



**Response to draft
ACT Carers Charter**

January 2011

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 continuation of the Ngunnawal people's living culture.

Enquiries on this submission may be directed to:

Dee McGrath

Chief Executive Officer

T: (02) 6296 9901

E: deem@carersact.asn.au

This document was prepared by:

Dee McGrath, CEO

Sue Thomas, Policy Manager

Natasha Flores, Policy and Research Officer

Carers ACT

2/80 Beaurepaire Crescent

HOLT ACT 2611

T: (02) 6296 9900

F: (02) 6296 9999

E: carers@carersact.asn.au

W: www.carersact.asn.au

Carers ACT sincerely thanks all Carers who have contributed to the research and consultation activities which inform its policy and representation activities.

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 families provide ongoing 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 7,000 families through our counselling, information, respite support, education, social support and case co-ordination services. Our services were assessed in 2009 to meet HACC and NCCP accreditation standards at a level of excellence.

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 welcomes the opportunity to comment on the draft ACT Carers Charter. Noting that Louise Gray and Associates will be providing feedback to the ACT Government on the results of its consultations with Carers, the Carers ACT's submission is provided on behalf of the organisation.

Background

As a result of lobbying from the National Network of Carers Associations and Carers Australia, Carers have been successful over the last few years in achieving recognition from both levels of government for the essential role they play in maintaining a health and welfare system that depends inherently on the provision of community based care.

The use of the term Carer can denote both paid and unpaid Carers. However, in its submission to the Residential Aged Care Abuse Taskforce (2006), Carers Australia argued that the term Carer should be reserved for family members or other people providing care on an informal basis. This recognises the extra responsibilities that a person has because they have a family member, partner or neighbour who has a chronic illness, disability, mental illness or who is frail aged.

There is no doubt that the ACT Government was one of the jurisdictions to formally acknowledge the important role of unpaid or family Carers. It has achieved this specifically through its *Caring for Carers Policy*, the *Caring for Carers in the ACT — a plan for action 2004-2007* and the *Carers Recognition Legislation Amendment Act 2006*.

Carers ACT began lobbying for an ACT Charter of Rights in 2007. This was envisioned as a Charter that would go further than the *Carers Recognition Legislation Amendment Act 2006*, by providing for the inclusion of Carer rights in decision making and establishing a core set of service delivery standards for agencies providing services to Carers. Although the ACT Labor Party committed to introducing a Charter of Rights for Carers in the 2008 election campaign, the draft ACT Charter was not finally released until October 2010.

In the intervening period, the Australian Labor Party's 2007 federal election policy document noted that some states and territories had passed Carers Recognition Acts 'to set a legislative standard for the treatment of Carers by government services'¹ and stated that if elected, Labor would focus on the needs of Carers and consider what legislation would be required at the federal level. Following overwhelming support for the development of a national and strategic approach to Carer recognition and policy (provided through Submissions and presentations at the House of Representatives Standing Committee on Family, Housing, Community and Youth

¹ ALP Policy Platform 2007

Inquiry into better support for Carers), the Australian Government announced in October 2009, its intention to develop a National Carer Recognition Framework. The framework includes legislation, a National Carers Strategy and an action plan.

The National Carer Recognition ACT commenced on 18 November 2010. The Statement for Australia's Carers (contained in the legislation) provides 10 dot points (see Attachment A), which to some extent restate or reframe certain fundamental human rights principles with reference to the status of the individual as a Carer. As well as setting out the rights of Carers, the principles cover the value of the Carer and the need to acknowledge their role (e.g. Principle 8 articulates the need to treat Carers with dignity and respect), the relational nature of the relationship between the Carer and the person being cared for, and importantly, acknowledgment of the unique knowledge and experience of Carers (Principle 7). Principles 9 and 10 provide specific guidance on the treatment of Carers: Principle 9 states that Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.²

The Australian Government has recently concluded consultations on the National Carer Strategy, with the Government announcing that the Strategy will be finalised by mid 2011. The discussion paper states that the Strategy is being developed to shape the long term agenda for Carers. Importantly, it will set out clearly how all levels of government will work together to make this policy a reality.³ The draft Strategy comprises five goals that the Australian Government has said will guide government policy and programs across the wide range of areas that impact on Carers.

The National Carer Strategy will also help ensure that the interconnected reforms currently being undertaken at the federal level across the disability, mental health, primary health, hospital and aged care systems – (all of which will be important to Carers) align with the goals and direction of the National Carer Strategy as they are rolled out.

It could therefore be argued that the work being undertaken by the ACT Government in this area has, to a large extent, been overtaken by the work at the national level. Carers ACT considers that while an ACT Carers Charter is an important means of demonstrating the ACT Government's commitment to Carers, it should complement and be consistent with the National Carer Recognition Framework. This could be achieved by waiting until the National Carer Strategy is finalised and then issuing an ACT Carers Charter that is more closely aligned with that document. Acknowledging that this is a national issue, the ACT Government could then frame their efforts as contributing to the national effort and, acknowledging that this is a

² Parliament of Australia, Parliamentary Library, Bills Digest no. 190, Carer Recognition Bill 2010, p.4

³ Australian Government, Towards a National Carer Strategy: A discussion paper from the Australian Government,

national issue, could frame their efforts as contributing to the national effort, and then recognise or use implementation legislation to mirror the Commonwealth approach.

The ACT Carers Charter

The draft ACT Charter, as it currently exists is somewhat contrary to the National Framework, which raises a number of problems. These are outlined below:

Definition of Carer

A fundamental difference between the federal and ACT models is highlighted in the differing definitions of Carer:

The *Carer Recognition Act 2010* defines a Carer as “an individual who provides personal care, support and assistance to another individual who needs it because that other individual has a disability, a medical condition, a mental illness, or is frail and aged”.

This is consistent with the Carers Australia definition, i.e. ‘Family Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are aged and frail’.

By contrast, the draft ACT Charter definition of a Carer is broader, defining a Carer as “a person who provides unpaid primary care to someone else who is dependent on the person for ongoing care and assistance”. The definition includes people who provide informal care and support to friends and relatives with needs associated with disability, ageing, ongoing physical or mental illness, or substance abuse, as well as Grandparents, Kinship Carers or Foster Carers who provide a caring role to children and young people. In fact, the ACT definition is so broad, it could cover any parent.

It is also important to note, as the discussion paper itself does, that ‘most states and territories have introduced a Carer Charter and/or Carer legislation to recognise and support Carers who provide unpaid care and support to a person with needs associated with disability, ongoing physical or mental illness or ageing’ (page 9). The definition adopted by other jurisdictions is consistent with that used in the national legislation.

While acknowledging that the broader definition has been necessary to ensure consistency with the *ACT Carers Recognition Legislation Amendment Act 2006* there are some inherent risks in having different Carers definitions.

Carers ACT is in no way suggesting that the cohorts included in the ACT definition do not perform important and valuable roles within the community nor that they do not deserve additional supports and services. There are, however, a couple of fundamental differences

between a Foster Carer and that of an unpaid informal or family Carer. For example, the family care role is rarely one taken on by choice; it comes about through circumstance. Foster Carers may, on the other hand, be seen as providing care for a child on a voluntary basis, and they receive a financial contribution for expenses incurred in caring for their foster child. Although the contribution in no way covers the full cost of care, the financial contribution is significantly higher than that provided through Centrelink to a family Carer who must provide daily personal care, as well as a minimum of 20 hours care (e.g. medication, feeding etc.).

Feeling acknowledged and respected can contribute to experiences of improved self esteem, coping resources and health and wellbeing. This is vitally important, as notwithstanding the many benefits of the caring role, research has found that unpaid family Carers have the lowest collective wellbeing of any population group. It is therefore critical that the recognition that Carers have achieved to date, and their need for future additional support is not jeopardised. As well as diluting the services and supports available to caring families, there is a risk that Foster Carers and Grandparent Carers may also miss out on their share of funding.

Although it could be argued at one level that the definition of Carers reflects all Carers in the ACT, the incorporation of additional cohorts into the Carer definition has the potential to dilute funding for services to family Carers who are already struggling with insufficient services and supports. An example of this dilution has been seen in recent times in the funding for the Carer Advocacy Service. Carers ACT lobbied hard to get a commitment to the establishment of a Carer Advocacy Service and in the lead-up to the 2008 ACT Election, the ACT Labor Party committed to providing \$800,000 over four years for this service. However, it was not until the 2010-11 ACT Budget, that the Government announced (reduced) funding of \$424,000 over four years for a Carer Advocacy Service. It would appear that the remainder of the promised funding has been allocated to Kinship/Foster Carer services, although it is not clear that these are new services. We hope the ACT Government can clarify this for us.

The promulgation of a broad definition of Carer, may also contribute to confusion among Carers about eligibility for services. For example: Carers ACT is not contracted by the Federal or ACT Government to provide support service to Foster Carers, unless they are caring for someone who has a disability, mental illness or chronic health condition. A more specific definition may help to improve clarity.

Having argued that the ACT Carer definition is very broad; it is at the same time very restricting, as it defines a Carer only as someone who provides unpaid *primary* care to someone...⁴ This definition immediately restricts the number of people who can be defined as a Carer and

⁴ The ABS publication: Disability, Ageing and Carers 4430.0 - defines a primary carer as 'a person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities or aged 60 years and over. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities (communication, mobility and self-care).'

ignores the fact that all members of the family normally perform a caring role. Strangely, this is a narrowing of the definition used in the ACT's *Carers Recognition Legislation Amendment Act 2006* which specifically broadened previous legislation to recognise that a person could have more than one Carer. It is also not consistent with other definitions used including the ABS's Disability, Ageing and Carers publications which define a Carer as a 'person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older persons (i.e. aged 60 years and over).'

Unless there is an agreed accepted definition of a Carer, we will continue to experience difficulties in accurately determining the number of Carers in Australia and will not be well positioned to roll out the necessary services and supports that unpaid family Carers require.

The Charter itself

The ACT Labor Party undertook to introduce a rights based Charter. The document released for comment in October 2010 is not rights-based. Therefore, the question is: how effective can it be in driving real change?

The 10 principles that incorporate the proposed ACT Charter do not add value and clarity and do not serve as an effective policy framework to guide the way the ACT Government and government funded services that support Carers are accessed and delivered.

Some specific comments in relation to the Principles themselves are:

- ❖ Principle 1 is covered in human rights legislation.
- ❖ Principles 2 and 3 are included in a number of service standards.
- ❖ Principles 4 to 7 are duplicative and Carers ACT would argue that it is not necessary to identify different groups of Carers as the principles should apply to all Carers regardless of ethnic background, Aboriginality or age.
- ❖ In Principle 8, the inclusion of the word "practicable" gives an "out".
- ❖ Principles 9 and 10 are covered in standards.

Additionally the language used is inconsistent, alternating between being simply practicable and then aspirational, e.g. Principle 8 states "The impacts of social exclusion on children and their Carers are recognised and responded to where practicable, whereas Principle 6 states - Young Carers (under 18 years) and Young Adult Carers (18-25 years) have access to supports that ensure equal life opportunities as their peers".

A number of other issues about the Charter's wording were raised by Carers in the consultation processes. As indicated earlier, we have not included these concerns in this Submission as they will be included in the report being written by Louise Gray and Associates.

It is evident that the *National Carer Recognition Act 2010* and the *National Carer Strategy* complement each other - Schedule 1 of the *National Carer Recognition Act 2010* – The *Statement for Australia’s Carers* – details 10 Principles and the 5 National Carer Strategy goals align closely with those 10 principles. Together they provide a solid foundation for the development of an action plan and the rollout of policies and services.

The *Statement for Australia’s Carers* does not apply to the exclusion of Carers Charters determined by States or Territories. It is therefore important that the ACT Carers Charter be meaningful so that the result is:

- a more consistent approach to responding to Carers’ needs
- better coordination between service providers
- a strategic, planned approach to funding and resource allocation
- participation by Carers at all levels of policy development and services planning; and
- greater recognition and support for Carers by the wider community.

Implementation

Monitoring and compliance

Implementation must include processes for assessing the impact of the legislation and policy, for monitoring compliance and providing a mechanism for Carers to raise grievances or complaints.

Additionally, the Charter *cannot* exist on its own. It will not have any standing unless it is complemented by an Action Plan that includes funding for priorities and contains commitments by the ACT on how the Charter will be progressed and measured. The Action Plan should be structured around the agreed 10 Charter Principles. Including Carers in the development of the Action Plan would assist with better priority setting around what people’s needs are and would assist in ensuring that resources are directed to the areas of greatest need.

The Plan should include realistic objectives and clear, measurable targets that can be easily monitored and assessed. Measures should comprise *evidence* of inclusion of the carer in service delivery, going beyond *awareness* of the carer and their role.

A coordinating committee or other independent type body such as the Carers Implementation Partnership could be given responsibility for monitoring the implementation of the Charter and Action Plan.

Its role would be to:

- develop a reporting structure that takes account of the role of individual agencies, but addresses the need for overall consistency
- develop and oversight compliance mechanisms to ensure that government departments and agencies are committed to achieving the necessary systemic reform
- review the reports which would be provided annually, and assess how the activities of the various agencies compare with the commitments provide for in the plan. Any gaps would be highlighted and discussions held with the respective agency about strategies that might be required to be put in place to meet the original objectives, and
- receive complaints from Carers on non-compliance and have sufficient power to take proper action to redress evident non-compliance.

The whole approach should aim to be economical in terms of resources and time so that the reporting process does not become unwieldy or sink under its own weight. If it is too cumbersome in terms of either the preparation or the evaluation of reports there will be a disincentive to all concerned to maintain it effectively.

Many ACT agencies receive funding from both federal and state bodies and may struggle with the burden of complying with different reporting requirements. Consistency with the National Carer Recognition Framework and its reporting requirements will assist ACT agencies to more easily comply with necessary reporting requirements.

Raising Awareness

Effective implementation will not occur without adequate resourcing to support an education and awareness raising program to inform Carers, governments, community care service providers, health professionals and others of their responsibilities under the framework. Increased awareness can then be embedded in the service's organisational values and codes of conduct.

Conclusion

In summary we support the development of an ACT Carers Charter, but maintain that the Charter must complement the national legislation and associated Strategy to ensure consistency across jurisdictions. Acknowledging that this is a national issue, the ACT Government could frame their efforts as contributing to the national effort, and then recognise or use implementation legislation to mirror the Commonwealth approach.

For the Charter to be meaningful and add value it must be followed by an Action Plan that includes funding for additional services. These additional services should then be rolled out in a coordinated manner so that services and programs funded by the ACT Government complement, not duplicate, those funded by the Federal Government.

As the recognized Association for Carers in the ACT representing many thousands of family Carers, we look forward to working with the ACT Government to developing an ACT Charter and supporting Action Plan that will lead positive change and action for Carers in the ACT.

Schedule 1—The Statement for Australia’s Carers

Note: See section 6.

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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.