



Carers ACT response to the Community Services Directorate Discussion Paper

“Towards One Human Services System with you at the centre”

November 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.

Carers ACT appreciates this opportunity to provide initial input into the ACT Government's consultation on the development of its Human Services Blueprint. We look forward to further involvement in consultations on the Blueprint, particularly with carers and their families to identify how strategies in the Blueprint will provide integrated, flexible and person centred support that improves and sustains their caring role, as well as improving the quality of life and wellbeing of the people they care for.

About carers

There are around 43,000 carers in the ACT who provide unpaid care and support to family members or friends with a disability, chronic condition, mental health issue, a drug or alcohol dependency or who are frail aged. Sometimes the people they support will have multiple conditions, which increases their need for support from their family and carers.

Carers are from diverse cultural and socioeconomic backgrounds, and can be very young (young carers) or can be aged in their 90s.

Overwhelmingly, families carry the caring responsibility in the community, providing support and assistance to their family members or friends. In the ACT, over 80 per cent of people with disability live with their family or family carer, and nearly 50 per cent of people with mental illness live with their carer.

The 2012 Survey of Disability, Ageing and Carers found that:

- 70% of primary carers,¹ and 56% of all carers are female
- 21% of carers are aged 55 to 64 years
- 37% of primary carers had a disability compared with 16% of non carers
- 4 in 10 primary carers (40%) reported spending 40 hours or more per week providing care, or the equivalent of fulltime employment
- only 42% of primary carers, and 63% of all carers were in the workforce compared with 69% of non carers aged 15 years and over
 - 27% of male primary carers worked full time, and 11% worked part time
 - 15% of female primary carers worked full time, and 24% worked part time
- almost two thirds (65%) of primary carers lived in a household with equivalised² gross household income in the lowest two income quintiles, compared with 36% of non carers
 - only 7% of primary carers had household incomes in the highest income quintile compared with 23% of non carers
- 43% of primary carers were more likely to care for their recipient, compared to any other relationship, 65% of male primary carers cared for their partner, while female primary carers cared more equally for a partner (32%) or their child (34%)
- Carers took on the role of the main unpaid carer because:

¹ Primary carers are defined as the person who has the prime responsible for the caring role.

² Equivalised income is based on the total income of the population living in private dwellings (ABS,2013).

- of their sense of family responsibility (63%)
- they felt they could provide better care than anybody else (50%)
- they felt an emotional obligation to undertake the role (41%)

Because of the demands of their caring role, sometimes for long periods carers are more likely than non carers to experience their own ill health and caring-related injury. In 2012, over one third of primary carers (37%) had a disability compared with 16 per cent of non carers. They are also likely to experience financial hardship because of their lower workforce participation and the associated costs of caring (medications, specialist therapy, transport, motorised equipment and cost of replacement care).

What caring families want from the Human Services Blueprint

For people with disability and age-related frailty, their carers and their families interaction with Human Services is a more prominent component of their lives than Canberrans without disability.

For this reason Carers ACT recommends that the Human Services Blueprint incorporates the following ACT and Australian Government frameworks and legislation so that carers or people with disability are appropriately recognised and supported within the Blueprint to have the same opportunities, as fully as possible, for workforce participation, social engagement, good health and wellbeing, and financial security.

Frameworks and legislation include, but are not limited to:

1. ACT Carers' Charter – Caring for carers

Extracts from the Charter:

The ACT Carers' Charter provides a policy framework to guide the way government and community services meet the needs of carers in the ACT ...

1. Carers are engaged in matters that affect them as carers.
2. Carers are valued and treated with respect and dignity.
3. Carers are supported to sustain their caring role.
4. Carers' diverse needs are acknowledged and appropriate supports provided.
5. Carers share a quality of life that is in accordance with community standards.

2. Carer Recognition Act 2010 Clth, and Schedule 1: Statement for Australia's Carers

Extracts from 'Part 3—Obligations of public service agencies and associated providers' of the Act:

7 Obligations of all public service agencies

(1) Each public service agency is to take all practicable measures to ensure that its employees and agents have an awareness and understanding of the *Statement for Australia's Carers*.

(2) Each public service agency's internal human resources policies, so far as they may significantly affect an employee's caring role, are to be developed having due regard to the *Statement for Australia's Carers*.

8 Additional obligations of public service care agencies

(1) Each public service care agency is to take all practicable measures to ensure that it, and its employees and agents, take action to reflect the principles of the *Statement for Australia's Carers* in developing, implementing, providing or evaluating care supports.

(2) Each public service care agency is to consult carers, or bodies that represent carers, when developing or evaluating care supports.

9 Obligations of associated providers

Each associated provider is to take all practicable measures to ensure that:

(a) its officers, employees and agents have an awareness and understanding of the *Statement for Australia's Carers*; and

(b) it, and its officers, employees and agents, take action to reflect the principles of the *Statement* in developing, implementing, providing or evaluating care supports.

The *Statement for Australia's Carers* includes 10 principles:

1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
2. 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.
3. The valuable social and economic contribution that carers make to society should be recognised and supported.
4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
6. The relationship between carers and the persons for whom they care should be recognised and respected.

7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.
9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
10. Support for carers should be timely, responsive, appropriate and accessible.

3. *National Carer Strategy 2011*

Extract from the Strategy:

“... Some carers shoulder their responsibilities alone; some share their responsibilities with others. Some do it full time, all day, every day, while others only occasionally. What they do not only makes a profound difference to the lives of those they care for, but makes an important contribution to the economic and social life of the nation.

Carers deserve the same opportunities as other Australians to participate in work and the community, and live a meaningful life. The Australian Government is determined to ensure Australia’s carers get the support they deserve from the Government and the community.

We have developed the National Carer Strategy to ensure that our community values and respects carers.”

The National Carer Strategy contains six priority areas for action:

- recognition and respect
- information and access
- economic security
- services for carers
- education and training
- health and wellbeing.

The Human Service Blueprint Discussion Paper identifies the diversity of the ACT population.

Likewise, ACT carers and their families are as diverse with diverse caring situations. Their caring situations will change over their own life course, as well as the life course of the person or people to whom they provide care and support. The National Carer Strategy states:

Caring is done by individuals who bring their life experiences, values, beliefs, attitudes, expectations, coping mechanisms, economic resources, culture and gender to caring. Caring is therefore shaped by the environment in which it occurs and by an individual’s history. As a result, every caring situation will be unique and every carer will care differently.

There is no one size fits or all or a generic solution to each caring situation, and the caring relationship between the carer and whom they care for. However, every carer and caring family in the ACT should be able to access services that meet their own needs.

Carers ACT acknowledges the aspirational themes throughout the Discussion Paper that identify:

- support will be person centred or planned to meet individual needs and choices
- people should be able to access support easily, without delays and before issues become a crisis
- people should be able to access the right services at the right time
- individuals are seeking new types of support
- better use of technology should mean people only tell their story once, can access services and information at times of their choice, and can improve communication and information sharing
- a 'One Human Services System' means people should access one system and not multiple agencies, multiple times.

reflect the expectations of carers and people in a contemporary society. The challenge for the ACT Government and the Human Services Blueprint will be to deliver an integrated, responsive and sustainable, person-centred system that also acknowledges carers and families also have needs and aspirations to be supported by the Blueprint.

Carers ACT knows that too often carers experiences indicate that current services fall short of the principles of the ACT and Australian Government frameworks and legislation above, as well as the proposed components of the Blueprint.

In the development of the ACT Government's Human Services Blueprint so that it integrates the recognition of and adequate support for carers, as well as the needs of the people they support the following need to be incorporated into the Blueprint:

- an equitable service provision so that all families have the same opportunity to access the best services that meet their needs
- a strengthened whole-of-government approach to the provision of supported accommodation so that caring families, particularly mature aged carers, are able to plan the transition of the person for whom they care into accommodation independent from their family before a crisis occurs³ (Carers ACT's response to the ACT Government 2014-15 Budget Consultation has supported accommodation as one of its three priority areas)

³ The ACT Government is the largest single provider of supported accommodation (particularly for people with high care needs) in the ACT. Carers ACT believes the implementation of the ACT NDIS launch site is an important opportunity for the ACT Government to support innovative accommodation solutions for people with disability and mental illness in partnership with families, philanthropic organisations and non government organisations. In 2010-11, accommodation was the highest National Disability Agreement expenditure by the ACT Government at 64.5%.

- an ongoing investment in carer support services to enable carers to sustain their caring role, particularly replacement care and flexible respite services. The national reform in aged and disability care is likely to reduce the availability of this important carer support, particularly for young carers and mature aged carers^{4,5} (Carers ACT's response to the ACT Government 2014-15 Budget Consultation has ongoing investment in carer support as one of its three priority areas)
- a separate carer assessment so their support needs are identified and provided, separate to the needs of the person for whom they care
- the inclusion of carers and families in discussions about relevant assessment and service provision for the person for whom they care (they often have more complete knowledge and understanding of the situation of the person for whom they care, how they react to change and other factors)
- an investment in carer awareness education for Human Services agencies and other agencies that will be the first contact point for carers in the 'One Human Services System' model (health, education, housing and the justice system), including referral to carer support services
- early planning during education to ensure smooth transition phases for a child and young person with disability, particularly transition to post school options, to ensure that they receive support at the right time to achieve the best educational outcomes and the opportunity to satisfactorily participate in employment or other post school activities⁶
- investment in provision of specific resources and support for more vulnerable carer groups, including older carers; young carers; Aboriginal and Torres Strait Islander carers and communities; culturally and linguistically diverse (CALD) carers and communities; and lesbian, gay, bisexual, transgender and intersex (LGBTI) carers and communities.

Other considerations

Carers ACT recommends that the following are also considered in the development of the Blueprint.

- Carer representatives should be included in all key, relevant ACT Government and Human Services advisory committees and groups so their lived experience and expertise inform key policy development and service delivery in the ACT.

⁴ Respite (including residential respite) was Carers ACT's second most accessed service in 2011-12. 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.

⁵ Also refer to the 2011 Centre-based respite delivered by Disability ACT report that states the pressure on limited government resources will only increase over time as the ACT population grows, with estimates that indicate a likely doubling of the ACT respite need; 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; older carers are more likely to have their own disability than non carers.

⁶ Carers ACT consultations with carers indicate that one of the greatest periods of risk for young adults with disability is immediately after they complete their secondary education. If supported employment or skills-based training are not available these young adults face the prospect of an unstructured day with no or limited supports or access to the networks and social situations. Carers may be forced to cease or reduce their workforce activities to provide the necessary daily support.

- Funding for provision of adequate support for Canberrans with physical, intellectual and mental health impairment that are not eligible for National Disability Insurance Scheme 'tier 3' support should be a priority of the Blueprint.
- The age split between disability and aged services should not be a barrier to seamless service delivery within the ACT and strategies to affect this should be reflected in the Blueprint. This is particularly important as people with physical and mental health impairment are likely to experience age-related disability earlier than 65 years of age, particularly younger onset dementia.
- Cross-border service provision agreements should be developed by the ACT Government to reflect Canberra's growth as a regional centre, the emerging wider demand for services from people outside the ACT that are part of the ACT's workforce and education system, as well as people in neighbouring regions wanting to access services in the ACT.
- Ongoing strategies to ensure that the non government sector's⁷ capacity and skills to provide quality and appropriate services that meet the choice of people with disability and carers and families are sustained. This includes adequate funding for programs delivered by this community sector.

References

- ACT Government (2011) *ACT Carers' Charter – Caring for Carers*, Canberra
- ACT Government (2013) *Towards One Human Services System – A discussion paper to inform the development of a Human Services Blueprint*, Canberra
- ACT Government Community Services (2011) *Centre-based respite care delivered by Disability ACT, Volumes 1 and 2*, Canberra
- Australian Bureau of Statistics (2013) *Report of 2012 Survey of Disability, Ageing and Carers*, Canberra
- Australian Government (2010) *Carer Recognition Act 2010 (Clth)*, Canberra
- Australian Government (2011) *National Carer Strategy*
- Carers ACT (2013) *Response to ACT Government 2014-15 Budget Consultation*, Canberra

⁷ The non government sector in the ACT is particularly active and has a high number of organisations, with about 50% more organisations per head of population than in NSW, according to the ACT Government's discussion paper on a Human Services Blueprint. This is likely to increase with sector changes under the NDIS launch site implementation.