



*Carers ACT response to the ACT Government*

**2016-17 ACT Government Budget Submission**

*Caring for Canberra's Carers*

October 2015

*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 45,000 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. Executive Summary and Recommendations

### Introduction

Carers ACT appreciates the opportunity to respond to the ACT Government's invitation to comment on priority commitments for its 2016-17 Budget.

There are around 45,000 unpaid, family and friend carers in the ACT.<sup>1</sup> Carers are an integral part of our health system and are the foundation of our aged, disability and community care system.

Carers ACT's key recommendation builds upon the ACT Government's earlier carer policy and legislative amendments and recommends the ACT Government develop and implement a carer strategy to support ACT carers within the changing aged and disability care<sup>2</sup> service environment.

Other recommendations include targeted support for older young carers and mental health carers, and our ongoing systemic advocacy for affordable, sustainable housing for people with disability and their caring families.

### **Recommendation 1: An ACT Carer Strategy supporting carers in the ACT**

Carers ACT recommends the ACT Government:

- invests in the development and implementation of an ACT Carer Strategy to support ACT carers sustain and continue their caring role through major change in the aged and disability community care sectors
- engages carers in the development of the recommended ACT Carer Strategy to identify and set priority focus areas to support carers' needs
- invests in comprehensive research (separate to national carer, aged or disability population studies) to provide important baseline information about carers in the ACT for planning purposes by the ACT Government and other organisations, as well as monitoring the impact of the recommended ACT Carer Strategy.

### **Recommendation 2: Assisting older young carers through education and employment transition**

Carers ACT recommends the ACT Government:

- invests in a specific program or initiative designed to identify, and support young carers aged 18 and over in the ACT to remain in education, secondary or tertiary, and undertake employment transition to increase their opportunity of economic and social participation
- collaborates with an organisation with young carer expertise in the research, design and evaluation of the recommended program or initiative.

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<sup>1</sup> Carer data source: Australian Bureau of Statistics (2013) *Disability, ageing and carers, Australia: summary of findings, 2012* adjusted in line with the ABS Series B Population Projections – there was a 6.3% increase in the number of carers in Australia since 2012. Source: Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015* for Carers Australia, June 2015, Canberra. Note: the adjusted number of carers in Australia in 2015 is 2.86 million people or over 1 in 8 Australians.

<sup>2</sup> Although this response refers to aged and disability care, people with chronic conditions or mental health issues are included in this terminology. This relates to the Australian Bureau of Statistics Survey of Disability, Ageing and Carers use of disability as a collective term.

### **Recommendation 3: Education and supports for families of people exiting detention facilities**

Carers ACT recommends the ACT Government invests in culturally appropriate education and support to strengthen the capacities of Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse carers and families when a family member is engaged in justice and mental health systems to:

- equip carers with information they need to prepare them for the release of the person back into the community
- promote family reconciliation and re-engagement
- promote community integration.

### **Recommendation 4: Housing pathways for people with disability and caring families**

Carers ACT recommends the ACT Government invests in housing pathways for people with disability and Canberrans at risk of homelessness recommended in the 2016-17 ACTCOSS Budget Submission.

## **2. An ACT Carer Strategy supporting carers in the ACT**

### **About carers in the ACT**

- 44,965 people in the ACT are unpaid carers, or informal carers<sup>3</sup>
- 21,792 males and 23,183 females in the ACT are carers
- 1,404 people in the ACT receive the Carer Payment and 5,585 receive the Carer Allowance, including young carers
- Deloitte Access Economics<sup>4</sup> estimates Australian carers will provide 1.9 billion hours of care in 2015
- It would cost \$60.3 billion to replace these hours of unpaid care with formal care services. (If we had to replace this care, our health and community services systems would be unsustainable.)
- Caring can be emotionally taxing and physically draining. Carers have the lowest wellbeing of any large group measured by the Australian Unity Wellbeing Index<sup>5</sup>
- Carers often ignore their own health and are 40% more likely to suffer from a chronic health condition
- Many carers are chronically tired and desperately need to refresh with unbroken sleep, a day off or an extended period with no caring responsibilities

### **Issues**

- a) Lack of an ACT Carer Strategy or Carer Plan

The ACT Government was an early national leader in its support for carers through specific carer policies and legislative amendments. These include *Caring for Carers in the ACT – A plan for action 2004-2007*, the *Carers Recognition Legislation Amendment Act 2006 (ACT)* and the *ACT Carers' Charter – Caring for Carers*. The development of carer strategies and carer legislation has occurred

<sup>3</sup> See 1 above.

<sup>4</sup> Deloitte Access Economics (2015) *The economic value of informal care in Australia in 2015*. Accessible <http://www.carersaustralia.com.au/storage/Access%20Economics%20Report.pdf>

<sup>5</sup> Australian Unity (2007) *Wellbeing of Australians: Carers Health and Wellbeing*, Special Report 17.1, Melbourne. Accessible <http://www.carersaustralia.com.au/storage/Wellbeing-Index-Special-Report-October-2007.pdf>

nationally<sup>6</sup> and in other jurisdictions since. It is time to build on the ACT's early leadership by progressing a Strategy or Plan moving forward.

The Caring for Carers policy review in 2008 found its principles were still relevant, but revealed the necessity to develop a streamlined model with a focus on specific carer needs. In its response to the review the ACT Government said:

... it will develop a new model with three areas of action that focus on the specific needs of carers – carer recognition, supporting carers and carers choice.<sup>7</sup>

Since the expiry of the Caring for Carers policy and the ACT Government's above response to the review the ACT does not have a recognisable carer strategy or action plan that describes the ACT Government's approach to carer support or its expectations of ACT Government agencies, community service organisations or other stakeholders about how they acknowledge, respect and support carers choices and needs.

Ideally, the proposed ACT Carer Strategy will acknowledge that lives of family carers are intrinsically linked to the people with a disability or who are frail aged to whom they provide care. Research indicates that adequate services and supports for the person who is ageing or with a disability would lead to a better life for all family members.

The proposed ACT Carer Strategy should:

- recognise carers and their significant role in caring for people who are aged or have a disability
- incorporate practical approaches to make a difference in carers' lives in their caring role
- identify strategies to identify and support young carers and carers from culturally diverse populations – Aboriginal and Torres Strait Islander, Culturally and Linguistically Diverse and Lesbian, Gay, Bisexual, Transgender and Intersex
- provide strategies in important areas such as employment, education and health and wellbeing
- include realistic objectives with clear, measurable outcomes
- be supported by a community awareness campaign

b) Major national aged and disability community care reform

There are major changes to the way national aged and disability care programs are to be funded<sup>8</sup> and delivered in the community. A focus on person-centred, consumer-directed care is a key change. The emphasis on person-centred, consumer-directed care means that the person with disability or who is frail aged is the centre of service delivery, and has increased choice and control about the

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<sup>6</sup> The Australian Government enacted the *Carer Recognition Act 2010 (Clth)* and the *Statement for Australia's Carers* (a schedule to the Act, with ten principles to be reflected in implementing, providing or evaluating care supports) in 2010. These were followed in 2011 by the development and implementation of a National Carer Strategy and Action Plan. The Act and *Statement for Australia's Carers* are accessible at <https://www.comlaw.gov.au/Details/C2010A00123>

<sup>7</sup> ACT Government (2008) *Caring for Carers Policy Review and Beyond ACT Government Response*, Canberra. Accessible [http://www.communityservices.act.gov.au/\\_\\_data/assets/file/0016/121750/Government\\_Response\\_to\\_Review.rtf](http://www.communityservices.act.gov.au/__data/assets/file/0016/121750/Government_Response_to_Review.rtf)

<sup>8</sup> Carers ACT notes that there are different jurisdictional responsibilities for aged and disability care in the community. However, we believe there is an obligation on the ACT Government to provide the best support for vulnerable Canberrans, including liaison with the Australian Government about special requirements for specific population groups.

services and supports included in their individual funded plan delivered in a community setting. The focus on person-centred care often means carer support services are not routinely considered by service providers, or are not included in an individual's aged or disability care plan.

This is contrary to the various national and state or territory frameworks that articulate the key role of carers in underpinning aged and disability services across Australia, including the need for carers to be considered as partners in care and to have their own care needs identified and supported. Further, it is well understood by government program planners that successful delivery of care in the community is heavily reliant on the informal support provided by carers.

The lack of access to carer supports by some carers is likely to be exacerbated because the current service system for carers is complex, fragmented and difficult to navigate. Carers need to access aged care, disability and mental health services, and find information for the person they care for. They also need to access their own carer support services.

The Australian Government also proposes to launch a national Carer Gateway<sup>9</sup> in December 2015 to provide information and services to carers regardless of the age and condition of the person they care for. There is uncertainty among carers and service providers about how these services will be funded.

c) Carer funding transition to new aged and disability care programs

A number of carer support programs and their funding will transition to the new aged (e.g Commonwealth Home Support Program) and disability (e.g NDIS) care programs under the national aged and disability care reform. These include a number of carer support programs that were previously incorporated into the National Respite and Carers Program and the Home and Community Care Program.

Along with aged and disability program funding being transitioned to the new programs, is the uncertainty about the future of block-funded carer services from 1 July 2017. The Australian Government has advised that funding agreements for the 54 Commonwealth Respite and Carelink Centres<sup>10</sup> have been extended until 30 June 2017 to ensure carers have continued access to emergency and short term respite.

Additional to this national reform are questions about funding for the proposed NDIS Information, Linkages and Capacity Building (ILC) Framework. For example, bilateral NDIS agreements identify that respite from Australian Government programs that support young carers and mental health carers will be transferred on an incremental basis to the National Disability Insurance Agency (NDIA) to fund individual packages. Knowledge on whether some of this funding will be reserved to provide respite opportunities for young carers and mental health carers is unknown.

The ILC Framework is intended to be a referral pathway via the NDIA to mainstream services,<sup>11</sup> such as housing and education for people with an NDIS individual funded package, and also to provide

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<sup>9</sup> The 2015-16 Federal Budget allocated \$33.7 million over four years to establish a National Carer Gateway. Source: Australian Government Department of Social Services (2015) *Carer Support Services – a National Carer Gateway*, May. Canberra. Accessible <https://www.dss.gov.au/disability-and-carers/news/2015/carer-support-services-national-carer-gateway>

<sup>10</sup> Carers ACT auspices the ACT and Southern Highlands Commonwealth Respite and Carelink Centres.

<sup>11</sup> Carers ACT is aware that although mainstream services have been included in NDIS funded individual packages that insufficient service providers, such as psychologists, limits access to some prescribed services.

information to and referrals for carers and people who are ineligible for an NDIS funded individual package.

People who are ineligible for an NDIS funded individual package will still require supports to enable them to cope with their condition(s) and will require a substantial amount of assistance from family and friend carers. This will be exacerbated if the funding level and availability of these services and carer support services do not meet the demand.<sup>12</sup>

#### **Recommendation 1**

Carers ACT recommends the ACT Government:

- invests in the development and implementation of an ACT Carer Strategy to support ACT carers sustain and continue their caring role through major change in the aged and disability community care sectors
- engages carers in the development of the recommended ACT Carer Strategy to identify and set priority focus areas to support carers' needs
- invests in comprehensive research (separate to national carer, aged or disability population studies) to provide important baseline information about carers in the ACT for planning purposes by the ACT Government and other organisations, as well as monitoring the impact of the recommended ACT Carer Strategy.

### **3. Assisting older young carers through education and employment transition**

The young carer focus in our budget submission recognises the need to improve and target support for older young carers aged 18 to 25 to improve their education, employment, financial and social opportunities their non carer peers experience.<sup>13</sup> While younger young carers (aged up to 18) tend to be caring for parents and grandparents older young carers, particularly those aged over 21, are more likely to be caring a partner or their own child with a disability and are the majority of young carers.<sup>14</sup> Many older young carers will not identify as a carer, and will not have accessed services to assist their caring role.

Importantly, research on young carers in receipt of Carer Payment and Carer Allowance payments indicated that the durations of care of young carers in the research group were below those of other carers in receipt of Centrelink assistance, while the durations of older young carers are similar to carers aged 25 to 54 years.<sup>15</sup>

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Organisations working with the NDIA in the ACT believe that the ACT Government should develop a program to attract specialist mainstream services to the ACT to address the unmet need.

<sup>12</sup> The NDIA is conducting consumer, carer and service provider surveys about the ILC Commissioning Framework via workshops up to the end of October 2015. Information about the ILC Commissioning Framework is accessible at [www.ndis.gov.au](http://www.ndis.gov.au)

<sup>13</sup> While Carers ACT focus in this budget submission is increased support for older young carers, it is important that policy interventions for younger young carers continue with a strong focus on education and begin at an early age.

<sup>14</sup> Bray JR (2012) *Young carers in receipt of Carer Payment and Carer Allowance 2001 to 2006: characteristics, experiences and post-care outcomes. Occasional Paper no.47*, Australian Government Department of Families, Housing Community Services and Indigenous Affairs. Accessible [https://www.dss.gov.au/sites/default/files/documents/02\\_2013/op47\\_text\\_print\\_ready.pdf](https://www.dss.gov.au/sites/default/files/documents/02_2013/op47_text_print_ready.pdf)

<sup>15</sup> See footnote 13 above.

For more information about young carers in the ACT see our response to the *ACT Community Services Directorate Community Consultation – What is important for children and young people in Canberra?*<sup>16</sup>

## Issues

### a) *Young carer education, social and economic disadvantage*

While young carers identify benefits from this increased responsibility they can also experience financial disadvantage and poorer health and wellbeing due to their caring. Young carers are at particular risk of ongoing socioeconomic disadvantage because of lower completion of education, and workforce participation. They need appropriate support to reduce this disadvantage and to enjoy similar life opportunities as non carer young adults. It is well recognised that education, particularly higher education, is directly linked with employment and income that can determine economic and social participation in the community.

An education inequity in the ACT issues paper stated that “a young person may experience difficulties at school for a variety of reasons and there are likely to be multiple, intersecting issues which impact on their lives and make it difficult to remain engaged in education.” Young carers are identified as an at risk group of disengaging from education.<sup>17</sup>

A Carers Australia 2013 report<sup>18</sup> supports the above statements about young carers and education:

- young carers aged 15-24 are less likely to participate in study—at school, university or TAFE than non carers
- approximately 40% of young primary carers are studying compared with approximately 60% of young people who are non carers
- older young carers aged 19-24 years are less likely to have completed Year 12 or equivalent (66%) compared with non carers of the same age
- 60% of young carers aged 15 to 25 years are not in paid employment compared to 38% of non carers in the same age cohort
- the reason young carers did not complete their education was not the value or importance of an education – it was linked to their responsibilities at home
- young carers had low satisfaction with their opportunity to participate in higher education, and once they had completed their caring role only a small proportion undertook further education

### b) *Lack of support for older young carers*

Carers ACT supports young carers through specific young carer programs, including the ACT Young Carer Program funded by the Australian Government Department of Social Services, and the ACT component of the National Young Carer Program. A key aim of these young carer programs is to

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<sup>16</sup> Carers ACT (2014) *Carers ACT response to ACT Community Services Directorate Community Consultation – What is important for children and young people in Canberra?* Canberra. Accessible <http://www.carersact.org.au/Assets/Files/Carers%20ACT%20Response%20to%20ACT%20Community%20Services%20Directorate%20Developing%20a%20Commitment%20to%20Children%20and%20Young%20People%20June%202014.pdf>

<sup>17</sup> The Youth Coalition of the ACT and ACTCOSS (2015) *Issues Paper: Educational Inequity in the ACT July 2015*, Canberra. Accessible [http://www.actcoss.org.au/publications/Publications\\_2015/1615sub-educational-inequity-in-act.pdf](http://www.actcoss.org.au/publications/Publications_2015/1615sub-educational-inequity-in-act.pdf)

<sup>18</sup> Carers Australia (2013) *Young Carers in Tertiary Education*. Accessible at [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

provide respite and information services for young carers aged 17 and younger who are at risk of not completing secondary education.

Carers ACT currently supports young carers aged 18 years and over through other programs, such as the ACT Commonwealth Respite and Carelink Centre, the Mental Health Carer Connection Program for carers living in North Belconnen and Gungahlin, and the Carer Counselling Program. These programs are funded by the Australian Government and will be subject to funding changes and uncertainties outlined in the above section of this document: 2. An ACT Carer Strategy supporting carers in the ACT c) *Carer funding transition to new aged and disability care programs.*

Last year the Australian Government introduced a national Young Carers Bursary Program for up to 150 eligible young carers aged between from 12-25 each year in 2015, 2016 and 2017. The program is to assist young carers in greatest need across Australia to continue to study and to relieve the financial pressure for them to undertake part-time work while studying and caring. Because of the excess demand for the 2015 bursary grants additional bursaries were announced, and applications closed in September 2015. This demand for bursaries and Carers ACT experience in supporting young carers aged 18 and over indicates further funding targeted to support older young carers remain in education – either secondary or tertiary – and to transition to the workforce is essential. As indicated above, evidence clearly identifies that young carers at risk of not completing secondary education are also at risk of not transitioning to employment. This outcome is likely to become a trajectory to future and ongoing socioeconomic disadvantage for these young carers and their families (partners or children they may have now and in the future). It also conflicts with a key principle in the *Statement for Australia's Carers* related to children and young people:

Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential. (Principle 2)<sup>19</sup>

#### **Recommendation 2**

Carers ACT recommends the ACT Government:

- invests in a specific program or initiative designed to identify, and support young carers aged 18 and over in the ACT to remain in education, secondary or tertiary, and undertake employment transition to increase their opportunity of economic and social participation
- collaborates with an organisation with young carer expertise in the research, design and evaluation of the recommended program or initiative.

#### **4. Education and supports for families of people exiting detention facilities**

Carers ACT coordinates the Mental Health Carers Voice Program, which is funded by the ACT Health Directorate. Program strengths are its carer representation on mental health advisory groups and broad connection with the ACT Government, mental health organisations and service providers and carers who support family members or friends with a mental health issue. The work of this program has identified a significant issue for families of people exiting detention facilities in the ACT, for which urgent action is recommended.

#### **Issue**

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<sup>19</sup> Australian Government (2010) *Carer Recognition Act 2010 (Clth)* and *Statement for Australia's Carers*, Canberra. Accessible <https://www.comlaw.gov.au/Details/C2010A00123>

Carers ACT also coordinates both the Aboriginal and Torres Strait Islander and the Culturally and Linguistically Diverse Carer Programs, which provides opportunities for carers to advise on issues relevant to them as carers and to their communities. This engagement has identified the complex family dynamics associated with mental illness, drug and alcohol misuse of family members or friends, particularly if the police or a mental health crisis team are involved.

In its response to the ACT Mental Health and Wellbeing Framework earlier this year Carers ACT provided the following carer comments.<sup>20</sup>

In a meeting with female Aboriginal Elders in 2015 coordinated by Carers ACT, participants disclosed how traumatised their family members are by mental illness, drug and alcohol misuse, and deaths by suicide or drug overdose. Women talked about how helpless they feel in getting help for relatives experiencing mental health and drug and alcohol issues. They described lives of worry, of walking on egg shells, and of being too scared to go to sleep at night. The Elders are concerned that there are not adequate services to look after their children and grandchildren. They described the stresses associated with calling police or the crisis team to their homes, the accusations from family members who feel betrayed and the disharmony this creates for them. They also expressed their concern that the people they care for are not being kept in psychiatric facilities long enough to stabilise the symptoms of their mental illness. One woman recalled how her son was discharged after only three days of inpatient care. He took his life several days later.

Families are reluctant to evict people experiencing comorbidity from their homes. They want to keep their children and grandchildren safe. This admirable trait occurs at the cost of their own health and wellbeing. Elders spoke of their fears for their own safety. These women feel helpless and powerless, and that they have nowhere to turn to (apart from each other). Their experiences are that the service system is mostly not interested in listening to them. They believe they have no alternative but to put up with volatile family dynamics. Not surprisingly, these Elders are worn out and traumatised by the complex, social and environmental situation in which they find themselves.

ACT Health has confirmed that one of its priorities for 2016-17 will be the expansion of detention exit community mental health outreach services. Carers ACT believes caring families engagement with the justice health and mental health systems should be supported through this ACT Health priority by providing community education for families of people exiting detention facilities. In a follow up meeting between Aboriginal Elders and a Carers ACT representative, participants talked about the challenges of accessing information about what to expect when a family member is released from a detention facility, and how to manage family dynamics. These carers also talked about their concerns for their loved ones in finding appropriate housing, getting a job, managing mental health and drug and alcohol addictions.

### **Recommendation 3**

Carers ACT recommends the ACT Government invests in culturally appropriate education and support to strengthen the capacities of Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse carers and families when a family member is engaged in justice and mental health systems to:

<sup>20</sup> Carers ACT (2015) *Carers ACT Response to the ACT Mental Health and Wellbeing Framework*, Canberra. Accessible <http://www.carersact.org.au/Assets/Files/MH%20framework.pdf>

- equip carers with information they need to prepare them for the release of the person back into the community
- promote family reconciliation and re-engagement
- promote community integration.

## **5. Housing pathways for people with disability and caring families**

### **Issue**

Housing continues to be a primary concern for Carers ACT members and their families caring for a person with a disability (physical, cognitive, sensitive and psychosocial). The need for secure, affordable and sustainable housing has been a constant priority for family carers in Carers ACT's recent ACT Government Budget Submissions, and was the catalyst for the Carers ACT 2012 Supported Living Summit.

Carers ACT is an ACTCOSS member and has participated in consultations to develop its 2016-17 ACT Budget Submission. Because of our ongoing commitment to housing pathways for people with disability and caring families<sup>21</sup> we particularly support their housing recommendations, which include recommended actions for people with disability and those at risk of homelessness.

### **Recommendation 4**

Carers ACT recommends the ACT Government invests in housing pathways for people with disability and Canberrans at risk of homelessness recommended in the 2016-17 ACTCOSS Budget Submission.

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<sup>21</sup> See footnote 3 above.