



**Response to the Draft ACT Strategic Plan for Positive Ageing
2009-2014**

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Department of Disability, Housing and Community Services
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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:
Annemarie Ashton, Policy Advisor

Carers ACT

Suite 5 Ground Floor
Churches Centre
54 Benjamin Way
Belconnen ACT 2617

T: (02) 6296 9900

F: (02) 6296 9999

E: carers@carersact.asn.au

W: www.carersact.asn.au

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We recognize the displacement and disadvantage they have suffered since European settlement. We offer our respects to their Elders, and celebrate the continuation of the Ngunnawal people's living culture.

Carers ACT sincerely thanks all Carers who have contributed to the research and consultation activities which inform our policy and representation work. We would also like to thank Elizabeth Watts for her contribution to the preparation of this submission.

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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 caring families 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 over 5,000 families through our counseling, 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.

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***Positive Ageing and the ACT Community
List of Recommendations***

1. That ACT Strategic Plan for Positive Ageing require dedicated telephones planned for government buildings to have capacity to contact the Commonwealth Respite and Carelink Centre directly on 1800 052 222.
2. That ACT Strategic Plan for Positive Ageing require Carers to be an identified target group for *healthdirect* promotions and that the level of promotion of the service to the wider community be significantly expanded.
3. That the ACT Strategic Plan for Positive Ageing require that the ACT Government invest in a 'healthy living and getting connected' campaign aimed at getting older Carers in touch with support services to enable improved wellbeing outcomes through health promotion and early intervention.
4. That the ACT Strategic Plan for Positive Ageing require improvement in promotion of the regional mini-bus service to assist older people in accessing transport to medical care facilities and community centres/organizations.
5. That the ACT Strategic Plan for Positive Ageing recommend the development of partnerships to implement new health promotion resources aimed at improving health and wellbeing for older Carers.
6. That the ACT Strategic Plan for Positive Ageing require the ACT Government to extend the proposed aged care GP locum service to Carers of older people and older Carers of people with disabilities.
7. That the ACT Strategic Plan for Positive Ageing require that ACT Government implement a community education program to promote the positive value of aged people and improve awareness of caring roles.
8. That the ACT Strategic Plan for Positive Ageing require the ACT Government to review the Guardianship and Management of Property Act 1991.
9. That the ACT Strategic Plan for Positive Ageing require the ACT Government to phase in higher floor targets for accessible design planning.
10. That the ACT Strategic Plan for Positive Ageing recognize the need for appropriate ongoing funding to support volunteer-based programs and not rely on volunteer-based services as a way of avoiding the investment in support services which will be needed to meet the increased demand caused by the ageing population.
11. That the ACT Strategic Plan for Positive Ageing include a requirement for improved linkage between disability, health, mental health and aged sectors – between Federal and State/Territory level, at a departmental level and at a service level.

12. That the ACT Strategic Plan for Positive Ageing include a requirement that ACTION Buses develop and implement an appropriate plan in consultation with mobility challenged people and Carers to enable the more efficient and effective use of disability accessible buses, and improve public transport access for older people.
13. That the ACT Strategic Plan for Positive Ageing include a requirement that regulation systems for scooters be fee-free for people with a health care card or senior card.
14. That the ACT Strategic Plan for Positive Ageing include a requirement that the ACT Government boost alternative care options to ensure that older Carers have sufficient access to respite and to assist in transitioning into supported accommodation options in the future, if required.
15. That the ACT Strategic Plan for Positive Ageing include a requirement that the ACT Government boost alternative care options to ensure that older Carers have sufficient access to increased workforce and community participation and extra support to appropriately plan for retirement given the demands of their caring role.

Positive Ageing and the ACT Community

Independence, participation, care, self-fulfillment and dignity are all vital human rights which should be freely available to every person living in the Australian Capital Territory and actively enabled by a whole-of-government and a whole-of-community response. Yet, the drafting of a social policy or strategic plan to promote those values recognizes the reality that many vulnerable people in the ACT face significant barriers to achieving any kind of functional equity.

Ageing should be a positive experience for individuals, for families and for communities. Older people have a wealth of experience and energy to offer for the benefit of individuals, families and the wider community. Older people may also need to receive supports, when needed, in a positive and enabling manner to maintain their optimum health and wellbeing.

Issues about ageing are highly relevant to the work of Carers ACT because:

- People who are ageing often provide care to other family members;
- People who have disabilities may have changing care needs as they age, which can impact on family Carers;
- Carers and care-recipients from Indigenous backgrounds are more likely to experience the effects of ageing at an earlier age; and,
- People who are ageing are more likely to have increased care needs.

On behalf of over 4,700 current members¹, Carers ACT welcomes an opportunity to provide comment on the Draft ACT Strategic Plan on Positive Ageing.

Care Needs of an Ageing ACT Population

The ageing of the ACT population is anticipated to produce an increase in the number of old and very old people. However, population projections indicate that ratios of available Carers to people with care needs aged 65⁺ will drop from 57:100 in 2001 to 35:100 in 2031². The expected shortfall in available Carers will greatly increase pressure on societies to provide the care and support needed by people who are unable to live independently.

Additionally, projections of need will be affected by factors other than the ageing of the population. People with disabilities are living longer due to advances in medical care, but many are also faced with the effects of premature ageing due to the complexities of their conditions. Changing family patterns and increasing economic pressures are also impacting on the way the ACT provides assistance to people with care and support needs.

It is vital that we react in a positive way to the future challenges of an ageing population and properly resource models of care which more effectively address the evidenced diversity of care and support needs for ageing people, and offer opportunities which maximize the social inclusion of all older Territorians.

¹ As at September 2009

² NATSEM (2004) *who's going to care? Informal care and the ageing population*. Canberra: National Centre for Economic Modelling, University of Canberra.

Strategic Priority 1 – Information and Communication

Provision of accurate and timely information is essential for ensuring effective care and social inclusion of all older people. Pathways to obtaining information also need to be clear and well-recognized by the wider community. The Commonwealth Respite and Carelink Centre (CRCC) in the ACT offers the strength of local knowledge delivered by local people who are also linked to an Australia-wide system of other local offices under the national freecall number. The CRCC service offered by Carers ACT has recently been evaluated at a very high quality against HACC and NCCP standards for service providers.

Older people accessing the ACT CRCC³ have reported that the value of the service lies in the following attributes:

- A real person answering the phone, not an automated menu system;
- A welcoming, empathetic attitude from well-trained, knowledgeable staff who understand the complexity of care situations;
- Accurate information that is up-to-date regarding service accessibility and anticipated waiting times;
- Timely responses and referral to appropriate services; and,
- Easy access to respite and counseling supports.

The Draft Plan proposal to introduce dedicated phones in government buildings needs to include direct access to the CRCC alongside Canberra Connect and the Citizens Advice Bureau. Direct linkage to the CRCC is essential as older Carers report that they are very discouraged and frustrated by ringing one number and being given another to call because the person on the end of the first phone number has insufficient knowledge, understanding or capacity to assist at an appropriate level to meet their need.

<p>Recommendation 1: That ACT Strategic Plan for Positive Ageing require dedicated telephones planned for government buildings to have capacity to contact the Commonwealth Respite and Carelink Centre directly on 1800 052 222.</p>
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The Draft Plan notes the provision of the *healthdirect* service as a core part of current services delivered to assist information and communication needs of older people. Yet, recent consultation on Carers needs conducted by Carers ACT⁴ has indicated a significant lack of community awareness about the *healthdirect* service, especially among people from culturally and linguistically diverse (CALD) populations.

Carers ACT observed, during these recent consultation activities, that when the *healthdirect* service was explained to Carers, their feedback was extremely positive about the potential for the service to be of particular use to them. Evidence indicates that the ACT Government needs to invest in greater promotion of this very useful service, especially to Carers. This is important because Carers often face significant

³ Ashton, A. (2009) *Understood, connected and supported*. Canberra: Carers ACT.

⁴ Carers ACT - *publication pending*

barriers in obtaining adequate primary health care for themselves and for the care-recipient due to the time and cost pressures created by the demands of a care role.

Recommendation 2: That ACT Strategic Plan for Positive Ageing require Carers to be an identified target group for *healthdirect* promotions and that the level of promotion of the service to the wider community be significantly expanded.

A final core consideration of any information and communication strategy must be the need to educate and inform people about how to reach out for support, and, more importantly, about when to reach out for support. Many older people hesitate before contacting Carers ACT or other community support services, and they often wait until a crisis necessitates a call. Greater community education regarding the positive benefits of getting involved in social and wellbeing activities, in early identification of health and support needs, and the importance of prevention of health problems, are all critical parts of the strategy that must be addressed in a sustained way which will help to reduce negative outcomes for many older people.

Carers ACT research indicates that social isolation and depression are evident in many older Carers in the community, yet both issues can be prevented through education. Reassurance about the welcome that older people will receive when contacting Carers ACT or other 'senior-friendly' organizations in the wider public domain is also essential for enabling early service contact.

Recommendation 3: That the ACT Strategic Plan for Positive Ageing require that the ACT Government invest in a 'healthy living and getting connected' campaign aimed at getting older Carers in touch with support services to enable improved wellbeing outcomes through health promotion and early intervention.

Strategic Priority 2 – Health and Wellbeing

Health and wellbeing for Carers and for care-recipients is essential for minimizing the need for escalated rates of formal service intervention as people age. As discussed above, many Carers face significant barriers in maintaining a healthy lifestyle due to the demands of the care role. Research conducted into Carer health and wellbeing⁵ by Deakin University indicates that Carers are a group who are more vulnerable to reduced health and wellbeing outcomes, with higher than normal rates of injury, depression, stress, chronic illness and poverty.

Research conducted by Carers ACT indicates that older Carers often need assistance and support to overcome the barriers preventing access to needed health care⁶. Supports identified include: availability of respite support, assistance with transport, practical education (e.g. healthy cooking classes), exercise classes, social support, and financial assistance. Yet many older people remain unaware of existing community supports which are available to assist them, such as the regional mini-bus service.

⁵ Cummins, R., et al (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University

⁶ Ashton, A., McGrath, D. (2008) *'Have your say' ACT election survey report*. Canberra: Carers ACT.

Recommendation 4: That the ACT Strategic Plan for Positive Ageing require improvement in promotion of the regional mini-bus service to assist older people in accessing transport to medical care facilities and community centres/organizations.

Carers ACT already offers a wealth of supports which can assist eligible Carers to improve their health and wellbeing, including respite services, education and some transport assistance. A research project in partnership with the University of Canberra is also currently underway to develop an appropriate and useful health promotion resource for Carers, based on evidenced need, which will greatly assist older Carers and those caring for older people to maintain good health and wellbeing.

Recommendation 5: That the ACT Strategic Plan for Positive Ageing recommend the development of partnerships to implement new health promotion resources aimed at improving health and wellbeing for older Carers.

Social isolation is a critical problem for many older Carers, who have to overcome the 'double disadvantage' of barriers caused by care roles and ageing. Carers ACT already offers a variety of social opportunities to Carers, which are predominantly accessed by senior members of the ACT community. However, further opportunities will need to be developed with the establishment of the new Carers Centre in Holt. Carers ACT looks forward to working with the ACT Government to establish new social activities for older Carers at the Centre, and at other community centres throughout the ACT.

The Draft Plan also notes a plan to offer a business hours aged care GP locum service to provide care to people who cannot travel easily. Carers of older people and people with disabilities often experience significant difficulty in obtaining suitable health care when unwell because they cannot get to a GP practice due to the level of their caring commitments. It would be extremely beneficial to Carers if the planned service could be extended to include Carers in their own right as well as aged people.

Recommendation 6: That the ACT Strategic Plan for Positive Ageing require the ACT Government to extend the proposed aged care GP locum service to Carers of older people and older Carers of people with disabilities.

Strategic Priority 3 – Respect, Valuing and Safety

Carers ACT strongly promotes improved respect, valuing and safety for older people through all aspects of service delivery and representation activities. For example, our Employed Carers program brokers funding to assist Carers of aged persons to access Red Cross personal alarms which enable better safety responses to frail aged people if they fall or become unwell. Carers ACT also assists many Carers to access courses to improve home safety for older people, including CIT 'Skills for Carers'.

Improved safety is especially important for older Carers, to prevent injury and promote sustainable care in the community. Carers ACT assists with obtaining supports to improve safety, for example, assisting with obtaining equipment needed for safe lifting or installing ramps for mobility assistance. Specialist programs also provide case coordination for many older Carers which can help to resolve safety issues, such as the

development of emergency plans, information on medication management or access to respite. Carers ACT also offers a wide range of Carer-specific workshops and support groups which encompass issues relevant to the safety of older people, such as dealing with difficult behaviours, managing grief and loss, and coping with mother/daughter relationships when caring for an aged person.

National and local research⁷ indicates that many people have a difficulty in recognizing or accepting the term 'Carer' as relevant to their identity or care role. They feel that their relationship to the care-recipient is the primary identifier, i.e. they see themselves as 'daughter' or 'husband' or 'mother' rather than 'Carer'. This perception can create barriers which prevent timely receipt of needed support.

Many Carers can also feel that their care role is little recognized or valued by the wider community. A community information program which supports positive language about care and ageing could improve awareness of care roles, assist in earlier self-referral to supports, and promote a higher social valuing of people who are ageing or who are providing care for someone who is aged.

Recommendation 7: That the ACT Strategic Plan for Positive Ageing require that ACT Government implement a community education program to promote the positive value of aged people and improve awareness of caring roles.

The Draft Plan notes that the ACT Government plans to work with the Australian Guardianship and Administration Council to standardize Enduring Power of Attorney arrangements on a national basis. Consultation with Carers has indicated that many people struggle with the complexity and inadequacy of the current Guardianship system. It is vital that current legislation is reviewed and amended to more adequately meet the needs of the whole family while also protecting the financial and human rights of the care-recipient.

Recommendation 8: That the ACT Strategic Plan for Positive Ageing require the ACT Government to review the *Guardianship and Management of Property Act 1991*.

Strategic Priority 4 – Housing and Accommodation

Vulnerable populations in the ACT are often at higher risk of losing their home and/or live in housing which is inadequate for their needs. Carers must be recognized as one of the ACT's vulnerable populations; as the demands of their care role leave them more likely to be disengaged or marginalized from the workforce and this reduces lifetime earning capacity and asset accumulation. The costs of providing care also contributes to Carers being more likely to experience increased levels of unmanageable debt and to have higher household costs (per dollar of income) when compared people who are not providing care.

⁷ Cummins, R., et al (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University; and Ashton, A., McGrath, D. (2008) *'Have your say' ACT election survey report*. Canberra: Carers ACT.

The Draft Plan asks Carers to consider the option of building a 'granny flat' to enable older family members to co-reside while still maintaining maximum independence. It is important that the ACT Government recognize the costs borne by Carers and their families when providing in-home care and especially when investing in the substantial costs of building and maintaining granny flats. Concessions are available to a limited number of people, such as those on pensions. Yet, Carers on low to middle incomes may be financially stressed by the costs of care, and need access to concessions in ACT Government charges and utility costs to enable them to provide care within their own home and prevent premature entry to residential care facilities.

As many Carers are on very low incomes and/or income support, they are often tenants of Housing ACT. Carers ACT has supported a number of Carers who have needed assistance with resolving issues with Housing ACT. While the department is very responsive to our involvement, it is evident that the guidelines relating to eligibility would be improved by increased recognition of people with care responsibilities, especially in regard to co-tenancy arrangements.

Carers ACT acknowledges the Territory Plan's floor targets for meeting Adaptable Housing Standard AS4299 Class C. However, it is critical that more principles of universal design are a core requirement for all housing developments to enable the ACT to meet future need for care in the community and ageing in place. Better design also avoids costly retro-fitting, which is frequently required for aged persons and people with disabilities. Carers ACT recommends that the ACT Government commit to increasing floor targets in accessible design planning which are gradually phased in over time until all new housing adheres to principles of universal design.

Recommendation 9: That the ACT Strategic Plan for Positive Ageing require the ACT Government to phase in higher floor targets for accessible design planning.

The Draft Strategic Plan notes that the ACT Government will develop and implement the *ACT Policy Framework for People with a Disability who are Ageing* within the next 12 months. Carers ACT supports the development of this policy framework, and offers assistance to the ACT Government in regard to the inclusion and consultation of Carers in the development of the framework.

Strategic Priority 5 – Support Services

Appropriate and accessible support services are essential for the continuation of care in the community for older people. Carers ACT is committed to providing quality services which effectively meet the needs of Carers. Carers ACT receives funding from a number of sources, including Home and Community Care (HACC), to deliver a variety of support services to Carers of people who are aged and older Carers of people with disabilities.

The Draft Plan calls for the active seeking of older volunteers to assist with delivery of support services to older people in the community. However, Carers ACT notes that delivery of appropriate and effective volunteer programs relies upon a minimum level of infrastructure, including a volunteer coordinator, training, supervision and ongoing support for volunteers. Ethically, volunteers should also not be used alongside, or in place of paid, professional workers.

Provision of services by a volunteer workforce also depends upon the availability of a pool of people willing and able to volunteer. However, Carers ACT is noting a significant drop in the availability of volunteers due to the need for active older people to stay in the workforce longer because of increasing costs of living and loss of superannuation savings in the Global Financial Crisis.

Recommendation 10: That the ACT Strategic Plan for Positive Ageing recognize the need for appropriate ongoing funding to support volunteer-based programs and not rely on volunteer-based services as a way of avoiding the investment in support services which will be needed to meet the increased demand caused by the ageing population.

The Draft Plan calls upon businesses to support employees who may have Carer responsibilities. Carers ACT currently delivers an Employed Carers program, which is funded by the Department of Health and Ageing. This program supports Carers of people aged 65 and older, and Carers of Indigenous people aged 50 or older. Carers ACT invites businesses to encourage Carers to contact us to see how they can be better supported to balance their work and care responsibilities.

The Draft Plan notes the establishment of a 'Virtual Village' within the ACT based on the 'Beacon Hill' model in Boston, MA. Carers ACT welcomes the trial of a model which offers innovative, flexible and responsive means of supporting older people in the community, as increased diversity in models of support available to families offers a positive benefit and moves the ACT away from a 'one size fits all' approach. Carers ACT looks forward to the planned trial of the 'Virtual Village' program providing a learning opportunity to better enable us to assist families in the ACT in caring for older persons.

Carers need choice and flexibility in the support options they can access. Innovation is essential for developing 'smarter' services which can better utilize existing and future resources to meet increasing demand for support. Carers ACT is actively working with government and other community sector organizations to improve care support models, to manage sector workforce challenges, and to meet anticipated and evidenced increases in demand for support. It is vital that stronger relationships are built across departments and across the sector to reduce fragmentation and build a more effective 'web' of supports to improve outcomes for Carers and older people.

Recommendation 11: That the ACT Strategic Plan for Positive Ageing include a requirement for improved linkage between disability, health, mental health and aged sectors – between Federal and State/Territory level, at a departmental level and at a service level.

Carers ACT has a constitutional mandate to represent the voices of its membership, and does so through a diversity of consultation and representation activities. Sound policy based on evidence collected in the ACT is essential for reform, whether looking at service delivery or funding models. It is critical that families (who are the people actually providing care to older people and people with disabilities) are recognized as the experts in determining the priorities for their own support needs and have realistic levels of choice in how and when they receive that support.

Strategic Priority 6 – Transport and Mobility

Access to affordable and efficient transport is an essential part of maintaining health and wellbeing for older people. Yet, mobility issues can significantly reduce ability to access transport independently, resulting in social isolation and poor wellbeing outcomes if people are not adequately supported. Carers ACT has been made aware of a number of key transport issues affecting older Carers of people with disabilities and older people with care needs.

People with mobility challenges who are accessing public transport have indicated that they often have problems in using disability accessible buses because they can wait for unacceptable amounts of time with non-accessible buses driving past until an accessible bus turns up. Carers have suggested that disability accessible buses need to be guaranteed on specific routes and times, and clearly marked on the timetable to enable users to plan their bus usage.

Recommendation 12: That the ACT Strategic Plan for Positive Ageing include a requirement that ACTION Buses develop and implement an appropriate plan in consultation with mobility challenged people and Carers to enable the more efficient and effective use of disability accessible buses, and improve public transport access for older people.

Carers ACT is pleased to see that a review of wheelchair accessible taxis has been commenced by the ACT Government. Issues of concern to Carers include the reliability of access to wheelchair accessible taxis, waiting times for service users and cost to families. Carers ACT is also pleased to support the ACT Government's implementation of a Companion Card system for the ACT, and notes that the scheme's recognition by ACTION buses will greatly improve access for Carers of people with disabilities who wish to utilize public transport.

The Draft Plan notes that the ACT Government is considering the regulation of scooters. These mobility-assist scooters are almost exclusively used by older people and people with disabilities. Both groups are highly vulnerable populations and have a high likelihood of having limited income. Carers ACT considers it essential that any regulation scheme must be completely fee-free for anyone with a health care card or seniors card.

Recommendation 13: That the ACT Strategic Plan for Positive Ageing include a requirement that regulation systems for scooters be fee-free for people with a health care card or seniors card.

Strategic Priority 7 – Work and Retirement

Active participation in community should be a right that is equally accessible to all ACT residents throughout their lifespan. Participation through work, education, volunteering and recreation is an important part of life which enriches both the individual and the whole community.

As noted previously, Carers ACT has an ongoing process of consultation to identify needs of users and potential users. A key finding of previous consultation activities

indicated that Carers have significant difficulty in planning for retirement as they often find that their unpaid work in providing care to another person is increasing rather than decreasing and that there may be limited options or even no options for alternative care provision.

Recommendation 14: That the ACT Strategic Plan for Positive Ageing include a requirement that the ACT Government boost alternative care options to ensure that older Carers have sufficient access to respite and which assist in transitioning into supported accommodation options in the future, if required.

Carers ACT delivers a Mature Aged Carers support program to assist older parent Carers of people with disabilities to obtain respite, practical supports and to plan for the future. Yet, planning for retirement should start long before families reach retirement age. Research indicates that reduced workforce participation across the lifespan of the caring role greatly affects the accumulation of assets and the ability to save for retirement. Carers ACT strongly supports improved identification of Carer needs, enablement of greater levels of participation in the workforce and community life, and early intervention to enable Carers to plan for an enjoyable retirement in their older years.

Recommendation 15: That the ACT Strategic Plan for Positive Ageing include a requirement that the ACT Government boost alternative care options to ensure that older Carers have sufficient access to increased workforce and community participation and extra support to appropriately plan for retirement given the demands of their caring role.