

Pre-Budget Submission 2017–18

January 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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Executive Summary

In the 2015-16 Federal Budget the Government announced new initiatives to improve support and services to Australia's family and friend carers. These were:

- A National Carer Gateway, similar in many respects to the My Aged Care Gateway, which was budgeted to cost \$10.9 million in 2015-16 and a total of \$33.7 million by 2018-19.
- An Integrated Plan for Carer Support Services (IPCSS) to streamline support services and improve the range, quality and delivery of services specifically for carers.¹

Both these initiatives arose from the recognition that aged care and disability care reforms had fractured access to carer specific supports and had made it harder for carers to get services in their own right. Not only did these reforms fracture access to, and the availability of, support services accessible to carers according to the age of the person receiving care (aged care for the over 65s and disability care for the under 65s), but it also created a new system whereby carers could only receive important support services as a by-product of the entitlement to assistance of those they cared for. It also made organising relief or a break from caring (respite) extraordinarily difficult for those caring for an older relative or friend and also someone under the age 65.

The Carer Gateway became available in December 2015, however it is still in need of further development.

The Department of Social Services (DSS) has undertaken a considerable amount of work in developing an Integrated Carer Support Service (ICSS) model which is at an advanced design stage in terms of national service architecture (service provision at the national, regional and local level) and the range of services which are to be offered to family and friend carers to support them in their caring role.

The model of service provision proposed by DSS in its latest consultation Discussion Paper does have merit.² It incorporates more online support than is currently available, while recognising the continuing importance of carers having one-to-one access to expert service providers at the regional and, to a lesser extent, local level. It also recognises the importance of peer support. Gaps in current service offerings are identified and incorporated into the model.

¹ https://www.dss.gov.au/sites/default/files/documents/05_2015/2015_budget_fact_sheet_-_support_for_carers_1.pdf

² https://engage.dss.gov.au/a-new-integrated-carer-support-service-system/

However, no matter how appealing the model might be in theory, its success or failure will depend on the adequacy of funding (including for transition arrangements), the reach and effectiveness of regional hubs, the availability of a range of local services in meeting demand, and the continuation of services not covered by the ICSS.

While the DSS Discussion Paper does not explicitly deal with funding, it indicates funding for existing programs will be used to finance the activities of the regional hubs which will replace a larger number of existing federally funded services. This funding is minus that previously allocated to three existing programs which is to be transferred to cover the costs of the NDIS.

These issues, along with others, are explored in more detail below.

Recommendation:

THAT the Integrated Carer Support Service model be fully costed and funded on the assumption of expected service demand and the inclusion of a range of new programs and activities that are incorporated into the model. It cannot be assumed that the model can be fully funded by efficiencies and savings from the existing funding envelopes for services that will be replaced by the ICSS. Otherwise it is probable that the new service landscape will actually diminish the quality and range of carer support services.

Discussion of Issues and Recommendations

On 6 November 2016 DSS released a Discussion Paper on a draft Service Delivery Model for a proposed new carer support service system. The model, if endorsed by Government, will substantially transform the delivery of carer support services across Australia.

Currently carer services funded by the Commonwealth Government are delivered through grants available to service providers for delivering a number of special purpose programs.

Existing funding for carer services³

National Respite for Carers Program (NRCP)

This is by far the largest of nationally funded carer programs. It is targeted to assist carers of:

- frail aged Australians (aged 65 years and over, or aged 50 years and over if Aboriginal or Torres Strait Islander);
- people with dementia;
- people with dementia and challenging behaviours;
- younger people with disability (people under the age of 65 years, or under the age of 50 years if Aboriginal or Torres Strait Islander);
- people with a terminal illness requiring palliative care;
- people with high care needs; and
- employed carers.

In 2015-16 the total allocation to this program was \$71.695 million. Eighty four percent (or \$60.298 million) was allocated to short-term emergency respite (or replacement care) for occasions when carers encounter circumstances where they are temporarily unable to continue to provide care (for example, health or family emergencies or other crises). Other sub-programs included the National Carer Counselling Program (\$4.886 million), the Carer Information and Support Service Program (\$3.958), and a small Consumer Directed Respite Program (\$2.553 million). In 2014-15 the NRCP supported 100,794 carers.

The vast majority of this funding was directed to 54 Carer Respite and Carelink Centres (CRCCs) which operate around the country.

³ All expenditure and level of carer support data in this section have been taken from Department of Social Services, Designing the new integrated carer support service, Discussion Paper 1, Appendix B, May 2016

Mental Health Respite: Carer Support (MHR:CS)

This program provides relief from the caring role through in-home or out-of-home respite or social and recreational activities; counselling, practical assistance, social inclusion activities, case management; and education, information and access. It also funds community mental health promotion. The highest priority is given to carers without access to similar respite or carer support through other government funded services. It also recognises that carers of people with pyscho-social disability frequently suffer very high levels of stress, particularly those who are caring for people with very challenging behaviours. 2014-15 it supported 40,644 carers. Carers Australia has found it difficult to identify allocated funding for this program.

Young Carers Respite and Information Services (YCRIS)

This program provides:

- Respite and education support services. It assists students up to and including 18 years of
 age with a significant caring role to access respite and age appropriate educational
 support. These services are delivered by the national network of CRCCs.
- Information, referral and advice services supports young carers with a significant caring role up to and including 25 years of age with information, advice and referral services, including referral to counselling. These services are delivered by Carers Australia and the network of State and Territory Carers Associations.

In 2015-16, \$8.186 million was allocated to this program and in 2014-15 it supported 7,715 young carers. The respite component of this funding is currently being transferred to the NDIS as a contribution to its costs.

The Young Carer Bursary

In 2015-16 this program was allocated \$1.235 million and supported 300 young carers.

Respite Support for Carers of Young People with Severe or Profound Disability (RSCYP)

In 2015-16 this program was allocated \$7,939 million and it supported 5,347 carers in 2014-15. It is being fully transferred to the NDIS as it is rolled out. My Time: Peer Support Groups for Parents and Carers of Children with Disabilities or Chronic Medical Conditions

The program was allocated \$3.77 million in 2015-16 and supported 2,755 carers in 2014-15.

Counselling, Support, Information and Advocacy (CSIA)

Was allocated \$10.5 million in 2015-16 and supported 13,457 carers in 2014-15

Dementia Education and Training for Carers

The program was allocated \$1.07 million in 2015-16. The number of carers supported is not known.

Clearly this multiplicity of programs, each with their own eligibility requirements and reporting arrangements and each requiring separate grant applications, places heavy administrative burdens on both government and service providers. The historical accumulation of sub-programs to meet particular needs for sub-groups of carers which assumed high priority at certain times has also created gaps for carers who do not fall into the particular demographic to which these programs are targeted.

Organisations striving to provide a suite of service supports to carers regardless of their own age and the age and condition of those they care for have struggled to coordinate funds from as many streams as possible.

The proposed new Integrated Carer Support Landscape

In order to remedy deficiencies in the current structure and quality of carer support services the Department of Social Services has put in an extensive effort over the past couple of years to identify an improved model.

The basic elements are:

- At a national level, it is envisioned that some services, such as phone and online counselling, will be delivered centrally, and the system as a whole will be supported by national infrastructure.
- At a regional level, it is envisioned that regional hubs will deliver services for carers more directly, including preventative and emergency supports.

 At a local level, local service providers would be contracted to deliver specific services, as coordinated by regional hubs.

The regional hubs (number and coverage unspecified) will be the main source of direct service delivery.

The objectives of this program would be to:

- support the identification of carers early in their caring journey, through awareness
 raising activities across the health sector and general community, particularly those
 in high risk carer cohorts (for example, young carers)*;
- provide high quality information and advice for carers based on their circumstances and needs;
- provide carers short-term support to navigate, coordinate and access other services;
- support the establishment and ongoing access to peer support groups and events;
- support carers to access relevant education and training programs in their area through maintenance of an online catalogue of programs available;
- through a national needs assessment and eligibility process, coordinate access to respite and targeted financial support;
- provide proactive support through monitoring and follow-up for carers experiencing strain:
- provide high quality coaching and mentoring for carers, relevant to their circumstances and needs;
- provide short term respite to enable carers to participate in counselling, coaching, education or peer support activities;
- provide emergency respite where carers are unable to continue their caring role due to crisis, or an unforeseen event;
- support carers to access planned respite and support services through collaboration with organisations such as My Aged Care and the National Disability Insurance Agency (NDIA);
- deliver targeted financial support to assist carers to stay in education and/or enter the workforce:

⁴ https://engage.dss.gov.au/a-new-integrated-carer-support-service-system/

- effectively connect carers to complementary supports though the development of effective relationships with providers within the region;
- provide carer-centric individual, family and group therapeutic counselling; and
- contribute to improved service development and individual carer outcomes through the recording and monitoring of the impact of supports provided.⁵

Activities highlighted in red are sometimes but by no means routinely provided by carer support organisation under the current system, often due to funding constraints.

In addition regional hubs are to:

- have a deep understanding of the services available for carers in their areas of responsibility through service mapping;
- forecast demand for the services to be delivered, using data about the carer population in their region;
- analyse and understand gaps in service delivery, within their region; and
- Identify and target high risk cohorts of carers in their region.⁶

These are also activities not currently undertaken by most carer organisations.

Funding concerns

Carers Australia does not believe that the role designated for the regional hubs can be delivered within the current funding envelope (minus the funds to be transferred to NDIS).

While acknowledging that some savings may come from streamlining the number of funded service providers through moving from CRCCs to a smaller number of regional hubs and the transformation of some elements of carer service delivery from face-to-face to online engagement, it is our view that the extra services and extra administrative responsibilities to be undertaken by the regional hubs will require an increase in funding for carer services. This is especially the case because a key object of both the Carer Gateway and the awareness raising activities of the hubs are likely to substantially increase demand. Funding will also be required to help existing organisations and their clients to transition to the new model.

⁵ https://engage.dss.gov.au/a-new-integrated-carer-support-service-system/

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Recommendation:

THAT the Integrated Carer Support Service model be fully costed and funded on the assumption of expected service demand and the inclusion of a range of new programs and activities that are incorporated into the model. It cannot be assumed that the model can be fully funded by efficiencies and savings from within the existing funding envelope for services that will be replaced by the ICSS. Otherwise it is probable that the new service landscape will actually diminish the quality and range of carer support services.