



**Response to
Caring for Carers Review and Future Model**

**for the Allen Consulting Group on behalf of the ACT
Government Department of Disability, Housing and
Community Services**

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Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We pay our respects to their elders and recognize the displacement and disadvantage they have suffered since European settlement. Carers ACT celebrates the Ngunnawal's living culture and valuable contribution to the ACT community.

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1. Executive Summary

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 family Carers living in the Australian Capital Territory. We represent unpaid family Carers who are providing care for people with disabilities, mental illness, chronic conditions, palliative care, or who are aged and frail. Carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education. This aspiration falls far short of the reality for many Carers, who have the lowest wellbeing scores for any group in Australia, being far more likely to suffer chronic health conditions and depression.

Carers ACT applauds the ACT Government's ongoing commitment to achieving the aspirations in the Caring for Carers Policy. The situation for Carers has changed significantly in the years since the first consultation period. Carers have a greater recognition by government for the essential role they have in maintaining a health and welfare system that depends inherently on provision of community-based care. However the challenges ahead, from economic pressures, workforce participation issues and the ageing Australian population, mean that Carers are more in need of effective support than ever. It is clear that a comprehensive strategy needs to be urgently developed to create a sustainable future for family Carers and their care-recipients. This submission addresses some central issues of concern for Carers, provides a critical assessment of the Action Plan process, and offers some comment on future direction to enable the sustainable support of Carers in the Australian Capital Territory.

There has been no demonstrable change in the number of Carers in the ACT. The ABS has advised Carers Australia that the Survey of Disability and Carers (SDAC) 2003 provides an accurate indication of population rates, and should be used instead of the Census data. The difference in figures simply illustrates the methodological differences between the Census and the National Household Surveys. The value of the Census data lies in its accumulation of demographic profiling information on those Carers who self-identified as such, and who completed the question.

Carers ACT has consistently called for the establishment of comprehensive and effective legislation, which not only provides recognition for Carers but is based on a secure foundation of equitable rights. Previous legislative reform amendments in the *Carers Recognition Legislation Amendment Act 2006* are insufficient for sustainable caring in the current socio-economic climate. It is vital that legislation, policy and action plans recognise the rights of Carers to be consulted and actively involved at every level (from systemic policy or service planning to the development of individual plans in support of ongoing care). Key needs to be addressed under new legislation include the provision of information to Carers; the right for them to be consulted regarding decisions of treatment and care which directly impact on them; and extension of duty of care provisions to ensure that the Carer's health and wellbeing is maintained.

Carers ACT strongly contends that systematic strategic reform to benefit Carers will never be a high priority for departments until they have a legal

obligation for compliance. The introduction of legislation is more likely to improve service delivery issues in the long-term, without resulting in a scary tidal wave of consumers. Western Australia is a prime example, as the introduction of the Carers Charter has led to reasonable and sustainable reform without any dramatic surge in new demand for services.

The Caring for Carers policy provided significant recognition and acknowledgement of the value of Carers' work to the ACT government and the wider community. The seven core principles stated in the policy did reflect the central themes for Carers at the time of consultation and they mostly remain quite apt. The Caring for Carers Policy has been described as an aspirational policy rather than as a definitive blueprint for social reform. The success of the policy depended upon implementation of a definitive Action Plan, with stepped goals that were achievable and properly resourced.

The initial Action Plan had a number of demonstrated positive benefits, including the improvement of information available to Carers, increasing community understanding of caring, and the establishment of ongoing practical supports, such as the Skills for Carers course. Analysis of the outcomes of the Action Plan led to the following reflections:

- Strategies were inconsistently met, with some doing very well, others having only token responses, and some seeming to have completely dropped off the agenda;
- Generic projects were often credited to apply to meeting Carer-specific targets, with no evidence of how Carers were specifically accommodated, assessed or assisted;
- Outcomes and evidence based reporting was mostly non-existent, with no independent audit of information or quality checks;
- Some of the funding decisions appeared to have questionable value to Carers.

The flaws in the Action Plan were mostly attributable to the lack of coherence in direction and management, and the size of the gap between the highly positive aspirations of the Policy when compared to the reality that exists for Carers.

The ACT government needs to establish a working party to comprehensively review the existing legislation, the Caring for Carers Policy and the direction of future Action Plans. This working party needs to include diverse Carer representation, in addition to departmental and sector representation. The Carer Implementation Partnership was established to broadly meet some of the ongoing strategic management of the Policy, however insufficient resourcing and the lack of legislative support for their work has greatly hindered progress. An extension of the existing Carer Implementation Partnership, with expanded terms of reference and additional resourcing may be a viable option for enhanced strategic management. Their role could include the strategic shaping of future Action Plans, working with relevant departments to guide reform through a process supported by compliance reporting, and to manage strategic funding projects for the benefit of Carers in the community.

Following the comprehensive review of issues raised in the discussion paper on the Caring for Carers Policy and Action plan, Carers ACT makes the following recommendations:

- The ACT government needs to establish a working party to comprehensively review the existing legislation, the Caring for Carers Policy and the direction of future Action Plans. This working party needs to include diverse Carer representation, in addition to departmental and sector representation.
- That the ACT Government review interactions of the Carers Legislation Amendment Act and the Caring for Carers Policy with other relevant legislation, including the Children and Young People Act.
- That the ACT Government consider an extension of the existing Carer Implementation Partnership, with expanded terms of reference and additional resourcing, to include the strategic shaping of future Action Plans, working with relevant departments to guide reform through a process supported by compliance reporting, and to manage strategic funding projects for the benefit of Carers in the community.
- That the ACT Government and relevant departments seek formal advice from the Australian Bureau of Statistics on the difference between Carer numbers reported for the ACT between the Survey of Disability and Caring 2003 and Census 2006 to prevent any potential miscalculation in future planning for Carer supports.
- The ACT government to commit to strategically funding the implementation of Carer support strategies aimed at increasing long-term Carer sustainability, in particular to combat issues of workforce participation and the ageing ACT population.
- The ACT Government to support an extension of the highly successful Mental Health Peer Support Program to all Carers.
- The ACT Government to provide recurrent funding for service provider education on Carer issues, and initiate a program to advise Carers of their rights and responsibilities under all relevant legislation, not just the Human Rights Act, especially in the areas of provision of information, treatment and care, and rights to maintain their own health and well-being.
- That the ACT Government commit to developing practical ways of supporting Carers in the use of powers of attorney, advanced care directives and guardianship orders.
- That future Action Plans be formulated, managed and assessed by a single independent body, with a priority for strategic reform and appropriate funding plans.
- That all departmental projects relating to the Caring for Carers Policy be required to have outcome plans detailing specific anticipated benefits to Carers, followed up by evidence-based reporting.

2. Introduction

Carers ACT is a non-profit, community based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 family Carers living in the Australian Capital Territory. We represent unpaid family Carers who are providing care for people with disabilities, mental illness, chronic conditions, palliative care, or who are aged and frail.

It takes a flexible and responsive organization to effectively support such a diverse population. Carers ACT provides a service focused specifically on the needs of the family Carer, from the crisis of diagnosis through to the adjustment in coping if the caring role has ceased. The organization is much more than just a safety net, as it has an active role in service provision, future planning and representation across the community services sector within the ACT. Carers ACT holds a vital role as the conduit between government and community. It ensures the continued sustainability of community-based care, and manages substantial levels of Government funding in the ACT.

Carers ACT believes that all Carers are entitled to the same rights, choices and opportunities as other Australians in order to enjoy optimum health, social and economic wellbeing and to participate in family, social and community life, employment and education. This aspiration falls far short of the reality for many Carers, who have the lowest wellbeing scores for any group in Australia, being far more likely to suffer chronic health conditions and depression (Cummins, 2007), and who are at higher than average risk of poverty (ABS, 2003).

Research has consistently shown that Carers are already a group more vulnerable to the pressure of external social and economic factors than the majority of non-Carers in the population. Yet anyone can become a Carer, at any time, as we all have family, friends or neighbours who may need our care at some time in their lifespan, due to accidents, chronic illness or simply from the increasing frailty of old age. Decisions on future supports for Carers, therefore, have a much wider reach than the current Carer population already resident in the ACT.

As the only ACT organization solely dedicated to supporting Carers, Carers ACT offers the Government a unique perspective and significant expertise on issues of relevance to Carers. Our representation is grounded firmly in the views and needs of our membership, backed up by systemic analysis of data from operational services and information from external research bodies. Carers ACT is a member of the national network of Carers Associations, and works to assist the government to recognize and address the growing needs of Carers throughout Australia. Carers ACT and the national network are now engaged in international Carer alliances with countries such as the USA, Canada and the UK to share research and information about supporting the diverse needs of Carers.

Carers ACT applauds the ACT Government's ongoing commitment to achieving the aspirations in the Caring for Carers policy. This continued with the Action Plan in 2004-07, and will expand further through consecutive Action Plans, based on the long term vision provided in the Caring for Carers Policy. Carers ACT was pleased to contribute to the initial public

consultation process which led to the establishment of the Caring for Carers Policy, the Action Plan, and subsequently the Carers Recognition Legislation Amendment Act, and is delighted to offer additional input regarding the implementation to date and guidance on future directions.

It must be noted that the very short timeframe allowed for public consultation has created some difficulty. The consultation timetable was in conflict with the review of the Mental Health Act, as both discussion papers were released in December with written comments closing in February. The short turnaround for comments was further complicated by the Christmas/summer holiday period, when many staff and Carers have leave and childcare commitments to manage. Carers ACT depends substantially on direct Carer input to all submissions and responses, to ensure accuracy and validity of representation. Few community organisations in the ACT are funded for systemic research or policy representation, despite consistent requests to provide such vital information for government reviews and submissions. It is, therefore, essential that sufficient time be allocated for effective and comprehensive community input, and to avoid perceptions that such consultation is purely tokenistic in nature.

The situation for Carers has changed significantly in the years since the first consultation period. Carers have a greater recognition by government for the essential role they have in maintaining a health and welfare system that depends inherently on provision of community-based care. However the challenges faced by Carers are more in need of effective support than ever. Research in the interim has given us a much better understanding of health and wellbeing needs. There is greater awareness of the impact of Caring on the economy, the economic pressures faced by Carers including workforce participation issues, and the challenge created by the ageing of the Australian population. It is clear that a comprehensive strategy needs to be urgently developed to create a sustainable future for family Carers and their care-recipients.

This submission is not intended to be a comprehensive treatise on all issues that need to be considered when reviewing the Caring for Carers Policy and Action Plan. Instead, it addresses some central issues of concern, provides a critical assessment of the Action Plan process, and offers some comment on future direction to enable the sustainable support of Carers in the Australian Capital Territory.

3. Counting Carers

The number of Carers resident in the ACT is questioned in the discussion paper, as page 5 states:

The ACT Government needs to understand the size and nature of the carer population to develop an effective carers policy. DHCS advice is that recent Australian Bureau of Statistics census data indicates that there has been a drop in the number of carers in the ACT. The recent data reports that in 2006 there were 25 936 carers in the ACT. This is over 8 000 less than found by a 2003 survey conducted by the Australian Bureau of Statistics – or a drop of 25 per cent.

There has been no drop in the number of Carers in the ACT, as a query to the Australian Bureau of Statistics has confirmed. The difference in figures simply illustrates the methodological differences between the Census and the National Household Surveys. The ABS has advised Carers Australia that the Survey of Disability and Carers (SDAC) 2003 provides an accurate indication of population rates, and should be used instead of the Census data. Indeed, as the Census Dictionary, 2006 (Reissue) (ABS Cat. No. 2901.0) states on the question relating to core activity need for assistance:

*While this topic is based on the criteria used in the ABS Survey of Disability, Ageing and Carers, the population measured will differ as a result of the different collection methodology used and reduced question format. On this basis, **data for this topic should be taken as an indication** of the characteristics of people who report a need for assistance, **not as the total prevalence** of people with a 'profound of severe core activity limitation' as represented in the survey data.*

Methodology variability also extends to different parameters in eligibility criteria. For example, the Census question asked about unpaid care in the 'last two weeks' only, which is quite a different concept from that in the SDAC which identifies Carers where the assistance is ongoing or likely to be ongoing for at least six months. This question would necessarily alter response rates for Carers who were accessing respite services or who were otherwise absent from the care environment temporarily (e.g. away for work, for family reasons, or in hospital).

Additionally, the Census question only asks about unpaid care provided by persons aged 15 years and over. Care provided by younger persons is excluded, whereas in SDAC a Carer can be a person of any age. SDAC reported 169,900 Carers aged under 18 years old, with 2,900 being Primary Carers. Young Carers report caring from as young as 5 years of age, however those under 18 are mostly aged between 10 and 13 years of age (Carers Australia, 2002).

The Census involves a single questionnaire completed by either each household member themselves or by a household member on behalf of other household members. It is composed of a large number of relatively simple questions. The Census is distributed nationally and is compulsory for all people to complete on a single nominated night. As a statistical method it has noted limitations. As the Australian Bureau of Statistics (ABS Cat. No. 2901.0) explains:

The Census form may be completed by one household member on behalf of others. Incorrect answers can be introduced to the Census form if the respondent does not understand the question or does not know the correct information about other household members. Many of these errors remain in the final data.

National household surveys, such as SDAC, require a detailed personal interview by a trained ABS interviewer who systematically gathers evidence at a complex level, explaining questions to participants and enabling highly accurate responses. The SDAC identifies Carers by interviewing the care-recipient (in the main) and running through a list of activities that they may receive assistance with. This means that the survey is likely to pick up people who would not necessarily self-identify themselves as Carers.

Non compliance and non-response are also critical factors when considering Census data. Despite having a legal requirement to complete the form, 4.2% of Australians did not complete a Census. Additionally, not all questions on the form are compulsory. The ABS notes that the non-response rate for the question on Caring had a significantly high rate of 10.1% overall (ABS Cat. No. 2901.0). Considering that Carers are one of the most time poor groups in Australia, it is quite plausible to expect that many would only complete the compulsory section and not read through the entire document.

The Australian Bureau of Statistics has, therefore, provided advice to Carers Australia and the network of Carers organizations that figures provided in the SDAC are to be used in preference to numbers counted in Census 2006. The value of the Census data lies in its accumulation of demographic profiling information on those Carers who self-identified as such, and who completed the question.

4. Caring in the ACT

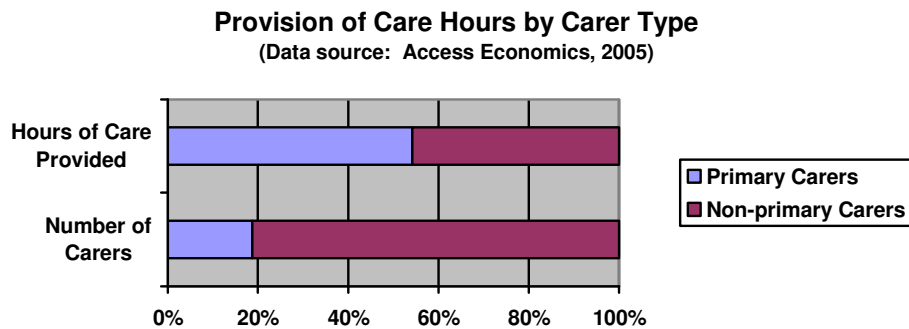
The ACT Government has asserted that “Canberrans ... have a right to share in the benefits of our community and to contribute to that community.” (ACT Govt., 2007, p.11). The profile of Caring in the ACT is now much better known than at the time of the original policy development period. Carers ACT and the ACT Government are more aware of the challenges facing Carers at present, and into the near future, as the ageing demographic impacts on social and economic lifestyles in the ACT. The challenges facing our community in the years ahead, from both internal and external factors, will require innovation, creativity and a strong focus on sustainable, equitable solutions.

Carers have an essential role in maintaining the health and social welfare system, which relies upon a model of community care. The work of Carers is of substantial economic benefit to the ACT Government, saving a conservatively estimated \$524.6 million per annum in replacement formal care services.

Caring in the ACT: An Essential Part of the Community			
Number of Carers in ACT:	43,000 ¹	Number of Primary Carers (<i>percentage of total ACT Carer population</i>):	8,600 ¹ (20%)
Estimated annual cost of replacing unpaid care with formal care in the ACT:	\$524.6 million pa ²	Estimated annual opportunity cost to ACT economy from Carers' reduced participation in workforce	\$88.9 million pa ²
Sources:	¹ Data extrapolated from ABS (2003) Survey of Disability, Ageing and Carers ² Carers ACT, using model developed by Access Economics (2005) applied to SDAC data.		

It is clear that if Carers did not provide this care, government or other care services would be unable to provide an equivalent quality or level of care. Successive governments have recognized that supporting Carers through funding organizations such as Carers ACT provides a very cost effective way of achieving health and wellbeing benchmarks. Failure to adequately support Carers will have an immediate and dire impact on the economy, as replacement of informal care with formal care has been conservatively calculated at 3.5% of GDP (Access Economics, 2005). It is clear that a systematic breakdown of community-based care would be a health-care disaster for the ACT population.

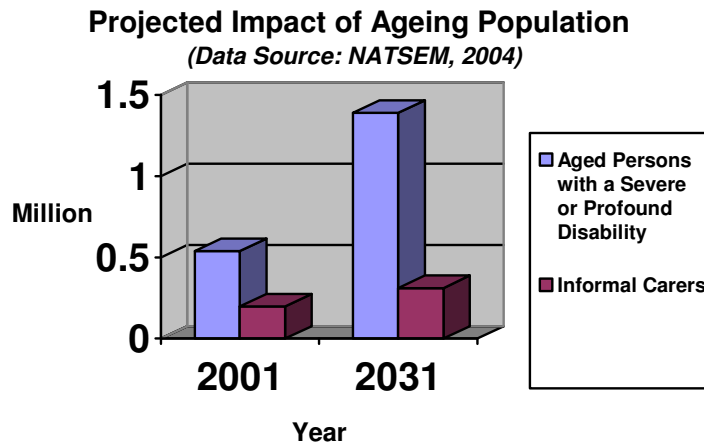
Care needs are not homogenous across the population. Support needs vary with the complexity of issues for the care-recipient, the availability of other forms of informal support, the skills level of the Carer and their individual health factors. Of the 43,000 Carers in the ACT, 20% (approximately 8,600 people) are estimated to be Primary Carers who provide of 54% of total care hours required by care-recipients, as the following chart clearly demonstrates:



Recent research published in the Australian Unity Wellbeing Index (Cummins, 2007) has shown that Carers are already a group at risk, more vulnerable to the pressure of social and economic factors than the majority of non-carers in the population. This research also provided support to the perception that Carers as a group are significantly more highly stressed and extremely time poor in comparison to other population groups. It found evidence that "consistent, daily immediate caring responsibility is sufficient to severely damage wellbeing" (Cummins, 2007 p. 37). While caring is a normal part of life, the role does go beyond that of usual family relationships and creates additional stress and strain beyond common expectations. People needing care usually prefer to live in the community but it is now well-recognized that they may need assistance to do so.

Given that the demographics of Australia's population are changing toward a greater number of older people in the community and a greater number of people with disabilities, it is likely that more people will need both informal and formal care. A NATSEM study, *Who's going to care? Informal care and an ageing population* (2004) found that, over the next thirty years, persons over 65 years are projected to account for 63 per cent of all profoundly and

severely disabled persons (up from 44 per cent in 2001). Over the same period, the ratio of Carers available to provide care to this group will drop from 57 Carers for every 100 people in 2001 to just 35 for every 100 by 2031. As the following graph so clearly illustrates, the gap between those who can provide care and those who need care is widening to a chasm:



This national trend will impact on the Territory, as the *Canberra Social Plan: Progress Report (June 2007)* states

The ACT is distinguished by the fact that, because of low fertility rates and longer life expectancy, the median is increasing more rapidly. In that sense, it can be said that the 'ACT is ageing faster' than any other jurisdiction.

Clearly, there is a compelling case for government and community to work together to assist Carers in their role, and develop a responsive support structure that will also address the expected demographic challenges of the future in a responsible and sustainable manner.

5. Legislation for Carer Recognition and Support

Carers ACT now calls for the establishment of comprehensive and effective legislation, which not only provides recognition for Carers but is based on a secure foundation of equitable rights that ensures their protection under the Act, and provides access to information which enables the continued provision of effective care. Legislation is more than just being about "creating rules (Coaldrake, 2004); it is a critical component of social structure. It provides a foundation of support to underpin policy development and service provision. It outlines the rights and responsibilities of all people affected by the Act, and it ensures their due protection under the law. Reviews of policy or service delivery often highlight areas where legislative direction is needed. It is vital that the voices of Carers are heard and considered during this process to enable the construction of a better foundation based on just and equitable principles.

The ACT *Carers Recognition Legislation Amendment Act 2006* provided for amendment to the *Discrimination Act 1991*, the *Guardianship and Management of Property Act 1991*, and the *Human Rights Commission Act*

2005 but these amendments are very limited in their scope. For example, being a Carer cannot be used in a discriminatory way for employment, accommodation, education, club membership, access to premises, or relating to goods, services and facilities. The *Discrimination Act 1991* does not apply outside of the ACT or in relation to any complaint against a Commonwealth Department or Agency. Under the *Human Rights Commission Act 2005*, Carers can make a complaint as an agent of the Consumer. There is no provision for services to recognise Carers in their own right, i.e. for them to complain on how they are treated by services. Under the *Guardianship and Management of Property Act 1991* the amendment simply provides for all Carers to receive notification of a guardianship hearing. These amendments are insufficient for sustainable caring in the current socio-economic climate.

It is clear that increasing government and departmental recognition of Carers, the essential role of caring, and the enormous social and economic benefits to the community from caring must be underpinned by effective legislative recognition with definitive provisions on Carers rights and responsibilities. Policy without the support of strong and definitive legislation is a toothless tiger. It lacks direction, and any impetus engendered by the introduction of such policy usually fizzles out into lip service reporting over time. It is critical that effective policy have the support of legislative provision that requires compliance and is further strengthened by an independent assessment process. It would be considered foolish for a government to build a road without quality assurance checks along the way; similarly, a policy without adequate signposts and checkpoints soon wanders away from the point and becomes lost in the words.

The original consultation process by Minter Ellison identified a number of non-legislative reforms that were critical to the implementation of an effective Carer support strategy. Some examples of the reforms not addressed include:

- Extend the Mental Health Peer Support program to all Carers;
- Extend service provider education for service provider and clinical staff (Carers ACT developed and implemented such a program with significant success, but due to the lack of recurrent funding the program has ceased. A continuous program is needed due to high rates of staff turnover in the sector);
- Develop practical ways of supporting Carers in the use of powers of attorney, advanced care directives and guardianship orders;
- Review interactions with other relevant legislation, including the Children and Young People Act.

There is a case that extended terms of reference for the Carer Implementation Partnership (another critical non-legislative recommendation) would have enabled these recommendations to be fully implemented and appropriately assessed.

It must also be noted that Minter Ellison may have failed to grasp a fundamental issue about community perceptions of service delivery, policy and legislative need. They stated that two conflicting messages had emerged from the consultation as to whether rights-based legislation could address Carer needs, and found that there was little or no broad based

support for such legislation. It can be legitimately argued that this perception was in error. The majority of people in the wider community have little understanding of what legislation is and how it fits in with policy and service issues. This specialist level of understanding is usually found in people with tertiary education in law, politics, business, sociology or civil administration.

Participants in the consultative process may have legitimately failed to understand the significance of how substantive legislation with appropriate provisions can provide top-down direction for policy development, which in turn filters down into improved service delivery. They may have been so focused on the service delivery issues, which were having such impact on their lives and work, that a 'bill of rights' would seem quite irrelevant in some aspects. It is also noted in the Minter Ellison report that "there were disappointingly few written submissions" (Coaldrake, 2004) to provide supporting evidence for their conclusions. Regrettably, Carers are very time poor, and it takes concerted effort to conduct effective consultation. Most do not have time to read a newspaper, attend meetings, review discussion papers, and then write formal submissions. Necessarily, Carers will prioritize the care of their loved ones over bureaucratic process; and it would be imprudent to confuse a lack of vocality with a lack of concern.

Carers ACT, therefore, made every effort to ensure that Carers views were put forward by submitting recommendations based on comprehensive research to the initial Carer Policy review. Regrettably, many of these recommendations were not adopted by the ACT Government following the initial consultation process.

The separation of policy and service delivery from legislative reform or creation is especially difficult for those professionals and Carers at the 'coalface' of caring because they are necessarily focused on, and are experts in, the analysis of issues and impacts at the micro level. Anecdotal evidence from consultants carrying out other legislative reviews has confirmed this issue, as a number have discussed their frustrations in continually receiving submissions which are focused on service delivery issues or policy issues rather than relevant to the specific legislation under review. This further demonstrates the vital need for the community sector to be sufficiently funded to attract and retain professionals with the capacity to provide crucial systemic analysis, to advise on strategic direction, and to develop sector depth in policy and research. Indeed, to move beyond sole reliance on departmental policy work will broaden perspective and increase diversity of data for the Government's long term benefit.

The initial consultation process leading to the development of the legislation and policy provided a beginning, but we need to move forward to better meet the current needs of Carers. The ACT Government needs to make a strong and unequivocal commitment to strengthening the legislative and policy foundation that will support Carers in their provision of community care. All Carer-related policy should aim to build a responsive and inclusive system, appropriately supported by sufficient funding. As such, all legislative and policy revisions will need to be accompanied by comprehensive education programs on rights and responsibilities; for service providers, health professionals, Carers, and care-recipients.

It is vital that legislation, policy and action plans recognise the rights of Carers to be consulted and actively involved at every level, from systemic policy or service planning to the development of individual plans in support of ongoing care. Key needs to be addressed under new legislation include the provision of information to Carers; the right for them to be consulted regarding decisions of treatment and care which directly impact on them; and extension of duty of care provisions to ensure that the Carer's health and wellbeing is maintained. Without a strong base of legislative support requiring compliance, it is inevitable that policy will remain subject to the whim of a four-year electoral cycle.

Indeed, a continuation of the denial of information to Carers is actually a breach of their own human rights - as their dignity, personal wellbeing and safety may depend on knowledge of care and treatment issues which will directly affect them in their caring role. The Government must formally recognise that the structure of a community care model, which underlies all aspects of the health and social welfare systems in Australia, necessarily extends the duty of care of treating professionals beyond the care-recipient to the Carer, who is providing the essential support that enables the model to exist.

The strength of the Western Australian system lies in the fact that policy directives are underpinned by definitive legislation in the provisions of the *Carers Recognition Act 2004*, which requires service compliance. The provisions of the Charter relating to compliance set minimum standards for relevant government departments to meet on Carer consultation, inclusion, information and recognition. Compliance is required through annual reporting to a separate independent body, the Carers Council, which also provides advice to the Ministers for Health and Disabilities on issues of Carer concern.

At the time of initial consultation, the main arguments against adopting comprehensive stand-alone legislation were based on the ACT's unpreparedness to meet anticipated extra service demands emanating from a rights-based Act, and a perception that many key discriminatory issues could be dealt with under the Human Rights Act. While the Human Rights Act and the ACT Human Rights Commission are exemplary reforms, they do not provide sufficient legislative direction or protection for Carers. They have essentially a reactive role, which is primarily based on resolving complaints against discriminatory practice in a limited number of circumstances, and in addressing service delivery complaints regarding health and disability service providers.

Carers ACT strongly contends that systematic strategic reform to benefit Carers will never be a high priority for departments until they have a legal obligation for compliance, due to the pressure departments are under from competing priorities. The introduction of legislation is more likely to improve service delivery issues in the long-term, without resulting in a scary tidal wave of consumers. Western Australia is a prime example, as the introduction of the Carers Charter has led to reasonable and sustainable reform without any dramatic surge in new demand for services. It must also be recognised that unmet demand in the ACT does exist, and will continue to exist, even if the ACT government refuses to acknowledge Carers' rights to a fair deal, whether they are from a working family or not.

6. The Caring for Carers Policy

Carers are far more than just an advocate for the care-recipient, as they have a central role in provision of emotional support and practical assistance, in addition to providing direct care and ongoing supervision of health and well-being. The Caring for Carers policy provided significant recognition and acknowledgement of the value of Carers' work to the ACT government and the wider community. The seven core principles stated in the policy did reflect the central themes for Carers at the time of consultation, and (subject to a potential revision in wording of the first principle, to better reflect the fact that many Carers do not have a choice about taking on or continuing caring roles) they mostly remain quite apt. Each principle has an associated list of objectives which, in total, were quite consistent elaborations of the principle statements. The discussion points accompanying the objectives were generally well-informed, respectful and reasonably accurate.

The Caring for Carers Policy has been described as an aspirational policy rather than as a definitive blueprint for social reform. It could be argued that while aspirational policy is nice on paper, the gap between the reality and the goal was so wide that it inevitably led to over-expectations that were doomed to disappointment. Aspirations which are not backed by strategic planning and demonstrated long-term commitment to action remain nothing more than dreams and illusions. So where did the policy go wrong? The success of the policy depended upon implementation of a definitive Action Plan, with stepped goals that were achievable and properly resourced. As the Policy was not supported by legislative provisions for reporting and compliance; it effectively lacked backbone and teeth. The Policy described only end-points rather than considering beginnings and pathways. To put it simply, the Caring for Carers Policy set the goal posts in position, but forgot to provide the players, the pitch, the rule book or even an umpire.

7. The Action Plan

As part of the preparation for this submission, Carers ACT has audited key parts of the Action Plan 2004-2007 against the reported outcomes listed in the Interim and Final Progress Reports. Due to time and funding constraints it was not possible or desirable to address every single aspect of the Action Plan, or waste resources by duplicating the anticipated methodology of the reviewing consultants. Instead, the project conducted a quality check on a range of outcomes reported, and specifically looked for measurements of success or assessments of unmet need for Carers in the ACT. Several key issues and messages were evident:

- Strategies were inconsistently met, with some doing very well, others having only token responses, and some seeming to have completely dropped off the agenda;
- Generic projects were often credited to apply to meeting Carer-specific targets, with no evidence of how Carers were specifically accommodated, assessed or assisted;
- Outcomes and evidence based reporting was mostly non-existent, with no independent audit of information or quality checks;

- As a whole, the Action Plan lacked cohesive management and direction, and some of the funding decisions appeared to have questionable value to Carers.

It was clear that some strategies had been more successful than others. For example, strategy 1 on improving access to information and resources for Carers was very highly met. Specific Carer-need projects in this section, such as Skills for Carers at CIT, were usually clearly defined and outcomes adequately reported. The main flaw in this strategy was the fact that many programs of ongoing value had been given limited one-off funding which meant that they had stopped when funding ran-out, as was the case for the Service Provider Education Kit project.

Several of the strategies had no outcome at all listed in the Progress reports. For example, the recommendation for a web portal for Carers was listed only as under review by the Department of Disability, Housing and Community Services. The feasibility study to develop a new model of respite care for Indigenous families has seemed to have stalled, as has the Companion Card for Carers project. Of most concern was the review of Young Carers needs for legislative protection under the Children and Young People Act, which was to be referred by request from the ACT Government to the Commissioner for Children and Young People for consideration. Discussion with Linda Crebbin, the Commissioner for Children and Young People, has indicated that no such request from the ACT Government has yet been received.

There was consistent evidence that generic programs were frequently claimed as the sole or central criteria for a department's activities in addressing the needs of Carers. For example in the final progress report, it was reported:

ACT Health supports the following services that provide information and support to carers:

- ACT Branch of the Australian Breastfeeding Association
- Canberra Rape Crisis Centre Nguru Program
- Companion House
- Karinya House
- Men's Link
- ACT Branch of the Pregnancy Support Service
- SIDS and Kids
- Women's Centre for Health Matters, including the following mutual support groups that include carers:
 - Asian Mother Friendship Group
 - Women's Sew and Needle Club
 - Pearce Older Women's Network

There is no accountability in this statement. There is no mention of any attempt to identify Carers within these groups, no reporting of specific strategies initiated to assist Carers in these groups and no measurement of any outcomes or other successes from any presumed or planned assistance. In fact this statement implies a nonsensical presumption that 'because Carers may exist in this group, and we generically support these groups to exist, we have assumed that we have somehow provided specifically targeted and appropriate information and resources to Carers'. Additional

information on membership of such groups reveals that, while they may have an intrinsic and valuable role for general community support, there are significant limitations with assumptions of effectively targeted Carer support, as “there are only five women in the group ... all of the women in Sew and Needle are members of either the Supporting Asian Mothers or Women’s Wellbeing groups” (Maslen, 2008).

Outcomes and evidence-based reporting was rarely provided in the progress report, in fact much of the accountability seemed to rely on little more than ‘tick the box’ as ‘completed’ or ‘ongoing’. The report lists a number of projects in the ACT which received funding, but includes no information as to outcome or effectiveness. There is a suggestion in the report that provision of funding seems to assume that Carers have been supported. A strategic, independent system of assessment would greatly assist in determining the effectiveness of projects funded under the grant system.

Unfunded strategies also lacked sufficient accountability. For example, Item 2A claims:

under changes to the Public Rental Housing Assistance Program (PRHAP) in June 2006 the needs of specific groups have been targeted, particularly individuals within these groups with a range of critical needs and risk factors. This includes people with disabilities and mental health issues and their carers where appropriate

Yet, analysis of the discussion paper, facts sheet, information sheets and Minister’s letter to tenants all available via the website for download at <http://www.dhcs.act.gov.au/hcs/reformspublichousing/publichousingreforms> again reveals no substantive or targeted mention of Carers, let alone any definitive statement that would meet the stated strategy to ensure accommodation and tenancy responses support those in caring relationships. There is no detail of any initiation of Carer-specific strategies, and certainly no evidence of benefit to Carers documented. The inadequacy of coherence between the goal of the strategy and the reported action is absurd, as availability of suitable housing is a critical issue for those Carers in the ACT who live below the poverty line and are at continual risk of homelessness.

Overall assessment of the Action Plan indicated that it lacked a cohesive direction, it was insufficiently resourced, and was devoid of any independent measure of quality or standard of achievement for Carers. Carers ACT maintains that three vital factors prevented the formulation and delivery of an effective Action Plan which could have achieved sustainable and lasting improvement for Carers: legislation requiring departmental compliance; establishment of an independent body to direct and assess compliance; and sufficient funding for effective reforms to be delivered and supported.

8. The Carer Implementation Partnership

It may be argued that the formation of the Carer Implementation Partnership was aimed at providing a similar independent body to WA’s Carers Council, without making legislative provision to support such a body. Minter Ellison recommended an extension of the terms of reference of the Partnership: to

create work programs for relevant agencies' to oversee both legislative and non-legislative reforms; and to report on the outcomes on each of these tasks. The Partnership was also recommended to "review evidence of the effectiveness of the WA Carers Act and consider the applicability to the ACT of any aspects that have proven to be effective" (Coaldrake, 2004).

Indeed the current terms of reference of the Partnership do broadly reflect the aspiration of such a body, as it is to monitor the implementation of the Caring for Carers Policy and Action Plan, and also to re-examine priority areas and to recommend priority actions to the Minister. Once again the aspiration fails to meet with the reality of structure and funding. The partnership meets annually for a period of no longer than two hours. This is an insufficient commitment to enable more than a micro-thin surface level of attention to and discussion of critical issues relating to the terms of reference.

Membership of the Partnership is broadly inclusive of a number of Carers and Carer representatives. This representation would be further enhanced by inclusion of additional participants with high-level experience in strategic management. The minimal time allocation for meeting and the lack of general resourcing to support the Partnership inhibits strategic planning. Similarly, without legislative support, the Partnership may be inadvertently perceived as lacking authority when providing advice to the Minister.

The Partnership has been allocated grant funding to allocate each year. It has been of concern to Carers ACT that \$200,000 annually is less effective when distributed in numerous small-scale grants which are inherently of limited effect to the wider Carer community. For example, the allocation of \$60,000 for a respite camp to a group with only 11 members, when other groups can provide quality respite retreats for 100 Carers at less than half this cost, is patently wasteful. The appropriateness of allocation of grants is also contentious, as many of these projects are duplicating existing projects.

Carers ACT considers that much of the funding managed by the Carer Implementation Partnership would be more effectively allocated into strategic work to build community capacity. The provision of fewer and larger grants would also need to ensure a higher degree of planning for projects. These projects need to have appropriate measures of output, documented evidence of impact, and a sufficient level of accountability in reporting.

9. Recommendations

- The ACT government needs to establish a working party to comprehensively review the existing legislation, the Caring for Carers policy and the direction of future Action Plans. This working party needs to include diverse Carer representation, in addition to departmental and sector representation.
- That the ACT Government review interactions of the Carers Legislation Amendment Act and the Caring for Carers Policy with other relevant legislation, including the Children and Young People Act.

- That the ACT Government consider an extension of the existing Carer Implementation Partnership, with expanded terms of reference and additional resourcing, to include the strategic shaping of future Action Plans, working with relevant departments to guide reform through a process supported by compliance reporting, and to manage strategic funding projects for the benefit of Carers in the community.
- That the ACT Government and relevant departments seek formal advice from the Australian Bureau of Statistics on the difference between Carer numbers reported for the ACT between the Survey of Disability and Caring 2003 and Census 2006 to prevent any potential miscalculation in future planning for Carer supports.
- The ACT government to commit to strategically funding the implementation of Carer support strategies aimed at increasing long-term Carer sustainability, in particular to combat issues of workforce participation and the ageing ACT population.
- The ACT Government to support an extension of the highly successful Mental Health Peer Support Program to all Carers.
- The ACT Government to provide recurrent funding for service provider education on Carer issues, and initiate a program to advise Carers of their rights and responsibilities under all relevant legislation, not just the Human Rights Act, especially in the areas of provision of information, treatment and care, and rights to maintain their own health and well-being.
- That the ACT Government commit to developing practical ways of supporting Carers in the use of powers of attorney, advanced care directives and guardianship orders.
- That future Action Plans be formulated, managed and assessed by a single independent body, with a priority for strategic reform and appropriate funding plans.
- That all departmental projects relating to the Caring for Carers Policy be required to have outcome plans detailing specific anticipated benefits to Carers, followed up by evidence-based reporting.

10. Conclusion

Carers ACT considers the Caring for Carers Policy to have a significant value to Carers in the community. The ACT government needs to establish a working party to comprehensively review the existing legislation, the Caring for Carers policy and the direction of future Action Plans. It is clear that the Policy would benefit from the support of comprehensive legislation, providing for the establishment of an independent body to manage the future direction and implementation of strategic reform. This body could be an extension of the existing Carer Implementation Partnership, with expanded terms of reference and additional resourcing. Their role would include the strategic shaping of future Action Plans, working with relevant departments to guide reform through a process supported by compliance reporting, and to manage strategic funding projects for the benefit of Carers in the community.

The initial Action Plan had a number of demonstrated positive benefits, including the improvement of information available to Carers, increasing community understanding of caring, and the establishment of ongoing practical supports, such as the Skills for Carers course. The flaws in the Action Plan were mostly attributable to a lack of coherence in direction and management, and the size of the gap between the highly positive aspirations of the Policy when compared to the reality that exists for Carers. It is critical that this gap be diminished as Carers contribute so much to the social and economic benefit of the entire community, and it is the best interests of all to create long-term and sustainable supports which will meet the challenges of changing socio-demographic patterns in the near future.

11. References

- Access Economics (2005) *The economic value of informal care*. Canberra: Carers Australia
- ACT Government Chief Minister's Department (2007) *The Canberra social plan: Progress report June 2007*. Canberra: ACT Government.
- Australian Bureau of Statistics (2003) *Disability, ageing and carers, Australia: Summary of findings*. (ABS Catalogue No. 4430.0)
- Australian Bureau of Statistics (2007a) *Census Dictionary, 2006 (Reissue)*. (ABS Catalogue No. 2901.0)
- Australian Bureau of Statistics (2007b) *2006 Census Tables: Unpaid assistance to a person with a disability (a) by age by sex. Count of persons aged 15 years and over. Based on place of usual residence: Australian Capital Territory*. (ABS Catalogue No. 2068.0)
- Carers Australia (2002). *Young Carers Research Report: Final Report*. Canberra: Department of Family and Community Services.
- Coaldrake, M. (2004) *Report on the review of carers legislation in the ACT: ACT Department of Disability, Housing and Community Services*. Canberra: Minter Ellison Consulting.
- Cummins, R., Hughes, J., Tomy, A., Gibson, A., Woerner, J., Lai, L. (2007) *The wellbeing of Australians – Carer health and wellbeing*. Melbourne: Australian Centre on Quality of Life, Deakin University.
- Department of Disability and Community Services (2006) *2005-06 progress report on the implementation of caring for carers in the act - a plan for action 2004-07 (Incorporating the 2005-06 progress report on the implementation of the government response to the report on review of carers legislation in the ACT) Authorised by Ms Katy Gallagher MLA Minister for Disability and Community Services ACT Government*. Canberra: Department of Disability and Community Services.
- Maslen, S. (2008) *Marginalised and isolated women in the ACT: Risk, prevalence, and service provision*. Canberra: Women's Centre for Health Matters
- NATSEM (National Centre for Social and Economic Modelling) (2004) *Who's going to care? Informal care and the ageing population*. Canberra: Carers Australia.