



Submission to the 2013-14 ACT Budget Consultation

March 2013

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 this opportunity to respond to the ACT Government's 2013-14 Budget consultation.

The Carers ACT 2013-14 ACT Budget response focuses on four strategic priorities for carers and the people they support. These include:

- Supported accommodation for people with disability and people with mental illness
- Enhanced flexible respite services
- Transition of young people with disability to adulthood
- Training for National Disability Insurance Scheme (NDIS), aged care and mental health reform.

This response is informed by Carers ACT consultations with carers, including our Annual Service Evaluation 2011-12.¹ Our recommendations reflect the key issues in the Carers ACT 2012 Election Campaign *What Carers Want!*,² the major ACT political parties commitments in the lead up to the 2012 ACT Election, and major ACT and Australian Government reform in aged care, mental health and disability services – particularly the NDIS.

2. Strategic Budget Priority One: Supported accommodation for people with disability and people with mental illness

Improve planning for more innovative models of supported living options and more places and community support for people with disabilities and people with mental illness and their carers.

Develop better resources for carers and their families to plan transition of people with disability or mental illness to their own homes, including essential support for legal and financial planning. (Carers ACT 2012-15 Strategic Plan)³

The urgent need for an increased supply of diverse supported accommodation options that meet the needs of people with disability or mental illness has been recognised by governments at all levels.

¹ Carers ACT (2012a) *Carers ACT Annual Service Evaluation 2011-12*, October 2012.

² Carers ACT (2012b) *What Carers Want! Carers ACT 2012 Election Campaign*, August 2012.

³ Carers ACT (2012c) *2012-15 Strategic Plan*, September 2012.

Carers ACT hosted the Supported Living Options Summit in 2012, with the support of the ACT Government and other sector organisations, which prefaced the Australian Government's decision to include the ACT as an NDIS launch site. A Call to Action and the summit report were provided to the ACT Government, and identified that the urgency of this issue required the ACT Government to work collaboratively or in partnership with community organisations, philanthropic organisations and families to develop innovative supported accommodation models.⁴

The issue of supported accommodation continues to be a priority for Carers ACT and ACT carers. Our 2011-12 Annual Service Evaluation revealed that "fear about the future" and "supported accommodation" were two of the most common concerns for carers. The concern about supported accommodation was often framed as a fear about the future when the carer or family could no longer maintain their caring role. Carers stressed the need for supported accommodation options to be appropriate to individual needs and preferences.⁵

Carers ACT acknowledges the ACT Government's response to the identified need to improve planning and supply of innovative models of supported living options and more places and community support for people with disabilities and mental illness. It has implemented a Principle Based Supported Accommodation Committee (PBSAC), and the 2012-13 ACT Budget included funding commitments to increase supported accommodation options in the ACT.

It is important that the PBSAC has a focus on developing a planning blueprint (preferably based upon the outcomes of Carers ACT's proposed economic and social analysis review of supported accommodation) to develop an alternative range of supported living models to better meet current and future demand.

The ACT Greens committed \$250,000 for the support of this economic and social analysis in its 2012 election campaign and that it be provided in this budget. Carers ACT believes that this analysis will be essential in meeting supported accommodation needs in a long term and sustainable, way with appropriate consideration of how it will interact with and complement the housing, community infrastructure and supported accommodation eligibility under the NDIS.

⁴ Carers ACT (2012d) *Carers Supported Living Summit: A report on the Carers ACT Summit of 14 March 2012*, April 2012.

⁵ Carers ACT (2012a) *Carers ACT Annual Service Evaluation 2011-12*, October 2012.

Recent advice provided by the Australian Government has clarified that the NDIS arrangements will not directly address supported accommodation infrastructure or capital spending proposals (apart from “in some circumstances”). Although some participant’s plans may include living support arrangements they will not address specific housing and accommodation needs.

The recently released draft NDIS Rule: *Supports for Participants* states that housing and community infrastructure around supported accommodation includes:

- supports that build a person’s capacity to live independently in the community, including living skills training, money and household management, social and communication skills and addressing behaviours of concern, where these needs arise from a person’s functional impairment;
- supports to assist a person to obtain and maintain accommodation or tenancies where these support needs arise from their functional impairment;
- user costs of capital in some circumstances;
- reasonable and necessary home modifications to private dwellings (and legacy public or community dwellings in limited circumstances).⁶

Therefore the gap in services for supported accommodation will remain and become more critical unless further addressed in this budget cycle.

At the last election, the ACT Greens also promised a commitment of \$1.5 million in capital funding and \$200,000 annually in running costs for the ‘HOME’ model of mental health housing to be replicated in Canberra. The HOME model (operating in Queanbeyan) was the preferred supported accommodation option for people with mental health at the Supported Living Options Summit.⁷ Carers ACT recommends that the forthcoming budget should include this commitment.

In tandem with the need for supported accommodation, carers and families indicate that they want a planned transition to supported accommodation so that the carer and family are better placed to support the person they care for make this transition. Carers Victoria recommends that a bottom-up, pre-emptive model is needed, and that this model needs to include:

⁶ Australian Government (2013) *Draft National Disability Insurance Scheme Rules – Supports for participants*, February 2013.

⁷ Carers ACT (2012d) *Carers Supported Living Summit: A report on the Carers ACT Summit of 14 March 2012*, April 2012, pages 15 and 22-23 for summit participants’ views on appropriateness of the HOME model for people with mental illness.

Support with legal and financial planning – including wills and estate planning, special disability or family trusts, testamentary trusts, family agreements, contracts for family property management, and planning ongoing representation arrangements for the person with a disability.⁸

Carers ACT recommends that this provision of additional support for carers and their families to plan for the transition of the person with disability or mental illness that they care for to supported accommodation or more independent living arrangements is included in the 2013-14 ACT Budget. This support includes legal and financial planning as the lack of these supports are often barriers to progress, as families don't know where to start or can't afford legal and financial services.

Recommendation 1

Carers ACT recommends that the ACT Government continues to support policy initiatives for supported accommodation in the 2013-14 ACT Budget through:

- a. Further investment in a partnership program with community and private organisations and families to develop a broad range of supported accommodation options which offer genuine quality of life, with meaningful activities and appropriate care levels to better meet the needs of people with disability and mental illness**
- b. Funding of the ACT Greens commitment to provide \$250,000 to undertake an economic and social analysis of models of supported accommodation**
- c. Funding of the ACT Greens commitment to provide \$1.5 million in capital funding and \$200,000 annually in running costs for the HOME model of mental health housing**
- d. Provision of programs to support carers and their families plan for transition to supported accommodation, including legal and financial planning.**

⁸ Carers Victoria (2011) *Pre-Budget Submission 2012-13, A Brighter Future for Victorian Caring Families*.

3. Strategic Budget Priority Two: Enhanced flexible respite services

Increase the availability of adequate planned respite so that carers have more opportunities to participate in the workforce and activities that reduce their social isolation (Carers ACT 2012-15 Strategic Plan)

Respite services are an important element of support for carers, whether they care for a person with disability, mental illness, chronic conditions, dementia or age-related frailty. Adequate access to respite services supports carers to participate in activities that most non carers take for granted, such as having time to look after their own needs, doing things with friends and other family members, and being able to continue in or enter the workforce.

Our 2011-12 Annual Service Evaluation found that respite (including residential respite) was Carers ACT's second most accessed service (37%) after information provision (43%). Carers viewed respite as an essential support in their caring role, with respite services described as central to their ability to maintain their own health and wellbeing, workforce engagement, social connection and ability to maintain their caring role.

Respite helped me to relax by getting away from my stressful caring situation at home; provided company for me – through outings, classes, info and discussion groups.

How about [providing] long-term respite as opposed to crisis-driven? Need a bit more flexibility in the provision of help and more say about preferred type of care.

My main pressure is from needing respite care to enable me keeping my work commitments.
(Carer respondents, Carers ACT 2011-12 Annual Service Evaluation)⁹

The ACT Government has undertaken a comprehensive review of centre-based respite delivered by Disability ACT. The review's report identified several factors that are expected to impact on the way the government will deliver respite services. These include:

- There are concerns that demand will exceed supply for the respite care services provided by Disability ACT.
- Pressure on the limited resources will only increase over time as the ACT population grows, with estimates that indicate a likely doubling of the ACT respite need.

⁹ Carers ACT (2012a) *Carers ACT Annual Service Evaluation 2011-12*, October 2012.

- If respite fails to meet the needs of carers, and carers are unable to cope, clients will require accommodation support options at approximately five times the cost per client.
- There is a need for short-notice respite.
- Carers were on average older than non carers, and more likely to have a disability.
- Identification of the need for change towards a client-centric service model, which would focus on the needs of carers and people with disability.
- A more flexible approach that improves respite care, carer wellbeing and the support relationship is required.

The report also recommended that further development is necessary to identify and meet respite needs of Aboriginal and Torres Strait Islander people and people from non English speaking backgrounds.¹⁰ Carers ACT suggests that the development of respite services that meet the need of Lesbian, Gay, Bisexual, Transgender and Intersex people with disability and their carers and families is also required.

With carer assessment and support services to be provided outside the NDIS, the adequate provision of respite services by the ACT Government will be an essential support service for carers of people with disability, mental illness and age-related frailty to sustain their caring role, and to assist their transition to supported accommodation when required.

Recommendation 2

Carers ACT recommends that the ACT Government continues its investment in respite care services in the 2013-14 ACT Budget, including longer-term respite care, to provide client-centric respite services that better respond to the diverse needs and choice of carers, as well as transition to supported accommodation.

¹⁰ ACT Government Community Services (2011) *Centre-based respite care delivered by Disability ACT, Volumes 1 and 2*, November 2011.

4. Strategic Budget Priority Three: Transition of young adults with disability to adulthood

Increase supports to carers and young adults with disability to support their successful transition to adulthood (Carers ACT 2012-15 Strategic Plan)

Another key strategic priority for Carers ACT is a focus on effective policies and program supports for carers of young adults with disability to assist their development and transition to adulthood. This was also a priority in our 2012-13 Budget Submission to the ACT Government, and identified in our 2011-12 Annual Service Evaluation as a concern for carers.

Over recent years our consultations with carers of children and young people with disability or mental illness clearly indicate that the period of greatest risk for these young people is immediately after they have completed their secondary schooling. If supported employment or skills-based training are not options, these young adults find themselves facing the prospect of an unstructured day which may have no or limited supports or access to the networks and social situations which many of us take for granted. Carers may be forced to relinquish or reduce their workforce activities to provide the necessary daily support for their son or daughter with a disability or mental illness.

Carers tell us:

- There is a need to recognise that transitioning from school with its structured environment and peer friendships to post school activities can create stress and anxiety for a young person with disability or mental illness, and for their carers and families.
- There is a need to include early planning for transition to post school options to ensure that the young adult has the life skills needed to satisfactorily participate in employment opportunities or other post school activities.
- The single most important improvement to the education system for students with special needs would be to allocate educators to act as case managers, particularly through school transition phases.¹¹

Carers ACT acknowledges the ACT and Australian Governments' recognition of the important need to provide budgetary support in this area in the 2012-13 ACT Budget, through the ACT NDIS launch site's focus on young people and the ACT Enhanced Service Offer and transitional arrangements for 2013-14.

¹¹ Comments from carers in Carers ACT-facilitated carer consultations during 2009-11.

Employment opportunities are always improved by lowering the costs to business. ACT Labour's pledge at the last election to provide a rebate of \$4000 to business for each new employee with a disability who has completed Year 12 has been welcomed by Carers ACT, caring families of young people with a disability and the wider community and should be included in the 2013-14 ACT Budget.

For many young people with a disability, meaningful employment opportunities can make an enormous difference to their wellbeing and, for those with psychosocial disabilities, their recovery and ability to sustain wellness as well. For many of their carers and families it reduces their financial disadvantage as many carers are able to continue or not reduce their own employment.

The Enhanced Service Offer (grants available July 2013 until June 2015) also provides opportunities for eligible young people with disability or mental illness to transition to adulthood, develop additional skills, increase their community engagement and improve their quality of life, and that of their carer and family.¹²

Recommendation 3

Carers ACT recommends that the ACT Government continues to support the successful transition to adulthood of young people with disability in the 2013-14 ACT Budget through:

- a. Increased capacity of the education system to allocate a case manager to assist families plan the transition to post school options, including employment, for young people with disability and mental illness**
- b. Further investment in early intervention and sustainable programs that develop support to young adults with a disability to engage in meaningful and skills-based training or employment**
- c. Funding of the ACT Labor commitment to provide a \$4000 rebate to business for each new employee with a disability who has completed Year 12 schooling**
- d. Targeted strategies and adequate capacity of the ACT Government and the community sector to promote the Enhanced Service Offer to carers and families of young people with disability to support their transition to adulthood.**

¹² ACT Government (2013) *Enhanced Service Offer Fact Sheet*, 8 March 2013.

5. Strategic Priority Four: Training for NDIS, aged care and mental health reform

Provide training and resources for people with disability, their carer and family to make informed choices about changes to service delivery, including individually funded care packages. (What Carers Want! Campaign Overview)

A key requirement for the implementation of ACT and Australian Government reform will be the need for carers to receive timely and appropriate training and information so they have the capacity to support people with disability, mental illness or who are aged develop suitable individual support packages. This training and information should be contextualised to meet ACT service delivery and program requirements.

Carers of people with disability or psychosocial disability who are not eligible for a comprehensive NDIS support package will need information about available or continuing services.

Carers ACT's consultations with and presentations to carers of people with disability or mental illness about the NDIS strongly indicate that they have limited understanding of what the NDIS and the ACT NDIS launch site will mean to them and the people they care for. Similarly carers of people who are aged have limited awareness of the implications of the *Living Longer, Living Better* aged care reform, particularly with its increase in home care support packages.

As people with disability or mental illness, their carers and their families need support to transition successfully to supported accommodation, Carers ACT recommends that carers and the people they care for will also need support to successfully transition to a service where the client has more choice and control of their individual support package, particularly enhanced services if they are eligible for a Tier 3 NDIS support package. Likely changes and challenges for clients and their carers and families to understand and plan for include:

- the caring relation is likely to be different with less reliance on carers and families
- another agent may have more involvement in planning individual support packages
- the need to develop new skills if clients or their nominated person choose to self-manage their packages
- carers will need support to transition from being the major provider of care to increased capacity to engage in community activities or employment.

While funding has been provided to ACT agencies to train people with disability in advocacy, as well as service providers, in NDIS readiness is welcome, consideration to providing training and awareness for carers is also required to prepare them for the NDIS and aged care reform that is soon to be implemented.

Recommendation 4

Carers ACT recommends that the ACT Government through the 2013-14 ACT Budget invests in training and resources to improve carers awareness of the NDIS and aged care reform, and training to build their capacity to better support the person they care for transition to development and management of their self-directed packages.