. These arrangements for services should be reflected in the upcoming bilateral agreements for the full scheme.

The National Disability Insurance Agency should report, in its quarterly COAG Disability Reform Council report, on boundary issues as they are playing out on the ground, including identifying service gaps and actions to address barriers to accessing disability and mainstream services for people with disability.”⁴

We would add to this recommendation that the Australian, State and Territory Governments should make public continuity of supports and services and identify service gaps and actions to address them arising in relation to carer supports. The rationale behind this recommendation is that, to the very large and publicly acknowledged extent to which all disability support services rely on the contribution of family and friend carers, there is both a moral and economic justification to ensure that carers do not lose access to support services in their own right through NDIS transition arrangements.

The rollout of the Information, Linkages and Capacity Building Program

With respect to Information, Linkages and Capacity Building (ILC), this program aims to achieve a great deal with limited funds (\$132m). The effectiveness of the program in catering for the needs of people who are ineligible for packages is a major concern.

We fear that people found ineligible for packages will have difficulty in accessing the supports they need through the ILC or mainstream services.

The first ILC grants process recently closed for applications with decisions not yet announced, and it is difficult to assess their impact at this point. Further funding for ILC

⁴ Productivity Commission, Position Paper: *National Disability Insurance Scheme (NDIS) Costs*, June 2017, p.196

won't be made available in the jurisdictions until 2018 and 2019, creating real concern about what services and support will be available until this time.

Also of concern is the fact that funding for many services providing community support to people without packages have been folded into the NDIS. As registered providers with the NDIS, these providers are unable to apply for funding under the Information, Linkages and Capacity program. The effect is likely to be a considerable reduction in access to experienced quality providers available to non-NDIS participants.

Recommendation 2:

- The NDIA consider the funding disparity between the NDIS and ILC and have the flexibility to transfer funds between the NDIS and ILC as the Scheme matures.
- That ILC grants funding be implemented earlier in jurisdictions.
- That there should be further consideration of the impact on ILC performance of restricting ILC funding to providers who are not registered under the NDIS.