



*Carers ACT response to NDS Policy Paper*

**The place for block funding in the NDIS**

**January 2014**

*Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We offer our respects to their Elders past and present, and celebrate the Ngunnawal people's living culture and valuable contribution to the ACT community.*

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***Who is Carers ACT?***

*Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 carers living in the Australian Capital Territory.*

*These carers provide ongoing unpaid care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail. Carers ACT currently provides direct support to around 8000 families through our counselling, information, respite support, education, social support and case coordination services. We continue to meet national accreditation standards for delivery of our services to carers at a high level.*

*Carers ACT has a constitutional mandate to represent the voices of carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All carer participation in policy work is voluntary.*

*Carers ACT is a member of the National Network of Carers Associations, and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing outcomes for caring families.*

## 1. Introduction

Carers ACT welcomes the opportunity to provide a response to the NDS “The place for block funding in the NDIS” policy paper and appreciates the NDS has raised important issues for people with disability, their carers and families within this paper. In particular, Carers ACT strongly supports the following propositions and recommendations:

- There must be block funding available to help manage the future liability of the NDIS [National Disability Insurance Scheme] and to ensure that all participants can exercise choice and control. As the NDIS design is tested in launch sites, and as funds and related responsibilities progressively transfer from state governments, it is critical that governments and the NDIA [National Disability Insurance Agency] review and confirm the appropriate use of block funding.
- One key element is early and community-based support that helps to avert crisis and build resilience. This requires information, advice, referral, community development and crisis prevention services, none of which are easily purchased out of individual packages. This is especially so when the service is delivered to a public audience, or when the person requiring support is not yet an NDIS participant.
- That people with disability and their families will not necessarily be aware of the benefits of information and support networks at a time of change ... Many of these services are currently funded by state governments, directly or as a component of a broader service contract. This funding may be at risk during transfer to the NDIA. NDS asks that the NDIA and governments negotiate to ensure ongoing funding for information and advice services, to prevent the loss of valuable expertise and infrastructure.
- The NDIA needs to make some flexible, non-recurrent funding available for providers to manage difficult transitions, ensuring participants can still access essential services.
- There is a very real risk that essential services, expertise and social capital will be lost in the transition to the NDIS if governments and the NDIA do not actively recognise the need for some ongoing block funding.

We are also aware that our colleagues from other Carers Associations are providing responses to NDS because of the interdependent relationship between the NDIS and carers and the people for whom they care.

Carers ACT’s response reflects our understanding of the rollout of the NDIS launch sites, particularly in the ACT from 1 July 2014, and comments and feedback from carers and our colleagues in the Network of Carers Associations.

## 2. About Carers ACT

Carers ACT is the key organisation in the ACT providing specialist carer support services to the 43,000 carers in the ACT.

In 2012-2013 Carers ACT responded to over 9700 calls and provided information and advice to more than 5000 carers through our Carer Advisory Service and the Commonwealth Respite and Carelink Centre. It also made over 5500 referrals for carers to over 70 ACT community organisations.

## Carers Supported by Service Type



The graph above illustrates the range of carer support services provided by Carers ACT during 2012-2013 across all its programs. The above services were all funded through specific ACT and Australian Government block funded programs that included ageing, disability and mental health and specialist support for Indigenous and CALD carers and families. Carers ACT also received ACT Government funding for an individual Carer Advocacy Service.

With the implementation of Australian Government reform Carers ACT will lose funding from some programs (Young Carers Program, Respite Support for Carers of Young People with Severe and Profound Disability and some mental health carer support) at June 2014 as a percentage of program funding will be rolled into the NDIS, and other funding will be rolled into other government initiatives such as the Aged Care Gateway.

This reduction will have an impact of Carers ACT's business model,<sup>1</sup> but of greater concern to the organisation is the need for the continuation of adequate block funded services to underpin the caring role of carers, their capacity to sustain this role, and also assist them maintain their own health and wellbeing.

### 3. Carers and NDIS-readiness

During 2012-2013 Carers ACT coordinated several NDIS forums (including for the ACT NDIS Taskforce) to raise awareness of the scheme amongst carers. Last November we also held two focus groups with carers on their use and expectations of respite for children and young adults with disability. Although there has been much NDIS discussion in the media, through ACT Government announcements, and awareness raising activities by government and community organisations it was clear that the majority of carers and families had no or little understanding of how the

<sup>1</sup> The NDIS also provides opportunities for Carers ACT through specialist disability services, such as the award-winning Branch Out Café hospitality and training program for young people with disability, and Fraser House that supported 46 families and provided 19,159 hours of out of home care during 2012-2013.

commencement of the ACT NDIS launch site in July 2014 would impact on them as carers or the level of available, or type of, services for an eligible family member with disability. For example:

- Carers were unaware that services they receive, such as respite, will need to be included in the individual NDIS package of the individual at market or NDIA scheduled rates that will be significantly higher than the current reduced or no cost services because of block funding.

Carers indicated that this would limit their access to some of these 'essential' services – assuming that they were included as a choice in an individual's NDIS package. Carers indicated that if this level of support wasn't available there was a likelihood that they or others they knew would have no choice but to relinquish the family member for whom they care into the care of the ACT Government.<sup>2</sup>

- Carers have no or little experience of managing individualised funding packages. Only 200 of the expected Tier 3 eligible ACT NDIS clients are likely to have experience with individualised packages or funding.
- Carers were unaware that as the focus of the NDIS is on assisting the person with disability exercise choice and control there is no specific carer needs assessment. Although the expectation of the NDIS is that carers and families will spend less time on caring, the Productivity Commission indicated that over 80 per cent of the care under an NDIS will still be provided by carers and families.<sup>3</sup>

The ACT Government expects that over 75 per cent of eligible Tier 3 participants in the ACT NDIS launch site will have a carer.

It is important to emphasise here that carers welcomed the NDIS and saw it as a means to improve services and outcomes for their family member with permanent and significant disability or psychosocial disability – they were unaware that specific services they relied upon may not be assessed as being necessary, or included as a choice in an individual's NDIS package, or even be affordable within that package.

Carers ACT raised the need for carer-readiness and carer support under the NDIS in its 2014-2015 ACT Budget Submission and continues to raise this and other issues with the ACT Government and the Australian Government, including the National Disability Insurance Agency (NDIA), through our contributions to Carers Australia's responses to papers and in meetings with ministerial staff and departments.

For example, Carers Australia's response to the Draft 2013-2106 NDIA Strategic Plan earlier in January again raised the issues about carer needs assessment and ongoing carer support programs:

... We were encouraged to read that the NDIA's planning is to take account of the needs and aspirations of both people with disability **and carers**, but require further clarification on how this would happen. All advice we have received about the development of the NDIS makes it clear that the NDIS is to achieve the participant's needs and aspirations, although the

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<sup>2</sup> This would incur a much higher cost to the government. Around 22 people with disability in the ACT are relinquished into the care of the government each year because families are unable to maintain their caring role.

<sup>3</sup> Productivity Commission (2011) Final Report into Disability Support and Care, August 2011.

sustainability of care is a consideration in the planning process. Deliverables 1 and 2 in Outcome C [see insert below] give the impression that carers support needs will be met through the NDIS, but we are concerned about how carers would access support programs as they are not NDIS participants in their own right.

We have previously been advised that as the NDIS process does not include a formal carer needs assessment carers needs will continue to be met through existing programs outside of the NDIS. However, some carer support programs (Mental Health Respite: Carer Support; Young Carers Respite and Information Services Program, Respite Support for Carers of Young People with Severe and Profound Disability) have been identified as both cash and in-kind contributions to the NDIS.<sup>4</sup>

***Insert by Carers ACT***

***Deliverable 1***

*Adopt a flexible approach in planning to take account of participants' and carers' needs and aspirations and the evolution of available supports.*

***Deliverable 2***

*Enable the provision of sustainable care by carers, families and other significant persons for people with disability. Source: National Disability Insurance Agency (2013) Draft 2013-2016 NDIA Strategic Plan p.6*

As Carers Australia indicated above there is still considerable uncertainty about the availability of and access by carers to specialist carer block funded programs through or outside the NDIS. This also applies to some programs that support their family members with permanent and significant disability or psychosocial disability.

The uncertainty also applies to people who will not be eligible for Tier 3 NDIS individual packages, more so as there is no national definition of Tier 2 eligibility although about 800,000 people with disability and their family and carers are expected to be in this tier. There is also uncertainty about how the community capacity and supports for people with disability who do not receive funded support (Tier 2) will be built.<sup>5</sup> This is relevant in the ACT as its NDIS launch site is about to be rolled out.

#### 4. Transition to the NDIS

By July 2016, 5000 Canberrans are expected to be NDIS launch site participants, with 2500 participating in year one from July 2014 to June 2015 and 5000 by June 2016.

The NDS policy paper includes an emphasis on the need for block funding during the transition to the NDIS, and Carers ACT supports this emphasis and associated NDS recommendations.

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<sup>4</sup> Carers Australia (2014) Response to the Draft 2013-2016 NDIA Strategic Plan.

<sup>5</sup> National Disability Insurance Scheme (2013) 'Imagining and planning for the future under a NDIS' in the Participant Workbook; and referenced in the Draft 2013-2016 NDIA Strategic Plan.

Over three quarters of the Tier 3 ACT NDIS launch site participants are expected to have a carer. As indicated above, a small proportion of eligible NDIS clients in the ACT have experience with individualised funding and they and their carers will need assistance with the new way of doing things under the NDIS.

Carers ACT believes that investment in capacity building for eligible clients to participate fully in the NDIS is essential (noting that through the NDIS Practical Design Fund some capacity building and awareness activities are happening).

Carers ACT also believes that block funded services through the transition phase are necessary as:

- There will be a phased in assessment process of eligible ACT NDIS clients over 2014-2016
- Eligible clients and carers will continue to need to access support services until the individual assessment occurs and a package is in place and chosen services are available
- Individuals who are assessed as ineligible for an NDIS Tier 3 package will continue to require some level of support
- Carers who support eligible Tier 3 clients or other people with permanent and significant disability and psychosocial disability will require specific carers services (such as counselling or support groups) currently provided through block funding to maintain their caring role and their own health and wellbeing.